

The Lived Experience of Quality of Life (QOL) in Relation to Dementia Progression

Helen Scanlon

Professor James McGuire

David Powell

Dr Sarah Butchard

Dr David Connelly

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Contents

Introductory Chapter: Thesis Overview	1
Chapter 1. Narrative review	6
The Self-Report of Quality of Life (QOL) for Individuals with a Dementia	6
1.0 Background Literature	6
1.01 Dementia	6
1.02 Dementia: Prevalence, Statistics and Projections	6
1.03 Quality of life (QOL)	7
1.04 Quality of Life and Dementia	8
1.05 The Needs of those with Dementia	9
2.0 The Current Status of Dementia: National Policies	9
3.0 Systematic Searching and Article Selection for Current Review	11
3.01 Objectives	11
3.02 Search Criteria	11
3.03 Recent Reviews of Quality of Life Measures for Individuals with Dementia	13
3.04 Quantitative Articles	17
3.05 Summary and Critique of Quantitative Articles	22
3.06 Qualitative Articles	25
3.07 Summary and Critique of Qualitative Articles	29
4.0 Conclusion	31
References	34
Chapter 2. Empirical Paper	39
Can Individuals Living with Dementia think about their Future Quality of Life (QOL)?	39
Abstract	39
Introduction	40

Method	42
Participants	42
Sampling Procedures	43
Study Design	43
Interview Content	44
Procedure	44
Data Analysis	45
Results	47
“Focus on Relationships”	47
“Sense of Self”	48
“Integrating Dementia”	49
“Psychological Needs”	50
“Personal Experience of Dementia”	51
“A Sense of Finality”	52
“Hope”	52
“Dementia as a Social Problem”	53
Respondent Validation Focus Group	53
Discussion	55
Conclusion	61
References	62
Chapter 3. Concluding Discussion	66
Section 1: Extended Discussion	67
1.0 Study Overview	67
2.0 Discussion of the Current Study Findings	68
2.01 The Lived Experience of Dementia	68
2.02 The Concepts of Person-Centred Care and Personhood	68

2.03	The Maintenance of Personhood in Dementia	70
2.04	The Challenges of Person-Centred Care and Personhood	73
2.05	The Importance of Relationships in Person-Centred Care and the Impact on Quality of Life	74
	Conclusion	78
	Section 2: Professional Report	79
	Background of the Study	79
	Aims and Methods for the Study	80
	Findings	80
	“Focus on Relationships”	80
	“Sense of Self”	81
	“Integrating Dementia”	81
	“Psychological Needs”	81
	“Personal Experience of Dementia”	82
	“A Sense of Finality”	82
	“Hope”	83
	“Dementia as a Social Problem”	83
	Clinical Relevance of the Results of the Study	83
	Recommendations for Practise Based on the Results of the Study	84
	Maintaining Meaningful Relationships and Social Networks	84
	Adjustment and Adaptation	85
	Enabling Difficult Conversations	85
	Social Awareness of Dementia and Stigma	86
	Section 3: Future Directions and Research	87
1.0	Introduction	87
2.0	Background Literature	87

2.01	Stigma	87
2.02	Impact of Stigma	88
2.03	Challenging Stigma	88
3.0	Future Research Proposal	89
3.01	Rationale for Research	89
3.02	Aim and Methods	89
3.03	Design	90
	References	91
	Appendix	96
	Appendix A	97
	Appendix B	99

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The Lived Experience of Quality of Life (QOL) in Relation to Dementia Progression

Introduction

Measuring the quality of life (QOL) of individuals who live with long-term health conditions and illnesses has become more important in the absence of cure (Department of Health [DoH], 2013). Dementia is an intractable, progressive and terminal illness and recent research from the Alzheimer's Society (2012) has highlighted that a large proportion of those with dementia report that they do not live well with dementia and indicates the impact of this on QOL. Historically, there was an assumption that individuals living with dementia, due to their cognitive impairment, were unable to comment and talk about their QOL, however more recent research has shown that this is not the case (Woods, 2012).

There are a number of ways in which QOL can be explored. For example, a number of scales have been developed which can collect information through a variety of methods including: self-report (e.g., Dementia Quality Of Life: Brod, Stewart, Sands, & Walton, 1999), report by-proxy (e.g., Alzheimer's Disease Health-Related Quality Of Life: Rabins, Kasper, Kleinman, Black, & Patrick, 1999), observational (e.g., Dementia Care Mapping: Kitwood & Bredin, 1992) or through a combination of such methods. Quality of life is highly subjective and this poses challenges for the collection of information about QOL. Numerous studies have highlighted the discrepancy between self-report and proxy report QOL scores (for a review see Ettema et al., 2005), and difficulties with observational methods such as observer bias are evident. Such observations suggest that self-report, where possible, is the gold standard for the measurement of QOL (Cahill & Diaz Ponce, 2011), although this is also not without difficulty (Ettema et al., 2005).

Self-report scales of QOL for those living with dementia certainly have their utility; however, the application of such scales for those with advanced dementia seems variable. This may partly be due to the loss of verbal communication and understanding (Johnson et al., 2009). This is further explored as the main focus of the narrative review which discusses and critiques the body of research which has been published in the last ten years which has focused on the self-report of QOL. The studies reported in the review; three quantitative articles and three qualitative articles discuss different methods for the collection of information regarding QOL from those individuals living with dementia. Findings from the review suggest that whilst self-report scales for QOL can be highly useful and effective, it seems their most effective use is with individuals who have mild to moderate dementia (Karim, Ramanna, Petit, Doward, & Burns, 2008; Trigg, Jones, & Skevington, 2007a; Trigg, Skevington, & Jones, 2007b). Some studies included in the review reported the inclusion of participants with advanced dementia. However, it would seem that participants with advanced dementia are more likely to struggle answering some questions, leading to missing values: a similar observation was reported by Ettema et al. (2005). The review highlights, therefore, the growing need for accurate self-report measurement of QOL for those with advanced dementia. The qualitative studies reviewed indicated that interviews employing semi-structured or unstructured frameworks could be successful in gaining meaningful information from those living with advanced dementia about their QOL (Clare, Rowlands, Bruce, Surr, & Downs, 2008; Cahill & Diaz-Ponce, 2011).

It seemed as though there were numerous advantages from using a qualitative method for collecting information from those living with dementia, and therefore this was the methodology adopted in the study. The empirical study invited participants to think about their QOL in the context of their diagnosis of dementia and to also consider their expected future QOL in light of advancing dementia. Given some of the challenges of communication

from those with advanced dementia, the study recruited those with mild to moderate dementia to think about the future. Thinking about the future of dementia was anticipated to be highly emotive and potentially very distressing for participants, therefore through the use of one-to-one interviews, participants could be asked difficult and challenging questions sensitively.

Participants described factors which impacted on their QOL such as reciprocal relationships, impact of skill loss and being supported by relatives. However, thinking about the future seemed more challenging for the participants. Some participants did express fear and uncertainty when asked to think about the future, and this was something that the majority of participants did not want to do. However, some participants expressed difficulties which their spouse or partner had when it came to considering the future and the terminal nature of the dementia. For some participants, having such conversations may be important and not doing so could be detrimental to QOL. This was discussed in the professional report for healthcare professionals, amongst other recommendations and clinical implications from the findings of the current study.

Perhaps some of the fear and uncertainty generated by thinking about the future in terms of dementia, which the participants expressed, was related to stigma and misperceptions about dementia. There is little research on the impact of stigma for those living with dementia (Mukadam & Livingston, 2012), most of the research is focused on psychosis (schizophrenia) and therefore, exploring stigma in the context of dementia was considered as a direction for future research. In the Dementia Strategy, the DoH (2009) drew attention to stigma and the social awareness of dementia; this has remained a matter of interest for the current government, reflected in multimedia advertising and other campaigns. Future research based on the findings of the current study, might focus upon ways in which stigma and the misperceptions about dementia could be further explored.

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The Self-Report of Quality of Life (QOL) for Individuals with a Dementia

1. Background Literature

1.01 Dementia

The World Health Organisation (WHO), (2012) define dementia as “a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities.” Dementia is not a term for one single disease, but describes a number of different types of cognitive deterioration. Common types of dementia include Alzheimer’s disease, vascular dementia, and dementia with lewy bodies and less common forms of dementia include fronto-temporal dementia (FTD), Creutzfeldt-Jakob disease (CJD) and Human Immunodeficiency Virus (HIV) related cognitive impairment. Adding to the complexity of dementia, dementia can also occur as a secondary illness to Parkinson’s disease and Huntington’s disease. Dementia is a progressive and deteriorative illness which impacts not only on memory but also on other cognitive functions such as attention and concentration, language, visuo-spatial skills and executive function (Alzheimer’s Society, 2013).

1.02 Dementia: Prevalence, Statistics and Projections

Traditionally, dementia was seen as an illness which affected older individuals, however, dementia is being diagnosed more frequently in younger individuals and is not a natural part of growing older (Alzheimer’s Society, 2013). The Alzheimer’s Society (2013) estimate that between the ages of 40 and 64, one individual in 1400 will develop dementia, between the ages of 65 and 69, one in 100 will develop dementia, between the ages of 70 and 79, one in 25 will develop dementia and over the age of 80, one in six individuals will develop dementia. These statistics highlight the number of individuals, younger than 65 who are

getting diagnosed with dementia as well as the number of individuals older than 65 developing dementia.

Currently, the number of individuals living with dementia in the United Kingdom (UK) is estimated at 800,000. By 2021, it is estimated that there will be over one million individuals living with dementia in the UK (Alzheimer's Society, 2013). The statistics are worrying for a number of reasons. Firstly, of those who live with dementia, many report that they do not live well with dementia (Alzheimer's Society, 2012). For example, 77% of individuals with dementia report feeling anxious and depressed, 75% feel society cannot meet their needs, 67% feel excluded from their community, 61% feel lonely at least some of the time, 48% of individuals with dementia feel like they are a burden on their family and 44% report reduced social contacts following diagnosis, taken from the report "*Dementia 2012: A National Challenge*" (Alzheimer's Society, 2012). Secondly, causing further worry are the financial implications of caring for those individuals living with dementia. Currently, it is estimated that the national expenditure is approximately 23 billion pounds (Alzheimer's Society, 2013). However, a vast amount of care is provided by informal caregivers (i.e., spouses and sons/daughters) which means the estimated expenditure of 23 billion pounds is likely to under-estimate the true figure (Alzheimer's Society, 2013). Informal care is currently estimated to be valued at 8 billion pounds (Alzheimer's Society, 2013).

1.03 Quality of Life (QOL)

Dementia can impact on quality of life (QOL). Quality of life may not only affect the individual living with dementia, but also the individual's family (Ready & Ott, 2003). Quality of life is defined by The WHO as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex

way by the person's physical health, psychological state, level of dependence, social relationships, personal beliefs and their relationship to salient features of the environment'' (cited in WHO, 1997, pp.1). Good QOL has become increasingly recognised as an important outcome for individuals living with dementia (Thompson & Kingston, 2004) and the present coalition government have requested National Health Service (NHS) Trusts measure patient outcomes for enhancing QOL in the presence of long-term health conditions (Health and Social Care Information Centre, 2012).

1.04 Quality of Life and Dementia

From reviewing a number of articles within this field, many authors referenced the work of Lawton (1983, 1994). Lawton (1983) suggested that there were four key areas of QOL for older adults including psychological well-being, behavioural competence, objective environment and perceived QOL. Within this framework, objective QOL is depicted by objective environment and behavioural competence, whereas subjective QOL is depicted by psychological well-being and perceived QOL (Lawton, 1983). In relation to the QOL of individuals with Alzheimer's disease, Lawton (1994) suggested QOL could be measured by behaviour which can be objectively observed and measured. Observational assessments remain in use today, for example the Dementia Care Mapping (DCM) tool (Kitwood & Bredin, 1992). This is because for individuals with advanced Alzheimer's disease, they may lose the ability and capacity to verbally comment on their own QOL and for this reason, subjective states of individuals with dementia have not been measured as routinely but are likely to contribute to QOL (Lawton, 1994). Furthermore, Lawton (1994) argued that health related quality of life (HRQOL) has focused on deficits from average ability and the capacity which individuals lose to complete activities. A more inclusive QOL assessment should encompass states which seek to engage, uplift and enrich an individual's life, regardless of

whether or not an individual can complete an activity (Lawton, 1994). Therefore, in addition to behaviour and cognition, Lawton (1994) also suggested that more research should focus on internal states (emotions and feelings) and how we can measure internal states and their contribution to QOL.

1.05 The Needs of those with Dementia

The work of Tom Kitwood is also highly relevant when considering dementia. In his book *“Dementia reconsidered: the person comes first”* (Kitwood, 1997) Kitwood highlighted the importance of a person-centred approach and reported similar observations to Lawton (1994). Kitwood (1997) suggested that all individuals need love, and this need does not change for individuals with dementia. Comfort, attachment, inclusion, occupation and identity are five linked and overlapping needs which are essential for the care of individuals living with dementia (Kitwood, 1997). These five needs become more important with the development of dementia due to potential vulnerability and individuals perhaps becoming less able to meet their own needs independently (Kitwood, 1997). Kitwood (1997) argued that meeting one area of need (i.e., attachment) is likely to have an impact on other areas of need (i.e., comfort and identity) and if all areas of need are met, individuals with dementia should feel as though they have a sense of self-worth and of being valued. It is arguable that in meeting these five areas of need and increasing a sense of self-worth and value, it is highly likely that an individual’s perceived QOL may be enhanced, at least in part.

2. The Current Status of Dementia: National Policies

In 2009, the British government launched a new dementia strategy. The report, *“Living well with dementia: a National Dementia Strategy”* (Department of Health: DoH, 2009), adopted three key steps in order to improve the QOL for individuals with dementia and their caregivers. They were firstly, provision of better access for information about dementia and

the removal of stigma; secondly where possible, to ensure early assessment, diagnosis, treatment and support; and finally to develop better services which reflect the changing needs of individuals with dementia and their caregivers.

In 2010, a further policy document, “*Quality outcomes for individuals with dementia: building on the work of the National Dementia Strategy*” (DoH, 2010), was published with revised outcomes for individuals with dementia. The priority objectives of this report were good quality, early diagnosis and intervention, improved quality of care in hospitals, better living within care homes and reduced use of antipsychotic medication. In this new initiative, the coalition government wanted an outcome-focused approach to achieve better transparency of standards and monitoring and for individuals to be provided with better information. This was to ensure that individuals knew the standard of care to expect from services and how one service compares to another in terms of provision.

In March 2012, the Alzheimer’s Society published their report on how well individuals are living with dementia. The report aimed to understand how people lived with dementia based on what was important to them and monitored progress and opportunities for action. The Alzheimer’s Society (2012) found that 17% of individuals living with dementia reported that they do not live well with dementia, 55% reported that they live quite well and only 22% reported that they live well with dementia. Following this, a progress report on the dementia challenge was published (DoH, 2012). The focus was on three challenges. The first was to create better communities for individuals with dementia to live in. This included increased awareness and understanding about dementia, for individuals with dementia to feel included and have independence and control in their lives. So far this challenge has led financial institutions to develop dementia-friendly protocols and various schools in the UK have held classes on dementia understanding and awareness, in an effort to reduce stigma.

The second challenge which focused on healthcare examined timely diagnosis, better care in hospitals, community and care homes. Initiatives such as dementia risk assessments in hospitals have generated more referrals to memory services, achieved timely diagnosis and led to better and more understanding hospital care. There is little information in the progress report on improving care and standards for living well with dementia in care homes and more focus is given to timely diagnosis and living well with dementia in the community. The third challenge is about improving the quality of research for individuals living with dementia.

Finally, the Alzheimer's Society (2012) report that QOL remains variable for individuals living with dementia and QOL should remain a focus within the advancing research on dementia care.

3. Systematic Searching and Article Selection for Current Review

3.01 Objectives

Given the current focus of QOL in dementia in legislation and policy making, this review focuses on research which has explored QOL measurement for individuals living with dementia. Quality of life is highly subjective and individualistic and therefore a review of the recent published research examining the use of self-report methods was given particular attention. Articles across the stages of dementia (mild, moderate and advanced) were considered however, there is particular discussion on how such measures can be used with individuals in the more advanced stages and the methodological challenges for doing this.

3.02 Search Criteria

Wide search terms such as "quality of life", "QOL", "dementia" and "quality of life measure" were used to search four databases: Medline, PsycInfo, Scopus and Web of Knowledge. This retrieved a total of 1,794 papers published between 2002 and 2012. A very

recent ten year period was considered appropriate given the volume of work already completed in this area and the number of reviews already completed. Following exclusions (e.g., QOL of caregivers, depression and mood related conditions, other physical health problems including Parkinson's disease, quality of care and articles only investigating young onset dementia), 120 articles remained. The 120 articles were divided into four categories; 1) self-report QOL measures (18 articles); 2) investigation of the impact on one factor (e.g., music) on QOL (21 articles); 3) articles comparing self-ratings of QOL with proxy measurement (70 articles) and 4) overall discussions about QOL and dementia (11 articles). The current review focused on the first area; self-report QOL measures. Of the 18 articles in this area, six were selected for this review. The six selected were British and Irish papers (three qualitative and three quantitative) in addition to two reviews on QOL measures taken from the category of overall discussion about QOL in dementia. Such reviews (two) did report proxy measures of QOL in addition to self-report QOL measures, and were included to help understand how far this particular field of research has developed and to compare the number of self-report measures with proxy report measures. The 12 excluded articles were studies based in Spain, Australia, Taiwan, China, Germany, Holland and America where perhaps the status of dementia care and developments for QOL conceptualisation and measurement, are at different stages and adhere to different national policies. Whilst some of those countries may be ahead of the UK in terms of dementia and QOL and may have developments which as a country we could learn from, the studies conducted within the UK are more likely to reflect a similar healthcare system. Finally, articles including a proxy rating were excluded from this section (self-report QOL measurement), however, one paper is included which reported a proxy rating. The decision was made to include this article

because it was about the validation of a self-report measure, the proxy rated element of this article measured QOL with a different assessment to the self-report measure being validated.

3.03 Recent Reviews of Quality of Life Measures for Individuals with Dementia

Scholzel-Dorenbos et al. (2007) reported a review which investigated the application of QOL measures in dementia care. Nine measures were compared including:

- Alzheimer's Disease Health-Related QOL (ADRQL) (Rabins, Kasper, Kleinman, Black, & Patrick, 1999)
- Cornell-Brown Scale for QOL in Dementia (CBS) (Ready, Ott, Grace, & Fernandez, 2002)
- Discomfort scale – Dementia of Alzheimer Type (DS-DAT) (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992)
- The Dementia QOL scale (DQOL) (Brod, Stewart, Sands, & Walton, 1999)
- Measurement of health-related QOL for people with dementia (DEMQOL) (Smith et al., 2005)
- Qualidem (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2007)
- Quality of Life – Alzheimer's Disease (QOL-AD) (Logsdon, Gibbons, McCurry, & Teri, 2002)
- Schedule for the Evaluation of Individual Quality of Life (SEIQOL) (O'Boyle et al., 1993)
- Vienna List (Porzolt et al., 2004)

The measures were compared to see to what extent domains which individuals with dementia consider important for QOL, domains which professional caregivers consider as important for care recipients' QOL were represented and the psychometric properties of the measures were also assessed and reported (Scholzel-Dorenbos et al., 2007).

The authors found that no single measure could be used across all the stages of dementia and in all care settings. However, the SEIQOL, QOL-AD, DS-DAT and Qualidem were recommended as good measures because they incorporated both individuals with dementia and caregivers' opinions about QOL and they best represented domains of QOL which were considered important to both individuals with dementia and caregivers (Scholzel-Dorenbos et al., 2007). Between those four measures (SEIQOL, QOL-AD, DS-DAT & Qualidem), Scholzel-Dorenbos et al. (2007) reported that they can be applied across the different stages of dementia and in a variety of environments.

The authors recommended the use of the SEIQOL but the psychometric properties of the SEIQOL were not discussed within the main body of the paper and were only presented in tables. Examining the psychometric tables, the SEIQOL was the weakest measure in terms of internal consistency, required a trained interviewer to administer the measure and is not dementia specific. For the remaining recommended measures, the authors report the psychometric properties of the QOL-AD as favourable in the main text, a description supported by reliability values, but provide considerably less detail in reporting on the psychometric properties of the other recommended measures (DS-DAT & Qualidem). Looking at the table presented within the paper, reliability values for the Qualidem, range from moderate for internal consistency (0.60-0.90) and from moderate for inter-rater reliability (0.66 – 0.88) and higher for the DS-DAT.

Finally, in terms of self-report QOL measurement, the review reported by Scholzel-Dorenbos et al. (2007), included one self-report measure (DQOL). Even though the authors highlight the importance of self-ratings for QOL rather than proxy ratings of perceived QOL, psychometrically, the DQOL has only moderate to good internal consistency (0.60-0.89) and moderate to high coefficients also for test-retest reliability (0.64-0.90). Overall, it would

seem as though scales with better reliability values are generally obtained from measures which include proxy ratings of QOL or are observational; whereas for measures which are based entirely on self-report, reliability values tend to be lower (Scholzel-Dorenbos et al., 2007). This may lead health professionals to use proxy rated measures even though the difficulties with doing this are noted (Ready & Ott, 2003). This compromise (between good psychometric properties and self-report) may lead to greater unmet need for individuals with advanced dementia should proxy rated or observational measures be used in isolation. More research is needed to explore the advanced stages of dementia and the self-report assessment of QOL where observational or proxy rated measures are more likely to be used.

Ready and Ott (2003) reviewed literature on QOL and dementia from 1966 to 2002 including all articles which reported the development of QOL measures for dementia and assessments of the psychometric properties of the measures. Generic QOL measures were excluded as were measures of QOL for illnesses in which dementia may be a symptom (for example Parkinson's disease). Measures included:

- Activity and Affect Indicators of QOL (Albert et al., 1996)
- ADRQL (Rabins et al., 1999)
- CBS (Ready et al., 2002)
- DCM (Kitwood & Bredin, 1992)
- DQOL (Brod et al., 1999)
- Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP) (Burgener, Twigg, & Thorlton, 2002)
- Quality of Life in Late-Stage Dementia (QUALID) (Weiner et al., 2000)
- QOL-AD (Logsdon et al., 2002)

- Quality of Life Assessment Schedule (QOLAS) (Selai, Trimble, Rossor, & Harvey, 2001)

Ready and Ott (2003) reported that all the measures discussed were influenced by the QOL model presented by Lawton (1983, 1994), however there were differences with the application and implementation of the measures. Despite all the reported measures assessing QOL in individuals with dementia, all but one measure (DQOL) included proxy reports for QOL. Measures including Activity and Affect Indicators of QOL, ADRQL, DCM, PWB-CIP and QUALID did not include any self-rating element and measures including CBS, QOL-AD and QOLAS, included a self-rating element alongside a proxy rated measurement. Ready and Ott (2003) highlighted the difficulties with proxy rated measures of QOL due to the highly subjective nature of QOL, but acknowledged the challenges of self-report in the more advanced stages of dementia. In addition, proxy rated measures of QOL can be affected by caregiver burden and depression (Ready & Ott, 2003) which leaves any QOL score difficult to interpret. Individuals with dementia in the mild to moderate stages can comment on their own QOL (Trigg, Skevington, & Jones, 2007b) but this review indicates that between 1966 and 2002 only one measure for QOL (DQOL) in dementia has been developed which relies entirely on self-ratings (Ready & Ott, 2003) and highlights the need for further research focusing on the self-report of QOL.

Both of the reviews just considered highlight the difficulties with the assessment of QOL for individuals with dementia and report on the number of measures which are observational, are entirely proxy rated measures or include a proxy rated element. Also, both reviews describe the DQOL which is the only self-report measure included and highlight the ability of individuals with mild to moderate dementia to comment on their QOL. Despite both reviews highlighting the nature of the difficulties associated with including a proxy rated

measure for the assessment of QOL for individuals with dementia, the majority of measures continue to rely solely on, or at least include a proxy rated element, even for individuals with a mild to moderate dementia. This raises the question about those individuals with advanced dementia where they may be unable to use effective verbal communication to express their thoughts and feelings. Using proxy rated measures may become even more difficult to rely on as it is possible that as dementia advances, caregivers may experience more stress and burden which leaves the assessment of QOL of individuals with advanced dementia in particular, in need of more research. The use of proxy rated measures for advanced dementia also poses a further difficulty; perhaps as dementia advances, it becomes harder for a caregiver to imagine him or herself in the same position and judge another individual's QOL, perhaps leading inadvertently to unmet need.

3.04 Quantitative Articles

The reviews above provide detail to help selection of the appropriate measure and consider a number of QOL measures. In particular, the Scholzel-Dorenbos et al. (2007) and Ready and Ott (2003) reviews considered what the measures assess in terms of QOL, how the measures assess QOL and their psychometric properties. This part of the present review focuses on the description and critique of articles which focus on self-report QOL. The discussed articles report the DQOL and BASQID (Bath Assessment of Subjective Quality of Life in Dementia) and information extracted from them is displayed in the table below (see Table 1).

Table 1

Overview of the Quantitative Articles Reviewed

Authors and date	Scale	Main findings
Karim, Ramanna, Petit, Doward, and Burns (2008)	DQOL	DQOL considered a good and reliable self-report scale for QOL in mild to moderate dementia.
Trigg, Jones, and Skevington (2007a)	BASQID	BASQID was a reliable and valid scale for collecting subjective information about QOL in those with dementia.
Trigg et al., (2007b)	BASQID	BASQID was a scale which explains the experience and perceptions of those with mild to moderate dementia using a biopsychosocial framework.

Note: BASQID = Bath Assessment of Subjective Quality of Life in Dementia.

Trigg et al. (2007a) examined the reliability of an item pool of a new self-report measure for QOL in dementia (BASQID). This measure was developed following previously conducted in-depth interviews with individuals with mild to moderate dementia in an attempt to capture domains important in QOL. Based on 45 interviews, nine domains for QOL were selected as follows: “health”, “social interaction”, “function”, “mobility”, “occupation”, “energy”, “sleep”, “psychological factors” and “environment”. Within each domain different factors were included, for example, the domain “health” included satisfaction with physical health, mental health, pain and feeling unwell (Trigg et al., 2007a). A total of 44 items were included in the initial version of the measure and each item was rated according to how satisfied the respondent was (e.g., not at all satisfied, a little satisfied, satisfied, very satisfied

and extremely satisfied) and the intensity (e.g., not at all, a little, a moderate amount, quite a lot and a great deal). Higher total scores on the measure indicated better QOL. To assess the validity of the scale, a global rating for QOL was also included which also had a five item response scale.

Trigg et al. (2007a) recruited 60 participants with a diagnosis of dementia with a Mini Mental State Examination (MMSE), (Folstein, Robins, & Helzer, 1983) score of 12 (mild to moderate dementia) or above. Half of the participants (selected through quota sampling) were reassessed two weeks later to assess item stability. All but one of the participants were able to complete the 44 item measure but of the initial 44 items, 20 exhibited problems (i.e., poor validity and poor association with other items). These were therefore excluded from the item pool which left 24 items. For the 24 item measure, Trigg et al. (2007a) reported good internal consistency (Cronbach's coefficient alpha: 0.91) and test-retest reliability was favourable with a correlation coefficient of 0.82 over a two week period. Trigg et al. (2007a) concluded that the reduced item pool for the BASQID (24 items) is a reliable and internally consistent measure which can be used to assess self-reported QOL of individuals with dementia over time. The authors also highlighted differences between the BASQID and existing QOL measures such as the DQOL and the QOL-AD because it not only includes questions about feelings as in the former measure (DQOL), but also includes the opportunity to appraise different areas (Trigg et al., 2007a). Similarly to the QOL-AD, the BASQID allows for activities which may be completed but judged to have a poor performance. However, the BASQID can still produce high levels of satisfaction with those activities unlike the QOL-AD (Trigg et al., 2007a).

In their second paper, Trigg et al. (2007b) continued with modifications to the BASQID and reported the psychometric properties of the final measure. The study consisted

of two stages; the first examined item reduction and analysis and the second determined the psychometric properties. For stage one, 60 participants were recruited and a different set of participants (150 participants) for stage two. All participants had a confirmed diagnosis of dementia, obtained an MMSE score of 12 or above and attended a memory clinic (Trigg et al., 2007b). Firstly, item reduction processes of the original 44 item version of the BASQID were analysed alongside the Geriatric Depression Scale (GDS) (Skeikh & Yesavage, 1986). Trigg et al. (2007b) also asked caregivers to complete the World Health Organisation Quality of Life (WHOQOL-BREF), (WHOQOL group, 1998) for validation purposes (asking participants to complete another measure was deemed excessive by the authors). Half of the participants at this stage participated in measure stability analyses. Secondly, in assessing psychometric properties, the authors invited participants to complete the MMSE score to explore the relationship between cognitive ability and QOL (Trigg et al., 2007b). Within stage two, a subset of 36 participants who had started acetylcholinesterase inhibitor treatment for Alzheimer's disease were tested twice (with a three month interval), for the responsiveness of the measure to clinical change (compared with a clinician rating scale).

Trigg et al. (2007b) retained items from stage one based on their psychometric properties (items were retained if their eigenvalue was above 1.0 and were eliminated if they failed to load at least 0.4 on any factor or if they loaded on more than one factor) which left 14 items for stage two analysis. The resultant scale was reported to have high internal consistency (Cronbach's alpha: 0.89), which remained acceptable when the scores were separated into three groups depending on MMSE score. Test-retest is possible given there were no significant differences between time points one and two (although this was taken from stage one data; 44 item measure of which the remaining 21 items were embedded within). In terms of construct validity, as expected there was only moderate correlation with

the GDS and low to moderate correlation with the WHOQOL (Trigg et al., 2007b). Furthermore, discriminant validity was also supported as there was no association between the BASQID and MMSE score. Content validity was considered acceptable given the construction of the items within the BASQID was based on qualitative interviews (Trigg et al., 2007a). The sub-sample in stage two examined responsiveness and analyses produced small effect sizes with results which did not reach significance. Based on their analyses, Trigg et al. (2007b) concluded that the BASQID (14 item measure) is a short and effective instrument for the measurement of self-report QOL for individuals with mild to moderate dementia (Trigg et al., 2007b).

Finally, Karim et al. (2008) replicated the original DQOL study which is an American measure of QOL (Brod et al., 1999) and sought to modify it if for use with a UK population. The D-QOL is a 29 item measure which includes scales of “self-esteem”, “positive affect/humour”, “negative affect”, “feelings of belonging” and “sense of aesthetics” (ability to notice and appreciate surroundings) which are rated with a five item response scale.

The study consisted of three stages; adaptation, piloting and validation. Firstly, the researchers and a panel of lay individuals examined the measure making several changes to language and wording to ensure that the measure would be interpreted as intended by a UK population. Secondly, 15 participants with mild to moderate dementia (MMSE score ranged from 12-23) with an age range of 70-87 years, piloted the measure and further, small changes were made to wording. Thirdly, the final version was validated using 36 participants with a mean age of 78 (ranging from 60-92) and who all lived at home; some were cared for by their spouse or son/daughter and the remainder had formal caregivers. The participants within this stage were asked to rate their level of cognitive ability (most rated it as moderate), their

perception of their general health and QOL. In addition, participants were invited to complete the MMSE (although the scores are not reported).

The authors found that the DQOL is a stable measure given there were no significant differences in MMSE scores and DQOL scores following a two week interval (Karim et al., 2008). The measure was reported as having an acceptable level of internal consistency (Cronbach's alpha was generally around the 0.70 level for all sub-scales) except for "feelings of belonging" which was lower (0.56-0.71). For construct validity scores were likely to be affected by the small sample sizes; however, at time point one correlations ranged from 0.01 to 0.75 and at time point two, correlations ranged from -0.24 to 0.76 (although no table is presented for time point two correlation values). "Sense of aesthetics" correlated poorly with all other scales at time point one and two, whereas correlations between the other scales "self-esteem", "negative affect", "positive affect" and "feelings of belonging" were adequate. Convergent validity was limited to a small number of significant correlations (Karin et al., 2008). The authors concluded that the UK version of the DQOL is a valid instrument for measuring the QOL of individuals with mild to moderate dementia.

3.05 Summary and Critique of Quantitative Articles

Karim et al. (2008) concluded that the UK version of the DQOL obtained similar validation scores to the original study, however, the authors did not reproduce all the values reported by Brod et al. (1999) and only reported the range of correlations for construct validity. Reviewing the findings by Brod et al. (1999), however, this is only in part true for some of the values found in the study reported by Karim et al. (2008). Furthermore, whilst the reliability of the DQOL (UK version) is supported, the construct validity scores reported by Karim et al. (2008) are perhaps confusing and insufficient. For construct validity, discriminant and convergent validity scores should be reported (Campbell & Fiske, 1959) but

it would seem that the authors do not report any discriminant validity scores which leaves it difficult to ascertain whether the measure has construct validity. In fact, for convergent validity, the authors include self-perceptions of cognitive ability and whether the DQOL can distinguish between different levels of perceived dementia severity. Evidence suggests that dementia severity and QOL are not associated; that severe dementia is not associated with poor QOL (Trigg et al., 2007b) yet it would seem (although not explicit) that the authors suggest that dementia severity and QOL are associated by including them in convergent analyses. The reduced clarity of the reported findings in this article perhaps prevent an accurate understanding for the analyses conducted by Karim et al. (2008). In fact some of the correlations and p-values reported in the article by Karim et al. (2008) do not support the measure as well as the authors suggest they do and perhaps the evidence is weaker than the authors suggest. In addition, Karim et al. (2008) recruited participants who lived at home; however, whilst all participants did so, they were cared for by a range of caregivers (spouse, adult children and formal caregivers) which may lead to very different experiences of care which may impact on QOL. This may have impacted on the validation scores reported by Karim et al. (2008).

Both articles, Trigg et al. (2007a) and Trigg et al. (2007b) report the BASQID as a newly developed, self-report QOL measure for individuals with mild to moderate dementia. However, the studies reported by Trigg et al. (2007a & 2007b) are unclear in terms of their item reduction (initially 44 items resulting in 14 items). Initially, Trigg et al. (2007a) reported the BASQID as a 44 item measure and following item reduction analyses, left a 24 item measure. Following this paper, Trigg et al. (2007b), returned to their 44 item measure, scaled this down to 21 and then to 14 (the measure is finalised as a 14 item measure). Whilst both papers independently are clear, it is confusing why the authors in their first paper reduce

the measure from 44 items to 24 items, and then in their second study, reduce the measure from 44 items to 21 items. The authors in their second paper (Trigg et al., 2007b) do make reference to their initial item reduction (Trigg et al., 2007a) but the lack of continuity between the papers is confusing for the reader, leading to uncertainty about what was different between the two item reduction processes which left a difference of three items. There also seems to be a discrepancy between the number of interviews conducted to initially determine the areas of QOL to be included within the measure. In their earlier paper, the authors report 45 interviews (Trigg et al., 2007a) and in their later paper the authors report 30 interviews (Trigg et al., 2007b). Furthermore, Trigg et al. (2007b) included a sub-sample of participants who had recently commenced acetylcholinesterase inhibitor medication to potentially slow the effects of dementia. The authors included this sample to investigate how responsive the BASQID was to clinical change over a three month period (Trigg et al., 2007b) by comparing BASQID ratings to a clinician QOL measure. This leads the reader to assume that the authors anticipated that the acetylcholinesterase inhibitors would actually have an effect and slow cognitive deterioration and that this could lead to changes to QOL. This is contrast to their earlier and expected finding that BASQID scores were not associated with dementia severity.

Finally these articles suggest that the measurement of self-report QOL for individuals with dementia is progressing forwards. However, the research was with individuals with mild to moderate dementia and does not shed any light on the self-report measurement of QOL of those with more advanced dementia. The authors do not suggest any possible modifications which could be made to accommodate some of the difficulties which individuals in the more advanced stages may have.

3.06 Qualitative articles

Thus far, the reviews explored report on quantitative measures for exploring QOL in individuals with dementia. The following articles (see Table 2) by Cahill and Diaz-Ponce (2011), Clare, Rowlands, Bruce, Surr and Downs (2008) and Byrne-Davis, Bennett and Wilcock (2006) report qualitative studies which explore the QOL of individuals with dementia.

Table 2

Overview of the Qualitative Articles Reviewed

Authors and date	Aims and method	Main findings
Cahill and Diaz-Ponce (2011)	Thematic analysis to understand the QOL of those with advanced dementia in formal care	Relationships, activities, attachments and affect were all associated with good QOL. Lack of pleasurable activities within the environment
Clare et al., (2008)	IPA to understand the experience of living in formal care and the impact on QOL of those with moderate to advanced dementia	Participants expressed distress relating to varied losses, coping strategies for living in care with dementia, fear, uncertainty and lack of control.
Byrne-Davis et al., (2006)	Grounded theory in focus groups to understand QOL in dementia	Model of QOL suggests that those with dementia use an evaluation system to re-assess QOL when facing life changing events such as dementia.

Note: IPA = interpretative phenomenological analysis.

Cahill and Diaz-Ponce (2011) used a thematic analysis to explore the QOL of 61 individuals (male and female) living in nursing homes (mean average length of stay of two years and

nine months). The mean age of the participants was 85.3 years (ranging from 62 to 100 years) and the mean MMSE score was 12.6 (ranging from 1 to 26), with a range covering mild, moderate and severe dementia (Cahill & Diaz-Ponce, 2011). Data were collected using semi-structured interviews framed around a 15 item questionnaire including questions such as “what makes you happy?” and “what is it like living here?”

In their findings, Cahill and Diaz Ponce (2011) reported four key themes including; “social contact”; “attachment”; “pleasurable activities” and “affect”. “Social contact” encompassed factors such as family, fellow residents and staff, and the theme “attachment” included factors such as connectedness, feeling at home or missing home. The theme “pleasurable activities” encompassed outings, structured and unstructured activities and finally the theme “affect” included factors such as happiness, sadness, depression and loneliness (Cahill & Diaz-Ponce, 2011). The authors found differences within their sample based on the level of cognitive impairment, for example those who had advanced dementia expressed unhappiness with lack of social contact with family, staff and fellow residents as well as lack of engagement in structured and pleasurable activities (Cahill & Diaz-Ponce, 2011). In addition, participants with advanced dementia expressed momentary pleasures more frequently and were more likely than those with mild to moderate dementia to want to return to their previous home (Cahill & Diaz-Ponce, 2011).

Using Interpretative Phenomenological Analysis (IPA), Clare et al. (2008) explored the QOL of individuals with dementia living in residential homes, similarly to Cahill & Diaz-Ponce (2011). Participants were invited to comment on the subjective experience of living in long-term care to contribute to the improvement of the QOL and care for residents. The authors used an existing data set collected from 81 participants living in a total of 10 care homes including generic mixed care facilities, homes with separate specialised dementia care

units and dementia specialist units (Clare et al., 2008). The mean age of the participants was 83.4 years (ranging from 59 to 96 years) and the mean MMSE score was 9.76 (ranging from zero to 20) with the majority of participants scoring 11 or lower on the MMSE score, suggesting that the majority of participants had moderate to severe dementia (Clare et al., 2008). Data were collected using unstructured interviews.

Clare et al. (2008) reported four key themes which emerged from the data; ‘‘nothing’s right now’’ (including sub-themes of not knowing what is happening, loss, unhappy life, feeling no good and feeling frightened and wanting help); ‘‘I’m alright, I’ll manage’’ (with sub-themes of being okay here, individuals are friendly, individuals being helpful, others having their own lives, time goes on and I’m getting older and accepting that); ‘‘I still am somebody’’ (including sub-themes of reminiscence, good background, wish to return home, grateful for retained abilities and others worse off); and finally ‘‘It drives me mad’’ (with sub-themes of wanting to be active, wanting freedom and feeling like going crazy). Clare et al. (2008) concluded that the participants had developed ways to cope with living in an environment which they would not have necessarily chosen to live in. The impact of living in a nursing home was related to lack of control and uncertainty which was exacerbated by loss relating to the effects of dementia. This led to feelings of frustration and anger from the participants (Clare et al., 2008). Feelings of loss were also related to lack of personal and positive relationships for the participants in the study which led to feelings of distress, resulting in feeling alone and disorientated. Clare et al. (2008) concluded that long-term care for individuals with dementia needs to be improved urgently with a focus on allowing residents the opportunity to become engaged in appropriate activities and occupation, as well as encouraging autonomy and personal agency.

Finally, using grounded theory methodology, Byrne-Davis et al. (2006) aimed to create a model for the construct QOL in dementia. Twenty five participants were recruited for the study whose ages ranged from younger than 65 years to older than 80 years (exact ages were not reported). However, the mean average MMSE score was reported at 13.5 (ranging from two to 25), 12 participants had moderate to severe dementia and all the participants lived in the community. Participants were invited to take part in focus groups and consider questions such as “how would you describe your quality of life?” and “what gives your life quality?”

Themes found by Byrne-Davis et al. (2006) included “relationships”, “financial security”, “physical environment”, “spirituality” and “psychological well-being”. Based on the themes, Byrne-Davis et al. (2006) proposed a model based on three cognitive processes. Firstly, coping mechanisms can be a way in which QOL is evaluated e.g., if individuals make appraisals which result in dissatisfaction, resources are then evaluated to cope with that issue. Secondly, social comparisons can be made to enhance QOL judgements (e.g., another individual also with dementia could be perceived as worse off than him or herself) and that dispositional factors could impact on QOL appraisals through social comparisons (such as own self-efficacy compared to another individual with more advanced dementia). Thirdly, happiness could be seen as a way of contributing to QOL (e.g., happiness is not the same as QOL, but the authors theorised that individuals use a measure of happiness to evaluate their QOL), (Byrne-Davis et al., 2006). Therefore the authors suggested that QOL assessment by individuals is informed by a process of evaluation of issues important to that individual. Coping and response shift processes help individuals to cope with issues which may impact on QOL and such processes (coping and response shift) are present in the way individuals usually deal with life in general and are not specifically related to illness. Quality of life therefore, can be conceptualised as being influenced by external factors, social

comparisons and dispositional factors and when external conditions change, ways of normal adapting will bring the appraisal of QOL to the level it was at previously (Byrne-Davis et al., 2006), however, this will vary between individuals according to the number of external (e.g., social supports) and dispositional (e.g., coping style) factors. In terms of healthcare, the authors concluded that if an individual was unable to participate in an activity, this would usually require an external intervention in order to raise the perception of QOL. However, the model suggests that it would be possible to raise QOL using dispositional processes alone, rather than external interventions (Byrne-Davis et al., 2006).

3.07 Summary and Critique of Qualitative Articles

Cahill and Diaz-Ponce (2011) and Clare et al. (2008) clearly demonstrated that individuals with more advanced dementia are able to comment on their own QOL using qualitative methods such as interviews, which is in contrast to the use of psychometric assessment measures such as the studies described earlier.

Cahill and Diaz-Ponce (2011) and Clare et al. (2008) clearly reported data which illustrated how they had arrived at the themes generated from the analysis which allows confidence in their findings. In addition, Cahill and Diaz-Ponce (2011) focused their findings towards the more advanced stages of dementia which is encouraging as the majority of the existing research focuses on the mild to moderate stages. The findings of Cahill and Diaz-Ponce (2011) are also reminiscent of Kitwood's (1997) theory of the psychological needs of individuals with dementia. Their findings that participants with more severe dementia reported that the nursing home was not their home and they wanted to return home, may be reflective of the attachment and comfort needs of individuals with dementia (Kitwood, 1997). The findings from Clare et al. (2008) for the need of occupation and autonomy, are also reminiscent of Kitwood's (1997) theory.

However, Cahill and Diaz-Ponce (2011) identified the lack of proxy-ratings to confirm self-ratings of QOL as a weakness of their study. This seems in contrast to the authors' suggestion that self-ratings of QOL are a gold standard which perhaps suggests the authors lack confidence in their findings. In clinical practice, having proxy ratings in addition to self-ratings raises the dilemma about which is given more weight should the ratings differ. Potentially, this could mean that the QOL needs of individuals with dementia go unnoticed.

The study reported by Clare et al. (2008) utilised data from a large number of participants (81) compared to the recommended number of participants for IPA which is four to ten (Smith, Flowers, & Larkin, 2009). It is unclear how much time was given for the analysis and how many researchers analysed the data for such a large number of participants. In addition, the sample consisted of participants ranging in age from 59 – 96 with similar age ranges reported by Cahill and Diaz-Ponce (2011) and Byrne-Davis et al. (2006). Such an age range included individuals with an early onset diagnosis of dementia and it is likely that an individual with a younger onset dementia may have very different ideas about QOL in dementia compared to an individual with a later life onset of dementia. It is unclear from both sets of findings what influence this may have had within the themes generated from the analyses.

Finally Byrne-Davis et al. (2006) reported that a diagnosis of dementia does not affect QOL differently to other events in life and the way in which QOL could be reinstated after the event, requires the same processes which are automatically applied to deal with other life events (Byrne-Davis et al., 2006). This proposal from their model should however, be interpreted with caution as the authors included participants in their sample who did not have enough insight to know (or remember) that they had a diagnosis of dementia and the impact of this is difficult to evaluate. In addition, the model suggests that external interventions are

not always required because individuals with dementia may use internal and dispositional strategies to cope with changes to their perceived QOL (Byrne-Davis et al., 2006). Within the context of healthcare this is a positive proposal because it suggests that individuals with dementia are not passive within their environment and may retain skills to cope with any challenges and difficulties which may arise. However, it may also encourage health professionals not to try to make modifications to the environment to help improve QOL and therefore perhaps it is more useful to emphasise that a combination of external and internal factors could help in the improvement and enhancement of QOL.

4. Conclusion

Given the large number of individuals estimated to be living with dementia by 2021 (Alzheimer's Society, 2013) and the number of individuals who currently report not living well with dementia, it is not surprising that the care of individuals with dementia in this country requires urgent change. In the absence of a cure for dementia, the shift in focus to QOL requires a healthcare system which is proactive and responsive and can evaluate the QOL of those living with dementia in a meaningful way.

The articles reviewed highlight the developments which have been made in the last ten years regarding the assessment of QOL of individuals with mild, moderate and advanced dementia which are promising. From the research reviewed, it would seem that quantitative QOL measures can be useful with mild to moderate dementia, can focus on different aspects of QOL and be used in a number of different environments. However, there is an added complication when QOL measures include proxy rated elements (which seem to be the majority) or are entirely proxy rated. With the presence of proxy ratings which may be different to self-ratings, health professionals could be faced with the challenge of which ratings to give more weight to or the challenge of finding of a compromise. Furthermore, the

difficulties of relying on proxy rated assessments of QOL include the often reported discrepancy between self-ratings and proxy ratings of QOL which are well documented (Ready & Ott, 2003). Therefore, whether the measure has a proxy rated element or is entirely self-report, potentially the individual with dementia may be faced with not having their needs met in terms of QOL. However, the self-report quantitative QOL measures reported were found to have compromised psychometric values which highlight the dilemma between the degree of importance attached to this and employing quantitative measures which include or are entirely based on proxy ratings, but have better psychometric properties.

If self-report methods are to be considered a gold standard (Cahill & Diaz Ponce, 2011) for the measurement of QOL it would seem that qualitative methodology is a more appropriate way of enabling individuals to comment. It would also seem that this method of assessment is appropriate for those with mild and moderate dementia. However, the number of studies which have employed qualitative methodology is much lower than studies which employed quantitative methodology. Given that the report *Dementia 2012: A National Challenge* (Alzheimer's Society, 2012) reveals the variability of how individuals are living with dementia, perhaps a qualitative approach would provide the opportunity for individuals to comment on the wider aspects of QOL which may perhaps be areas of QOL not covered within quantitative measures.

Research has focused on the stages of dementia and which measures and methodologies may be most appropriate for use during those different stages and in which environments. It could be argued that whilst dementia can be split into mild, moderate and advanced stages, the individual lived experience within each stage is likely to be very varied. With this in mind, perhaps a phenomenological approach to account for the individual

experience of dementia and QOL would provide a meaningful approach and one which could be applied proactively.

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Can Individuals Living with Dementia think about their Future Quality of Life (QOL)?

Abstract

Purpose: Care of those living with advanced dementia in formal settings should focus on person-centred approaches; however this is not without challenge. As dementia advances, individuals may lose the ability for effective verbal communication which may lead to some needs going unmet. The present study aimed to explore what constituted quality of life (QOL) within the context of dementia and whether participants could consider their QOL in the future as a way of informing their own person-centred care. **Design and Methods:** This was a phenomenological qualitative study which explored the lived experience of ten individuals living with dementia through the use of semi-structured interviews. The interviews were transcribed and analysed according to the principles of interpretative phenomenological analysis (IPA). **Results:** Participants were able to talk about a number of factors which informed QOL. However, whilst participants reported that thinking about the future was too difficult, to an extent, they did express thoughts concerning the future in terms of relationships and things important to them. **Implications:** The findings identified areas where healthcare services could help improve the experience of living with dementia. These areas include facilitating emotionally difficult conversations about death and dying with loved ones, helping the future with dementia feel less frightening and uncertain and the maintenance of meaningful relationships.

Key Words: Dementia, Person-centred Care, Relationships, Personhood.

Introduction

Recently, dementia has been a topic commonly discussed in the media, following advances in government policies and objectives. Dementia and long-term health conditions have become a priority for the National Health Service (NHS) which is not surprising given the financial spend in such areas (Department of Health [DoH], 2013). For dementia specifically, it is estimated that there will be over one million people living with dementia in the UK by 2021 (Alzheimer's Society, 2013) and according to the Alzheimer's Society (2012), many of those currently living with dementia report that they do not "live well" with dementia. How well individuals described living with dementia was based on what was personally important to them. Given the expected rise in the number of individuals living with dementia, enabling them to live well is of national interest and priority as current financial spend is not sustainable (DoH, 2013).

To enable individuals to live well with dementia and in the absence of a cure, attention has turned towards improving the quality of life (QOL) in a way which applies person-centred approaches rather than biological and medical approaches (Penrod et al., 2007). Quality of life can be described as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of dependence, social relationships, personal beliefs and their relationship to salient features of the environment" (The World Health Organisation: WHO, 1997, pp.1). Measures including the Quality of Life - Alzheimer's Disease Scale (Logsdon, Gibbons, McCurry, & Terri, 2002) and Dementia Quality of Life Scale (Brod, Stewart, Sands, & Walton, 1999) can be used to explore the QOL of those living with mild to advanced dementia. Such measures can be applied usefully

and meaningfully with those who have mild to moderate dementia; for a review see Ready and Ott (2003). However, there can be challenges with the administration of such measures with those living with advanced dementia where difficulties may arise and participants may not be able to respond to some of the questions (Hoe, Hancock, Livingston, & Orrell, 2006). Advanced dementia can impact on verbal communication and comprehension which can mean that individuals may not understand the questions asked, or may not be able to respond verbally, or in some cases both, which could make it difficult for those with dementia to express and have their needs met (Johnson et al., 2009). As a solution, proxy ratings from formal and informal caregivers have been utilised. However, due to the highly subjective nature of QOL when proxy ratings from caregivers and self-ratings have been compared, there are often discrepancies (Sloane et al., 2005). Discrepancies can occur due to caregiver burden and depression which can inadvertently affect proxy ratings (Vogel, Mortensen, Hasselbalch, Anderson, & Waldemar, 2006) which suggests the need for the self-report of QOL for those living with advanced dementia.

For some of those living with advanced dementia, nursing or residential home care may be required. For some, this can be a traumatic experience given the loss of a number of attachments simultaneously (Browne & Shlosberg, 2006). When this occurs, for some this could manifest in what is termed “challenging behaviour” including behaviours such as calling out and aggression (Andrews, 2006) which are thought to reflect unmet need (Stokes, 2000), and perhaps indicate poor QOL. Kitwood (1997) reported that the experience of care directly impacts on QOL and Sloane et al., (2005) found that individuals with dementia living in nursing and residential homes have poorer QOL than those living in the community. The incidence of challenging behaviour on the part of those living with dementia in nursing and residential home care is estimated at just under 73% of those surveyed (Alzheimer’s Society,

2013). In recent years there has been a drive to reduce the use of antipsychotics for the treatment of challenging behaviour (Banerjee, 2009) which indicates a need for psychologically based approaches (Ballard & Corbett, 2010).

Qualitative approaches for exploring QOL of those living with dementia can be useful for exploring meaning and lived experience which quantitative research cannot always capture (Beuscher & Grando, 2009). There were two aims for the study; firstly how QOL was conceptualised and secondly whether individuals with mild to moderate dementia can consider their future needs in order to maintain and enhance QOL. In essence, the research question was: can individuals with dementia inform their own future, person-centred care, should they lose the ability for effective verbal communication?

Method

Participants

Ten participants aged between 65 and 88 years old, including five females and five males were recruited for the study. All were white (British). They had mixed levels of education and socioeconomic status. All participants had been diagnosed with dementia and received support from a community mental health team (CMHT). All participants lived at home and were supported by their spouse, apart from one participant who lived alone but was supported by her daughter. The majority of participants had Alzheimer's disease dementia (six), two had vascular dementia, one had mixed dementia and the remaining participant had fronto-temporal dementia. The amount of time participants had lived with dementia varied between six months and six years; however, all participants retained capacity to consent to take part in the study. Capacity to participate was important because inviting participants to think about their future in relation to their dementia was highly emotive. All participants had been

diagnosed with dementia for at least six months; this was considered a long enough period of time to adjust or at least have begun to adjust to their dementia diagnosis.

Sampling Procedures

Participants were recruited from an older people's CMHT in the North West of England. The lead researcher regularly met staff of the employing NHS Trust and gave verbal presentations to assist with the recruitment for the study. Clear inclusion criteria were presented including: 65 years or older, male or female, confirmed diagnosis (excluding young onset dementia) for at least six months, lived in the community, retained capacity to consider participation and retained ability to participate in an interview. Exclusion criteria included young onset dementia, those without a confirmed diagnosis, those newly diagnosed with dementia, those already living in formal care and those with significant co-morbid mental health or physical health conditions. Those with mood disorders were not excluded from participating because change in mood often accompanies a diagnosis of dementia, however, those who were experiencing suicidal ideation at the time of recruitment were excluded and those with major speech impediments were excluded for transcription purposes. Of the 14 individuals approached to participate in the study, ten (71%) consented to participate.

Study Design

This was a qualitative study, employing interpretative phenomenological analysis (IPA) which recommends data collection between four and ten participants (Smith, Flowers, & Larkin, 2009). Due to the nature of the sample it was anticipated that 60 minute interviews may be too long, therefore ten participants were recruited for the study to participate in interviews planned to last approximately 40 to 60 minutes, though this was dependent on the ability of the participants.

Interview Content

Data were collected during interviews using a semi-structured questionnaire (*Appendix A*); participants took part in one interview only. Questions were formulated in accordance with the research objectives and designed not to be leading or closed, for example: “Can you tell me about a time when your dementia got the better of you?”, “Can you tell me about what is important for you at the moment?” and “Can you tell me how your dementia may impact on your quality of life in the future?” Following the interviews, participants were invited to take part in an optional focus group to take place at a later stage to discuss the validity and provide feedback on the themes which were drawn from the data.

Procedure

Eligible participants were identified by the CMHT and were given information leaflets about the study. They were asked if the lead researcher could telephone them to answer any questions they may have. If at that stage the potential participant agreed initially to take part, an appointment was made for the interview to take place (at a location of their choosing). Participants were also asked if they wanted to receive a copy of the questionnaire in advance. Due to the potentially distressing nature of the research, safety protocols were put in place and where possible, the lead researcher asked that the participant had someone (of their choosing) with them at the time of the interview (although that person did not need to be in the same room where the interview took place). Where this was not possible, the lead researcher asked the participant for next of kin contact details who could be contacted if necessary. Participants were also advised that should they become very distressed the researcher would contact the CMHT to arrange for a follow up telephone call or visit depending on the level of need. At the interview the researcher obtained informed consent after assessing capacity (that the potential participant was able to weigh up taking part against

the risks associated with participating) and were assured that they could withdraw at any time. All interviews were conducted by the lead researcher only. Two participants became distressed during the interview which was then paused; both participants wanted to resume the interview, which the researcher was in agreement with. Interviews lasted between 25 minutes and 70 minutes and were guided with a semi-structured question format. Interviews were transcribed verbatim and were analysed using IPA methodology. Once the data had been categorised into themes, participants were invited to a focus group as part of the respondent validation process. Five of the participants attended this meeting and were asked to comment on their individual quotations and whether they thought the themes were an accurate reflection of what they discussed. The lead researcher spoke to each participant at the group separately in order to address this. Ethical and local NHS ethical requirements were met by the research team.

Data Analysis

IPA explores the meaning which individuals ascribe to living with particular experience and for this reason IPA is especially appropriate within healthcare. IPA invites individuals to explore how they make sense of and understand a particular condition and through using a thorough and complex interpretative analysis, attempts are made to access an individual's inner world and their thoughts associated with it. In this sense, IPA is an idiographic methodology.

Analysis takes place across several stages. Initially, transcripts were read and re-read to allow the researcher to become fully immersed within the data, this was assisted through the use of listening back to the interviews whilst reading them simultaneously. Secondly, the transcripts were examined for descriptive, linguistic and conceptual comments during this noting stage following procedures specified by Smith et al. (2009). Following this stage, the

transcripts were examined individually for emergent themes; this process was repeated twice and validated to ensure the emergent themes were well grounded in the data. Once emergent themes had been developed for all the transcripts, the emergent themes from each transcript were examined for similarities and formed into clusters. This was repeated for each transcript to allow for individual differences in line with this phenomenological approach. Finally, at the group-level analysis stage, the clusters across all the transcripts were compared with each other and arranged into group level super-ordinate themes. An extract detailing the process is presented (see Table 1). Within each super-ordinate theme, sub-themes were identified and illustrated with direct quotations with aliases to ensure anonymity (*Appendix B*). To ensure validity, the lead researcher was involved with every transcript and the rest of the research team took a number of transcripts each to compare notes and thoughts with the lead researcher and any differences were reconciled through discussion. In addition, a focus group was held with the participants to allow for their feedback on the super-ordinate themes and quotations and again, any differences were resolved through discussion.

Table 1

A Transcript Extract to Illustrate Analytical Procedure (Alice)

Transcript Extract	Initial noting	Emergent Theme	Subtheme	Super ordinate theme
“But you can manage to, to work things out, and to sort things out and to look after things and to look after the family things.”	Use of words manage and cope, realistic targets not expecting too much of herself.	Realistic of targets and capabilities.	Healthy adjustment.	Integrating dementia.

Results

The lived experience of QOL within the context of a dementia diagnosis revealed eight key themes: “focus on relationships”, “sense of self”, “integrating dementia”, “psychological needs”, “personal experience of dementia”, “sense of finality”, “hope” and “dementia as a social problem.” The group super-ordinate themes and the related cluster themes are presented (see Table 2).

“Focus on Relationships”

The impact of dementia on relationships was variable, for example, one participant spoke about how dementia created more conflict within relationships: “Been married nearly what, 50 odd years and for the first 50, I don’t we said a bad word to each other, but recently there have been” (Rod). Another participant discussed the impact of dementia on his relationship with his wife when they socialised: “Not putting things right together in front of people when Barbara’s in their company, that’s when I want to go away. I don’t want her to suffer if, if I’m here and I’m losing for want of a better use of words again, my marbles” (Jim). This led to discussions about the supportiveness of those relationships, sometimes positive and other times less than positive. For example, one participant spoke about feeling safe: “Because I’m in a, in a position with a, a big, a good family and friends I tend to feel as if that’s given me a comfort zone” (Ted). Conversely Rod spoke about his feelings in relation to the support he received as less positive: “Well Sharon is very good, she always has been, but I think she might be getting a bit fed up of me.” Beyond supportive relationships “Burden” was talked about for example: “If it got any worse, and nobody, you know, if I was a pain to anybody, I wish that God would take me, I wouldn’t want to be here” (Rose). Finally, it also seemed important that the participants were supportive of their loved ones: “I look at people,

and I'm sympathetic to them, and I'm kind to them, I hope, and in the same way as I've always been, and caring about people, and I don't ignore them" (Alice).

“Sense of Self”

This theme seemed reminiscent of Kitwood's (1997) theory of personhood, that despite an illness characterised by loss, retaining identity remains possible. Some participants spoke about ways in which they had retained their sense of personhood in the context of changing ability: “As far as I'm concerned, you, it might take you a bit longer to, to do things, but you still do the same things, and you still look out of the same eyes and still see the same things, so it's, it's no change” (Alice) and Rose: “I still bite my nails like mad, erm, I've always been a worry, haven't I? All, all my life I worried, I hated school, every second of school, and I can still think of school with that worry, and hatred”. There were discussions about inclusion and maintaining connections which appeared to help participants retain some aspects of their sense of self. For example, one participant talked about her positioning in the family and not standing out: “That's how it, how I've been, you know. You can't be er, sit one side and look at things differently, when you're one of seven children can you? You've got to get on with it haven't you” (Rose). Other participants talked about finding commonalities and similarities with other individuals and took comfort from this: “When I'm with the group I can be just myself, er, not having to think about things as much cause you are just talking and, erm, and but forgetting is, is so easy” (Ted). Finding commonalities with peers perhaps helped participants make sense of and retain their sense of identity within the context of illness characterised by loss. Finally there was a sense of relationships feeling reciprocal, remaining active within relationships, confirming and retaining personhood: “I think that you've got to feel that when you meet people, they smile naturally, and they don't move them, and I don't feel that at all, I feel that one is open to them and they're open to us”

(Alice) and Rose talked about teamwork: “Well we go to the shops together mostly. It’s a very combined operation that we have, if that’s the right word”.

“Integrating Dementia”

Some participants described a period of adjustment indicative of a process which took time. For example, one participant reported an initial period of shock with diagnosis which was followed by a period of time where she accepted dementia as part of her life: “It’s just the first, when I first got to know, I was shocked, you know, for a few months actually, it did affect me, cause I lost a lot of weight, went down to 8 stone, from 9 stone 4, but I’m creeping up now” (June). Another participant spoke about accepting changes in ability: “I mean you try to keep everything looking spick and span, but if one didn’t manage that, well, so what? It could be remedied” (Alice). However, some participants conveyed a sense of being forced and controlled: “Well, it’s a thing, you think, you think of family at first, and then I, I convinced myself that it’s about, well, hell, I’ve got it, that’s it, nothing, nothing you can do about it is there? You’ve got to, you’ve got to commit yourself on that one, there’s nothing I, you can do” (Alan) and: “I suppose when something really takes over your brain, it’s out of your hands, there’s nothing you can do about it, is there” (June). Some participants talked about ways which seemed to facilitate adjustment; social comparison to others who they perceived as worse off was discussed. For example: “I don’t know what the clinical definition is, but I don’t know, I feel that, oh there’s a lot of others worse than me, I don’t think of it as that, I mean I might forget the odd things, but I don’t think of it as dementia” (Alice). Other ways in which participants facilitated the process of adjustment included trying not to worry: “But then I think well there’s no point in thinking about it now, it’ll happen when it’s going to happen” (Janet) whereas others focussed on taking one day at a time: “I’ve just got to take it in step by step then I can do it at times” (Ted).

“Psychological Needs”

Most participants talked about direct losses as a result of dementia: “I can’t read now at all, to, to, to make them, because you, when I put that through there, and I then go, no there’s another one there, by, by the time I get to there, it’s gone” (Jane). Consequently, some participants appeared to experience psychological difficulties following the loss of skills: “Yeah, it’s made, it’s made me hopeless at doing things, such as, if I wanted to go out, and make a competition, or make a, something, I’m stupid about it” (June) which seems indicative of further loss (self-esteem and confidence). For some participants, there were more intense emotional reactions reflecting grief and bereavement for example: “I felt what the use of crying about it, but I just felt so, I’d got nothing.....Nothing at all” (Jane) and: “I know I’m not going to achieve what I want to achieve with her” (Jim). Loneliness was a recurring thought: “It might be not seeing as much, because I don’t go out with other, I stay in the house most of the time” (Rod) and Jim expressed frustration with lack of company: “I just said because I’m on my bloody own all day, that’s why I want a bloody dog, I may as well talk to the dog as four walls, and that was another one, I was getting lonely sitting in the house.” Some participants seemed to develop ways to manage some of their emotional needs through reminiscence: “I feel I’d like to go back to the south end to (location), because I have got a lot of friends there, school there, teachers there, churches there, er and sometimes, between you and I, er, I’d like to return there” (Rod) and: “Always had a big family around me, and then I, I met Les, and er, I’ll tell you about my dad, my dad was a lovely man, very rough and ready, and ordinary, he’d be the first to tell you that wouldn’t he Les? And he said to, when I first said I was going out with this son of a minister, he said, son of a minister? He said, but he always said, he’s a, he’s a bloody fine fellow, but he’s a son of

a, a minister, but that doesn't matter. Now, that's my dad, but I love my dad, and I love my mum, so I've had a great family around me'' (Rose).

“Personal Experience of Dementia”

Dementia was described as a journey, characterised by periods of intensity and fluctuation. For example, one participant talked about times when dementia got in the way: “I felt me, because they understand and they they put me on the straight and narrow if, if I tend to lose the bit now and again” (Ted) and another spoke about deterioration: “At first it wasn't, it wasn't like that, but it's generally got a bit you know, more, and I think that that, as you're aware of it coming, more than you know, more than it has been, I think that's a bit more, you think, oh no, it's getting you know, so that's how I'd say it was” (Janet). Such findings suggest that the needs of individuals with dementia can change throughout the course of dementia, rather than remaining static. Some participants found their experience of dementia negative: “Sometimes we find it, and everything becomes clear, but then you come back out and you've lost that room again, it's as if the rooms are on a, you know, on a, say the, the rooms are mainly just, they spin round and then you can't find that room again, yeah” (Bill) and some appeared to live well, despite dementia: “Er, everything. I've got a good family, I've got a, I still feel that life even though I'm, you know¹” (Ted). Other participants also talked about the uncertainty about the future of dementia: “Well that's the frightening side of it, the unknown is is the important side that you need to know but it its its like throwing dice in the air and you, you sort of situations where to assess that its, unless it's being assessed many times over when in the past year it's that I've no idea” (Ted). Finally, some participants talked about dementia as one part of life: “And my daughter, the other daughter

¹ Some quotes used to illustrate themes appear to end mid-sentence. This is perhaps understandable in the context of dementia.

is going to try and find somewhere, there's quite a lot of things going on at the moment'' (Janet).

“A Sense of Finality”

Thoughts about endings were mixed; some expressed sadness: “I want my age to be different so I can live with my wife, that's the biggest worry I have. I don't want to go, I don't want to really go before my wife” (Jim), others acceptance: “Well it's, it's just a continuation of life” (Ted) and some related to fear: “So that's my one fear, that it gets worse, but it won't get worse, 'cause I ask God to help me” (Rose). In extending thoughts relating to life ending, some participants talked about leaving something behind, whether that was something concrete or something more abstract; however, both seemed of significance. Jane discussed leaving things for the welfare of her now adult children: “I would never, I'd never let the house go, even to go to stay with any of them, because that house is for the children, and I'd, I'd, I'd never pass it out, I'd never pass out” whereas Rose talked about the passing on of personal qualities: “Yeah, she, that's our daughter, she is, she's a, what is she?PA.....She's a lovely girl.....She's just like him, so you see, you can take a bow too can't you?” Finally, from some participants there seemed to be a sense of recounting their lives: “I've done a lot of interesting things. I've met interesting people, and, with my work, and my, my job was interesting in the company, and meeting people like famous person and people like that made life interesting, and so I was, I've been very happy with my life” (Alice) which may be reminiscent of participants reviewing their life as they approach the final stages.

“Hope”

In this theme, some participants expressed hope in relation to medical research developing better medication for dementia. There were expressions which suggested desperation for

help: “It makes me feel that I wish there was something they could do” (Janet) and desperation for dementia not to get worse: “Again I don’t think I can really, haven’t thought about that because I tend to feel, what I’ve been given I’m hoping gonna make me on a steady keel all the time” (Ted). Hope was also expressed: “When somebody tells you like, the doctor came and he said well I’ve got one on my books who’s had it for 10 years....Well, he may as well as given me a million pound, I felt that good when he went out” (Jim). Such findings reflect the desire which some participants felt about not wanting their dementia to reach the advanced stages and also perhaps, to reverse the effects of dementia all together.

“Dementia as a Social Problem”

In this final theme, some participants expressed thoughts consistent with social awareness and stigma. For example, participants commented on how knowledge about dementia appears to have increased through the media: “People are only just getting used to, to dementia, a lot of it is thanks to television, cause they’re showing a lot more, see they’re doing a lot of advertising” (Jim). Other participants commented on some of the stereotypes some individuals can hold about dementia: “It’s not a contagious disease, cause people seem to shy away when you say, you know, you’re, oh, you know, you’re a lunatic” (Bill). Such findings reflect how dementia can be perceived in society.

Respondent Validation Focus Group

The participants who attended the group were in agreement with the quotations and most theme headings. The subtheme “feeling like a burden” was originally called “burden.” Some participants commented that whilst they felt like a burden, they were not physically a burden to their spouse or family. Also, some participants reported at the group that whilst they felt able to think about endings, it was their spouse or family who could not.

Furthermore, some participants reported that they felt as though their spouse or family had already started to grieve for them, even though they were still alive.

Table 2

Master Table of Themes

Super-ordinate themes	Subthemes
Focus on relationships	Impact of dementia on relationships Support from others as a positive experience Support from others as a less positive experience Feeling like a burden Supporting others
Sense of self	Retained personhood Inclusion Reciprocal relationships
Integrating dementia	Healthy adjustment Forced adjustment Facilitating adjustment Adjustment through social comparison
Psychological needs	Primary loss Secondary loss Grief reaction Isolation Attachment behaviour
Personal experience of dementia	Dementia as a journey Dementia as a negative experience The unknown Living well with dementia Dementia among other parts of life
A sense of finality	Endings Legacy; leaving something behind Life review
Hope	Medical investment
Dementia as a social problem	Social awareness Stigma

Discussion

The current study invited participants to think about their QOL in relation to dementia and to consider their future QOL as a way of exploring whether participants could inform their own person-centred care. The present findings suggest that individuals with dementia are able to participate in qualitative research and comment on their QOL, in line with other research (for a review see Steeman, de Casterle, Godderis, & Grypdonck, 2006). The current study also demonstrated that participants were able to consider mortality and to some extent, their wishes and needs for the future when supported to do so.

Dementia is an illness for which there is no cure and the process associated with it is irreversible, therefore attention has focussed on the maintenance and enhancement of QOL. For those living with life-long partners, the diagnosis of dementia seemed to prompt the partner to become a caregiver which suggests transformation of the relationship. This reflects a review by Baikie (2002) who found that the spouse identified themselves as “spouse-carer” with both roles viewed as equally important (pp.296). The observed change to the relationship seemed to preserve personhood for most of the participants who also expressed a positive experience of the support they received. This could suggest that retaining personhood is closely related to supportive relationships. Sometimes support was experienced as less positive and this could perhaps put individuals at risk of losing their personhood. Furthermore, Quinn, Clare and Woods (2009) reported that the nature of a relationship prior to dementia can have an effect on the care giving experience, which in turn could impact on the care provided. This therefore, may impact on the care recipient’s experience of the care provided, thus making it a less positive experience and posing a threat to good QOL.

In the current study it was important that participants were not only active and supportive in relationships but that relationships were reciprocal and this seemed reflective of good QOL. Reciprocity within relationships seemed significant which reflected research by Hellstrom, Nolan and Lundh (2005) who suggested that QOL should be based on the individual as part of a system of relationships. Ronning (2002) found that those relationships which were deemed to be most supportive, were also reported as reciprocal in nature. Perhaps if people with dementia are enabled to provide support and contribute in relationships their experience of receiving support is easier. Perhaps being unable to provide support could exacerbate illness thus creating an illness role where individuals living with dementia require being looked after and cared for, posing a threat to personhood. These findings suggest a relational view of personhood which was advanced by Kitwood (1997) who suggested that personhood is based on emotions, feelings and relational capacity and despite dementia, individuals still need social interaction and relationships in order to have good QOL. This theory remains influential in current dementia care as it facilitated a move from biological and medical approaches to more person-centred approaches (Woods, 2012).

The current study demonstrated loss through dementia. Furthermore, the findings show the psychological impact of such losses (secondary losses) on self-esteem and confidence which could perhaps be a risk factor for the development of depression, which in turn could impact on QOL. Depression and anxiety are common in those living with dementia (Steffens & Potter, 2008) and it may be that those at increased risk of depression are those who experienced psychological difficulties following the loss of some skills. Furthermore, some of the participants who expressed psychological difficulties also expressed grief and bereavement reactions which may increase the risk of depression. Interestingly, those who seemed to experience psychological difficulties as a result of losing

skills, also seemed to express feelings of forced adjustment. Perhaps those individuals, who adjust with difficulty to their dementia diagnosis and feel controlled and forced by dementia, are more at risk of psychological difficulties which could have a negative impact on QOL. The participants who seemed to be more accepting of their diagnosis were less likely to express psychological difficulties.

Thinking about the future seemed more challenging for participants. There were some expressions of fear due to the uncertainty of dementia and participants seemed to develop ways to avoid such thoughts. The DoH (2013) reported that for people over the age of 55, dementia was the most feared illness and perhaps this was reflected in the present findings. If we are to think about personhood and QOL as more relational, then perhaps thinking about the future with their spouse and loved ones could address and alleviate some of the fear associated with dementia; however, more research is needed to investigate this and in particular when those living with dementia do not have a spouse or loved one. Participants reported that their loved ones found it difficult to think about life ending and the future of dementia and perhaps their fear and reluctance inadvertently influenced the feelings of the individual living with dementia, impacting on QOL. A sense of endings was also addressed by some participants and despite mixed emotions relating to this, it was clear that some participants had considered their own life ending and leaving loved ones behind, some had considered leaving behind financial investments to ensure the welfare of their family and others seemed to be at a stage of life review.

Some participants expressed thoughts about life ending before dementia became very advanced which seems to suggest the intolerable nature of advanced dementia. Such observations perhaps suggest that participants felt that a future with advanced dementia could mean poor QOL. This could be reinforced by the reflection from the response validation

group that some participants felt as though their spouse or family had already started to grieve for them. This may have been in preparation that spouses or family knew the dementia could get worse and life could lose quality, perhaps reflecting the intolerable nature of advanced dementia. It seemed that despite a reluctance to think about the future, there was some awareness about the future of dementia which was illustrated from social comparisons with others living with dementia whom the participants perceived as worse off than themselves. There were other themes about social awareness and stigma. The future of dementia seems to be characterised by fear and uncertainty but perhaps through the removal of stigma and increased social awareness, individuals may be able to look to the future of dementia with less fear and more certainty, and be reassured that their QOL and maintenance of personhood is just as important in the advanced stages, as it is in the earlier stages of dementia. Furthermore, also from the response validation meeting, some participants reported that whilst they were able to consider endings, it was their spouse or family who were reluctant to do so and perhaps this is reflective of fear and uncertainty. Currently, the Government has focussed attention on the creation of dementia friends and communities to increase opportunities for building relationships (DoH, 2012). Perhaps this could also help to take the first steps for the removal of stigma related to dementia.

Despite promising results, there were several weaknesses with the current study. The sample was a population of individuals, living in the community with dementia, who had access to services with good facilities and opportunities. This may have impacted on the results of the study because perhaps the sample was not completely typical of the dementia population, or of the finding that many of those living with dementia report that they do not live well with it (Alzheimer's Society, 2012). In addition, inviting participants to think about the future of dementia whilst they still lived in the community with their loved ones may have

been too physically and emotionally difficult. Imagining themselves in a different environment and potentially losing effective verbal communication may have been too much to ask of this vulnerable population. Furthermore, despite obtaining good insight for what gives individuals living with dementia good QOL currently, there is no reason to suggest that the same things, important for QOL, would remain important for the future. Finally, most of the participants requested that their spouse or other family member was there during the time of the interview. This could be a weakness because participants may have wanted to protect their spouse or loved ones and changed their narrative. However, there were times when participants were left alone with the lead researcher and it was observed that participants spoke more openly. For example, Jim spoke quite openly and explicitly about certain care practises he would not want his wife to undertake. Therefore, having a spouse or family member present, could have impacted on the narratives. However, the findings demonstrated that individuals living with dementia need social contact and relationships. Furthermore, those living with dementia do not want to be passive in those relationships, but retain an active and contributory role. Perhaps if advanced dementia care could maintain this, the lived experience of dementia in the more advanced stages could be more positive. However, further research could focus on what support would be necessary for loved ones to maintain meaningful relationships into advanced dementia; what meaningful relationships would look like and how they could be facilitated with paid caregivers for those who lack personal relationships.

Qualitative methodological approaches can be a useful way of gaining insight into how an individual living with dementia makes sense of his or her experience. This study demonstrates that such approaches can perhaps be flexible in their approach and create conditions which promote and enhance the ability of those living with dementia to participate

in research (Gibson, Timlin, Curran, & Wattis, 2004). Through warmth and genuineness, those living with dementia can respond and make meaningful contributions (McKillop and Wilkinson, 2004) and anecdotally, participants reported finding the process therapeutic; though this needs more research.

This study demonstrated that those living with dementia can talk about QOL and what is important for them. However, thinking about the future with dementia was frightening and perhaps there is a role for health professionals to try to make the future of dementia less frightening and less uncertain. For those who want to engage in such conversations, this may make such conversations less challenging and difficult. A way in which this could be achieved is through implementing recommendations from the Government to help with the reduction of stigma which remains associated with dementia. In addition, participants commented on the needs of their spouses and loved ones, and also their spouse's avoidance of thinking about the future and life ending. Perhaps service provision has largely focused on supporting the individual living with dementia and their spouse separately. Perhaps working with the individual and their spouse together and facilitating challenging and difficult conversations, particularly in relation to endings and legacy, could be a useful intervention. It is likely that for couples who have been together for years, historically challenges and life's adversities have been faced together and as a partnership, perhaps the future of dementia and planning for the future could be faced in the same way. Finally, life story work has become very popular in nursing and residential homes as a way of improving QOL and enabling person-centred care (Thorgrimsen, Schweitzer, & Orrell, 2002). In extending this, perhaps life story work could take place earlier in the experience of dementia, whilst those living with dementia and their spouse and loved ones could contribute effectively and meaningfully, rather than relying on third party information. It is likely that this would have an immediate

therapeutic effect as well as having long-term benefits for their future care needs. This is reflective of findings by Haight et al. (2003) who found there were benefits to both the caregiver and care recipient in life story work.

Conclusion

The present study provides a phenomenological account of how individuals living with dementia make sense of their QOL within the context of a diagnosis of dementia. From such accounts, it is possible that some of what participants talked about will remain important in the future and help to maintain their QOL. For most participants, thinking about the future was difficult and laced with fear and uncertainty, however, what was clear was the importance of reciprocal relations and social contact which is highly informative in person-centred care in dementia.

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Concluding Discussion

This final chapter includes three sections. After firstly providing an overview of the current study “Can individuals living with dementia think about their future quality of life?” an extended discussion of the findings follows. The second section is a professional report based on the findings from the current study for healthcare, multidisciplinary professionals working with older adults who live with dementia. The third section considers how the current piece of research could be extended and built upon in order to further develop this challenging but important area of research, and to further improve the lives of those living with dementia.

Section 1: Extended Discussion

1. Study Overview

The current study invited participants who lived in the community to comment on their quality of life (QOL) within the context of living with dementia. Quality of life was central; how advancing dementia could impact on it and what may maintain or enhance QOL in the future. It was anticipated that if individuals living with dementia could comment on what would be important for their future QOL, this could inform and contribute to their person-centred care in the future, particularly if they require more formal living and care arrangements. Ten participants (five male and five female) took part and contributed to eight themes drawn from the data. The themes were; “focus on relationships”, “sense of self”, “integrating dementia”, “psychological needs”, “personal experience of dementia”, “a sense of finality”, “hope” and “dementia as a social problem.” Participants were able to consider and express what gave their life quality in the context of a dementia diagnosis; however, thinking about the future was more difficult and demonstrated fear and uncertainty.

Further feedback was gained at a focus group to validate the findings with the participants. The focus group allowed for a further and more in-depth conversation with five of the participants. Some participants expressed the view that whilst they had thought about the terminal nature of their illness, their spouses were unable to consider that and were reluctant to discuss it. In addition, despite the spouse’s reluctance to consider the terminal nature of dementia, some of the participants felt as though they had already started grieving for them, even though they had not died. Such findings highlight the way in which the health profession can further ease some of the difficulties experienced by those living with dementia

and their loved ones and become involved in facilitating and enabling conversations about death and dying if appropriate.

2. Discussion of the Current Study Findings

2.01 The Lived Experience of Dementia

Dementia care has changed significantly. The field has moved from a predominantly biological and medical perspective to exploring the individual accounts of those living with dementia and giving individuals with dementia a voice (Woods, 2012). Such advances have increased the understanding of the unique and individual experience of dementia, facilitating a move towards person-centred dementia care.

Whilst research advances have been significant, Ready and Ott (2003) report some of the dilemmas and challenges of research in this area. For example, the majority of the research has been with individuals living with mild to moderate dementia (Clare, Rowlands, Bruce, Surr, & Downs, 2008). For those living with more advanced dementia, the self-report of QOL has been more challenging due to difficulties with verbal communication (Johnson et al., 2009). Kitwood (1997) suggested that it was not possible to fully experience the world of another person and this perhaps reflects research findings which demonstrate discrepancy between self-ratings and proxy ratings of QOL (Scholzel-Dorenbos et al., 2007). Such findings demonstrate the difficulties other individuals, even close relatives, have when estimating the QOL of another individual with dementia, highlighting the importance of self-report QOL (Cahill & Diaz Ponce, 2011) and the maintenance of personhood across all stages of the dementia process.

2.02 The Concepts of Person-Centred Care and Personhood

Woods (2012) reported that individuals with dementia are able to comment and report on their QOL and that health care professionals should always seek to include the views of those

with dementia. In writing about the contributions of Tom Kitwood, Woods (1999), reported that for those around the individual with dementia, there is a need to try to understand and include the voice of individuals with dementia. Kitwood (1997) demonstrated how an individual's life story, experiences and environment can interact with dementia and how such factors can exacerbate the symptoms of dementia in some circumstances. Such observations underscore the importance of person-centred care for those living with dementia (Woods, 2012). Person-centred care has been described as “user focused, promote independence and autonomy, provide choice and control and be based on a collaborative team philosophy. It takes into account service users' needs and views and builds relationships with family members” (The Health Foundation, 2013, “What is Person-Centred Care,” para. 2). Kitwood (1997) argued that in order to provide good person-centred care for those living with dementia, the maintenance of personhood was essential. Perhaps when personhood is maintained, QOL is maintained also (Murray & Boyd, 2009).

The concept of personhood was first explored by Kitwood and his colleagues at the Bradford Dementia Care Group (1997) based on their work with individuals living with dementia. They defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, pp. 8). Kitwood (1997) suggested that care practices which undermine personhood can have an adverse effect. Meacher (1972) reported that historically, some of the conditions of formal institutionalised care for older people living with dementia were detrimental to their mental health and well-being. This was in addition to the effects of dementia. Kitwood (1997) based on further observations, grouped such practices under the definition of malignant social psychology. Malignant social psychology included infantilisation (treating those with dementia like children) and outpacing (presenting

information and communicating too quickly for an individual with dementia) among others (Kitwood, 1997). Based on the current findings, it was interesting that some of the participants expressed ideas consistent with malignant social psychology and which undermined their personhood. For example, Bill reported feeling invisible: “You know instead of saying, people saying, oh how are you? You know, it’s how is he? And you, you feel weird when that happens, you know” which illustrates that even currently, those with dementia face threats to their personhood, however inadvertent this may be. More recently Sabat (2008) extended the ideas of Kitwood (1997) and talked about malignant positioning. This is the process whereby people with dementia are seen as patients who are ill and inferior compared to other individuals who do not have dementia, thereby seen as having secondary status. Perhaps this was reflected in the experiences of Bill and also another participant who seemed to express feeling worthless as a person: “Because, how can I put it? Erm, I’m not myself, I’m not, I’m not as, I wasn’t bad ages ago, but I’m, I’m a ruddy non entity now” (Alan).

2.03 The Maintenance of Personhood in Dementia

Kitwood (1997) suggested that the needs of individuals living with dementia do not change but instead become more important in light of cognitive deterioration. In addition to love, Kitwood (1997) suggested there are five areas of need including: attachment, comfort, inclusion, occupation and identity which should ideally be met within dementia care. The findings of the current study demonstrate that some of the participants expressed thoughts similar to the areas of need suggested by Kitwood (1997). The current study developed the subtheme “attachment behaviour” where some of the participants appeared to reminisce and talk about past relationships, family members or locations where they previously lived which were not always prompted by the researcher. This may have been a self-soothing strategy

which enabled the participants living with dementia to feel comforted in times of isolation and insecurity through the reminiscence of attachments. This reflects research about the importance of attachments in dementia (Browne & Shlosberg, 2005). Kitwood (1997) suggests that for those living with dementia, feelings of isolation and insecurity were more frequent due to memory loss, disorientation and language difficulties. In terms of comfort, a number of participants described close and loving relationships with their spouse and this is perhaps reflected in subthemes such as “support from others as a positive experience” and “reciprocal relationships” where participants expressed feeling supported and cared for as well as the continuation of meaningful and reciprocal relationships. Perhaps for the subtheme “support received as a less positive experience” the support and care provided may have been perceived as inappropriate by the care recipient with the ideas about care from the caregiver being projected on to the care recipient (Wiles, 2011). It would seem that when support was not experienced in this way, the participants did not feel comforted. The importance of inclusion was also demonstrated in the current study. Some participants spoke about identification with peers; finding acceptance and comfort with the ability to be oneself and not worrying about the symptoms of dementia, for example Ted talked about: “When I’m with the group I can be just myself, er, not having to think about things as much cause you are just talking and, erm, and but forgetting is, is so easy.” A sense of occupation and keeping busy appeared helpful for the participants in the current study who demonstrated a need for agency and being active in relationships and with family. The importance of occupation was also referred to with continuation of hobbies. Furthermore, participants talked about maintaining their identity; it was important that they had a continued role of looking after others and maintaining activities that were once hobbies and enjoyable. Some

participants demonstrated that they still had the same worries and concerns which could have reflected an attempt to retain their identity.

Building on the work of Kitwood (1997) some research has highlighted the impact of loss of those living with dementia (Harris & Keady, 2004). The experience of loss may risk the maintenance of personhood, and therefore identifying and understanding loss from the perspective of the individual with dementia is important. Harris and Keady (2004) found that participants reported a sense of loss in terms of their abilities and skills which started to deteriorate following their diagnosis of dementia. Furthermore, the authors found that individuals started to feel separated from the world around them, finding communication and involvement in meaningful activities more challenging (Harris & Keady, 2004). These findings were also reflected in the current study where participants reported primary losses (i.e., losses of skills and abilities as a result of the impact of dementia) and secondary losses (i.e., loss of self-esteem and confidence due to the experienced primary losses). Perhaps the impact of secondary losses reported in the current study could lead to participants feeling separate as reported in the findings from Harris and Keady, (2004) which may prove a threat for the maintenance of personhood.

Despite the experience of loss, Clare, Roth, and Pratt (2005) reported that individuals living with dementia find ways to compensate and adjust to the losses caused by dementia. Such methods included psychological strategies such as trying to stay positive and taking one day at a time (Clare et al., 2005). Perhaps when the participants demonstrated ways of adjusting to the losses brought about by dementia, this was perhaps indicative of participants independently trying to maintain a sense of personhood. Adjustment methods were also reflected in the findings of the current study. Most participants talked about ways in which they tried to cope with the effects caused by the dementia. For example, like the findings by

Clare et al. (2005) Ted also talked about taking things one step at a time: “I’ve just got to take it in step by step then I can do it at times” and practical strategies such as organisation were discussed by Alice: “Well, I don’t sit worrying about it. I, as I say, I’ve, I can cope with what I’m doing, and things are fairly well organised, so that things look after themselves.” Furthermore, adding to the results reported by Clare et al. (2005) findings from the current study illustrated that coping through social comparison was useful. The participants’ comparisons of themselves to others whom they perceived as having a worse experience of dementia, seemed to assist adjustment. For example: “So long as I think, so long as I’m not like some poor devils are in the world, who you know, who erm, you see elderly people who are crippled, who saliva’s coming out of the mouths and they don’t know what day of the week it is, they don’t know where they are” (Jim). Similar findings were also reported by Byrne-Davis, Bennet, and Wilcock (2006), who suggested that the conceptualisation of QOL can be influenced by social comparisons and is a coping strategy used by those living with dementia.

2.04 The Challenges of Person-Centred Care and Personhood

Dewing (2008) agreed with Kitwood (1997) that underlying person-centred care was the notion of personhood. However, Dewing (2008) reported that the ideas of Kitwood (1997) have been widely accepted without critique, suggesting that the idea of personhood and person-centred care are unsuitable for nursing and care practice. Perhaps neglected by Kitwood (1997) was the observation that caring for an individual with dementia can be a highly challenging and existentially difficult job role (Dewing, 2008). In addition, McCarthy (2006) found that nurses within older people’s services generally observe person-centred care of those with dementia as an ideal level of practice and reported feeling sceptical about person-centred care working in clinical practice. Furthermore, O’Connor et al. (2007)

reported that there was limited empirical evidence about the nature of person-centred care and how this should actually look in clinical practice. However, perhaps this is due to the nature of person-centred care and personhood; perhaps it is difficult to identify how it should look in clinical practice because of the individualistic nature of such concepts. There is also some evidence to suggest that a caring approach which supports personhood could perhaps delay at least some of the negative consequences of dementia (Cohen-Mansfield, Parpura-Gill, & Golander, 2006). This is indicative of the importance of a person-centred approach which formal (and informal) caregivers should be supported to provide.

Perhaps the suggestions of Adams and Gardiner (2005) would make the notion of person-centred care easier to implement. Relationship-based care which not only includes the needs of the individual with dementia, but also includes the needs of the carer and health professional, may help some of the principles of person-centred care be translated into practise (Dewing, 2008). Findings from the current study suggested that it was important to participants that their spouses and family were cared for and looked after which perhaps suggests that relationship-based care is not only important for formal and informal caregivers, but important for the individual living with dementia also.

2.05 The Importance of Relationships in Person-Centred Care and the Impact on Quality of Life

Kitwood (1997) reported that personhood was not maintained in isolation. Personhood is maintained through social relationships and social contact and without which those living with dementia would deteriorate quicker.

Hellstrom, Nolan, and Lundh (2005) reported a case study which explored the experience of a couple, one of whom had a diagnosis of dementia. The study took place over a period of 18 months and the individual with dementia and their spouse/partner were

interviewed separately. However, both interviews took place at the same time to explore the views and experiences of the couple using a grounded theory approach. Hellstrom et al. (2005) found that the spouse supported his wife with dementia in a way which did not undermine her ability, but instead subtly helped her to draw on her strengths so she could achieve the same things which always made her happy. This seemed to be reflected in the current study. One of the super-ordinate themes found in the current study was “focus on relationships” which conveyed subthemes such as “support received as a positive experience” and “support received as a less positive experience.” Perhaps the more positive experiences of care were related to support which did not undermine or restrict personhood. Support which draws on an individual’s retained skills by creating environments and strategies which assist an individual to be independent perhaps results in retained personhood and a better experience of care. Perhaps those experiences of support which were reported as less positive were ways in which personhood was being inadvertently undermined. The study reported by Hellstrom et al. (2005) illustrated that a sense of self and personhood are created and maintained within social relationships which are sensitive to the needs of those living with dementia. The current study also developed the subtheme of “reciprocal relationships” which suggested the importance of processes such as remaining active and contributory within relationships to maintain a sense of self and good QOL. This reflects findings from Molyneaux, Butchard, Simpson, and Murray (2012) who found that couples engaged in completing activities together, even if they had previously done such activities separately. This seemed to reflect ways of minimising the impact of dementia and maintaining closeness in their relationship (Molyneaux et al., 2012) supporting good QOL.

Hellstrom et al. (2005) also found that the spouse found ways to maintain the self-esteem and confidence of the individual living with dementia. For example, he spoke about

long-standing hobbies and interests which maintained his wife's self-esteem; however, when she started to struggle with such activities he developed discrete and unrestrictive strategies to help her to continue to engage in such activities. The current study also reported a theme of "secondary losses" which described the psychological impact of losing skills due to dementia, for example the loss of self-esteem and confidence in ability. One participant described the loss of a grandfather role and his loss of confidence for taking his granddaughter out on his own. Interestingly, the same participant at the focus group talked about how secondary losses can be regained through the support of carers and working together. This perhaps reflects and highlights the relational aspect of personhood and the importance of it for maintaining QOL.

There are two potential weaknesses of the study reported by Hellstrom et al. (2005). Firstly, perhaps the way in which data was collected, i.e., through separate interviews and secondly, perhaps the couple in the case study reported a markedly different experience of dementia compared to other couples. Clare and Shakespeare (2004) reported a study where joint interviews were held with the individual with dementia and their spouse. Very different findings were reported which demonstrated resistance and restriction (Clare & Shakespeare, 2004). Clare and Shakespeare (2004) also found that an individual's experience of living with dementia was shaped by their personal relationships. However, they found that spouses could be resistant to thinking about the future of their loved one's dementia. This appeared to be evident in the way which carers actively avoided conversations about fear and worry in relation to the future of the individual living with dementia. Clare and Shakespeare (2004) reported that this was because they were keen to avoid what they perceived might be distressing for the individual with dementia (Clare & Shakespeare, 2004) and potentially him or herself. This finding reflects feedback from the current study where during the focus

group two participants expressed their spouse's resistance to consider the future and terminal nature of dementia. Perhaps this is reflective of Kitwood (1997) who proposed that malignant social psychology is partly maintained by deep rooted anxiety which individuals hold in relation to dementia. Worries about dementia often focus on the likelihood of becoming dependent and that death will be slow and extended, which may perhaps in part explain some of the resistance for avoiding such conversations. More recently this has been shown to still exist. The Department of Health (DoH), (2013) found that in adults older than 55, the most feared illness was dementia and therefore Kitwood's (1997) claims for some of the underlying reasons for practises consistent with malignant social psychology might still exist today. Such anxieties seem to hold spouses back from thinking about the future which perhaps reinforces the frightening nature of dementia to those who are actually living with it. This reflected findings from the current study which found that some participants expressed that advanced dementia in the later stages was perceived as frightening and uncertain. We know that dementia is a terminal illness which deteriorates, that is certain, and yet participants reported the uncertain nature of dementia. Perhaps some of the uncertainty is a result of those living with dementia being protected by their loved ones and perhaps health professionals. However, this is complicated by the unpredictability of dementia which may add further uncertainty. Such findings highlight the importance for more relation-centred work (including formal caregivers) as part of maintaining personhood and thus QOL for those living with dementia. Clare et al. (2008) found that for those living with dementia in residential homes, fear was something also expressed which suggests that the presence of fear is present throughout the course of dementia and deserves attention.

3. Conclusion

Despite the criticisms and challenges of person-centred care, the notion of personhood is clearly important for the maintenance and enhancement of QOL for those living with dementia. Perhaps findings from the current study and the findings of others discussed, demonstrate that personhood is not only multifaceted but highly individualistic and subjective. There is no doubt that person-centred care may be very difficult and challenging for formal and informal caregivers to facilitate and implement. Even though it is likely that there are a number of services which operate in ways consistent with person-centred care, reduced National Health Service (NHS) expenditure is likely to impact on available resources and staffing (Royal College of Nursing, 2010) which will consequently impact on care. Dementia and long-term health conditions are at present, one of the main areas of focus with the Government and health organisations. Perhaps if person-centred care could be clearly defined and operationalised to assist implementation, this could be a worthwhile investment in the sense that if those living with dementia sustain good QOL, their future psychological health needs could be kept to a minimum.

Section 2: Professional Report

Professional report aimed for the staff of the community mental health team (CMHT) from which participants were recruited from and staff from other older adult community mental health teams.

Background of the Study

Exploring the quality of life (QOL) of those living with dementia has become increasingly important over the last decade in light of an absence of cure (Scholzel-Dorenbos et al., 2007). Given that the numbers of those living with dementia is estimated to rise (Alzheimer's Society, 2013), more attention has been given to how individuals live with and make sense of their diagnosis of dementia (Woods, 2012).

Dementia is now a priority for the National Health Service (NHS) given the associated costs (Department of Health [DoH], 2013), particularly for those who require formal long-term care. Moving into formal care can be a traumatic experience which can coincide with the loss of multiple attachments and familiarity (Browne & Shlosberg, 2006). For some, this trauma can be expressed as challenging behaviour due to difficulties with verbal communication. It is likely that the incidence of challenging behaviour is indicative of poor QOL for the individual with dementia as well as making the working life of formal care givers more stressful and demanding. If such individuals are unable to express their needs in a way which we, as healthcare professionals can understand, then potentially there is widespread unmet need among individuals living with dementia, perhaps inadvertently contributing to poor QOL.

Aims and Methods for the Study

This study aimed to invite those living with dementia (for at least six months) in the earlier stages of dementia to comment on their QOL. The study also aimed to consider their future needs for QOL in light of their advancing dementia. Perhaps if those living with dementia in the earlier stages can think about their needs for the future, then perhaps they could inform their own future person-centred care and help ensure the maintenance of good QOL. The information from participants was collected through one-to-one interviews at the homes of the participants.

Findings

Ten participants took part in the study. This allowed for the collection of in-depth information about the participant's QOL and their feelings about the future. The information collected was organised into themes based on similarities within what the participants said. Overall, eight themes were identified and an explanation of the themes is provided below.

“Focus on Relationships”

This theme illustrated the impact which dementia can have on relationships. Most participants talked about a sense of being supported and cared for by their spouse/loved one but there were different appraisals of this support. Some participants reported a positive experience of this support and others reported a less positive experience. There seemed to be a fine line between being supported and feeling like a burden on their family, and it seemed that feeling a burden was an unpleasant and unwanted feeling for the participants. Finally whilst being supported, it was important that the participants themselves were able to support and care for their spouse and loved ones.

“Sense of Self”

This theme reflected the identity of the participants. For most of the participants there was a sense of retained identity and familiarity with oneself. Sense of self also seemed to be related to meaningful connections with others. A sense of inclusion was important; that participants were able to meet with and have opportunities to socialise with peers and feel comfortable with being themselves. A sense of feeling reciprocal within relationships also seemed important for a participant’s identity which seemed to indicate that identity is not just about the individual, but how they see themselves in meaningful relationships with other people. Participants demonstrated that being active and contributing within relationships helped to retain identity and was seen as important for QOL.

“Integrating Dementia”

Participants expressed their feelings about adjustment in this theme. Whilst some participants talked about an initial feeling of shock after their diagnosis, most described psychologically useful ways of adjusting to their diagnosis, whereas some participants described an adjustment in which they felt controlled, had no choice and felt forced. Despite how the participants felt about their adjustment, there seemed to a number of ways in which the participants used to facilitate it. Such methods included comparing themselves to others whom they perceived as worse off than themselves, taking one day at a time and trying to remain positive. Such methods appeared to help those living with dementia to adjust to their diagnosis, albeit to varying extents.

“Psychological Needs”

This theme reflected a number of different emotions. Feelings such as isolation, grief and bereavement reactions as well as feelings of loss were expressed. Feelings of loss were multifaceted including primary losses (direct loss of skills and abilities due to dementia) and

secondary losses (psychological impact of losing primary skills such as self-esteem and confidence). It seemed as though the loss of skills and abilities through dementia impacted on more higher-level psychological difficulties such as self-esteem, confidence and mood, which is suggestive of the psychological impact of losing skills in memory, driving and reading for example. Sometimes participants reminisced about earlier parts of their life and about members of their family as they were growing up. Perhaps this was a way of comforting themselves following the impact of loss on their QOL.

“Personal Experience of Dementia”

This theme highlighted each participant’s unique experience of dementia. Most participants described a “journey” of dementia; characterised by fluctuation and varying levels of intensity. Participants described occasions where sometimes the dementia “got the better of them”. Some participants talked about the negative experiences of dementia whilst others appeared to live well with dementia; the former was characterised with uncertainty and fear about the advanced stages and the latter about their hobbies and doing things with family. Some participants described dementia as only one part of their life and that there were a number of things happening in their life which deserved equal or more attention.

“A Sense of Finality”

Some of the participants expressed thoughts relating to existential factors. There were mixed feelings about life ending; some participants saw death as a natural part of life and acknowledged the terminal nature of dementia. In stark contrast, others described a life where they only existed, rather than lived and worries about leaving their loved ones behind. Some participants described their wishes for ensuring that that their family and loved ones would be looked after following their passing. Sometimes this was expressed as practical investments and other participants talked about the passing on of qualities which they

believed would see their family through. Either way, there was a sense of legacy in leaving things behind. Finally, there was some evidence that participants started to review and reflect on their life perhaps suggesting their acceptance of their older age.

“Hope”

This theme illustrated that despite dementia and their feelings about it, participants retained some hope for improved medicine and science. Some participants hoped for medication that would mean they did not reach the advanced stages of dementia. Advanced dementia seemed to be something which the participants associated with poor QOL. Their desperation to avoid this seemed to be illustrated with improved medicine for dementia.

“Dementia as a Social Problem”

Finally this theme demonstrated that the participants were aware of the stigma and lack of accurate understanding of dementia that some individuals in society have. In addition, participants were very aware of some of the stereotypes held by individuals in relation to dementia which reflects the importance of tackling the stigma around dementia and providing accurate information and education.

Clinical Relevance of the Results of the Study

The results highlight the subjective experience of dementia and each participant’s unique response to it. Participants demonstrated that during the early to moderate stages of dementia, they are able to express thoughts relating to their QOL, what contributes to good QOL and potential threats to maintaining that good QOL.

Supportive and reciprocal relationships were important for the participant’s QOL. Where support was perceived as positive, it was likely to be appropriate and sensitive without undermining capability and retained skills. Being supportive was also important. Feeling

active and having meaningful, connected relationships likely helped the experience of receiving support as well as helping to maintain good QOL.

For some of those living with dementia there may be the increased risk of low self-esteem, depression or anxiety. Dementia as an illness can cause a loss of everyday abilities and skills. Following the loss of such practical and life-long skills and abilities, it would seem that some participants are consequently likely to experience psychological difficulties. Finally, the future of dementia was perceived as frightening and uncertain. This made thinking about the future and their future needs difficult. While it is likely that what gave the participants good QOL currently will continue to do so, we cannot be fully sure of that due to the potentially changing needs of those living with a deteriorating illness. The DoH (2013) reported that for those adults who are aged 55 and over, dementia was reported as the most feared illness. Perhaps this fear not only contributed to the fear expressed by those living with dementia, but their spouse and loved ones also. Therefore fear could be something which a lot of individuals experience, but are reluctant to express so as not to cause further distress.

Recommendations for Practise Based on the Results of the Study

Maintaining Meaningful Relationships and Social Networks

All the participants talked about the importance of meaningful relationships, both in terms of their sense of self and the important role that meaningful, connected relationships played in the maintenance of good QOL. It seemed from the findings that the participants who spoke about meaningful relationships seemed to also report good experiences of receiving support from spouses and loved ones. This suggests that the support provided did not undermine the individual's sense of personhood in anyway. It is important that such relationships are maintained and facilitated and perhaps when such relationships run the risk of breaking

down, i.e., perhaps when dementia reaches the advanced stages, this could be a time which service users are prepared for and perhaps when health professionals could step up their support and enable meaningful relationships. When such meaningful relationships break down, this is when QOL seems to be most vulnerable.

Adjustment and Adaptation

As in other long-term health conditions, there is no cure for dementia which indicates the need for a process of adjustment and adaptation (Samson & Siam, 2008). If the individual living with dementia cannot adjust and adapt to their diagnosis of dementia, it is likely that there would be a much more adverse effect on the QOL of the individual. In the current study, most of those who felt forced and controlled by their diagnosis of dementia were also likely to express feelings consistent with a grief or bereavement reaction as well as other psychological difficulties. Perhaps if they were to adapt and adjust to dementia in a more healthy way, they would be less likely to experience such difficulties.

Many of the participants in the study expressed feeling grateful for the support offered by the hospital and also the groups which allowed the participants to feel comfortable and accepted among peers. Therefore perhaps a therapeutic group aimed at adjustment and adaptation following the diagnosis of dementia could be a helpful step forward and a proactive measure against the development of psychological difficulties. Furthermore, in light of reduced NHS spending, group work can be a way of providing support to a number of individuals simultaneously which may be an attractive investment for commissioners.

Enabling Difficult Conversations

Thoughts relating to the future were varied. Most of the participants in the current study reported that they did not want to think about the future. Respecting this wish is important, however, there was still very real lived fear about the future which is perhaps something

which should be given attention. If fear is something shared by those living with dementia and their carers then perhaps a joint intervention would be of most benefit. Life story work can be therapeutic and very beneficial to those living with dementia but it is not something that is offered as a matter of routine. This could be an intervention offered to those living with dementia and their spouses/loved ones which could be something they develop together. There could be several advantages to this. Firstly, a physical record would be created to document memories and help to retain identity. Secondly, it could be something that stays with the individual and be particularly beneficial should they enter formal care allowing professional care staff to know what the individual was like pre-dementia. Thirdly, the document could inform person-centred care and potentially reduce any incidence of challenging behaviour by creating an environment consistent with their personality. Finally, indirectly, the document may help ease conversations about death and dying between individuals with dementia and their spouse/loved ones should this be something that is wanted through the process of life review.

Social Awareness of Dementia and Stigma

Fear associated with the more advanced stages of dementia could be informed by stigma and social awareness. Government policies include initiatives about increasing social awareness and the removal of stigma through education and media advertising. In addition to service user involvement, perhaps reaching out into the community and targeting different age groups (different to that of the service remit) could be beneficial, perhaps through educational programmes and awareness days in schools and local businesses, for example.

Thank you for taking the time to read about the study: “Can individuals living with dementia think about their future quality of life (QOL)?”

Section 3: Future Directions and Research

1. Introduction

The findings from the current study illustrated that for many of the participants thinking about the future was frightening and uncertain. For those participants who were able to consider the future of their diagnosis of dementia, they reported reluctance from their spouse to acknowledge such thoughts. A number of participants expressed the view that they did not want to think about the future which is something that should be respected; however, living with fear about the future is something that should be addressed, particularly if this impacts on QOL. The Department of Health (DoH), (2013) reported that dementia is the most feared illness among adults older than 55 years and it may be that some of this fear remains contributory after the development of dementia. It is likely that some of the fear about dementia, particularly advanced dementia, could be due to stigma and misperceptions about the condition.

2. Background Literature

2.01 Stigma

Mukadam and Livingston (2012) described stigma as “a state of social disgrace or discredit, which sets an individual apart from others in society” (p. 377). Unfortunately older adults with dementia face double stigmatisation, age and mental health difficulty (Graham et al., 2003). Much of the research published on stigma and mental health has been on psychosis with limited research about the effect of stigma on those living with dementia (Mukadam & Livingston, 2012). However, the dementia strategy (DoH, 2009) recognised the impact of stigma and the current Government has built on this by introducing dementia friends and

dementia communities in an effort to tackle stigma and increase accurate social awareness. The effectiveness of this however, is yet to be documented.

2.02 Impact of Stigma

A diagnosis of dementia can be distressing and upsetting, however, the impact of stigma can lead to further distress and suffering (Mukadam & Livingston, 2012). It is documented that stigma can lead to a number of additional difficulties including depression (Manos, Rusch, Kanter, & Clifford, 2009), low self-esteem and social isolation (Corrigan, 2004). In terms of dementia, some of the symptoms can lead to stigma and discrimination (Mukadam & Livingston, 2012) which can prevent individuals from seeking timely support and a diagnosis (Vernooij-Dassen et al., 2005). Devlin, MacAskill and Stead (2007) also reported the level of fear and anxiety associated with advanced dementia. The stigma of dementia was also highlighted by Husband (2000) who found that for some of those diagnosed with dementia, they were more concerned about what other individuals would think about them, rather than the impact of dementia itself on them.

2.03 Challenging Stigma

Mukadam and Livingston (2012) suggested that the social awareness of dementia needs to be accurate and accessible, demonstrating that individuals can and do live with dementia and function in society, reporting comparable QOL to those of a similar age without dementia.

In terms of programmes to reduce stigma, Schulze, Richter-Werling, Matschinger, and Angermeyer (2003) reported a study which focussed on reducing the stigma of schizophrenia among 14-18 year olds. It was hoped that targeting this age group meant that the effects of stigma could be counteracted before they arose. The programme included: asking participants to think about events in life which could cause distress, those which contribute to well-being and what helps them to feel better when they feel down (Schulze et

al., 2003). The programme also included the involvement of a young person with schizophrenia who shared his or her experiences with the participants. Following the programme, the participants held fewer negative stereotypes about those with schizophrenia and also reported that they would be more willing to enter into social relationships with those who had a diagnosis of schizophrenia (Schulze et al., 2003).

3. Future Research Proposal

3.01 Rationale for Research

The results reported by Schulze et al. (2003) are promising and suggest that increasing awareness of mental health among younger people can be advantageous. In terms of tackling stigma, increasing accurate social awareness about dementia through education, might be highly beneficial. Raising the awareness of dementia through the media (television and radio) has increased in recent years (Mukadam & Livingston, 2012) however, some may feel that current campaigns such as “fading away” are stigmatising and threaten personhood. However, it would seem that the fear and anxiety in relation to dementia remains which suggests that tackling stigma and increasing social awareness should continue to be a priority in terms of dementia research and legislation.

3.02 Aim and Methods

Research seems to suggest that there are gaps in what people understand about dementia (Devlin, et al., 2007). Therefore, if research can demonstrate what older children understand about dementia, perhaps the findings can be used to ensure that awareness about dementia is accurate, have the opportunity to correct misperceptions and also build empathy for dementia as an illness. Perhaps this could be part of a wider research area thinking about the stigma related to dementia and how this should be tackled and reduced.

Focus groups held in secondary schools consisting of a small number of children could be a useful way to collect information. In particular, areas for discussion could focus on; what do school aged children understand about dementia? Is their understanding accurate? What kind of emotions accompany their understanding and is there any evidence of stigma or stereotype within this age group?

3.03 Design

Recording and transcribing the focus groups to allow for a qualitative thematic analysis would allow for the development of themes which could help us to understand what young people understand about dementia. The themes may illustrate misperceptions and even stereotypes which could inform the development of a more formal educational programme to raise awareness and tackle the stigma associated with dementia, starting at a younger age.

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Appendix

Appendix A Interview Schedule

Appendix B Example of Full Transcript (Alice)

Appendix C Master Table of Themes

Appendix A

Interview Schedule

Please can you tell me how you felt when you were initially diagnosed with dementia?

Prompts: Associated thoughts, emotions, behaviours?

How do you think your life would be without your diagnosis of dementia?

Prompts: Has it had any positive effects – how? Has it has any negative effects – how?

Please can you tell me if your dementia impacts on your sense of satisfaction with your life?

Prompts: Has your dementia changed how you feel about the quality of your life? Does it have a positive/negative impact?

How have you been supported to try and keep a sense of satisfaction with your life?

Prompts: Family/friends/hobbies – helped or hindered?

Can you tell how your life has changed as a result of your diagnosis of dementia?

Prompts: If so, how has your life changed? If not, why has your life not changed? Can you tell me what you have you done to ensure this?

Can you tell me about a time when your dementia got the better of you?

Please can you tell me how your dementia changed the way you think/feel about yourself?

Are there any implications around your diagnosis currently?

Prompts: Do you have any concerns/worries about your diagnosis at the moment which you could tell me about?

Can you tell me what it is important for you at the moment?

Prompts: What keeps you happy in your life? What makes you think life is worth living?

Has this changed since your diagnosis of dementia?

Have you thought about how your dementia may progress in the future? If so, how?

Prompts: Will anything change? Memory, language, mobility?

In light of how your dementia may progress in the future, what do you think your needs will be?

Prompts: Physical/emotional/behaviour support?

Can you tell me then how your dementia may impact on your quality of life in the future?

Prompts: Will it affect your quality of life in a good way? If so, how? Will it affect your quality of life in a bad way? If so how?

If the dementia is predicted to affect quality of life in the future, what would help to maintain or enhance your quality of life in the future?

How do you think the people around you will know how to help you to maintain your quality of life in the future?

Prompts: Family/friends, care staff?

How do you see yourself in the future?

Prompts: If in a good way, how? If in a bad way, how? If in a bad way, how could it be improved?

How would you like to see yourself in the future?

Appendix B

Master Table of Themes for the Group

Super-Ordinate Theme: 1. “Focus on Relationships”

Impact of dementia on relationships.

Rod: I mean we've been married nearly what, 50 odd years and for the first 50, I don't we said a bad word to each other, but recently there have been, I don't like it.

Bill: God, I must have put her through hell, like, you know, then, like she's walking on egg shells, frightened of what I was going to say, you know or what she'd say in case it upset me, or, things like that, and you don't realise that er, your carer, is actually going through the same things, if, if not worse.

Alan: Oh, hell, why, I suppose it, it will progressively get worse the family suffered really, mother [wife] suffers with me.

Jim: Possibly not putting things right together in front of people when Barbara's in their company, that's when I want to go away. I don't want her to suffer if, if I'm here and I'm losing for want of a better use of words again, my marbles, erm, I don't want people in the background saying, God how's she putting up with him the way he is.

Support from others as a positive experience.

Ted: Because I'm in a, in a position with a, a big, a good family and friends I tend to feel as if that's given me a comfort zone.

Rod: she call, calls us I think once every night and stays here for about an hour and a half, and I love it you know

Alice: Our two sons, would be very happy to help if necessary, or organise things and so, from that point of view, I, I don't really have worries.

Janet: Although the people that I know very well have been very good.

Rose: Well knowing that my food is, is on the table, and Les's there, to watch over things. I'd be lost without this man you know.

Jane: Jenny's very good with er, what she does, you know, helping me, and er, so now, I've got no worry to say that I've got to do this

Bill: If we didn't, if I hadn't have had the, the support we've had off er, Hospital and, and the care team that have come out and all that, I think we'd have, we'd have er, I don't think I'd have been here really, cause they, they got us through them really, really dark days, and knowing that they're there at the end of a phone

Alan: Mother [wife] and the girls, you know, they're, that's, they're the only ones that keeps me sane

June: It's Hospital, and my son, and the way I'm looked after, and the way they care, but they're very, very caring in Hospital, they help you all they can.

Jim: So I've got a second family that's as good as my first family

Support from others as a less positive experience.

Rod: Well Sharon is very good, she always has been, but I think she might be getting a bit fed up of me

Janet: I'm keeping them waiting, although they say you know, no, it's all right, take your time, take your time, but it is difficult, cause you're not used to, you know, having that sort of thing, and so that's, I think that's the worst thing at the moment, yeah

Jane: Erm, well, all the while, if I could have to, have a little walk round of my own, without having to take somewhere with me

June: You know, but er, he's very protective, you know, towards me.....But, he can't do any more.....In fact, I'd like him to do a bit less really

Jim: I'm sorry at times, especially recently, and I'm getting myself worked up now, but erm, especially recently, I mean she's absolutely fantastic, honest to God, erm, and I don't want for anything at all, not a thing, you know. Too much washing, too much ironing, doesn't mean a thing to her, she just does it, yeah, does the house, you know, and when she goes out of a morning, she'll Hoover up before she goes out, and she'll just say, here you are, you don't have to do anything. I don't want that, I want to do it, you know what I mean

Feeling like a burden.

Janet: But on the other hand, sometimes they can't, because they haven't got the time, and they've got other things to do, you know, so there's things I can't do, when they're doing, which I would have done.

Rose: And if it got any worse, and nobody, you know, if I was a pain to anybody, I wish that God would take me, I wouldn't want to be here.

Jane: And that, you know, but she hasn't got a lot of time, now with me.

Bill: I couldn't put the burden on your, your kids, you know, cause they've got their own lives to live, you know, and that, and that's something I do think about is, you know, if what, what if something happens to Sue.

June: I do feel as if sometimes Paul could do with a little more, more help.....From the social services, but he hasn't asked you see.

Jim: That person hasn't got a clue what they're doing half the time, or they do have a clue, and they can't control it, like people wetting themselves and dirtying themselves, nothing to do with dementia, but it happens to people, you know, and that, that's what I've said to her, if I ever went like that, you must never tackle me, you must get a nurse in.

Supporting others.

Ted: I do help er situations with friends, family and whatever, I found that satisfying.

Rod: I think that I can stay alive for quite a while, do things help Sharon and help the family

Alice: I look at people, and I'm sympathetic to them, and I'm kind to them, I hope, and in the same way as I've always been, and caring about people, and I don't ignore them.

Janet: Because I want them to be you know, I want it to be fine for them.

Rose: Well, that everybody else and I love, is happy with me.

Jane: I'll stay that as long as I can for them, they keep me busy, looking after them

Bill: Before I was just thinking about myself, and now I think about her feelings

Alan: I love my family, and I don't like upsetting them, I'll leave it at that

Jim: She's my number 1 priority, and after that, it's my, believe it or not, it's my ex wife

Super-Ordinate Theme: 2. "Sense of Self"

Retained personhood.

Ted: I'm, still myself, still being able to talk to people, still being able to have a, a conversation, but I hope I'm not going to be losing that erm, security within myself

Alice: So, as far as I'm concerned, you, it might take you a bit longer to, to do things, but you still do the same things, and you still look out of the same eyes and still see the same things, so it's, it's no change.

Rose: I still bite my nails like mad, erm, I've always been a worry, haven't I? All, all my life I worried, I hated school, every second of school, and I can still think of school with that worry, and hatred.

Jane: but then again, he says some funny old things to me, and my other daughter says that she, she, she says some things which he, he, he does, he does, he does, he, no, what, what should I say? He should be pulled up, what, some of the things he, he says

Bill: I'd like to see myself as a, as er, a useful member of society, able to have an input into it, you know, I'd like to be able to make decisions I'd like to be able to potter round, like to be able to do things, you know, and, and I'd like to be able to, I've always liked to help people, and, and that's something that I'll always continue, I'd like to be able to do, you know

June: Er, that would worry me, er, if I couldn't do that so much, you know, I like my perfume and my talcs and all that, so up to now, I'm quite pleased I'm able to do that, you know.

Jim: You know I'm going, I used to be a good cyclist, I'm buying myself a bike, I'm going riding a bike again at 76

Inclusion.

Ted: When I'm with the group I can be just myself, er, not having to think about things as much cause you are just talking and, erm, and but forgetting is, is so easy.

Rose: Well it must be mustn't it? Because erm, that's how it, how I've been, you know.

You can't be er, sit one side and look at things differently, when you're one of seven children can you? You've got to get on with it haven't you?

Jim: I mean we've escorted blind men into Masonic order, er, they've been members for years and then all of a sudden gone blind, we've had people come in and then we've found out while they've been sitting there, bloody hell, Charlie's only got another 6 months to live..... You know, but they're accepted normally, you don't play it, we don't play up on them.

Reciprocal relationships.

Alice: I think that you've got to feel that when you meet people, they smile naturally, and they don't move them, and I don't feel that at all, I feel that one is open to them and they're open to us

Janet: It is, yes, cause he is, he's very good, yes, sometimes you know, we just, doesn't come together but, but nothing at all you know, that isn't normal.

Rose: Well we go to the shops together mostly. It's a very combined operation that we have, if that's the right word.

Jane: Well, I daresay they'd try, if, if, we, well we, we'd have to be or able to do it, cause I mean, we, there's things which you can't always do, but you try to do the best one.

Bill: I mean they talk about my quality of life, you know, it's, it's impacting on er, your carer's er quality of life and it impacts on my er, son and daughter.

June: Yeah, yeah, I've always been, they've always been very good to me..... Yeah, and I've been good to them hahaha.

Jim: I would say 95% of it tied into Barbara's quality.

Super-Ordinate Theme: 3. "Integrating Dementia"

Healthy adjustment.

Ted: Within myself, erm, I've been frustrated over a period of time but I, I can't really answer that others can help, answer it may be, but whether I've changed drastically I don't really know.

Alice: I mean you try to keep everything looking spick and span, but if one didn't manage that, well, so what? It could be remedied.

Rose: Well I have, what have I got to cry about? I've got nothing to cry about.

Jane: You won't do that forever.

June: It's just the first, when I first got to know, I was shocked, you know, for a few months actually, it did affect me, cause I lost a lot of weight, went down to 8 stone, from 9 stone 4, but I'm creeping up now.

Forced adjustment.

Ted: I, I tend to feel as if, I'm, I'm ok, and I've got, got to be positive. Sometimes without thinking about it, that's the way I am.

Rod: I'm getting by, but I hate having to get by.

Janet: You know, but knowing that, certainly at this time anyway, they can't, and that's what you've got to put up with....Sometimes it is hard.....Well, just because you know that that's what it's going to be.

Jane: I think oh, I'm fed up with this, I'm going to turn it off, you know.

Alan: Well, it's a thing, you think, you think of family at first, and then I, I convinced myself that it's about, well, hell, I've got it, that's it, nothing, nothing you can do about it is there? You've got to, you've got to commit yourself on that one, there's nothing I, you can do.

June: I suppose when something really takes over your brain, it's out of your hands, there's nothing you can do about it, is there?

Facilitating adjustment.

Ted: I've just got to take it in step by step then I can do it at times.

Rod: Yeah but as I say I don't worry about it because I never use it too much, but I do use it don't I Sharon, the Alzheimer's? But it's only now and again.

Alice: Well, I don't sit worrying about it. I, as I say, I've, I can cope with what I'm doing, and things are fairly well organised, so that things look after themselves.

Janet: But then I think well there's no point in thinking about it now, it'll happen when it's going to happen

Jane: Just take me off there, you know, worrying about things, it's no good to keep worrying at different things, no

Bill: she'll joke and, I, I think it's great, you know, cause I, I still like people to er, laugh and joke when we, cause that's what I've always done all my life, you know.

Alan: I'm not really blaming dementia, I, I think, if I let dementia get hold of me, well you're lost aren't you? Then aren't you?

June: I haven't really you know, I try not to think about it actually. When I say I try not to, if I, if I think, I just cast it aside and I just think, I'll take things as they come.

Jim: From time to time, altogether, 8 or 10 of us, you know. If they start going into discussing all different things in the past, I stand back, cause I'm not remembering some of what's been going on, and I'm not going to make a show of myself, you know.....I'll wink at Barbara you see.

Adjustment through social comparison.

Ted: That I couldn't answer. I don't really know because I'm lucky to be able to do certain things er, where when I am with groups of dementia people who are in a far far worse state that I can hope I would never be in. Erm and when I'm with them I try and cope and help them in many ways.

Alice: I don't know what the clinical definition is, but I don't know, I feel that, oh there's a lot of others worse than me, I don't think of it as that, I mean I might forget the odd things, but I don't think of it as dementia.

Jane: I suppose I could be in worse, whatsernames, as I say.

Jim: So long as I think, so long as I'm not like some poor devils are in the world, who you know, who erm, you see elderly people who are crippled, who saliva's coming out of the mouths and they don't know what day of the week it is, they don't know where they are.

Super-Ordinate Theme: 4. "Psychological Needs"

Primary loss.

Ted: Fit and sharp as I used to be (laughs), it sounds possible with special tablets which will bring me back the little bit I had

Rod: I was telling you about having the car, but we had a motorbike first and then a car, and they took the motorbike from us as well.

Janet: Well, going out, or doing messages, or you know, doing cooking, I'm not, I can't do the cooking anymore

Jane: I can't read now at all, to, to, to make them, because you, when I put that through there, and I then go, no there's another one there, by, by the time I get to there, it's gone.

Bill: I used to always lock the house up, you know, I'd always check everything, gas and electric and everything, and er, one day I didn't, just didn't lock the doors and we got burgled that night you know, and I've er, I've burnt the side of the cooker, cause I've left the oven on, or the gas on, or stuff like that, I've burned a few pans.

Alan: The thought of, the thought of, I, I used to pick the cards up, and I could see it straightaway, right? Then it, it, and, Christ what am I doing with this?

June: I've always been such an active person, but then it's coming slowly now, isn't it? where I can't clean, you see, and do things, you know, so it's sort of going slowly isn't it.

Jim: I could still go out and put my hands on trades people today, and erm, but I have to be careful now, because I know my work is not up to standard, and I put that down to dementia, cause there's nothing with my body movement, that can, should slow me down.

Secondary loss.

Ted: Mostly be sensibly in my, my head thinking I have changed, but, er, as I said before because I've got the back up of people around me, it's helped me erm, to keep er a steady, you know looking forward all the time.

Rod: Especially if I'm speaking to someone else, you know family, or anyone, I er, I feel as though I'm making a fool of myself, by saying somebody's words.

Janet: Just, I think, oh, I don't know, sometimes I don't, you know, I just think oh god, I don't do anything you know, I don't really know what I do.

Jane: Yeah, it's made, it's made me hopeless at doing things, such as, if I wanted to go out, and make a competition, or make a, something, I'm stupid about it.

Bill: Oh yeah, 100%, yeah, I mean I haven't got that confidence in myself, and, and I went through a stage erm, where I couldn't hit a golf ball to save my life, I, it was about 6 weeks, I could only hit it from here to the, and it, it was soul destroying.

Alan: Oh, awful, I had to give it up didn't I?....Made a, had a, had a big affect on me didn't it?

Jim: I get a bit upset when they erm, they being Barbara and her daughter, erm, I get a bit upset when they say, here you are, I'll drive, cause they're driving for a reason then, not because they want to drive, it's cause they don't trust my driving.

Grief reaction.

Janet: And so you feel that, you know, oh I wish it wasn't like this.

Jane: I felt what the use of crying about it, but I just felt so, I'd got nothing.....Nothing at all

Alan: And when you feel as though you can do, you, you used to be able to do something, pretty well.....Now I'm hurt.

Jim: I know I'm not going to achieve what I want to achieve with her.

Isolation.

Rod: It might be not seeing as much, because I don't go out with other, I stay in the house most of the time.

Jane: Sometimes I get a bit bitter, when you know, and I'm, if I've been sitting here, and no-one's come in, but Jenny comes in, she comes during the week sometimes, if she's got, she can come, but you see, the, the lads are working all day.

Jim: I just said because I'm on my bloody own all day, that's why I want a bloody dog, I may as well talk to the dog as four walls, and that was another one, I was getting lonely sitting in the house.

Attachment behaviour.

Rod: I feel I'd like to go back to the south end to (location), because I have got a lot of friends there, school there, teachers there, churches there, er and sometimes, between you and I, er, I'd like to return there.

Alice: And we lived here a long time now so we know the people in the area, well, I've lived, (place), all my life actually, so, but we've lived in this house a long time

Rose: Always had a big family around me, and then I, I met Les, and er, I'll tell you about my dad, my dad was a lovely man, very rough and ready, and ordinary, he'd be the first to tell you that wouldn't he Les? And he said to, when I first said I was going out with this son of a minister, he said, son of a minister? He said, but he always said, he's a, he's a bloody fine fellow, but he's a son of a, a minister, but that doesn't matter. Now, that's my dad, but I love my dad, and I love my mum, so I've had a great family around me.

Jane: Take the babies out, it was still, they were, they weren't open as what they are now, so erm, you could, it was closed of an afternoon, and they closed, at, well, but, I know, but I could only remember that part, erm, you could get the, the days, took the kids out, like, but I used to put them in bed, they'd be in bed, to go to sleep, and er, used to go up and see what they were doing, you know, all good, some were asleep, sometimes they weren't, but I just left them there, like.

Alan: Honestly I can't remember about it, I brood about it, and I keep running, running back in time to father's demise, and I do miss him.

Jim: I moved into U, selling UPVC windows and fitting UPVC windows, which I didn't have to manufacture, I bought them in, and I supplied and fitted, to the general public but also to builders who I knew and when we were switching over, I went chasing after them then just saying, look, I'm doing the windows and PVC now, so we moved into that, and I, I enjoyed it.

Super-Ordinate Theme: 5. "Personal Experience of Dementia"

Dementia as a journey.

Ted: I felt me, because they understand and they they put me on the straight and narrow if, if I tend to lose the bit now and again.

Rod: I'm a long way from it it's just coming now and again. I know I wasn't too er, er too much thought about it, something that won't bother me too much. But then it gradually got worse.

Janet: At first it wasn't, it wasn't like that, but it's generally got a bit you know, more, and I think that that, as you're aware of it coming, more than you know, more than it has been, I think that's a bit more, you think, oh no, it's getting you know, so that's how I'd say it was.

Jane: Cause at the time it wasn't too bad, but it was as the, 2 or 3 past, as it was going past, I might think time is going, and erm, you know, they'd been, I've been there a long time, no I think it must have been about 5 time when I had that, erm, but I don't know.

Bill: Seemed to have gone back to a stage where all I can remember is you know, like I found the doors from years and years ago, and this what I'm going to do, and I've just, that's there all the time now, I know I'm not going to lose that part again

Alan: I don't, well it doesn't really get any better.....Put it that way.

June: No, it's not really got that bad, I think it could be a lot worse later on.

Jim: And I can't explain that either. How come I can have it one second and it's gone completely the next second?

Dementia as a negative experience.

Ted: It's frightening. Erm, in one way but you tend to try and blank it out sometimes, you know I often, er, I don't really know.

Rod: I think life's horrible, to have the Alzheimer's so if there is any bad thing in your mind and I think for some reason or not, I am, I've had a few bad feelings in my mind and I don't whether to take them on against us or not.

Janet: So that's quite a thing I find. I can't bear it, it's horrible.

Rose: Well, only that I wouldn't like to get to the state where I can't do anything for myself, and I can't think for myself. I'd sooner somebody slit my throat, than to be like that.

Jane: It was only a little one they said, but what it did, I wished to look, they'd looked into to my brain to see what it was.

Bill: Sometimes we find it, and everything becomes clear, but then you come back out and you've lost that room again, it's as if the rooms are on a, you know, on a, say the, the rooms are mainly just, they spin round and then you can't find that room again, yeah.

Alan: I won't bring more into it, blooming heck, oh it's horrible, it's horrible.

June: Shocked, shocked.....Upset.....Upset

Jim: We don't really see ourselves aging, cause it's such a gradual process isn't it? so we don't really see ourselves age, but when we're a little bit off colour, we see ourselves age, cause we look in that mirror and we go bloody Nora

The "unknown."

Ted: Well that's the frightening side of it, the unknown is is the important side that you need to know but it its its like throwing dice in the air and you, you sort of situations where to assess that its, unless it's being assessed many times over when in the past year it's that I've no idea.

Janet: Yeah, yeah, I have thought that, but only you know, I don't think on those lines.

Sometimes I'll you know, just think well, you know, goodness knows what's going to happen here, you know.

Alan: Well, you, you know more than I know about it, I don't know whether I'm, whether or not I'll be like (knocks on wood) skipping about on the er, on the ballroom, I don't know, I've no idea

June: I was diagnosed, and I don't know how long it'll be before it goes worse, you know, I think it depends really.....Everybody's different aren't they?

Living well with dementia.

Ted: Er, everything. I've got a good family, I've got a, I still feel that life even though I'm, you know.

Alice: I don't know who, I think it's over a certain age, they say, dementia, but I wouldn't have described it as that, at all, so that's just a, a clinical opinion is it? Or what is the, but from my point of view, I'm still able to do most things, and see most things and I can read the paper, and, and, and remember everything I read in the paper, and so I, I don't you know, see a lot more that I could have, could do.

Bill: It makes you think that, stop taking things for granted, like, like, I realise that I always took my wife for granted, just assumed she'd do everything

June: Which I'm really not a miserable person, if er, if you were to sit in a chair rocking, you know, if you're sitting rocking, and you don't know hahaha, if you're sitting rocking and you know about it, well, I think it would affect you, you know

Dementia among other parts of life.

Janet: And my daughter, the other daughter, is going to try and find somewhere, there's quite a lot of things going on at the moment.

Jane: And this arm, I done this myself, I erm, had the car, opened this door, and it hit it, and I, I fell against the door, and erm, it knocked er, what was it, I think it was this, this one, knocked the thing out didn't it? knocked the thing off... Yeah, took the dislocate from that, and it was knocked out.....And then they had to take, they had to go down and take it down....And then they had to come and take it again, because it wasn't right, it wouldn't go back, erm, and now, that's as far as I've got the only blank, that's, now, that's as far as it goes now.

June: I think up to now, that would be difficult, erm, with that and all the other problems I've got, you know, they're all sort of together.

Super-Ordinate Theme 6: “A Sense of Finality”

Endings.

Ted: Well it's, it's just a continuation of life.

Rod: I hope it's a long time before the end

Rose: So that's my one fear, that it gets worse, but it won't get worse, 'cause I ask God to help me

Bill: Obviously it will shorten your life, you know, but I mean that's a proven fact, that, you know, people with dementia live, er, don't live as long as they expect, life expectancy.

Alan: I'm just hanging on really, I'm just hanging on.....Well, for living.

Jim: I want my age to be different so I can live with my wife, that's the biggest worry I have. I don't want to go, I don't want to really go before my wife.

Legacy; leaving something behind.

Rod: I like to do anyone any favours that I can, and I don't like to do anything sneaky on people or that sort of thing. Or even taking anything belonging to another.

Rose: Yeah, she, that's our daughter, she is, she's a, what is she?PA.....She's a lovely girl.....She's just like him, so you see, you can take a bow too can't you?

Jane: I would never, I'd never let the house go, even to go to stay with any of them, because that house is for the children, and I'd, I'd, I'd never pass it out, I'd never pass out

Alan: I'd prefer her temper, or temperament.....I prefer that.

June: I think his dad and me really, although his dad was brought up different, erm, his er, we were brought up more with love, my family, with all the children, and father erm, they were sort of like Victorian, you know, that type, you know, but they were nice people, yeah.

Jim: I would think my son coming out on top and beating his, his habits and erm, him winning the battle with his son, like I had to win the battle with my son.

Life review.

Rod: I worry about them a few times, thinking yeah, you know why couldn't we have done that and all, that but most of the time we've had houses and now we haven't, so we just thought ok, we like this one.

Alice: I've done a lot of interesting things. I've met interesting people, and, with my work, and my, my job was interesting in the company, and meeting people like famous person and people like that made life interesting, and so I was, I've been very happy with my life.

June: It's when you get your home and your property round you, you know, you have extra money to do, and erm, why keep it if you like clothes.

Super-Ordinate Theme: 7. "Hope"

Medical investment.

Ted: Again I don't think I can really, haven't thought about that because I tend to feel, what I've been given I'm hoping gonna make me on a steady keel all the time

Janet: Well, the best way of all would be to have somebody to say, oh yes, we've got this now, you know, and we can give you this, and it might.

Janet: It makes me feel that I wish there was something they could do

June: No worse hahaha, might be this tablet hahaha, I have a lot of faith in it.

Jim: when somebody tells you like, the doctor came and he said well I've got one on my books who's had it for 10 years.....Well, he may as well as given me a million pound, I felt that good when he went out.

Super-Ordinate Theme: 8. “Dementia as a Social Problem”

Social awareness.

June: But I don't know why, never heard of it years ago did you? No, but it must have been there mustn't it? There must have been as many people with it, but er, they were just sort of left, you know, so we're cared for more now aren't we?

Jim: I think people are only just getting used to, to dementia, a lot of it is thanks to television, cause they're showing a lot more, see they're doing a lot of advertising.

Stigma.

Bill: I think if the people who are around us and, and, and if people are made more aware of actually what dementia is, you know, it's not a contagious disease, cause people seem to shy away when you say, you know, you're, oh, you know, you're a lunatic, you know, and it's, and it's just, it's just getting into people's head that, you know, it's just, it's just a breakdown in the, in the electrical circuits.

Jim: I don't think it'll be treated as a er, horrible thing, oh keep away from them, he, he's got dementia or she's got dementia.

