

THE UNIVERSITY OF HULL

Wellbeing in dementia: Clinicians' perspectives

Being a Thesis submitted in partial fulfillment of the requirements for
the degree of Doctorate in Clinical Psychology
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by

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Acknowledgements

I would like to dedicate this thesis to my grandparents, Barbara and John Vince;

The best people I know.

First and foremost, I would like to extend my sincere gratitude to the eleven Old Age Psychiatrists who took such a large amount of time out of their extremely busy schedules to share their world with me. Not only has their willingness to participate made the research possible at all, but also improved my own practices as a clinician. I would also like to thank the kind people at MSNAP and the Old Age Psychiatrists who attended the focus group for their help in developing the empirical research project.

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Overview

The portfolio thesis is divided into three parts:

Part one is a systematic literature review exploring the relationship between self and staff-proxy assessments of quality of life in dementia. The review aimed to provide an exploration into the relationship between ratings made between self and staff-proxy rating as well as the factors that may explain or predict any differences between ratings. A systematic search of four databases identified 12 relevant studies. The findings of the studies are analysed using narrative synthesis and forest plots. Results are discussed in relation to clinical practices and research.

Part two is an empirical paper that explores the subjective understandings and lived experiences of Old Age Psychiatrists in relation to positive wellbeing in dementia. Qualitative data was collected using semi-structured interviews and analysed using Interpretive Phenomenological Analysis (IPA). Eleven psychiatrists from three NHS Trusts participated in the research. Three super-ordinate themes and nine sub-ordinate themes emerged from the data. These themes are discussed in relation to the wider literature base.

Part three comprises the appendices supporting the systematic literature review and empirical paper. It also includes a reflective statement of the primary researcher's experiences of the research process.

Total Word Count (including figures and tables but excluding appendices):

20608

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**Part One: The relationship between self and staff-proxy assessments of
Quality of Life in Dementia: A systematic review**

**The relationship between self and staff-proxy assessments of Quality of
Life in Dementia: A systematic review**

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Short running heading: Assessing QoL in dementia: self and proxy ratings

This paper is written in the format ready for submission to the *International Journal of Psychogeriatrics*.

Please see Appendix A for instructions for contributors.

Word count (excluding references): 8835

Abstract

Background: Assessing quality of life (QoL) is an important consideration in dementia care. However, agreement between self and proxy ratings using standardized measures is typically low. To date, there has been no attempt to formally document the extent of the difference between self and staff-proxy QoL ratings nor has there been systematic review of the literature pertaining to factors that may explain or predict such differences.

Method: A systematic review was conducted of four data sources. Results were presented using narrative synthesis and forest plots.

Results: Twelve studies were reviewed. People with dementia rated their QoL higher than staff proxies in all reviewed papers, with significant differences reported in five studies. There was marked variance in the level of agreement between raters for different dimensions of QoL measures reported between studies. Five studies reported mixed results regarding the relationship between the differences between self and proxy QoL ratings and demographic characteristics of the person with dementia, however significant associations were reported between the level and agreement and some key proxy-characteristics.

Conclusions: There is a paucity of high quality research investigating the factors that explain and predict the level of agreement between self and staff-proxy assessment of QoL using standardised measures. There was no consistent

evidence that better agreement between ratings is associated with higher functioning of people with dementia, nor that level of agreement is better for observable dimensions than subjective dimensions. Further quality research is needed to better understand the factors underlying differences between self and proxy QoL ratings.

Key words: Assessment; Dementia; Measure; Proxy, Staff; Systematic Review; Quality of Life

Introduction

In the continued absence of a medical cure, current care practices for people with dementia focus on supporting people to cope with their illness and enhancing quality of life (QoL) rather than focusing solely on limiting and minimizing its symptoms (Droes et al. 2006). In accordance, QoL is often considered a key outcome both in clinical practice and research trials (Moniz-Cook et al. 2008). In addition, UK national policy and guidelines have also paid increased attention to the QoL of people with dementia, with improving and supporting QoL fundamental to the National Dementia Strategy for England (The National Dementia Strategy [DOH], 2009).

QoL is broadly recognized as a multi-dimensional construct comprising physical, psychological and social elements (Selai et al. 1999) and involving both objective (behavioral competence and environmental) and subjective (perceived QoL and psychological wellbeing) domains (see Lawton, 1994). As noted by Bowling et al. (2015) measuring the QoL of people with dementia has important implications for ensuring that cost-effective support is in place to maintain their QoL until death. Whilst there now exist a number of standardized measures of QoL, which vary with regards to the domains they assess (Scholzel-Dorenbos et al. 2007), most are based on Lawton's 1994 model (Jonker et al. 2014) and have a comparable focus (Bowling et al. 2015). Despite the plethora of measures now available, there is a relative paucity of research

reporting on their psychometric features. In particular, the available literature suggests that many measures have limited reliability and validity particularly when assessed using staff-proxies (Bowling et al. 2015).

A significant challenge for clinicians and researchers attempting to measure QoL outcomes in dementia lies in the extent to which self and proxy ratings of QoL can be regarded as valid and complementary. This is a particular challenge in relation to people living with more advanced forms of dementia. Proxy assessment of QoL is often required when self-rated assessment is not possible (Crocker, Smith and Skivington, 2015) and collecting information from multiple perspectives may facilitate a more holistic assessment of QoL (Eiser and Morse, 2001; Claire et al. 2014; Moyle et al. 2012; Scholzel-Dorenbos et al. 2007). However, as reported for many long-term health conditions (Crocker et al. 2015), agreement between self and proxy ratings of QoL in dementia is typically low (Bowling et al. 2015). A number of recent reviews have highlighted differences in self and proxy ratings of QoL (Beerens, 2013; Crocker et al. 2015; Perales et al. 2013) and have consistently indicated that proxies tend to underestimate QoL in comparison to people with dementia and that self and proxy ratings of QoL show different associations with factors such as mood, cognition and activities of daily living (ADL).

It has traditionally been assumed that any differences between self and proxy ratings merely indicate that people living with dementia are unable to provide accurate accounts of their QoL due to cognitive and communicative

impairments and compromised awareness (Selai et al. 1999). However, it is now generally accepted that self-report can be used to assess QoL using standardized assessment measures (Jonker et al. 2014), with some suggesting that self-reports are the best method of assessing QoL in people with dementia (Claire et al. 2014). An alternative key reason underpinning the poor agreement between self and proxy assessments of QoL is the inherent difficulty in judging the subjective QoL of another person. Existing literature has consistently reported greater agreement between self and proxy ratings for objective dimensions of QoL, which relate to discrete and observable aspects of functioning, than for subjective dimensions that are more related to a person's perceptions of emotional well-being and life satisfaction (Selai et al. 1999; Jonker et al. 2014). Furthermore, it is possible that variance between scores may also be, in part, explained by differences in the perceived importance of each QoL domain between self and proxy raters (Droes et al. 2006), and the inherent tendency of proxy-raters to make downward social comparisons of another's subjective experience at personal, interpersonal and societal levels (Crocker et al. 2015).

Whilst predictors of self-rated and proxy-rated QoL have been examined and reviewed independently (Beerens, Zwakhalen, Verbeek, Ruwaard and Hamers, 2013) previous reviews in this field have not focused particularly on the level of agreement between self-rated QoL and that rated by staff caregivers as proxies. As literature has reported significant differences between family and staff-proxy ratings of QoL (Crocker et al. 2015) it cannot be assumed that the factors influencing staff-proxy assessment of QoL are the same as those that

influence family-proxies, possibly due to differences in relationships and roles between the groups. To illustrate, Bryan et al. (2005) reported differences in the associations found between QoL ratings and clinical measures of illness severity for staff and family proxy raters. They identified better associations between observable dimensions of health and functional status and measures of illness severity for the staff-proxy group, whereas stronger associations were reported between family-proxy ratings and psychological/social dimensions, suggesting that there may be differences in the extent to which staff and family proxies are influenced by bias and confounding variables when assessing QoL.

To date, there has been no review of the literature pertaining to factors that may explain or predict the difference between self and staff-proxy ratings of QoL and the extent of differences between self-ratings and staff-proxy ratings of QoL has not been formally documented across studies. A review is therefore necessary as although it may be best practice to use self-report to assess QoL, this may not be not always possible or appropriate (Moyle et al. 2012) and, in addition, it cannot be assumed that factors influencing the discrepancies between self and family-proxy ratings of QoL also hold true for staff proxies. As staff-proxies typically play an important role in supporting the QoL of people with dementia, particularly as dementia progresses, this represents an important gap in our current understanding.

As such, this systematic review of relevant literature aimed to examine and

determine the variance between self and staff proxy ratings of QoL where studies have used established and standardized measures, as well as considering the factors that may predict variance between ratings. A greater understanding of these factors is likely to aid clinicians in interpreting divergence in QoL ratings and supporting people living with dementia to maximize their quality of life. It may also point toward valuable future directions that research into QoL in dementia could take.

Two research questions underpinned this systematic literature review:

1. What is the level of agreement between self and staff-proxy ratings of QoL in people with dementia?
2. What factors explain and / or predict differences between self and staff-proxy ratings of QoL in dementia?

Method

Literature Search Protocol

The following online databases were selected and searched in January 2015. These databases were selected to reach literature published in the fields of psychology and health:

- CINAHL
- PsycINFO
- PsycArticles
- Web of Science

Search terms were selected based upon similar reviews in dementia research (Banerjee et al. 2009; Bowling et al. 2015; Graske, Fischer, Kuhlmeier and Wolf-Osterman, 2012) and other clinical groups (Grange, Bekker, Noyes and Langley, 2007) followed by subsequent initial searches to identify any additional key words used within the literature in this clinical population. The Boolean phrase N3 was utilized to help ensure retrieved papers focused on assessments of QoL. Final search terms were:

(dementia or alzheimer*)

AND

("quality of life" OR QoL OR "health related quality of life" OR HRQoL) N3
(assess* OR measure* OR scale OR questionnaire OR tool* OR index OR
battery)

Inclusion and exclusion criteria

To ensure all relevant literature was identified for inclusion in the review no quality-based, temporal or geographical limitations were included in the search protocol. All titles and abstracts were read and assessed against the inclusion

and exclusion criteria.

The following inclusion criteria were applied:

- Studies that employed standardized measures of quality of life or health related quality of life (assessment based on standardized assessment of QoL not clinical indicators associated with QoL e.g. depression).
- The presence of a clinical diagnosis of dementia within the clinical sample
- QoL was assessed by both people living with dementia and staff proxy ratings.

Articles were excluded at this stage based on one or more of the following criteria:

- QoL was assessed solely by observational measure (paper included if observational measures were used in conjunction with other standardized assessment)
- Data reporting staff-proxy ratings of QoL could not be determined from other proxy-rated QoL (e.g. family).
- Staff proxy's relationship to the person with dementia was unclear (e.g. if it was not clear that the proxy rating was completed by a staff-proxy).
- Data did not differentiate between people with dementia and people with other neurodegenerative diagnoses or mild cognitive impairment.
- Papers utilized the same sample as another paper included in the review but did not add additional information regarding review questions (e.g. additional exploration of predictors of variance). When applicable, the

earliest article published was included in the review and subsequent papers excluded.

- Review article, book, discussion paper or comment about measurement issues
- No English translation available

Data extraction

A data extraction tool was developed to collect relevant information from each study (Appendix E). This included the authors, aims, participant and proxy characteristics, QoL measures used, findings and conclusions, including key factors predicting and reasons attributed to any variance in self and proxy ratings.

Quality Assessment

A bespoke checklist was developed to assess the methodological quality of included studies, as no existing checklist was found to meet the needs of the current review. The checklist (Appendix B) was adapted from three existing checklists developed to assess quality in healthcare research and research utilizing correlational methodology, thus better reflecting the nature of the literature base and question under review. Questions 1-15 and 19 were adapted from Downs and Black (1998), a widely utilised assessment of quality for healthcare intervention research. Question 3 was adapted from NICE (2012) to reflect the importance of a theoretical consideration of predictor variables.

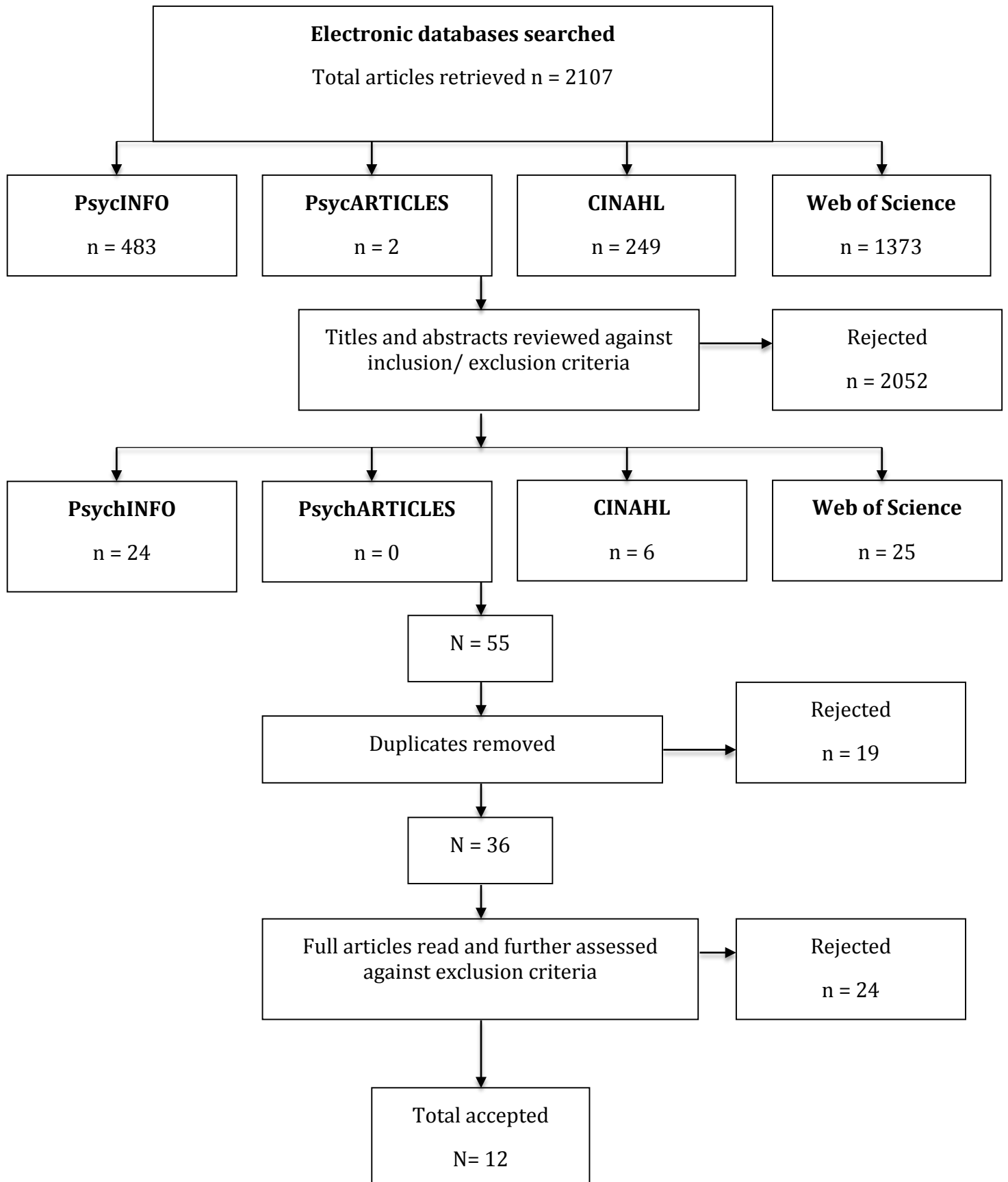
Questions 16-18 were adapted from Thompson, Diamond, McWilliam, Snyder and Snyder (2005), who offer a widely-cited appraisal of methodological quality of studies using correlational designs.

The following were considered to be key determinants of methodological quality in relation to the review questions: the rationale for inclusion of variables associated with QoL; the psychometric properties of measures used to assess QoL and associated variables; and whether all relationships between QoL and associated variables were reported. Therefore, the corresponding questions within the quality assessment tool (questions 3, 5, 6 and 17) were weighted to better reflect the bearing of those items on the quality of each study in relation to the review questions and so ensure that quality scores reflected the extent to which papers reported on these factors rather than a mere presence or absence of such. The scoring of these items was weighted in terms of fully=2, partly=1 and no=0.

Analysis of findings

Despite the quantitative nature of the papers included in the review, significant heterogeneity between papers (see below) precluded the full use of meta-analysis or synthesis of regression analyses to summarize findings. As such, results were summarized using a narrative synthesis (Popay et al. 2006), with forest plots presented to capture the variance in differences between self and proxy QoL ratings.

Figure 1. Search Diagram



Results

Study Characteristics

Figure 1 summarizes the literature search and retrieval process. In total, 12 papers were included in the review reporting from 10 separate samples. Nine papers reported dementia-specific measures of QoL, whilst three reported general measures of QoL.

Table 1 shows selected data extracted from the studies. Of the 12 studies included in the review, nine used the Quality of Life in Alzheimer's Disease (QoL-AD) (Logsdon, Gibbons, McCurry and Terri, 1999) to assess QoL in self and proxy samples, with three using the adapted QoL-AD developed by Edelman et al. (2005) for people in residential care. One paper used the Nottingham Health Profile¹ [NHP] (Bucquet, Condon and Ritchie, 1990) one the Duke Health Profile [DHP] (Parkerson and Broadhead, 1990) and one the EuroQol ED-5Q [EQ-5D] (Selai, Trimble and Rossor, 2000) as their primary QoL measure.

In addition to the QoL-AD, proxy-rated QoL also was assessed using the Alzheimer's Disease Related Quality of Life [ADRQL] (Rabins, Kasper, Kleinman, Black and Patrick, 2000) in three papers and the Quality of Life in Dementia [QoL-D] (Albert, Del Castillo-Castaneda, Sano, Jacobs, Marder, Bell

¹ French Translation

et al. 1996) in one paper. In addition to the QoL-AD, self-rated QoL was also assessed using the Dementia Quality of Life Scale [DQoL] (Brod, Stewart and Sands, 1999) in two papers and both self and proxy rated QoL by the QoL-D in one paper.

Most studies were cross-sectional in design with only one utilising a longitudinal experimental design (Wenborne et al. 2013). Studies used correlational methodology and analysis of variance to explore the relationship between QoL ratings and various other variables, with six and two studies also employing regression analysis to explore variance in self/proxy QoL scores and the difference between scores respectively.

Clinical participant sample sizes ranged from 24 (Wenborne et al. 2013) to 410 (Sloane et al. 2005) and staff proxy participant sample sizes from two (Coucill, Bryan, Bentham, Buckley and Laight, 2005) to 410 (Sloane et al. 2005). Most papers reported the age and gender of clinical sample participants, with mean age ranging from 76 (Coucill et al. 2001) to 86.5 (Hoe et al. 2006) and all showing a bias towards female gender, with percentage of female participants ranging from 56% (Coucill et al. 2001) to 88% (Spector and Orrell, 2006).

Papers varied with regards to excluding participants based on Mini-mental State Examination [MMSE] score, with mean MMSE scores of included participants ranging from 5.5 (Wenborne et al. 2013) to 15.7 (Boyer et al. 2004).

Eight papers reported proxy job title. The most common staff-proxy was auxiliary nurse but included studies also included nurses (Boyer et al. 2004; Sloane et al. 2005) and psychiatrists (Coucill et al. 2001) as well as other care providers including physicians and psychologists (Boyer et al. 2004). It is, however, important to note that sample sizes of proxy-raters from psychiatry and other professions were typically small, ranging from two (Coucill et al. 2001) to 13 (Boyer et al. 2004). Two papers reported the mean duration of time in post as 3.9 years (Crespo et al. 2012; 2013) and 8.5 (Spector and Orrell, 2006). Importantly for the current review, only four papers, from three data sets, reported demographic variables of proxy samples (Crespo et al. 2012; 2013, Gomez-Gallego et al. 2012; Spector and Orrell, 2006). The mean age of proxy participants in these studies ranged from 35.5 (Gomez-Gallego et al. 2012) to 40.3 years (Spector and Orrell, 2006) with female gender bias ranging from 84 % (Gomez-Gallego et al. 2012) to 96.7% (Crespo et al. 2012; 2013).

Table 1. Key factors extracted from reviewed studies

Study	Country	Quality Score	Standardized QOL measure	Other variables assessed for their relationship to the difference between self and proxy ratings
Beer et al. 2010	Australia	13/24	QoL-AD (self & proxy) ADRQL (proxy only)	
Boyer et al. 2004	France, Belguim, Luxemborg, Switzerland	15/24	Nottingham Health Profile	<p>Demographic variables of PWD:</p> <p>Age [< 80 years, ≥ 80 years]</p> <p>Gender;</p> <p>Living arrangement [home/ hospital/ nursing home];</p> <p>Other variables associated with PWD:</p> <p>Cognitive status [< 18, ≥ 18] (MMSE);</p> <p>Physical status [Independent, dependent for a single activity] (Katz Activities of Daily Living Index);</p> <p>Dementia duration [< 4 years, ≥ 4 years]</p> <p>Variables associated with staff proxy:</p> <p>Professional role [nurse, auxiliary nurse, other]</p>
Coucill, Bryan, Bentham, Buckley & Laight, 2001	UK	16/24	EQ-5D (Health Classification System and Visual Analogue)	<p>Other variables associated with PWD:</p> <p>Dementia severity (Clinical Dementia Rating)</p>

			components)	
Crespo, Bernaldo de Quiros, Gomez, & Carlos Hornillos, 2012	Spain	22/24	QoL-AD (Edelman et al. 2005 adaption)	
Crespo, Hornillos & Bernaldo de Quirós, 2013	Spain	20/24	QoL-AD (Edelman et al. 2005 adaption)	
Edelman, Fulton, Kuhn & Chang, 2005	USA	12/24	QoL-AD (Edelman et al. 2005 adaption)	Demographic variables of PWD: Living situation [Special care facility, assisted living facility]
			Dementia Quality of Life (self-rated only)	Other variables associated with PWD: Cognitive Functioning (MMSE);
			Alzheimer's Disease-Related Quality of Life (Proxy-rated only)	Functional status (Katz Activities of Daily Living Scale); Depression (Cornell Depression Scale for Dementia); Co-morbidity (Cumulative Illness Rating Scale-Geriatrics)

Gómez-Gallego, Gómez-Amor & Gómez-García, 2012	Spain	17/24	QoL-AD	
Hoe, Hancock, Livingston & Orrell, 2006	UK	13/24	QoL-AD	
Novella, Jochum, Jolly, Morrone, Ankri, Bureau & Blanchard, 2001	France, Belgium, Luxemborg, Switzerland	13/24	The Duke Health Profile	<p>Demographic variables of PWD:</p> <p>Age [60-80 or 81+];</p> <p>Gender;</p> <p>Other variables associated with PWD:</p> <p>Cognitive status [10-15, 16+] (MMSE);</p> <p>Physical status [Independent, dependent for a single activity] (Katz Activities of Daily Living);</p> <p>Living arrangement [home/ hospital/ nursing home];</p> <p>Professional role [nurse, nurses' aid, other]</p>
Sloane, Zimmerman, Williams, Reed, Gill & Preisser, 2005	USA	12/24	QoL-AD (Edelman et al. 2005 adaption);	
			QoL in AD-Activity;	
			Dementia Quality of Life (self-rated only);	
			QoL in AD positive affect	

			(Proxy-rated only); QoL in AD negative affect (Proxy-rated only); ADRQL (proxy only)	
Spector & Orrell, 2006	UK	19/24	QoL-AD	<p>Other variables associated with PWD:</p> <p>Cognitive functioning (MMSE)</p> <p>Variables associated with staff proxy:</p> <p>Age;</p> <p>Duration working in the home;</p> <p>Duration working with older people;</p> <p>Job satisfaction (Job Satisfaction Index, Aspects of Work Inventory);</p> <p>Hope (Approaches to Dementia Questionnaire);</p> <p>Person-centeredness (Approaches to Dementia Questionnaire)</p>
Wenborn, Challis, Head, Miranda-Castillo, Pophal, Thakur, Illes & Orrell, 2013	UK	14/24	QoL-AD	

Quality Assessment

The methodological quality of all papers was assessed by the first author, with a subsample (n=4) assessed by a peer for the purpose of reliability checking the adapted checklist. Differences between quality scores ranged from 0-1 point for all double-reviewed papers (see Appendix D), and there was therefore no need for further rating. Final quality scores reported are those of the first author. See Table 1 and Appendix C for full quality assessment scores.

Total quality scores ranged from 12 (Sloane et al. 2005) to 22 (Crespo et al. 2012). Studies typically had high quality for explicitly stating the selection and screening criteria of the clinical sample, as well as for analysis and presentation of key findings. With the exception of the four aforementioned studies, key characteristics of the proxy-sample were not reported and therefore most papers scored poorly in relation to this. Four papers provided a rationale for the selection of all associated variables explored (Crespo et al. 2012; 13; Gomez-Gallego et al. 2012; Spector and Orrell, 2006) with two further papers providing a rationale for some variables but not all (Beer et al. 2010; Coucill et al. 2001). With the exception of Sloane et al. (2005) and Beer et al. (2010), all papers explored or provided a description of the psychometric properties of the measures used to assess QoL but only three papers provided such information regarding associated variables (Crespo et al. 2012; Edelman et al. 2005; Gomez-Gallego et al. 2012), with only Crespo et al. (2012) reporting psychometric properties for every measure used. Most papers reported effect sizes for all relationships explored, with four papers reporting some but not all

relationships (Beer et al. 2010; Edelman et al. 2005; Gomez-Gallego et al. 2012; Hoe et al. 2006).

Level of agreement between self and proxy ratings of QoL

Papers were assessed for suitability for a meta-analysis to calculate the overall difference between self and proxy ratings reported in the literature. See Appendix G for details of this process. Heterogeneity of suitable papers (shown in Figures 2 and 3) was assessed using RevMan 5.3 (2012). Analyses showed that the studies displayed considerable heterogeneity in the difference found between self and proxy QoL ratings ($I^2= 93\%$; $p< 0.00001$) and this was maintained when papers of lower methodological quality (Beer et al. 2010; Hoe et al. 2006; Sloane et al. 2005; Wenborne et al. 2013) were removed from the analysis ($I^2= 90\%$; $p< 0.0001$) (See figure 2 and 3). With the current data, there is insufficient statistical power to determine whether this high level of heterogeneity is a reflection of study-level variance or genuine heterogeneity within the data. Although the direction of effects was comparable across the studies (see figure 2) the level heterogeneity was such that it would have been misleading to report an average value for the difference between self and proxy ratings of QoL (Anderson et al. 2011). Therefore, results are presented using a narrative synthesis (Popay et al. 2006) rather than a meta-analysis but forest plots are included below to show both trends in differences between self and proxy rated QoL and levels of heterogeneity across the included studies.

Figure 2. Revman data for all studies meeting criteria for meta-analysis

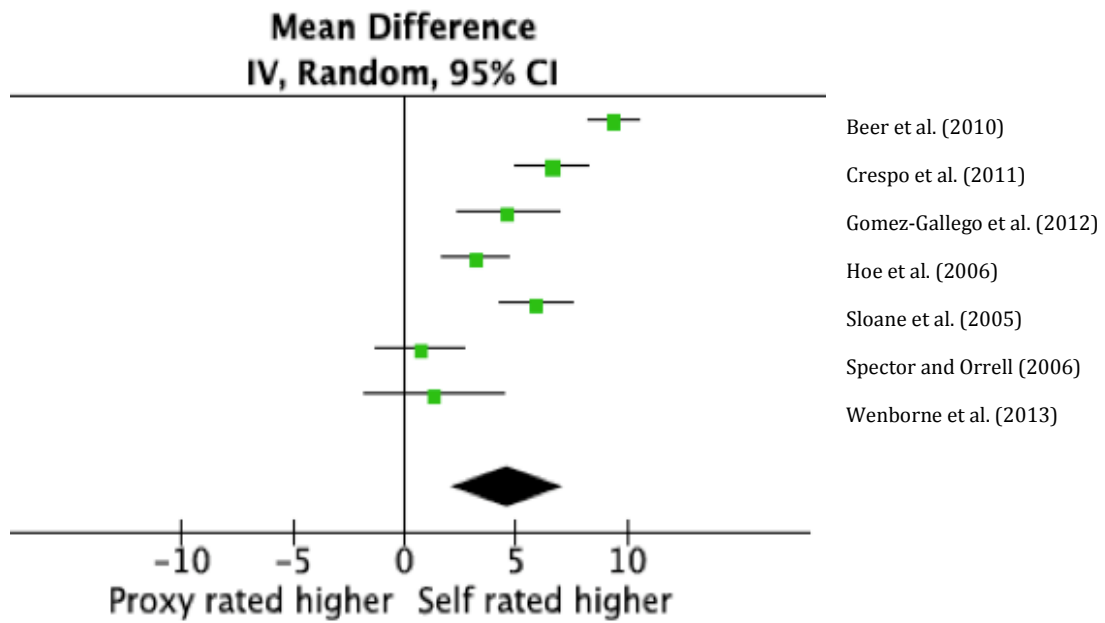
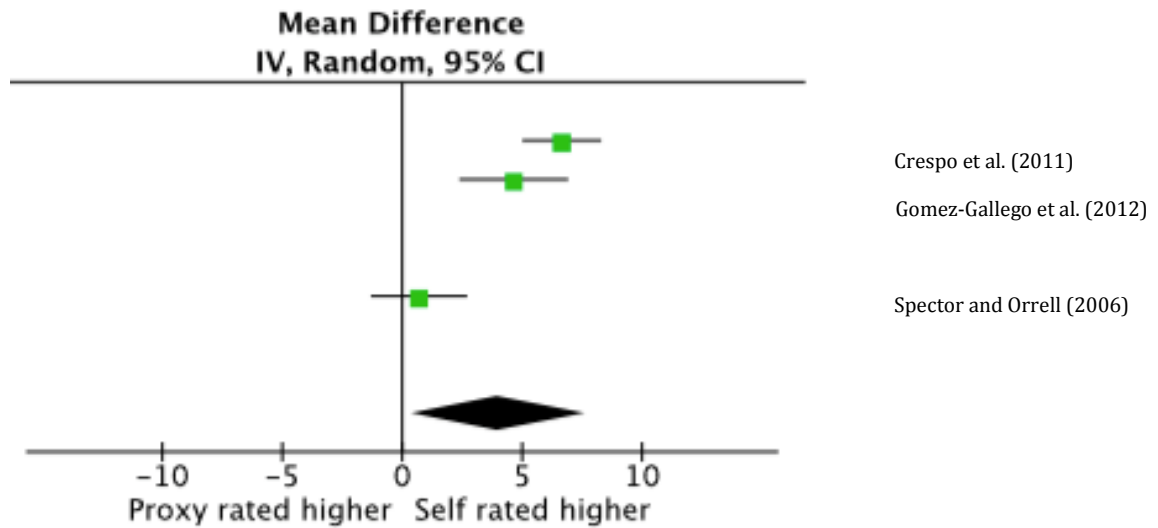


Figure 3. Revman data for high quality studies meeting criteria for meta-analysis



Findings generally showed a trend towards higher self-rated overall QoL than proxy-rated on all measures. Of the ten papers that explored the difference

between self and proxy scores, statistically significant differences were found in five papers reporting from four separate samples, with most reaching $p < 0.001$ (Coucill et al. 2001; Crespo et al. 2012; 2013; Gomez-Gallego et al. 2012), except Edelman et al. (2005) where $p = 0.003$. Effect sizes reported ranged from $F = 10.44$ (Coucill et al. 2001) to $F(2, 132) = 21.86$ (Crespo et al. 2012; 2013). The difference between scores was not found to be statistically significant in Spector and Orrell (2006) with $p = 0.48$ ($t(75) = 0.72$). Although Edelman et al. (2005) was of lower methodological quality, and so should be interpreted with caution, Spector and Orrell (2006) scored highly for methodological quality. Therefore, variance in findings within the literature may not be fully explained by methodological shortcomings in some papers. However, differences between the effect sizes reported may be, at least in part, a reflection of the different measures used to assess QoL.

Self and proxy QoL-AD ratings were significantly correlated in some papers (Beer et al. 2010; Gomez-Gallego et al. 2012; Hoe et al. 2006) and not in others (Crespo et al. 2012; Edelman et al. 2005; Spector and Orrell, 2006; Sloane et al. 2005). There was variation in the methodological quality of papers (up to 10 points) reporting correlations between these scores, but this did not appear to be related to whether the paper found a significant correlation or not. The level of agreement between self and proxy ratings was low to moderate (as defined by Nunnally, 1978; Nunnally and Bernstein, 1994) on the QoL-AD, (Crespo et al. 2012; Gomez-Gallego et al. 2012; Hoe et al. 2006), the DHP (Novella et al.

2001), and generally low on the NHP (Boyer et al. 2004) the QoL-D Activities (Sloane et al. 2005) and the EQ-5D (Coucill et al. 2001)².

Of the nine papers using the QoL-AD, mean point differences between ratings ranged from 0.4 (Edelman et al. 2005) to 7.8 (Beer et al. 2010). On the NHP, mean point differences between the dimensions ranged from -0.7 to -14.28 (Boyer et al. 2004). For the DHP mean point difference ranged from -2.83 to -9.82 between dimensions (Novella et al. 2001) and on the EQ-5, scores indicated no better than fair agreement (Altman, 1991) across all dimensions with kappa scores ranging from $k= 0.03$ to $k= 0.4$ between dimensions (Coucill et al. 2001).

Agreement by QoL dimension

Three papers of variable quality reported self and proxy ratings by dimension using the QoL-AD³, (Crespo et al. 2012; Hoe et al. 2006; Spector and Orrell, 2006) with one paper of lower quality reporting ratings by dimension using the DHP (Novella et al. 2001). Factors scoring both high and low were largely consistent between groups but results demonstrated marked variance in the level of agreement between raters for different dimensions of QoL measures.

² Based on classification defined by Altman (1991)

³ Or an adapted version

There were notable differences between the papers regarding the level of agreement between ratings at a dimension-level using the QoL-AD. Greater agreement, as defined by significant Spearman rank correlations and insignificant Wilcoxon z values, was reported for 'Physical Health', 'Family' and 'Friends' by Spector and Orrell (2006). This was not supported by Crespo et al. (2012). In their paper of higher methodological quality, they found the measure-specific dimension 'Ability to make choices' was the only dimension to show a significant correlation between self and proxy ratings without also showing a significant difference between ratings.

Specifically, 'Life overall' was the only dimension to show significant differences between ratings in both papers. Crespo et al. (2012) also found significant differences between ratings for 'Energy', 'Mood', 'Friends' and 'Ability to do things for fun' that were not reported by Spector and Orrell (2006), whilst, Spector and Orrell (2006) reported significant differences in 'Marriage' and 'Memory' that were not reflected in Crespo et al. (2012). Significant differences were also reported between the measure-specific dimensions of 'Ability to keep busy', 'Ability to take care of self', 'Ability to live with others' and 'Ability to make choices in life' in the adapted QoL-AD (Crespo et al. 2012) and 'Ability to do chores' in the non-adapted QoL-AD (Spector and Orrell, 2006).

Three papers of variable quality used intra-class correlation coefficient [ICC] to explore the relationship between self and proxy ratings on the QoL-AD at a dimension level, with similarly mixed findings (Crespo et al. 2012; Hoe et al. 2006; Spector and Orrell, 2006). No dimension showed significant correlations

across all three papers. 'Marriage', 'life as a whole' (Hoe et al. 2006; Spector and Orrel, 2006) and 'Family' (Crespo et al. 2012; Hoe et al. 2006) showed significant correlations in two papers of variable quality. Significant ICC scores were also reported for 'Memory', and 'Ability to do chores'⁴ by Spector and Orrell (2006); 'Friends' and 'Ability to do things for fun'⁵ by Hoe et al. (2006) and 'Energy', 'Ability to keep busy'⁶ and 'Ability to make choices'⁷ by Crespo et al. (2012). The dimensions 'Ability to do chores' (Spector and Orrell, 2006), 'Energy', 'Ability to keep busy' and 'Ability to make choices' (Crespo et al. 2012) showed both significant correlations and differences, suggesting that self and proxy-ratings of these dimensions have a relationship despite the significant differences between the scores given by people with dementia and staff-proxies.

Although it is possible that some of the difference in the significant relationships reported may be explained by the use of an adapted measure by Crespo et al. (2012), marked differences were observed both between papers using the same adaption of the QoL-AD (Hoe et al. 2006; Spector and Orrell, 2006) and for dimensions common to both measures (e.g. 'Energy') in studies rated to be of higher methodological quality (Crespo et al. 2012; Spector and Orrell, 2006) suggesting that study-level variance does not fully explain these differences.

⁴ Measure-specific dimension

⁵ Measure-specific dimension

⁶ Measure-specific dimension

⁷ Measure-specific dimension

Three papers of more moderate methodological quality (relative to those above) explored the agreement between ratings using the ED-5Q, NHP and DHP (Boyer et al. 2004; Coucill et al. 2001; Novella et al. 2001). Coucill et al (2001) reported low agreement between ratings, based on Altman's (1991) classification, for all dimensions of the EQ-5D with the exception of 'Mobility', for which agreement was moderate. Although direct comparisons cannot be drawn due to differences between the measures, Boyer et al. (2004) also found low agreement across most dimensions of the NHP, as defined by Nunnally and Bernstein's (1994) classifications of ICC scores, with the exception of 'Physical Mobility' and 'Pain', which were rated moderate. In contrast, Novella et al. (2001) reported moderate agreement between ratings across all dimensions of the DHP, also based on Nunnally's (1978) classification of ICC scores⁸, with the exception of 'Anxiety', which was rated poor by a small margin (ICC=39.3). It is likely that differences may be, in part, a reflection of the differences between measures used, as well as variable methodological quality of the papers.

Boyer et al. (2004) and Novella et al. (2001) also explored the level of discrepancy between ratings using analysis of variance [ANOVA] and Cohen's d respectively. 'Physical mobility' was found to be the only dimension of the NHP that showed a significant difference between self and proxy ratings, $t = -4.08$ ($p < 0.001$) (Boyer et al. 2004). Similarly, despite significant correlations, Novella et al. (2001) found 'Physical Health' as the only dimension to significant differences ($d = 3.1$, $p = < 0.05$) between self and proxy raters using the DHP.

⁸ Categories defined by Nunnally are the same in all publications referenced by authors.

This suggests that although scores were related, proxies rated 'Physical Health' significantly lower than people with dementia using the DHP.

Factors that explain and / or predict differences between self and proxy-rated QoL ratings

Only five papers (Boyer et al. 2004; Coucill et al. 2001; Edelman et al. 2005; Novella et al. 2001; Spector and Orrell, 2006) conducted analyses to explore factors that may explain or predict the difference between self and proxy scores, with only two conducting regression analyses (Boyer et al. 2004; Spector and Orrell, 2006). There was marked variance between these papers with regards to the variables they investigated in relation to QoL ratings (see Table 1).

Independence in Activities of Daily Living

The difference between ratings was significantly associated with the level of independence in activities of daily living [ADL] of the person with dementia in one study of modest quality (Boyer et al. 2004). In this study increased dependence (assessed using Katz Index, 1970) was significantly associated with larger differences between ratings in bivariate analysis, with higher dependency found to be the only variable that explained significant variance in the difference between ratings in multivariate analysis ($p= 0.0004$). This suggests that disagreement between self and proxy ratings of QoL was most marked for people with dementia who were dependent in multiple aspects of ADL. (Boyer et al. 2004). However, these findings were contradicted by Novella

et al. (2001), who found no significant relationship between the difference between ratings and level of independence in ADL functioning also based on Katz Index (1970). It is possible that this difference is, in part, explained by differences in measure used (NHP and DHP respectively) although it should be noted that both measures are suggested to provide a more health-focussed assessment of QoL (Brod et al. 1999).

Cognitive Function

Literature was mixed with regards to the relationships reported between differences in QoL ratings and the level of cognitive functioning of the person living with dementia. One paper reported a non-significant association between years since onset of dementia and the difference between QoL scores (Boyer et al. 2004), suggesting that actual level of cognitive functioning has a greater impact upon agreement between ratings than time since diagnosis. Whilst larger differences between ratings were associated with lower MMSE scores in a bivariate analysis ($p=0.04$) reported by Boyer et al. (2004) and Edelman et al (2005), this was contradicted by other literature of both lower and higher quality in bivariate (Novella et al. 2001) and multivariate (Spector and Orrell, 2006) analyses. Coucill et al. (2001) further contradicts the findings of Boyer et al (2004) and Edelman et al. (2005). In their study of slightly higher methodological quality, level of agreement between ratings on the EQ-5D was not better for those with higher CDR scores than those with lower scores, indicating that dementia severity did not influence agreement between ratings. However, it is important to note that although focused on cognition, the CDR

reflects the wider functioning of a person with dementia and therefore findings may be confounded by the influence of other variables on the agreement between ratings.

Demographic Factors

Differences between QoL ratings were not significantly related to the age of the person with dementia in two studies of variable quality (Novella et al. 2001; Spector and Orrell, 2006). However, being aged over 80 was found to be significantly associated with the difference in ratings in bivariate analysis ($p=0.01$) in one study of lower quality (Boyer et al. 2004), with increased age associated with larger differences between ratings. No included study reported a significant relationship between the difference in QoL ratings and the gender of the person with dementia (Boyer et al. 2004; Novella et al. 2001). No study explored associations with culture.

Place of Residence

The living arrangement of the person with dementia was not significantly associated with differences in QoL ratings in one study (Boyer et al. 2004). In contrast, place of residence was found to have a significant impact on the level of agreement between ratings in two papers of lower quality (Edelman et al. 2005; Novella et al. 2001). Novella et al. (2001) found higher mean discrepancies between ratings for people living in nursing homes compared to

their own home, with the lowest discrepancies for those based in hospital. Similarly, Edelman et al. (2005) reported significant differences between ratings for people living in special care settings but not people in assisted living facilities, and also reported a significant negative correlation between the difference in ratings of QoL and MMSE scores in a special care subsample but not the assisted living subsample. This suggests that care setting may mediate any relationship between level of agreement between ratings and level of cognitive impairment of the person with dementia.

Staff factors

Spector and Orrell (2006) explored the relationship between the discrepancy in ratings and staff factors (see Table 1). They reported that 2% of variance was accounted by proxy age, duration at the home and duration working with older adults, which increased to only 3% when adding proxy satisfaction, hope and person-centeredness. Thus, these authors concluded that none of the staff factors explored were found to be a significant predictor of the difference between staff and proxy ratings of QoL, using the QoL-AD.

Two papers of comparable quality considered the effect of professional group on the level of agreement between self and proxy ratings, reporting conflicting results (Boyer et al. 2004; Novella et al. 2001). Using the NHP, Boyer et al. (2004) found that pairwise agreement between ratings was better, as defined by higher ICC coefficients, for nursing auxiliaries than it was for nurses or other

health-care professionals. Correlations ranged from ICC= 0.11 to 0.49, ICC= 0.09 to 0.51 and ICC= 0.12 to 0.38 respectively. Conversely, Novella et al. (2001) found pairwise agreement was highest amongst other professionals, followed by nurses and worst with nurses' aides, with results showing moderate to good agreement in 6/10, 4/10 and 0/10 respectively based on Nunnally and Bernstein's (1994) classifications of ICC coefficients in their study of slightly lower quality. Although Boyer et al. (2004) and Novella et al. (2001) used different measures of QoL, both are arguably more health-focussed assessments (Brod et al. 1999) that are based on comparable dimensions and, as such, it is unlikely that the discrepancies between their findings can be fully explained by the different measures used.

It is important to note that the above literature may be limited by methodological quality, which varied considerably between the five papers (up to six point difference). In particular, the findings of Boyer et al. (2004) and Novella et al. (2001) may be limited by their use of cut-off classifications (e.g. age < 80) without a clear rationale. This may have confounded relationships reported and should therefore be considered when generalising from these results or making comparisons with conflicting findings presented in other research. Furthermore, the professional body included within the category of 'Other professional' was not well defined or reported within the literature, but was identified as physician, psychologist, psychotherapist or other care provider by Novella et al. (2001). Therefore, it is possible that results reporting the relationship between other professionals and the differences between ratings are confounded by the different roles of professionals included in this group as well as the small

sample sizes. Additionally, all five papers failed to report on the psychometric properties of every measure used to assess associated variables, which may be argued to further limit the validity of conclusions drawn from their analyses.

Discussion

Overview and Integration of the Findings

Consistent with existing literature (Crocker et al. 2015; Perales et al. 2013), the current review indicates that there are important differences between QoL ratings made by people with dementia and their staff proxies on standardised and widely used assessments, and also points toward factors that may contribute to these differences. Differences were reported between self and proxy ratings of QoL in most papers. Most of these were found to be significant, with the only exception being Spector and Orrell (2006). As this study did not appear to show any marked disparities with other studies regarding methodological quality, measures used or sample characteristics, it is unlikely this can be adequately explained by methodological differences between the papers.

The literature was also mixed with regards to papers that reported significant correlations between self and proxy ratings at both the overall score and dimensional level. Again, this is likely to be result of true study-level heterogeneity, i.e. differences in influential characteristics of the samples, rather than methodological differences between papers. Whilst a full meta-analysis of

findings relating to differences in QoL ratings could not be conducted due to the limitations of the literature base, the general trend of ratings demonstrated that staff-proxies consistently rate QoL lower than people living with dementia across a range of standardised assessments. No study reported that people living dementia rate their QoL as lower than do staff-proxies.

Literature exploring the factors that may explain and predict such differences between self and staff-proxy ratings is perhaps still in its infancy; only five papers directly assessed the impact of associated variables on the level of agreement between QoL scores. The available research was mixed with regards to the variables found to be significantly associated with differences between ratings, although this may have been, at least in part, a reflection of the different measures used to assess QoL and associated variables as well as variance in methodological quality of the papers.

Despite these shortcomings, the overall findings of the review are noteworthy in several respects. Importantly, there appears to be no consistent evidence that the level of agreement between self- and staff-proxy ratings of QoL is associated with any key characteristics of the person living with dementia. Reviewed studies varied with regards to the reported relationship between the level of agreement between ratings and the level of cognitive and adaptive functioning of the person with dementia. However, the validity of findings across these studies may be limited by the methodological quality of the papers and the absence of any assessment of multicollinearity between levels of cognitive

and adaptive functioning (see Beerens et al. 2013). Therefore, clear conclusions about the relationship between level of independence and the difference between ratings therefore cannot be drawn based on existing literature due to a paucity of methodologically sound research.

Similarly, evidence concerning the relationship between demographic characteristics of the person with dementia and the difference between QoL ratings was mixed within the literature, with Boyer et al. (2004) reporting conflicting results to other studies of both higher and lower quality that explored the same variables. These differences do not appear to be fully explained by shortcomings in the quality of Boyer et al. (2004) in comparison to other literature or marked differences in study design, measures employed or the sample used, although again all papers may be confounded by unreported collinearity between variables that could explain some of the differences in findings.

Transitioning into residential care is associated with profound changes in a person's circumstances, rather than solely signifying a difference in environment. As such, living arrangement is likely to have complex relationships with other associated variables, possibly including cognitive and adaptive functioning and interactions between these variables could impact on ratings of QoL. To illustrate, Edelman et al. (2005) highlighted that the living arrangement

of the person with dementia may mediate the relationship between the difference in QoL ratings and level of cognitive functioning, finding that increased cognitive impairment was only significantly associated with a greater difference between scores for people residing in special care facilities. This potential mediating relationship is important when considering the difference in QoL ratings between people with dementia and their proxies and is, at present, poorly controlled within the literature.

A comparably small number of papers explored the relationship between differences in ratings and characteristics of the staff-proxy (Boyer et al. 2004; Novella et al. 2001). Overall, whilst the review's findings indicate that the professional group of the staff-proxy-rater may have a significant impact on the level of agreement between ratings, clear conclusions cannot be drawn regarding this relationship based on the available literature due to the conflicting results reported and small, poorly defined staff-proxy samples used within the studies.

The extent to which staff-proxy attitudes and approaches impact on levels of agreement between QoL ratings remains an open question. Whilst Selai et al. (1999) suggest that an unavoidable limitation of proxy-ratings is the effect of the proxies' own attitudes biasing their ratings, preliminary evidence from the reviewed literature indicates that staff-proxy attitudes, at least in terms of hope, job satisfaction and person-centeredness, do not appear to affect the level of agreement between their ratings of QoL and the rating made by people with

dementia, but only one study directly examined such issues (Spector and Orrell, 2006). It also should be noted that proxy-attitudes and experiences show significant associations with self-rated and proxy-rated QoL individually (Spector and Orrell, 2006) suggesting that this may affect the subjective rating of each individual.

The current findings suggest that the amount of time spent in the shared-environment by the proxy does not impact upon the level of agreement between self and staff-proxy ratings of QoL, as postulated by Crocker et al. (2015). Although it was not directly explored by any study within the review, factors that may reasonably be associated with the increased amount of time spent in shared environment, such as amount of time working at the home (Spector and Orrell, 2006) and the level of care given based on living arrangement (Edelman et al. 2005) did not predict better agreement between self and proxy ratings of QoL. However, it should be noted that these differences may also be explained by different measures used to assess QoL as well as the level of time spent in the shared environment and further research is needed to explore this relationship fully.

Furthermore, no paper within the current review explored the impact of the communicative ability or mood of the person with dementia and the level of agreement between self and staff-proxy ratings of QoL. Both mood and communicative functioning have been identified as conceptual issues when assessing QoL in dementia (Selai et al. 1999). In particular, it has been

suggested that communication difficulties may pose a potential barrier to proxy-assessments of QoL (Edelman et al. 2005). Furthermore, mood has been found to have different relationships with QoL scores rated by people with dementia and their proxies in both the current review, and previous research (Beerens et al. 2013). As such, these variables may have an important influence on the level of agreement between self and proxy ratings of QoL and so represent a significant gap in current literature.

The findings of the current review challenge the popular assumption that agreement between self and proxy ratings is higher for observable dimensions than for subjective dimensions (Bryan et al. 2005; Crocker et al. 2015; Selai et al. 1999). The reviewed papers showed marked differences in the relationships reported between ratings at a dimension level but overall did not show a trend towards better agreement for objective dimensions. Despite the differences between papers, both subjective ('Family', 'Friends', 'Ability to make choices') and objective ('Physical Health') dimensions of the QoL-AD were identified as showing the best agreement between ratings as defined by significant correlations and an absence of significant differences. Papers generally reported poor between-group agreement in both objective and subjective dimensions of QoL as well as significant between group differences in ratings of both observable and subjective dimensions.

As discussed, the available literature showed a notable lack of consistency in the relationships reported between scores at a dimension level. Such

differences were observed both in the dimensions found to reach significance in bivariate analysis, but also in those found to show best agreement. For example, 'Physical Health' was one of the dimensions showing the best agreement in the QoL-AD by Spector and Orrell (2006) but was found to show significant differences using the DHP by Novella et al. (2001). Although it is possible that conflicting results such as this are explained by the different measures used as well as the variable methodological quality of the studies, this highlights the lack of agreement within the literature regarding the dimensions that show the best and worst agreement between self and proxy ratings of QoL. Thus, the findings of the current view suggest that differences between ratings (at least when comparing people with dementia and their staff proxies) are not purely a reflection of the difficulties in rating subjective dimensions of another's QoL, nor are they most pronounced for dimensions linked to functional ability of the person with dementia as suggested by previous literature (Selai et al. 1999).

As discussed by Byran et al. (2005), differences between self and proxy ratings can be understood as either indicative that one rater has inaccurately assessed QoL, based on the assumption that there is a 'true' level of QoL to be assessed, or conceptualised as reflective of different perspectives that are of equal validity and importance. Arguably, differences between self and proxy-ratings of QoL in people with dementia have traditionally been conceptualised as indicative of one rater providing an inaccurate assessment of the QoL. Although the assumption that people with dementia are unable to self-assess QoL is now largely discredited (Jonker et al. 2014), it may be argued that differences

between ratings are still perceived as an incorrect assessment of 'true' QoL made any one or other rater, as illustrated in the widely held assumption that differences are caused by difficulties assessing subjective dimensions of QoL. It is, however, possible that differences in QoL rating are in fact reflective of reported differences in the perspectives of people with dementia and their proxies (Beerens et al. 2013; Drees et al. 2007) that are equally valid and accurate.

Strengths, Limitations and Methodological Quality

This review builds on our current understanding of the factors that could influence staff-proxies in assessing QoL using standardised assessments. However, the findings must be considered in light of the limitations of both the literature base and review itself.

As discussed, the methodological quality of the available literature was a significant limitation that may affect the validity and generalisability of findings reported. Although the quality of most papers reviewed was acceptable, this tended to vary considerably between papers. Furthermore, most papers were limited by a lack of theoretical background as to the selection of associated variables explored or consideration of the psychometric properties of measures used to assess them. Additionally, the impact of potential collinearity between variables and the use of inappropriate cut-off classifications (e.g. of MMSE or ADL) was a key issue in some papers. Therefore, although discrepancies

between papers may be due to genuine heterogeneity within the data, results may also have been confounded or masked by the methodological limitations of the research.

Although the consideration given to the methodological quality of research throughout the narrative synthesis may be considered to be a strength of the current review (Popay et al. 2006), it is possible that the quality assessments conducted were subject to bias. Authors were not contacted to provide any additional information to contribute to quality assessment criteria and therefore it is possible that quality assessment scores do not reflect the true methodological quality of some papers. In addition, only literature published in the English language was included in the review therefore findings may be subject to publication bias. Therefore, any critique of the quality of selected papers should be considered in light of these potential sources of bias.

In order to capture all the relevant literature in this small field of research, papers were not excluded based on their selection criteria, for example whether they verified the diagnosis of dementia within their sample or whether they imposed a minimum cut-off MMSE score for the sample of people with dementia, or their administration procedure for collecting self-rated QoL ratings. Subsequently it was not possible to determine whether diagnoses of dementia had been validated for one paper within the review (Sloane et al. 2005)⁹, nor was it possible to verify that findings were not affected by differences in the

⁹ Validation diagnosis in Edelman et al (2005) provided in Edelman et al (2004).

cognitive functioning of people with dementia between samples (despite similarities in the mean reported MMSE of participants/administration procedures in papers that compared the relationship between cognitive functioning and agreement between ratings). Whilst it is possible that the inclusion of such papers may have confounded the results, the risk of this was minimised by the explicit consideration of such limitations when comparing conflicting findings.

Directions for Future Research

Further research of sound methodological quality is needed to explore the relationship between self and staff-proxy ratings of QoL and the extent to which there is true variance in the level of agreement between ratings. Such an understanding would be an important addition to the literature base, as it could offer a guide as to the amount of variance that might be expected between ratings of QoL based on who is completing the measure and so give further insight into the comparability of ratings of QoL made by staff-proxies.

There is also considerable scope for further exploration of the variables that might predict or explain differences between self and proxy reports of QoL, as the current review does not support the assertion that this can be sufficiently explained by difficulties in conducting subjective assessments of another person. In particular, methodologically sound research should further explore the relationship between level of agreement between scores and the mood and

level of functioning (cognitive, adaptive and communicative) of the person with dementia, the professional group of the proxy-rater and the attitudes of the proxy-rater to build on initial findings reported and gaps within this review. In particular, it may be important to empirically confirm whether or not proxy-ratings of QoL are associated with the attitudes and opinions of the proxy-rater, as suggested by Selai et al. (1999), and how far proxy-ratings are influenced by downward social comparisons, as proposed by Crocker et al. (2015).

Conclusions

This systematic review of the literature explored the relationship between QoL as rated by people with dementia and their staff-proxy. Proxy-rated QoL was found to be consistently lower than self-rated QoL using a range of standardized measures. There is a small body of research exploring the factors that may explain and predict the difference between scores, however the validity and generalisability of findings is reduced by the small number of papers reporting conflicting results and key methodological shortcomings across most papers. Despite these limitations current understandings suggests that the level of functioning of the person with dementia and the attitude/ professional group of the proxy rater may predict the level of agreement between ratings but findings were inconsistent. Further research of sound methodological quality is needed to understand the factors that may explain and predict the difference between ratings, as the current review does not support that common assertion that differences are largely caused by difficulties in judging the subjective state of another person.

Conflict of interests

None.

Description of the author's role

A. Vince designed, conducted and wrote the review under the supervision of Dr C Clarke and Dr E Wolverson.

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Part 2: An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis

An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis

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Abstract

Background: Literature suggests a disparity between best and current practice in diagnostic disclosure of dementia. A clearer understanding of Psychiatrists' perceptions of positive wellbeing in dementia is crucial when considering factors that may impact their experience of such clinical encounters and adherence to best practice guidelines.

Method: Qualitative analysis of interviews completed with 11 psychiatrists highlighted three superordinate themes regarding their understanding of what it means to live well with dementia and their lived experiences of discussing this with people.

Results: Three super-ordinate and nine sub-ordinate themes emerged from the data: (i) 'The levels of wellbeing' (Subthemes: Continuing with life as much as possible, Keeping a sense of who they are, Acceptance of the self as a person with dementia), (ii) 'Living well is a process' (Subthemes: Disclosure can set the scene for wellbeing, Positive but realistic messages, Whose role it is to support wellbeing?), (iii) Ideal care vs real care (Subthemes: Supporting wellbeing is not prioritised, Time, Fragmentation of care).

Conclusions: Results demonstrated that participants had a holistic view of wellbeing in dementia that had moved away from traditional reductionist conceptualisations. However, nihilistic attitudes were prevalent in participants' accounts. Such attitudes were largely a consequence of significant discrepancies between ideal and real care available post diagnosis, and posed key tensions and ethical dilemmas for participants. The behaviors used to

manage the negative affect associated with these tensions and dilemmas, and impact on adherence to best practice is discussed.

Key words: Well-being, dementia, disclosure, Psychiat*

Introduction

Rising prevalence rates and early diagnosis initiatives (Department of Health [DOH], 2009), have prompted researchers to understand more about the wellbeing of individuals living with dementia. The profound negative impact dementia can have and the significant challenges it poses to wellbeing are not in doubt (Banerjee, 2010). However, a diagnosis of dementia is not synonymous with a total loss of wellbeing (de Boer, Hertogh, Droes, Riphagen and Jonker, 2007). There is no clear consensus in policy defining living well with dementia, although the importance of an individual's wellbeing, quality of life and quality of care has been identified (The National Dementia Strategy [DOH], 2009).

Although understood as an on-going process rather than a single event (Fisk, Beattie, Donnelly, Byszewski and Molnar, 2007), the diagnostic disclosure of dementia meeting has been identified as an important point that may influence the subsequent wellbeing of people with dementia (Aminzadeh, Byszewski, Molnar and Eisner, 2007). The importance of discussing wellbeing during diagnostic disclosure is highlighted by its presence in best practice guidelines (National Institute of Health and Clinical Excellence [NICE], 2012) and national frameworks and initiatives (DOH, 2009; Doncaster, Hodge and Orrell, 2012). For example, the Memory Services National Accreditation Programme [MSNAP] (Doncaster et al. 2012), emphasises: support for people and their carers that ensures sufficient time for disclosure (standard 3.8.5), a focus on implications of diagnosis and the support available (standard 3.8.7.9N), and the importance of

providing a variety of information regarding living positively and maximising quality of life (standard 3.8.7.8M).

Despite this, there is a wealth of evidence suggesting that disclosure is often not delivered in accordance with best practice (Carpenter and Dave, 2004). Literature has identified that clinicians' experiences of diagnostic disclosure are influenced by clinical (capacity, diagnostic uncertainty, predicted consequences), internal (nihilistic perceptions of dementia) and external (time, post-diagnostic support available) factors (Cornett and Hall, 2008; Kock and Iliffe, 2010), and that disclosure can deviate from best practice due to clinicians' lack of confidence (Moore and Cahill, 2013) and feelings of futility or stigma (Werner et al. 2013). It is possible that a number of these factors are underpinned by therapeutic nihilism. This can be described as the attitude that disclosing a diagnosis is not worthwhile due to a lack of available treatments or benefits (Koch and Iliffe, 2010). Therapeutic nihilism has been found to be prevalent within clinicians' attitudes towards dementia (Ahmed, Orrell, Iliffe and Gracie, 2010; Hansen, Hughs, Routley and Robson, 2008; Moore and Cahill, 2013; Werner et al. 2013).

As the key belief underpinning therapeutic nihilism in relation to dementia is a lack of hope for the future, it may be that nihilistic attitudes extend to doubts about the possibility of living well with dementia. Arguably, it is possible that this may suggest an underlying belief that life with dementia is hopeless and precludes positive wellbeing. Factors that influence nihilistic views about

positive wellbeing in dementia are under-researched and relatively unknown. However, it has been suggested that the amount of post-diagnostic support available (Moore and Cahill, 2013), and the level of experience of the clinician (Ahmed et al. 2010) may be important factors. There is a small body of literature exploring clinicians' subjective experience of engaging in diagnostic disclosure, which has highlighted a relationship between nihilistic views about dementia and diagnostic disclosure that is not in accordance with best practice (Werner et al. 2013). In the absence of a clear definition of wellbeing in dementia, it is important to understand clinicians' subjective understanding in order to explore how this may interact with their perceived ability to engage in best practice with regard to diagnostic disclosure. This may provide important information relating to the training and supervision requirements of those frequently involved in the diagnostic disclosure process and so may help bridge the gap between best and current practice.

To date, there has been no research exploring clinicians' subjective experiences of engaging in discussions about positive wellbeing when sharing a diagnosis of dementia. Therefore, factors that may help and hinder clinicians from engaging in such discussions are not well understood. Furthermore, it is not known whether commonly reported nihilistic views extend to beliefs about the ability to live well with dementia, or whether this may have an impact on the clinicians' perceived ability to engage in such discussions in accordance with best practice guidance. Further research into these factors is necessary to target support and training appropriately. In addition, research into clinicians' experiences of the disclosure process tends to focus on the subjective

experience of General Practitioners [GPs]. There is a gap in the literature exploring the subjective experience of other professionals frequently involved in disclosure, such as psychiatrists (See Appendix J). Existing literature has identified potential differences between professional groups in terms of disclosure practices (Kaduszkiewicz et al. 2007) that must be researched in light of changing service structures in place within the UK.

Aims

- To explore psychiatrists' subjective understanding of living well with dementia.
- To explore psychiatrists' experiences of discussing wellbeing at the point of diagnostic disclosure.
- To explore barriers and facilitators to discussing living well during the disclosure meeting

Method

Participants

Eleven participants were recruited from three NHS Foundation Trusts in the North of England. Ten participants were employed as consultant psychiatrists¹⁰. Participants were not invited to participate in the research if: they did not consider diagnostic disclosure of dementia to be a major aspect of their job role,

¹⁰ Job title of remaining participant is not identified to protect anonymity

they were not actively involved with the diagnostic disclosure of dementia since 2009¹¹, or were not fluent in English. Table 1 outlines participants' demographic details. Although all participants regularly engaged in diagnostic disclosure, only one participant reported having received any additional training in breaking bad news, with only five having received any training in living well with dementia.

¹¹ The National Dementia Strategy for England (2009) outlined best practice guidelines that stated that discussions regarding positive wellbeing should be an important aspect of the diagnostic disclosure meeting.

Table 1. Participant characteristics.

Participant number	Years practicing as a psychiatrist	Specific training about positive wellbeing	Specific training about breaking bad news ¹²
1	22	Attending conferences	None
2	16	None	None
3	15	Attending conferences	None
4	26	None	None
5	28	None	None
6	15	None	None
7	24	None	None
8	8	Attending conferences (limited amount)	None
9	14	Local meetings; included in specialist training program	Training session (1/2 day)
10	10	None	None
11	27	Attending conferences	None

¹² Not inclusive of that provided in initial medical training

Design and Procedure

A MSNAP survey was conducted to inform the development and provide context to the current research (Appendix J). Due to its exploratory nature and focus on subjective accounts, the study employed a qualitative design. Data was collected via semi-structured interviews. The interview schedule (Appendix I) was designed to elicit the subjective understandings and experiences of discussing living well and was developed /refined with feedback from a focus group of practicing Old Age Psychiatrists. Ethical approval was secured by the University of Hull (Appendix K).

Individuals who met the inclusion criteria were identified by a clinical lead within each recruiting NHS Trust and via verbal advertising of the study by the first author at psychiatry CPD events. Potential participants were provided with an information leaflet (Appendix L) and invited to contact the author if they wished to participate in the study. Those who agreed to participate were required to contact the researcher to arrange a convenient time and location for the research interview. Overall, 18 individuals were invited to participate in the research.

All interviews were conducted at the participants' place of work. Prior to commencing the research interview the researcher reviewed the Participant information sheet, obtained written informed consent (Appendix M) and completed a demographic questionnaire (Appendix N). This was followed by an audio-taped semi-structured interview lasting on average 70 minutes (46-90).

Anonymity was protected by assigning each participant a unique participant number at the point of data-collection.

Data Analysis

Interviews were digitally recorded, transcribed verbatim and analysed using Interpretive Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009). For each transcript, data was analysed through reading and re-reading followed by initial coding before the identification and naming of themes. These were then explored between transcripts to identify commonalities and relationships across the data set and refined into themes across participants (see Appendix O for an example of this process). IPA recognises the researcher's contribution in this research process within its consideration of the double hermeneutic (Smith et al. 2009). This was particularly important considering the researcher out-group position (Dwyer and Buckle, 2009). A reflexive stance was adopted to ensure that the beliefs and attitudes of the primary researcher (see Appendix H) were bridled throughout the research process.

To support the credibility of coding by ensuring that themes were grounded and representative of the transcripts, the second author and an independent peer experienced with the methodology followed the steps 1 and 2 of the analysis process for a subset of data. Where any disagreement emerged, this was discussed until a consensus was reached. A group of six researchers familiar with qualitative methodology also reviewed accounts of themes in order to

further support their credibility. Smith et al. (2009) states that there is no benchmark number of participants that need to support an idea in order to validate its inclusion as a theme. Therefore, no theme was excluded if it was felt to be salient and meaningful but did not resonate across the whole data set.

Results

Table 2. Superordinate and subordinate themes generated from IPA analysis

Super-ordinate Theme	Sub-ordinate Themes
The levels of wellbeing	Continuing with life as much as possible
	Keeping a sense of who they are
	Acceptance of the self as a person with dementia
Living well is a process	Disclosure can set the scene for wellbeing
	Positive but realistic messages
	Whose role is it to support this process?
Ideal care vs real care	Supporting wellbeing is not prioritised
	Time
	Fragmentation of care

Three superordinate themes comprising nine subordinate themes emerged from the data. The first superordinate theme reflects participants' subjective understanding of what it means to live well in light of the threat of dementia. The second superordinate theme reflects participants' understanding of living well with dementia as a journey, of which diagnostic disclosure can be a key step that impacts upon peoples' subsequent wellbeing. The final superordinate theme considers participants' experiences of supporting people with dementia, highlighting the tensions and the ethical dilemma faced when comparing ideal care with the care they are able to provide. Themes are presented in Table 2.

The levels of wellbeing

The first superordinate theme is composed of three subordinate themes describing participants' subjective understanding of what it means to live well with dementia. Although participants believed that sources of wellbeing would vary significantly for different individuals, most understood living well with dementia as a combination of: continuing as much as possible, keeping a sense of self and accepting the diagnosis.

Participants' understandings appeared to be embedded in their medical training, and underpinning each subordinate theme was a largely nihilistic and reductionist understanding of dementia as a threat to wellbeing associated with a decline in functioning. Throughout participants' accounts were powerful undertones that although people could achieve a level of wellbeing with

dementia, this was done *in spite of the illness*. Dementia was portrayed as an aggressor that was associated with significant and ultimately inevitable loss:

“dementia just robs people of so many things and takes away, hacks away at who you are as a as a being.” (Participant 2)

However, this understanding was refined through clinical and academic experiences and there was recognition from each participant that psychological and social aspects of people’s lives are fundamental to their wellbeing. As such, living well with dementia was perceived to be a combination of medical, psychological and social factors viewed within the constraints posed by dementia:

“medical training and the understanding of illness and disability... is, erm a skeleton on which the experience of the people that you then see hangs”.
(Participant 1)

Continuing with life as much as possible

All participants described living well as continuing with life as much as possible whilst minimising the impact dementia had on a person’s life. On the whole, sources of wellbeing were viewed as being the same before and after diagnosis and thus living well with dementia was achieved through maintaining these sources for as long as possible. This was largely described as an active and external process that involved personal agency, and encompassed ideas of

coping, adjustment and placing the illness in the background rather than it dominating a person's life:

“changing one's lifestyle as little as possible. And understanding how as the dementia develops er, one can actually sort of accommodate, interests and...enjoyment. To actually mean that that could continue ...” (Participant 11)

Participants described the view that peoples' ability to continue with life was supported by a combination of medical and social interventions, highlighting the dangers of over-protective caring in all stages of the illness. However, there was a clear sense in most accounts that the ability to continue with life was reduced by the illness and efforts to minimise its negative impact were invariably time-limited:

“obviously unfortunately as the illness progresses peoples ability to do things that they might have enjoyed and got meaning from previously deteriorates”
(Participant 6)

Keeping a sense of who they are

For most, maintaining a sense of personal identity was seen as an integral part of living well with dementia. This was based around protecting one's sense of

self as a human being, as well an individual with their own likes, strengths and abilities. Some participants referred to this directly as personhood:

“that person’s sense of who they are and sense of personhood, and a-a being and you know their sense of [stutters] being a being” (Participant 2)

Whereas others spoke about how dementia and in particular the impact on driving impacted on a persons’ self-worth *“their, em self-worth seems to rest quite a lot on being a, competent driver you know and erm, it can be a real knock for them”* (Participant 4), with participants describing the disempowering and dehumanising effect when a sense of self was not maintained:

“maintaining some sort of, awareness about who this person is. Even if they’ve got the most advanced dementia... because otherwise... I think sometimes people become almost less human.” (Participant 2)

Dementia was viewed as a threat to a person’s sense of identity, and maintaining this was described as effortful *“but trying to see beyond that to the person”* (Participant 7) and at times hopeless, *“she’s losing everything about herself and he’s losing her as well”* (Participant 2). The way that sense of self could be supported and maintained was seen to change. In early dementia, participants spoke of protecting people’s autonomy, whereas in more advanced

dementia there was a view that others maintained the sense of self by knowing and supporting people's wishes. There was recognition that as well as the threat posed by cognitive changes, the reaction of others could damage a persons' sense of self in both the early and advanced stages of the illness:

“people have actually come back and said ‘Well you know I regret that... maybe I shouldn't have disclosed the diagnosis to those around me... I don't feel any different. Yet people are treating me as though I am, different. T-they don't seem to value my opinions” (Participant 11).

Acceptance of the self as a person with dementia

Participants felt that, on the whole, people were able to live better if they were able to emotionally accept their diagnosis but that this was not a prerequisite for achieving some level of wellbeing:

“I think there are people who can, at one level, erm, accept, a diagnosis of dementia and carry on with their lives as if they have not, heard the news...I would suggest that perhaps they'll live less well than those who are able acknowledge and accept it” (Participant 4).

This was described as a normal process that people and their families go through after any serious diagnosis and indeed in ageing:

“with all diagnosis let alone dementia which is a pretty, shocking one... people go through that process of erm you know, denial, crossness, sadness, and then hopefully acceptance” (Participant 8)

“they’re now, need to go through that phase where they, can reflect on their life and what it’s meant to them” (Participant 7)

However, there was a sense that peoples’ ability to go through this internal process was limited by their cognitive impairments, and that this level of wellbeing could not be achieved by everybody:

“the very thing that you would normally use, to help you make sense of what’s going on has been damaged. And so it’s doubly difficult for people with dementia” (Participant 7).

Although some described this as a normative process, there was an undertone in participants’ accounts of *having* to accept dementia in the absence of a cure. As such, it may be interpreted that rather than a state of acceptance reflecting some sort of personal growth post-diagnosis, accepting the diagnosis might be perceived as a way of coping with the helplessness of the illness that is necessitated by a lack of alternatives:

“accept it from an emotional perspective and then move on from that really rather than being, burdened by, by the despair that’s often associated with being told that you’ve got some form of, chronic progressive condition”
(Participant 4).

Living well is a process

This superordinate theme encompassed three subordinate themes relating to the process of living well with dementia, highlighting the complexities of discussing this with people at different stages in their journey with dementia.

Disclosure can set the scene for wellbeing

Living well was understood as on-going process given the progressive and uncertain nature of dementia and the multiple aspects that comprise wellbeing:

“when they’ve adjusted to the current situation, three months later or six months later or even less sometimes, the situation may radically change, and they’ve then got to readjust to that new situation” (Participant 7).

For some, living well with dementia was seen to begin before people are diagnosed due to peoples’ understandings and preconceptions of dementia, with others describing receiving the diagnosis as the starting point of living well.

Most participants perceived the diagnostic disclosure meeting as a key event in a person's life, seeing it as an opportunity to set the scene of life with dementia by opening up discussions about wellbeing and facilitating engagement with services which should then be on-going:

“the first person to see an individual like this, i-is never going to be to solve all the problems ourselves but t-to hopefully prepare the ground for people to be willing and able to accept support that they are gonna need in the future”

(Participant, 1)

“Cause I think that what you want to do is you want to try and build up a, a positive erm, a positive connection with someone. So that when they are actually in the process of having their diagnosis made, and their early experiences around, having dementia, you want them to look back on it i-n a good light”(Participant 11)

However, some also questioned the value of such discussions with people who are living with a memory impairment, and at a time when people may be shocked and overwhelmed:

“I wonder whether it has more impact on the carers potentially than for the, people who may not even remember” (Participant 8)

“Cause the diagnosis itself is often quite a shock. So if somebody suddenly started to turn around and (inhales) talked about living well with it erm, but so maybe its something to address a bit erm, later along the ...track .You know after you’ve received the diagnosis and it’s sunk in” (Participant 10)

Within participants’ accounts there was a sense that increased understanding of the illness and its symptoms could help set the scene for living well with dementia, with disclosure viewed as a potentially useful step that may relieve anxiety, enable advanced planning, and allow people access to support services:

“Putting a label on something... can help people understand some of their symptoms and their worries and that in itself can be an anxiety relieving process I’ve seen” (Participant 8)

However, there was a clear tension within participants’ descriptions of balancing the potential benefits that may accompany an increased understanding of dementia with the negative implications of diagnosis. Most participants only viewed direct diagnostic disclosure as a helpful step in supporting wellbeing if people were ready and wishing to hear their diagnosis:

“there’s nothing worse than somebody not really wanting to know and, just, plodding something on them, with a negative impact” (Participant 3)

This tension was particularly prominent in participants’ experiences of diagnosing people with mild dementia. Most participants who discussed this experience felt that early diagnosis was often detrimental to wellbeing, perceiving the costs to wellbeing as larger than the potential benefits:

“Unless or until there’s an effective treatment for people then we’re just inflicting diagnostic misery on people or potential diagnostic misery on people” (Participant 4)

Participants managed the difficulties in negotiating this balance by taking steps to ensure the disclosure was in line with the wishes and expectations of the person as far as possible. This was largely done by ensuring people were prepared to receive their diagnosis and tailoring (or it may be interpreted stalling) their language:

“I don’t think it’s, un-unreasonable to, to tailor your language to, erm, accommodate what people can handle. A-and sometimes that amounts to, not using a diagnosis which erm, is is going to be a block for people” (Participant 5).

Of note, one participant reported feeling a tension between supporting peoples disclosure preferences and encouraging acceptance but concluded that autonomy must be protected above all else:

“I’m saying in one sense I think it’s very important to be to be clear erm t-to show someone that you can have, absolute respect for them despite the fact they’ve got dementia. A-annd at the same point you’re being told that you know you can’t name the name. Then that’s almost that’s being contradictory isn’t it?”
(Participant 11)

Positive but realistic messages

Participants discussed the importance of giving people a positive message in supporting wellbeing. This was achieved by highlighting strengths and competencies, and through offering medical and social interventions. It was felt that this provided hope and a sense of control to both the person with dementia and the participant:

“[Absence of positive message] it’s not good for them and it’s not good for you... If you can offer something even if it’s, in a small way that allows people a little bit more control, that helps you to feel more useful too” (Participant 4)

These were generally experienced as rewarding conversations to have, but were underpinned by a tension between positivity and reality. Participants stressed the importance of remaining mindful of providing positive messages that were genuine and realistic, to enable people to manage the challenges associated with dementia:

"whilst there's all this this fantasy about, m-miracle cures and things...they're not gonna be able to get on with their lives and live well and, deal with all the things that they have to do" (Participant 2)

Although participants felt that there was usually something positive to be said, some participants were ambivalent about promoting a more positive message, as this was perceived to feel somewhat euphemistic:

"it's something of a euphemism I think t-to try and think in terms of living well" (Participant 5).

Again, there was some disparity between participants as to whether diagnostic disclosure was perceived to be an appropriate setting for giving a positive message. For some, providing positive messages at disclosure was perceived as a vital component of the disclosure process, whereas for others, it felt juxtaposed to the diagnosis and so positive messages were diluted within the disclosure meeting. Underpinning participants' accounts of proving positive messages was a sense of having to offer something to people because of the

perceived loss associated with receiving a diagnosis. This suggests that such conversations were perceived by participants as helpful in managing their patients, and also their own, nihilistic perceptions of dementia *“they need to take something positive and something good out um, out of those appointments otherwise, what’s the point really?” (Participant, 3).*

Whose role is it to support this process?

Participants reflected on the complexity of engaging in discussions about wellbeing directly, questioning whether it was indeed their role to support people through the process both at a practical and emotional level. At a practical level, participants questioned their role, considering the availability of the multi disciplinary team (MDT) many worked within, and service pressure to discharge people quickly from psychiatrists’ care. Most participants felt the whole MDT had a role in discussing wellbeing but varied in the extent to which they saw it as an integral aspect of their own role. There was also an acknowledgement that others may be better placed to have such discussions based on their expertise, relationship with the person, time available and relative cost of their service:

“jobs that don’t require your level of skill or your level of knowledge can be done by somebody else who, is cheaper... And actually that person...may well be better at that kind that side of things anyway” (Participant 2)

Conversely, others spoke passionately about discussions about wellbeing as key to their role, describing their feelings that the push towards pigeonholing the psychiatrist as diagnoser and prescriber was devaluing:

“you feel devalued I think really in terms of your contribution as a professional really. That people are, completely underestimating what it is that you actually do when you see patients and what you contribute to the process” (Participant 6)

Interestingly, whilst all participants felt that increased understanding and maintenance of functioning may support wellbeing, none perceived diagnostic disclosure or prescription of medication to constitute discussions about wellbeing. In fact, for many, discussions about wellbeing were perceived as completely distinct from diagnosis and prescribing, with some extending this view to the feeling that using the word dementia was detrimental to engaging in discussions about wellbeing:

“reminding somebody every time they come back to see me now I’m the [gender] that told you that you’ve got dementia and you can’t drive probably isn’t a good way of starting off the conversation so for the individual, having disclosed the diagnosis once I wouldn’t keep coming back to it.” (Participant 1)

Although the majority of participants focused on the practical complexity of discussing wellbeing, for some, there was a sense of a deeper questioning of their role as a doctor caring for a person with an incurable condition. Within this, many described the high and often unrealistic expectations placed on the psychiatrist by the patient and the MDT resulting in feeling that it was often their role to disappoint expectations. Although this was perceived to be part of the job, for some it created a sense of helplessness:

“there’s a degree of helplessness on my part, because, as a doctor I’m used to people coming to me, and I have to do something and they get better. Whereas this is an illness people come to me and no matter what I do I know they are not going to get better” (Participant 3)

Ideal care vs real care

Dementia was described as overwhelming for people, services and psychiatrists. In their accounts, participants discussed the discrepancies between the care they wished to offer in an ideal world and the care they were able to offer in reality. Providing a cure for dementia was viewed as an ideal but unrealistic expectation of care. In its absence, participants described the challenges of supporting people to live well within a context of limited and over-stretched services that do not pay equal attention to the psychological, social and medical needs of people with dementia, often resulting in a lack of appropriate support. Thus, participants experienced a number of key tensions

and dilemmas caused by the disparity between the care they feel people should have, and the care people receive in reality.

Supporting wellbeing is not prioritised

Most participants held the view that due to the immense financial pressures services currently face, people do not always get the care they should. In this climate participants' felt that services (and the psychiatrist in particular) are used as diagnosers and prescribers, with further involvement reserved for crisis management rather than supporting wellbeing:

“we cant do anything positive or you know you know, to be able to create something great for someone we have to wait until things get awful and then then the services swing into action” (Participant 8)

Many participants described how for them, the introduction of anticholinesterase inhibitors had a positive impact on people's ability to live well with dementia, both due to their medical effect but also the sense of hope, control and meeting of expectations of the medical encounter they gave people. As such, some participants described prescribing medication as a positive step and an aspect of their role they enjoyed:

“it empowers myself and my patient. That there is something that could be done about it. Not a great deal but there is still, some modification that can be brought in the course of illness” (Participant 3.)

“I think as doctors I don’t know maybe particularly me as a doctor I mean I like I do like being able to prescribe, something that I think might help” (Participant 10)

However, participants described how services were set up for diagnosis, with very little additional support available beyond medication:

“And it’s about bam bam bam ‘You’ve got dementia, bye. Here’s a here’s a prescription.’ Which, I do not see as good practice but there’s huge amounts of political pressure to do that” (Participant 4).

“that sense that we have to rely on medications for difficult behaviour. So I suppose that experience c-can be frustrating. When you’re not able to give people well the potential for living as well as they possibly could do” (Participant 8).

Social and psychological support described as essential for wellbeing was perceived to be significantly lacking by most, due to services that were either

partly functioning or present but unavailable. As such, participants felt limited in their ability to discuss positive wellbeing as in reality, people with dementia were being “*left in this void*” (Participant 8) in which they were let down by services and not getting the care they deserved:

“It is quite frustrating sometimes when you don’t have a fully functioning team or a, you know good level of resources, to manage such people” (Participant 9)

“but you do sort of feel a little bit of a fraud underneath all of that... ultimately people are sort of, just sort of surviving out there because of lack of... support and resources” (Participant 2)

This was described as overwhelming and unsatisfying, and created feelings of frustration and helplessness for both patients and psychiatrists:

“I think you're just kind of left in a little bit of a helpless role... you have an individual and their family sat there in front of you and you’re not able to give them what they need” (Participant 8)

Several participants also described feeling pushed into diagnosing people, with all the negative implications that that could bring, in the absence of offering them sufficient support. Although providing diagnostic disclosure that is in line

with a person's wishes was perceived to be vital, participants experienced an ethical dilemma when they were required to provide this in the absence of any post-diagnostic support:

“there is something, not quite right, ethically about ... putting what you have into diagnosis, without really thinking about what we put in to, erm, post diagnostic intervention” (Participant 5)

Consequently participants described a number of approaches that helped to manage their own feelings of helplessness caused by both the nature of the illness and the lack of services. Such as being proactive in their approach and using their position to stretch the limiters set by services in order to ensure that people got the care they should:

“keeps you erm, maybe being, proactive. Erm, at times being a bit balshy er whatever you need to do. Because you if you have a clear vision of what works and what doesn't.” (Participant 11)

Alternatively participants' experiences involved distancing themselves from services, and siding with their patients as a way of both encouraging engagement and managing their own emotions:

“And I actually say ‘yeah t-yeah. That is terrible.’... Cause mmm I kind of think well it’s indefensible sometimes and it’s not, mine to defend” (Participant 2)

Others also discussed lobbying for more services, although people varied in their hope as to whether the lack of support for wellbeing could or would change in the current economic climate:

“Well you’re trying to do your best in terms of your awareness of service development” (Participant 5).

Time

All participants within the study identified a disparity between ideal and real care in terms of time. Time was a barrier to engaging in discussions about wellbeing both at diagnostic disclosure and subsequent appointments *“There isn’t time to give a conversation like this the justice the depth that it needs” (Participant 1)* which was experienced as unsatisfying for participants and perceived to be ineffective for patients *“its just like bombarding these people.... But, I do that because it’s more efficient and I don’t think sometimes it’s that the best way” (Participant 2)*

Many also discussed that service pressures have a detrimental impact on the experience of both the participant and the patient. It was felt that the push for efficient diagnosis impacted on peoples' ability to process their diagnosis at both a cognitive and emotional level and so limited the ability to discuss wellbeing with them:

"I try to think about why I find it so difficult and I don't think it is just about the timescales erm, I don't know whether it's the the fact that when you seen them and at the first appointment you've given them that time to think ...which makes it easier for me when I see them again. Or whether it is just too much within an hour for somebody who has memory problems" (Participant 8),

Fragmentation of care

In addition to pressures on time and service availability, participants described how the push for efficacy has caused a fragmentation of services and a subsequent compartmentalising of the roles of different professionals.

Throughout their accounts many participants reflected on how this move towards separating aspects of care between professionals was perceived to have limited their ability to do their job as they would wish, describing the practical and emotional difficulties of disclosing a diagnosis to a person for whom they did not complete the assessment and crucially with whom they do not have a therapeutic relationship:

“that’s difficult when somebody has done that assessment and then to be able to quickly scan that to be able to give the patient and their carers the feedback that they require or how you come to that judgement, is a lot harder”

(Participant 8).

“I’m just some distant shadowy figure that has, you know has, that in a room, come up with, some form of diagnosis. But then, if they do come and see me I’ve got to try and build a relationship with that patient. One step behind them”

(Participant 4).

Participants managed this challenge in different ways. Some spoke of ensuring they were completing their part in the process as thoroughly as possible *“And if I follow that structure, eh, I know that I haven’t missed anything. So I haven’t neglected part of their care” (Participant 3).* Whilst others described having to stretch the rules *“you can cheat and decide that you’re gonna bring people back a bit earlier. Erm, which I have to admit I do quite regularly [laughs]” (Participant 11)* to ensure they felt able to appropriately support their patients.

Discussion

This study provides an insight into psychiatrists’ subjective understanding of what it means to live well with dementia and their lived experiences of discussing this with their patients. Wellbeing is understood as a multi-faceted

construct that is significantly influenced by the threat of dementia and a perceived lack of services. Engaging in discussions about wellbeing can be a positive and rewarding experience for participants, but is heavily affected by a perceived discrepancy between real and ideal care.

Accounts of positive wellbeing in dementia

The factors perceived to be important in the process of living well with dementia identified in this study correspond with a wealth of literature reporting the lived experiences of people with dementia. These are reflective of reports of the impact of receiving a diagnosis (Robinson, Gemski, Abley, Bond, Keady, Campbell et al. 2011) and the experience of using both emotion-oriented and problem-oriented coping (de Boer et al. 2007) to manage the uncertainty associated with dementia as well as the tension between self-protection and self-adjustment (Steeman, Casterle, Dierckx, Godderis and Grypdonck, 2006). It may be argued, therefore, that psychiatrists (in this sample) have a good understanding of what it is like to live with dementia, and the factors that can enable and hinder the process of living well following diagnosis.

All of the psychiatrists interviewed took a biopsychosocial position (Engel, 1981) in their subjective understandings of wellbeing. Although they varied in their view of whether it was their role or not, supporting psychological and social wellbeing was perceived to be of equal importance to addressing biological needs when encouraging and enabling a person with dementia to live well. Participants were in agreement that medication is 'one tool in the toolbox' when

supporting wellbeing, and that the use of medication in isolation of any psychological or social support was often insufficient in supporting the overall wellbeing of people with dementia.

Participants' recognition of the importance of biological, psychological and social factors in shaping a persons' wellbeing may be considered in reference to the theoretical conceptualisations of personhood (Kitwood, 1997) and selfhood (Sabat and Harre, 1992) presented within the dementia literature. The concept of personhood, introduced by Kitwood (1997), can be described as the attributes that make people human-beings, whereas the concept of selfhood, conceptualised by Sabat and Harre (1992), refers to a persons' held self-concept. Both concepts challenge the assumption of an inevitable loss of wellbeing as a consequence of neurological decline associated with dementia, instead stressing that it is the exposure to malignant social psychology as a reaction to biological changes in functioning that is the biggest threat to overall wellbeing (Kelly, 2010).

This holistic understanding was mirrored in participants' perceptions of the importance of individually-tailored biopsychosocial care and empowering social interactions in supporting people to function well, and maintain a sense of self following a diagnosis of dementia. However, underpinning all participants' understandings was a powerful sense of the limits of the potential to live well with dementia. This may be interpreted as suggesting that although there has been a clear shift in perspectives away from a narrow medicalised

understanding, for most participants, their understanding was not congruent with perceiving life with dementia from a position of a PERSON with dementia rather than person WITH DEMENTIA (Kitwood, 1997). Although all participants felt people could live well with dementia given holistic support, for most, the ability to support wellbeing throughout a person's journey with dementia was perceived as finite, and a loss of wellbeing was ultimately considered unavoidable due to the inevitable progression of the illness.

Experiences of discussing wellbeing

Consistent with existing literature exploring clinicians' experiences of diagnostic disclosure in dementia (Keighley and Mitchell, 2004; Werner et al. 2013), participants identified feelings of stigma, futility, difficulties handling the discussion and fear of eliciting negative emotions as barriers to engaging in discussions about wellbeing. Diagnostic disclosure involves the difficult balance between providing information and instilling hope, with exposing a person to the potential negative consequences of dementia (British Psychological Society [BPS], 2014). This tension was mirrored in participants' experiences of engaging in discussions about wellbeing, particularly at the point of diagnostic disclosure, with participants describing the tension between wishing to inform and encourage adaption to the illness with a desire to protect people from the negative implications and emotions a diagnosis can bring. This tension is reported within the literature regarding diagnostic disclosure (Cornett and Hall, 2008), but the present findings build on existing understandings by

demonstrating that similar tensions and dilemmas may exist in relation to discussing positive wellbeing in dementia, as well as highlighting the significant influence of availability of support in the development and maintenance of nihilistic attitudes.

Arguably, the most salient issue underpinning many of the barriers to engaging in discussions about wellbeing evidenced within this study was therapeutic nihilism. In contrast to the findings of Moore and Cahill's (2013) study of GPs, within this study the level of support available to the person living with dementia appeared to be a key contributor to psychiatrists' nihilistic attitudes regarding wellbeing. Participants consistently recognised that people with dementia could live well (or better), at earlier stages of the illness but only given appropriate support. Therefore, for most participants nihilistic views about life with dementia were largely a consequence of their perceptions of the marked disparity between ideal and real care available that rendered proactive and person-centred care inaccessible. As such, the current findings build on existing research (Hansen, Hughes, Routley and Robinson, 2008) by suggesting that psychiatrists perceive fewer benefits to disclosure, and so more costs, in the absence of adequate support structures and may therefore subsequently be more likely to deviate from best-practice disclosures (NICE, 2012) when they perceive a person to lack support.

At a deeper level, participants also reflected upon being placed in an ethical dilemma of disclosing a diagnosis with potentially negative implications without

sufficient post-diagnostic support either from them or from another service. The negative consequences of this for both the psychiatrist and the patient were powerfully described in their accounts of feeling '*a fraud*' and that people were being '*left in this void*'. To manage this, some participants described deviating from best practice disclosure in order to protect the wellbeing of their patient, and arguably themselves. Many described behaviours that may be considered consistent with reframing and stalling described in breaking bad news literature (Shaw, Brown and Dunn, 2013; Shaw, Dunn and Heinrich, 2012). Although participants were clear in stating the primary purpose of providing a positive but balanced message (reframing), was to promote the wellbeing of the patient, consistent with ideas of positive coping (BPS, 2013; Clare, 2002; Paterson, 2001), they also described that such conversations provided them with a sense of satisfaction. As such, reframing may be interpreted as enabling the psychiatrist to manage the negative affect triggered by the clinical encounter as well as supporting the wellbeing of the person with dementia (Shaw et al. 2012).

However, participants perceived abilities to engage in reframing in an honest and genuine way were severely limited by a lack of appropriate and longitudinal support available for the person living with dementia. As a consequence, many described managing such a dilemma by a) discussing wellbeing in more vague terms and b) discussing wellbeing at a later occasion and c) distancing themselves from services in which they work. This may be understood in terms of stalling, which can be defined as a delay or avoidance in delivering the news (Shaw et al. 2012) used as a form of emotion-focused coping by clinicians to create a sense of emotional distance between them and the news they are

delivering (Shaw et al. 2013). Again, although such behaviour was primarily understood as beneficial for patients, it may be interpreted that when participants felt reframing was disingenuous (be that due to the threat of dementia, perceived inappropriate early diagnosis or a lack of services) or beyond the scope of their clinical role, they engaged in stalling to manage the negative affect triggered. It may also, in part, reflect the lack of training participants had received in living well with dementia and/or breaking bad news (Table 1), which was lower than average (Appendix J).

No participant within this sample identified conversations about disclosure or medication as constituting discussions about wellbeing, despite identifying increased understanding/reduced anxiety following diagnosis and medication as potentially important factors in enabling a person to live well with dementia. In fact, many described conversations about wellbeing as distinctly separate from the process of diagnosis and prescribing. In explaining this, we postulate that although participants recognise these to be important ingredients of wellbeing the distinction made between diagnosis/ medication and supporting wellbeing within best practice (NICE, 2012) has led to participants' interpretation of these discussions as distinct from discussions about wellbeing.

Strengths and limitations

This study benefits from the recruitment of psychiatrists from three NHS Trusts. Whilst the methodology does not assume generalisability, the clinical applicability of the findings may be strengthened by the inclusion of participants

from a variety of locations as well as the sample size. Bar one, all participants were consultants. Although no clear and consistent differences were observed between this participant and others, research has previously identified that training and experience affect clinical experience of breaking bad news (Kaduszkiewicz et al. 2007), therefore it is possible that their differing level of training may have also influenced their experience of discussing wellbeing. It is also possible that findings are influenced by a recruitment bias. The researcher was overt in stating the positive stance of the study, therefore it is possible that only those who held more positive views about dementia volunteered to participate.

The researcher was of a different age, level of experience and profession (clinical psychology) to the participants. As recognised within the double hermeneutic of IPA, these out-group differences will have influenced the research process in both the influence of the researcher's own subjective assumptions and experiences and potentially, the participants' acceptance of an out-group researcher (Dwyer and Buckle, 2009). It should however be noted that out-group research has been associated with a number of benefits including: reduced risk of assumptions and undue influence in interpretations, and increased distance from that data that supports reflexivity, objectivity and wider interpretations linking data with context (Dwyer and Buckle, 2009). Although such influences are acknowledged within IPA and credibility was addressed by quality assessment checks, it is important to remain mindful of these issues (see Appendix H) when considering the results.

Conclusions and future directions

The current study complements a growing body of research exploring the experience of professionals by extending research to psychiatrists, and exploring how their understandings and experiences may interact with adherence to best practice guidelines.

These findings highlight serious concerns about the provision of support services in dementia care. They build upon a wealth of literature outlining the difficult balance professionals face between informing and protecting their patients in disclosure (BPS, 2014), by identifying that a lack of services is an important determinant in their judgement and so their perceived ability to engage in disclosure in line with best-practice.

Given the recognition of the importance of holistic biopsychosocial support, the lack of attention paid to supporting emotional acceptance following a diagnosis of dementia within guidelines and policy is also highlighted. There is a body of literature supporting the view that people experience a process of emotional acceptance and can be supported to live better with their condition if this is facilitated (de Boer et al. 2007). It is vital that this need is recognised within literature and policy and reflected in service provision if people are to be supported to a place of well-being that is qualitatively more than the minimisation of sources of ill-being, and thus more in-keeping with the World Health Organisation (WHO) definition (WHO, 2011) of living well as being more than just the absence of illness or infirmity.

Although psychiatrists are heavily involved in diagnostic disclosure within memory clinic provisions (Appendix J) they are not the only professionals involved in this process. In light of the current push towards moving diagnosis within primary care, further research is needed to explore GPs attitudes to wellbeing in dementia in the current climate. This is significant given that GPs receive less dementia-specific training than old age psychiatrists (Moore and Cahill, 2008), have shorter clinics and often less direct access to an MDT. Additional research is needed across professional groups to understand how attitudes, service provision and organisational culture may affect divergence from best-practice guidelines, the subsequent implications for practice and crucially the experiences of people receiving the diagnosis. Such understanding will be fundamental if we are to ensure people with dementia receive holistic and person-centred care.

Conflict of interests

None.

Description of the author's role

A. Vince designed, conducted and wrote the review under the supervision of Dr C Clarke and Dr E Wolverson.

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Appendix A: Guideline for Authors for the *International Journal of Psychogeriatrics*

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, “for debate” articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, “for debate” articles and book reviews, which are commissioned, contributions to International Psychogeriatrics are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal’s Science Citation Index Impact Factor (2013) is 1.892. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. International Psychogeriatrics uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. International Psychogeriatrics has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website

(<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

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To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply:

A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading 'Submission of randomized clinical trials' on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
2. That the authors have had full control of all the primary data.
3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. **The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final.** The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au , Professor Nicola Lautenschlager. Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: + 61 3 9816 0477. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Submission of papers reporting randomized controlled trials

In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In common with many leading medical journals *International Psychogeriatrics* has decided to follow this policy. Since 31 December 2006 we will not review any paper submitted to us reporting a randomized clinical trial unless the trial was registered in a public trial registry from the date it commenced recruitment or, if recruitment started before 30 November 2006, we require that the trial was registered no later than 30 November 2006. For further details on the

reasons for this policy see the June 2006 editorial, Ames, D. (2006). Registration of Clinical Trials submitted for publication in *International Psychogeriatrics*. *International Psychogeriatrics*, 18, 191-193.

All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.

1. A check list and flow chart in accordance with the CONSORT guidelines which can be found at <http://www.consort-statement.org>. Please send in the checklist as a supplementary file and include the flow chart as Figure 1 in the manuscript.
2. The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper.
3. The registration number of the trial and the name of the trial registry in which it was registered. Please add these to the last line of the paper's structured abstract. Trials that began enrolment of patients after 31 December 2006 must have been registered in a public trials registry at or before the onset of enrolment to be considered for publication in *International Psychogeriatrics*. Trials that began enrolment prior to 30 November 2006 must have been registered no later than that date. Our criteria for a suitable public trial registry are: free to access; searchable; identification of trials by unique number; free or minimal cost for registration; validation of registered information; inclusion of details to identify the trial and the investigator within the registered entry (including the status of the trial); research question; methodology; intervention; and funding and sponsorship disclosed.

Organization and style of research articles

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Each author must select only ONE country as their location. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author's email address, telephone number, fax number and postal address must be clearly stated.

Abstract: Abstracts for original research and reviews should be structured and incorporate 4 sub-headings: background, method(s), results, conclusion(s). Abstracts for protocol only papers should omit the third sub-heading (Results). Abstracts for case reports should have no sub-headings. Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.

Key words: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

Running title: This should contain no more than 50 characters including spaces.

Introduction: Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long.

Methods: Materials and procedures should be described in sufficient detail to enable replication. Any statistical procedures used should be outlined and their use should be justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for the statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered.

Further advice about statistics and International Psychogeriatrics can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. *International Psychogeriatrics*, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in *International Psychogeriatrics* for the year 2003. *International Psychogeriatrics* 16, 389-396. Both of these are available at the International Psychogeriatrics website by following the link to

Statistical Advice for intending contributors. This is also located under the related links icon at the journal homepage (<http://journals.cambridge.org/ipg>).

Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d , η^2 , Cramers V , 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t , F , χ^2).

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. Any methodological weaknesses of the study should be outlined, including limitations imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

Conflict of interest declaration: **This section must be completed.** This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading Conflict of Interest should be included with the single word "none" underneath it. For full details see below.

Description of authors' roles: **This section must be completed if the paper has 2 or more authors.** It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoon was responsible for the statistical design of the study and for carrying out the statistical analysis.

Acknowledgements: Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here.

References: **No more than 30** articles that have been published or are in press should be cited.

If authors believe that more than 30 references are essential this must be justified in the cover letter. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript.

International Psychogeriatrics uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term “et al.” should be employed, i.e., (Smith et al., 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith et al., 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.

For a journal article: **Smith, J., Jones, W. I. and Doe, J. T.** (1996). Psychogeriatrics for pleasure and profit: an expanding field. *International Journal of Unreproducible Results*, 3, 240–242. doi:12.3456/S123456789.

For a book: **Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V.** (2001). *Acute Confusional States*. New York: Cambridge University Press.

For a book chapter. **Park, K., Tiger, B. and Runn, F.** (1999). Psychogeriatrics in context. In G.Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260) Cambridge: Cambridge University Press.

Where an article or book chapter has more than six authors only the first author’s name should be given followed by the words “**et al.**”.

For further examples of reference style see papers in recent issues of *International Psychogeriatrics*.

Figures/Tables: The manuscript should contain no more than five figures or tables. The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the

data. The journal has a small budget to permit some colour to be printed in some issues but authors wishing to publish figures requiring colour to communicate the data may be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

Supplementary material: More detail about the submission of supplementary material is available below – see “Supplementary Material for online only publication” and “Instructions for contributors – Supplementary Material” in subsequent pages of this document.

Word limits: At present *International Psychogeriatrics* does not have a fixed word limit for articles, but because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Conflict of interest

Conflict of interest occurs when authors have interests that **might** influence their judgement inappropriately, regardless of whether that judgement is influenced inappropriately or not. *International Psychogeriatrics* aims to conform to the policies of the World Association of Medical Editors in regard to conflict of interest. For full details please see the website <http://www.wame.org/wamestmt.htm#fundres>. To this end all authors must disclose potential conflicts of interest so that others may be aware of their possible effects. Specifically, under the heading conflict of interest, all articles must detail:

The source(s) of financial support for the research (if none, write “none”).

A description of any sponsor’s role(s) in the research (e.g., formulation of research question(s), choice of study design, data collection, data analysis and decision to publish).

Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects

of a drug made by Bigpharma which directly competes with another drug made by Megadrug a declaration might say “Jane Smith has received research support and speaker’s honoraria from Bigpharma and has received financial assistance from Megadrug to enable her attend conferences.”

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of International Psychogeriatrics to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

“For Debate” Articles

From time to time International Psychogeriatrics will publish “For debate” articles on topics of a controversial nature. “For debate” articles will be commissioned by the editor, but readers are welcome to suggest possible topics for debate by contacting the editor at ipaj-ed@unimelb.edu.au. To view recently published debates see journal issues 19(6), 20(2), and 21(2).

Case Reports

Case reports will be accepted for review and considered for publication. They should be of 1200 words or less and should have no more than 10 references. An unstructured abstract of 100 words or less is required. When submitting case reports authors **must** enclose a **letter of consent to publication** from each of the patient(s) described or, if the patient(s) is/are deceased or not competent to consent the authors must indicate that they have obtained such consent from the patient’s legal guardian(s). These letters will be kept confidential.

Study protocol articles

Any author contemplating submission of a protocol only paper is advised to contact the editor of IPG via ipaj-ed@unimelb.edu.au to discuss the paper's suitability for submission prior to submitting it.

Qualitative research articles

Authors of qualitative research articles are advised to contact the editor of IPG via ipaj-ed@unimelb.edu.au to discuss the paper's suitability for the journal before submitting online.

Letters to the Editor

Reader's letters will be considered for publication. Letters should be no longer than 1,000 words and should have no more than 5 references. No abstract is required. Usually tables will not be published in the Letters section of the journal, but may be accepted for online publication as supplementary material at the journal website.

Supplementary Material for online only publication

International Psychogeriatrics has the facility to publish unedited figures, tables, appendices, any non-English sections, and other material which is not suitable for inclusion in papers published in the paper copy of the journal as supplementary online material attached to the electronic version of individual papers at <http://journals.cambridge.org/ipg>. This renders such supplementary material accessible without clogging the journal with materials that will be of interest to only a small minority of readers. If submitting such supplementary material please follow the instructions below. If referring to supplementary material in a paper the following form of words should be used "see table S1/figure S1/appendix A1 published as supplementary material online attached to the electronic version of this paper at <http://journals.cambridge.org/ipg>".

Instructions for contributors – Supplementary Material

There will normally be one of the following reasons for you to be supplying supplementary material to accompany the online version of your article:

1. You wish to link to additional information which due to its nature does not lend itself to print media (examples- full data sets, movie or sounds files etc...)
2. The Editor of the Journal has requested that you extract certain information from the original article in order to allow for space constraints of the print version.
3. You have requested additional material to be available to accompany an article that does not normally allow such material to be included (examples – sections not written in the English language, tables to accompany a correspondence article).

N.B. Please note that no copyediting or quality assurance measures will be undertaken on supplementary material (other than to ensure that the file is intact). The authors therefore warrant that the supplementary material that they submit is in a suitable format for publication in this manner. The material shall be published online in exactly the form that it is supplied.

Submission

Please follow the following instructions to supply supplementary material to accompany the online version of your article:

1. Each supplementary file must be supplied as a separate file. Do not supply this material as part of the file destined for publication in the print journal.
2. Each supplementary file must have a clear title (for example, Supplementary Figure 1).
3. Provide a text summary for each file of no more than 50 words. The summary should describe the contents of the file. Descriptions of individual figures or tables should be provided if these items are submitted as separate files. If a group of figures is submitted together in one file, the description should indicate how many figures are contained within the file and provide a general description of what the figures collectively show.
4. The file type and file size in parentheses.
5. Ensure that each piece of supplementary material is clearly referred to at least once in the print version of the paper at an appropriate point in the text, and is also listed at the end of the paper before the reference section.

Format and file size

- File sizes should be as small as possible in order to ensure that users can download them quickly.
- Images should be a maximum size of 640 x 480 pixels at a resolution of 72 pixels per inch.
- Authors should limit the number of files to under ten, with a total size not normally exceeding 3 MB. Sound/movie files may be up to 10 MB per file; colour PDFs/PowerPoint may be up to 5 MB per file; all other general file types may be up to 2 MB per file but most files should be much smaller.
- We accept files in any of the following formats (if in doubt please enquire first):

MS Word document (.doc) , Adobe Acrobat (.pdf), Plain ASCII text (.txt), Rich Text Format (.rtf), WordPerfect document (.wpd), HTML document (.htm), MS Excel spreadsheet (.xls), GIF image (.gif), JPEG image (.jpg), TIFF image (.tif), MS PowerPoint slide (.ppt), QuickTime movie (.mov), Audio file (.wav), Audio file (.mp3), MPEG/MPG animation (.mpg)

If your file sizes exceed these limits or if you cannot submit in these formats, please seek advice from the editor handling your manuscript.

Supply of author-generated artwork

Monochrome line subject illustrations supplied as hard copy only

These should have the author's name and figure number clearly marked on the back of each piece of artwork. The figures will be scanned at 1200 dpi and compressed using LZW. The scanning process can result in problems with some fine ornaments and with any grey tints used (e.g. tints can fill in; a Moiré interference pattern can be produced; or poor quality, patchy tints result). Illustrations of this kind may be acceptable in a desktop publishing format, but they do not proceed satisfactorily through the several stages before printing. Plain black/white is acceptable, but all other shades/tints should be replaced with distinct PostScript fills or custom fills.

Monochrome line subject illustrations supplied in digital form

Macromedia Freehand, Adobe Illustrator and Adobe Photoshop are the preferred graphics packages. Before submitting your artwork, please do the following:

- Where possible, please supply illustrations as TIFF or EPS files (300 dpi). When submitting EPS files you must convert your text within the file to artwork/outlines. If your EPS file contains a scanned image, you must ensure that you supply a full EPS, i.e. binary data. Do not supply PostScript files. PostScript files cannot be included within our integrated page make-up system, or worked on in any way. For best results please save your files as TIFF or EPS files. If files cannot be supplied in this way other formats can be handled (although we do not guarantee to use them).
- Draw or scan line artwork to finished size with appropriate line weights and typefaces.
- Indicate the file format (e.g. TIFF or EPS), the graphics software that you have used in originating the artwork files (e.g. Freehand 7.0, Illustrator 8.0, etc.) and the computer operating system used (e.g. Mac OS 8.6, Windows NT).
- Supply a laser print of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork or EPS files.

Pattern fills and tints

Artwork packages do not always generate pattern fills for output on image/platesetters. Imagesetters will interpret them differently from your Mac or PC and the result often looks pixellated or blocked. Where possible, use PostScript fills, custom fills and conventional tints. PostScript fills frequently do not display well on screen but they do print out correctly. It is best to avoid the use of complex or very detailed tints, patterns and symbols. These seldom reproduce satisfactorily when reduced to fit the page and when used in a caption or legend may be completely illegible when represented on a screen (for example during page make-up, or on the Web) or when output on low-quality CUP artwork instructions.doc 2 laser printers. Supplying as TIFF or EPS files (see above) alleviates this problem.

Please therefore:

- Use only the tints, patterns and symbols shown here.
- Use conventional fills: solids, tints, lines or cross-hatching.
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- Do not use a screen value above 133 lpi. Generally, 100 lpi is better (even when scanned at high resolution finer tints do not reproduce satisfactorily when reduced).
- If possible, use just one kind of screen (line angle or dot shape) and one screen value throughout the document.
- Do not use pattern fills from a graphics program, as these are usually bitmap patterns, which do not output adequately to plate/image setters.
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- Do not use .hairline. line widths in graphics packages.

Monochrome halftone subjects

Figures composed of (hard copy) photographs should be unscreened glossy prints presented at publication scale; each component part should be named with a lower-case letter. Photographic artwork is numbered as part of the sequence of figures, not as separate plates.

If supplying these in digital form, your repro house should follow these instructions:

- Scanning: Scan at a resolution that is around twice the intended screen value; for example scan at 300 dpi for 133 or 150 screen.
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- Data files: Supply data as TIFF files; if you wish to compress them, use lossless compression software such as the LZW compression package.

- Laser proofs: Supply a good quality laser proof of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork. If we are unable to use your electronic file, we can scan in the laser proof as an alternative until a revised file can be supplied.
- Line & tone combination: Files scanned as line & tone combination should be scanned at a higher resolution than a standard halftone to ensure better type/line quality, for example, 600 dpi.

Colour halftone or line subjects

- Do not submit line subject drawings with coloured tints unless the figure is required as a colour plate; use only black/white/greyscale.
- If supplying colour subjects in digital form, submit as TIFF or EPS files and choose CMYK colour mode when saving your scans. If you supply files as RGB we need to convert them to the CMYK printing process before we can print, this usually results in a slight change of the colour values; therefore all colour correction must be carried out in CMYK mode on your machine.

Checklists

- Always supply a printed directory of file names, laser proofs of all the figures, and a list of fonts/typefaces used in labelling artwork.
- Transfer media
- You can supply artwork files in any of the following media:

Apple Mac/PC:

- disks at 3.5 inch
- 100/250 Mb Floppy ZIP drive ▪ CD-ROM

Virus check

Before dispatching your disks please run them through a virus checker program. If possible, also check Word and Excel files for viruses.

General notes

Following acceptance of a manuscript the contact author should receive proofs within 1-12 weeks. They also will be required to complete and forward a copyright form and authors' checklist both of which will be forwarded to the corresponding author by email when the article is accepted.

The average time from an article being accepted to being e-published ahead of print as a First View article is 35 days, provided authors return proofs promptly. E-publication generates a doi number and counts as full publication for citation purposes.

Editorials, "For Debate" articles and book reviews are commissioned by the editor.

Reviewers who reviewed papers in the previous calendar year will be acknowledged in the journal each year. International Psychogeriatrics no longer publishes an annual index as modern computerised search techniques have rendered annual hard copy indices obsolete.

Contributors should refer to recent issues of the journal for examples of formatting (abstracts, headings, references, tables, etc.).

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Cambridge recommends that authors have their manuscripts checked by an English language native speaker before submission; this will ensure that submissions are judged at peer review exclusively on academic merit. We list a number of third-party services specialising in language editing and / or translation, and suggest that authors contact as appropriate. Use of any of these services is voluntary, and at the author's own expense.

Appendix B: Quality Assessment Tool

Adapted from Downs & Black (1998), NICE (2012) and Thompson et al (2005).

Criteria	Yes (Score = 1)*	No (Score = 0)	Unable to determine (Score = 0)
1. Are the aims/ objectives clearly described?			
2. Are hypotheses clearly stated prior to conducting analysis (i.e. a priori)?			
3. Did the selection of variables measured have a theoretical basis that was made explicit?*	0 = None of the variables had any theoretical basis 1 = some variables had theoretical basis 2 = All variables had some theoretical basis		
4. Are the main outcomes to be measured (QOL) clearly described in the Introduction or Method section?			
5. Is score reliability/validity reported for all QOL measures based on induction from a prior study or analysis of data within current study?*	0 = None of the QOL measures had reported reliability/validity data 1 = Some of the QOL measures had reported reliability/validity data some theoretical basis 2 = All of the QOL measures had reported reliability/validity data		
6. Is score reliability/validity reported for all other measures based on	0 = None of the other measures had reported reliability/validity		

<p>induction from a prior study or analysis of data within current study?*</p>	<p>data 1 = Some of the other measures had reported reliability/validity data some theoretical basis 2 = All of the other measures had reported reliability/validity data</p>		
<p>7. Were screening/selection criteria for study eligibility clearly described?</p>			
<p>8. Are characteristics of clinical sample population included in the study clearly described (e.g relevant personal characteristics)?</p>			
<p>9. Are characteristics of comparison proxy sample population included in the study clearly described (e.g relevant personal characteristics)?</p>			
<p>10. Is the clinical sample representative of the entire population from which it was taken?</p>			
<p>11. Is the comparison proxy sample representative of the entire population from which it was taken?</p>			
<p>12. If any of the results of the study were based on “data dredging” was this made clear? (score yes if results were not based on data-dredging)</p>			

13. Are the main findings of the study clearly described?			
14. Were the statistical tests used to assess the main outcomes appropriate?			
15. Does the study provide estimates of the random variability in the data for the main outcomes by standard error, standard deviation or confidence intervals?			
16. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes, except where the probability value is less than 0.001?			
17. Effect sizes are reported for each quality of life-other variable relationship, even when the outcome was not statistically significant.*	<p>0 = No effect sizes are reported for any relationships between QOL and other variables</p> <p>1 = The effect size is reported for a relationship between some of the other variables measured and QOL</p> <p>2 = Effect sizes are reported for all relationships between QOL and other variables</p>		
18. Is consideration/justification given when interval data (e.g. MMSE scores) is converted to nominal scale (e.g. 'low' & 'high')?			

19. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?			
20. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance <5%			
Total Score	/24		

Appendix C: Summary of Methodological Quality Assessment Scores

Study	Checklist Items																				Total Score
	1	2	3*	4	5*	6*	7	8	9	10	11	12	13	14	15	16	17*	18	19	20	
Beer et al (2010)	1	0	1	0	1	0	1	1	1	0	0	1	1	1	1	1	1	0	0	1	13
Boyer et al (2004)	1	0	0	1	2	0	1	1	1	0	0	1	1	1	1	1	1	1	0	1	15
Coucill et al (2001)	1	1	1	1	2	0	1	1	1	0	0	1	1	1	0	1	2	1	0	0	16
Crespo et al (2012)	1	1	2	1	2	2	1	1	1	0	0	1	1	1	1	1	2	1	1	1	22
Crespo et al (2013)	1	1	2	0	2	0	1	1	1	1	1	0	1	1	1	1	2	1	1	1	20

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Appendix D: Double Rated Papers

Quality scores attributed to a randomly selected sub-group of reviewed articles that were double-rated to ensure credibility of scores.

Paper	First Author Quality Score	Second Rater Quality Score
Beer et al (2010)	13	13
Crespo et al (2012)	22	21
Hoe et al (2006)	13	13
Sloane et al (2005)	12	12

Appendix E: Data Extraction Tool

Author (s) and Year of Pub.	
Title of Study	
Research Aims	
QOL Definition	
Participants Proxy (Job title/other characteristics)	
Participants PWD (Diagnosis/MMSE/Age/Residency/Location/Gender/Ethnicity)	
Sample Size (PWD/Proxy)	
Self-Rated QOL Measure(s) Used (Title/ administration procedure/completion rate)	
Proxy-Rated QOL Measure(s) Used (Title of measure/ administration procedure/ completion rate)	
Statistical Analysis (Techniques used)	

<p>Clear distinction between staff and family proxy data</p>	
<p>Main Findings</p> <p>(Means for self & proxy & difference values/ correlations)</p>	
<p>Factors that predict variance between ratings</p>	
<p>Perceived reasons attributed to variance</p>	
<p>Other variables measured</p> <p>(measurement tools)</p>	
<p>Conclusions</p> <p>(conclusions/strengths/limitations)</p>	

Appendix F: Studies Excluded Upon Reading Full Article

References for papers excluded upon reading full article:

Arlt, S., Hornung, J., Eichenlaub, M., Jahn, H., Bullinger, M., & Petersen, C. (2008). The patient with dementia, the caregiver and the doctor: cognition, depression and quality of life from three perspectives. *International journal of geriatric psychiatry*, 23, 604-610.

Barca, M. L., Engedal, K., Laks, J., & Selbæk, G. (2010). Quality of life among elderly patients with dementia in institutions. *Dementia and Geriatric Cognitive Disorders*, 31, 435-442.

Becker, S., Kaspar, R., & Kruse, A. (2006). Die Bedeutung unterschiedlicher Referenzgruppen für die Beurteilung der Lebensqualität demenzkranker Menschen. *Zeitschrift für Gerontologie und Geriatrie*, 39, 350-357.

Bureau-Chalot, F., Novella, J. L., Jolly, D., Ankri, J., Guillemin, F., & Blanchard, F. (2002). Feasibility, acceptability and internal consistency reliability of the Nottingham health profile in dementia patients. *Gerontology*, 220-225.

Crespo, M., Hornillos, C., & Mar Gomez, M. (2013). Assessing quality of life of nursing home residents with dementia: Feasibility and limitations in patients with severe cognitive impairment. *International Psychogeriatrics*, 25, 1687-1695.

Edelman, P., Fulton, B., Kuhn, D., & Chang, C. H. (2003). Measuring dementia-specific quality of life: Resident, staff, and observer perspectives. In *INTERNATIONAL PSYCHOGERIATRICS* (Vol. 15, pp. 253-253). 536 BROADWAY, NEW YORK, NY 10012 USA: SPRINGER PUBLISHING CO.

Edelman, P., Fulton, B. R., & Kuhn, D. (2004). Comparison of dementia-specific quality of life measures in adult day centers. *Home Health Care Services Quarterly*, 23, 25-42.

Edelman, P., Kuhn, D., Fulton, B., Kasayka, R., Lechner, C., Noelker, et al. (2002). Measuring dementia-specific quality of life from multiple perspectives in multiple settings. In *GERONTOLOGIST* (Vol. 42, pp. 409-409). 1275 K STREET NW SUITE 350, WASHINGTON, DC 20005-4006 USA: GERONTOLOGICAL SOCIETY AMER.

Ettema, T. P., Dröes, R., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: Development and evaluation of a dementia specific quality

of life instrument--validation. *International Journal of Geriatric Psychiatry*, 22, 424-430.

Gomez-Gallego, M., Gomez-Amor, J., & Ato, M. (2010). Assessing quality of life in alzheimer's disease: Agreement between patients, informal carers and professional carers. *Journal of Neurology*, 257, S165-S165.

Graeske, J., Fischer, T., Kuhlmeier, A., & Wolf-Ostermann, K. (2012). Quality of life in dementia care - differences in quality of life measurements performed by residents with dementia and by nursing staff. *Aging & Mental Health*, 16, 819-827.

Hickey, E. M., & Bourgeois, M. S. (2000). Health-related quality of life (HR-QOL) in nursing home residents with dementia: Stability and relationships among measures. *Aphasiology*, 14, 669-679.

Hoe, J., Hancock, G., Livingston, G., Woods, B., Challis, D., & Orrell, M. (2009). Changes in the quality of life of people with dementia living in care homes. *Alzheimer Disease & Associated Disorders*, 23, 285-290.

Kasper, J. D., Black, B. S., Shore, A. D., & Rabins, P. V. (2009). Evaluation of the validity and reliability of the alzheimer disease-related quality of life assessment instrument. *Alzheimer Disease and Associated Disorders*, 23, 275-284.

León-Salas, B., Olazarán, J., Cruz-Orduña, I., Agüera-Ortiz, L., Dobato, J. L., Valentí-Soler, M., et al. (2013). Quality of life (QoL) in community-dwelling and institutionalized alzheimer's disease (AD) patients. *Archives of Gerontology and Geriatrics*, 57, 257-262.

Missotten, P., Ylieff, M., Di Notte, D., Paquay, L., De Lepeleire, J., Buntinx, F., et al. (2007). Quality of life in dementia: A 2-year follow-up study.

International Journal of Geriatric Psychiatry, 22, 1201-1207.

Moyle, W., Murfield, J. E., Griffiths, S. G., & Venturato, L. (2012). Assessing quality of life of older people with dementia: A comparison of quantitative self-report and proxy accounts. *Journal of Advanced Nursing, 68*, 2237-2246.

Novella, J. L., Ankri, J., Morrone, I., Guillemin, F., Jolly, D., Jochum, C., et al. (2001). Evaluation of the quality of life in dementia with a generic quality of life questionnaire: The duke health profile. *Dementia and Geriatric Cognitive Disorders, 12*, 158-166.

Novelli, M. M. P. C., Dal Rovere, H. H., Nitrini, R., & Caramelli, P. (2005). Cross-cultural adaptation of the quality of life assessment scale on alzheimer disease. *Arquivos De Neuro-Psiquiatria, 63*, 201-206.

Rummel, C. P. (2013). Quality of life and the eye of the beholder: A multidimensional approach to assessing quality of life for persons with dementia. ProQuest Information & Learning). *Dissertation Abstracts International: Section B: The Sciences and Engineering, 74*.

Scocco, P., Fantoni, G., & Caon, F. (2006). Role of depressive and cognitive status in self-reported evaluation of quality of life in older people: Comparing proxy and physician perspectives. *Age and Ageing, 35*(2), 166-171.

Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith,

P., et al. (2005). Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9(10), 1-+.

Winzelberg, G. S., Williams, C. S., Preisser, J. S., Zimmerman, S., & Sloane, P. D. (2005). Factors associated with nursing assistant quality-of-life ratings for residents with dementia in long-term care facilities. *The Gerontologist*, 45, 106-114.

Zimmerman, S., Sloane, P. D., Williams, C. S., Reed, P. S., Preisser, J. S., Eckert, J. K., et al. (2005). Dementia care and quality of life in assisted living and nursing homes. *Gerontologist*, 45, 133-146.

Reasons for exclusion from review:

- Data reporting staff-proxy ratings of QoL could not be determined from other proxy-rated QoL (e.g. family): N= 1
- Data did not differentiate between people with dementia and people with other neurodegenerative diagnoses, mental health disorders or mild cognitive impairment: N= 4
- QoL was not assessed by both people living with dementia and staff proxy ratings: N= 5

- Staff proxy's relationship to the person with dementia was unclear: N= 2
- Assessment of QoL based on clinical indicators: N= 2
- No English translation available: N= 1
- Review article, meeting abstract, book, discussion paper or comment about measurement issues: N= 3
- Papers utilized the same sample as another paper included in the review but did not add additional information regarding review questions: N= 6

Appendix G: Meta-analysis Process

A meta-analysis was considered to calculate the overall difference between self and proxy ratings of QoL. All papers included in the review were assessed for inclusion in the meta-analysis. Papers and/or data sets from papers were excluded from the meta-analysis if they were found to meet one or more of the following criteria:

- Utilised data from the same sample or a sub-sample as another paper in the review¹³. In such circumstances, data extracted from the first paper published was included in the meta-analysis.
- Paper reported multiple measures of QoL taken from the same sample of participants. As two measures from the same sample could not be included¹⁴, the QoL-AD data was selected for inclusion in the meta-analysis¹⁵.
- The measure did not provide an overall QoL score rather than individual construct scores¹⁶.

Based on the above criteria seven papers were eligible for inclusion in the meta-analysis.

¹³ This was to ensure that overall sample size was not artificially increased.

¹⁴ This was to ensure that the overall sample size was not artificially increased.

¹⁵ QOL-AD selected as it was found to be used in all studies which were assessed to meet the other meta-analysis inclusion criteria.

¹⁶ Efforts to group variables may be unreliable.

Table. 1 Papers eligible for inclusion in meta-analysis

Paper	Measure	Total self- rating	Self-rated Mean	Self- rated SD	Total proxy- ratings	Proxy-rated Mean	Proxy-rated SD
Beer et al., (2010)	QOL-AD	N=226	M= 41.5	SD= 5.9	N=324	M= 32.1	SD=7.4
Crespo et al. (2011)	QOL-AD	N=102	M=37.6	SD= 6.71	N=197	M=30.95	SD=7.21
Gómez-Gallego etal(2002)	QOL-AD	N= 102	M=34.92	SD= 6.48	N= 25	M= 30.27	SD=4.82
Hoe et al. (2006)	QOL-AD	N= 123	M= 33.1	SD= 6.9	N= 224	M= 29.9	SD=6.3
Sloane et al. (20)	QOL-AD	N=120	M= 42.8	SD= 8.2	N= 410	M= 36.9	SD= 7.9
Spector & Orrell (2006)	QOL-AD	N= 76	M= 30.9	SD= 7.4	N= 76	M= 30.2	SD= 5.0
Wenborne et al. (20)	QOL-AD	N= 24	M= 32.29	SD= 7.17	N= 81	M= 30.93	SD= 5.76

Appendix H: Epistemological statement

The statement aims to explore the ontological and epistemological position underpinning the research questions and selected methodology adopted in the current study. A brief reflexive statement is also provided.

Ontology refers to the nature of reality (Ponterotto, 2005). Epistemology relates to the justification of knowledge (Carter and Little, 2007), referring to the study and acquisition of knowledge, and giving consideration to the relationship between the knower and the would-be knower in this process (Ponterotto, 2005). There is no correct epistemological and ontological stance when embarking upon research. It is however important, and arguably likely due to the iterative nature of research development, that the position assumed by the methodology selected is concurrent with both the aims of the research and the stance of the researcher, as different positions will result in different research products (Carter and Little, 2007; Larkin, Watts and Clifton, 2006).

Selection of Epistemological and Ontological Position Adopted

It is important to consider the position of the research paradigm, defined as the assumptions made about the social world, as this has been suggested to set the context of research (Ponterotto, 2005). Positivism assumes that there exists a reality that is separate from objects, and that this can be identified and objectively measured (Cohen and Crabtree, 2008) in a process in which the research participant and the researcher are independent of one and other

(Ponterotto, 2005). In contrast, the constructivist-interpretive position assumes that there are multiple realities, and that one's lived experience is subjective and context-dependent. This stance postulates that reality is socially constructed by a dynamic interaction between the research participant and the researcher (Ponterotto, 2005), and as such, the researcher is an active creator of the research (Carter and Little, 2007), whose values cannot be eliminated from the research process but can be 'bridled' through mindful acknowledgement (Vagle, 2009) and transparent reflection (Carter and Little, 2007).

As discussed in greater depth in my reflective statement (Appendix P), I spent much of the early development of this research considering a mixed methods study in which I aimed to explore participants' subjective understandings and lived experiences in relation to positive wellbeing with dementia, as well as investigating how these understandings and experiences may interact with their clinical practice. However, it became clear that considering both of these areas of research was beyond the scope of the current thesis and may, depending on the methodology selected, have involved methodologies with conflicting epistemological assumptions. Both were deemed to be valid and clinically useful areas of research in their own right, but for the purpose of this thesis I decided to focus on exploring the psychiatrists' subjective understanding and lived experiences of discussing wellbeing, as this was considered to be the natural starting point in such an under-researched field.

With these research aims in mind, quantitative methodology was deemed inappropriate considering its positivist position. It was not felt that the richness and diversity of participants' lived-experiences could be captured within quantitative methods, nor that the role of the researcher could be eliminated from the participants' development and description of their lived experiences. As such, a constructivist-interpretivist position, and subsequently qualitative methodology, was considered most appropriate to explore the research questions.

Selection of Methodology

This section will briefly describe the methodological approaches considered, and explain the reasons behind the final decision to utilise Interpretive Phenomenological Analysis [IPA] for the current research.

Thematic analysis is characterised by the categorisation of important ideas that occur in qualitative data into themes (Braun and Clark, 2006). Discourse analysis compiles a number of approaches that aim to explore how language is used to communicate understanding and meanings. Both of the aforementioned methodological approaches assume access to the lived-world of participants may be obtained through conversations, however may be argued to primarily offer descriptions of participants' accounts rather than deeper interpretations of their lived-experiences. Furthermore, neither approach recognises the impact of

the attitudes and values of the researcher on the research process during analysis of data (Pistrang and Barker, 2010). As such, both methodologies were rejected for the current study.

Grounded theory, introduced by Strauss and Corbin (1998), aims to identify key features of a phenomenon through categorisation of key themes within the data, which is then leads to the generation of theory (Pistrang and Barker, 2010).

This methodology was also discounted as the aim of the study was to conduct an exploratory investigation into the under-researched area of the lived-experiences of psychiatrists discussing positive wellbeing in dementia, rather than to generate new theory.

The final methodology considered was IPA. IPA is underpinned by a number of key concepts deemed important and appropriate for the current study:

phenomenology, hermeneutics and idiographic enquiry (Smith, Flowers and Larkin, 2009). Phenomenology refers to the study of human experience (Langdrige, 2007), with ones lived experiences firmly situation within their context, language and relationships (Smith et al. 2009). Hermeneutics considers the process of interpretation. Within IPA, there is a recognition of the double hermeneutic that arises when a researcher attempts to make sense of a research participants' phenomenology (second order sense-making), which is, in its nature, hermeneutic (first order sense-making). There is also recognition that the interpretations of both the research participant and the researcher will be influenced by their own subjective attitudes and values, with both parties

drawing on their personal resources to make sense of the phenomenon in question in an on-going and developing process (Smith et al. 2009). Finally, IPA's commitment to idiographic enquiry, which can be understood in terms of consideration of the particular, is evidenced in both in the depth of analysis undertaken, as well as the specific focus on lived experience of particular people within their particular context (Smith et al. 2009).

IPA's focus on understanding lived-experiences and consideration of the role of the interpreter within the double hermeneutic (Larkin et al. 2006) were considered appropriate and important when exploring psychiatrists' subjective understanding and lived experiences of discussing wellbeing in dementia. Adopting a phenomenological and idiographic approach is important to shed light in both a social experience and professional group that are largely ignored by current research. IPA is both inductive and deductive in its approach and as such, through the use of reflexivity, recognises the influence of the previous understanding of the researcher within the research process. This was considered of particular importance in the current research considering the different professional background of myself and the research participants (Dwyer and Buckle, 2009) in addition to the previous knowledge I had accrued throughout the development of the research and its accompanying systematic literature review.

Furthermore, the epistemological and ontological assumptions underpinning the constructivist-interpretivist position adopted by IPA are consistent with my own

beliefs and attitudes. I believe that our understandings and experiences are influenced by our values and social context. I think that people can articulate these subjective understanding and experiences and through this, allow me access into their lived-experience, but that my own subjective understandings and experiences will inevitably and unavoidably affect my perceptions of the information they have shared and, therefore, a new and joint reality will created through this two-way interaction. As a trainee psychologist, I have a keen interest in exploring the idiographic experiences of individuals and have the clinical skills to elicit this information through interviews. As such, IPA was considered the most appropriate methodology both for the research questions, and researcher.

Reflexive Statement

Reflexivity, the act of conscious meta-analysis (Finlay, 2002), considers the impact of the researchers attitudes, values and lived experienced, both within the double hermeneutic and throughout the entire research process. The aim of reflexivity is not to eliminate the voice of the researcher as is the aim in positivist methodologies (Potterotto, 2005), but rather for the researcher to be, as far as is possible, mindful and transparent in their awareness of their role in the co-construction of knowledge (Finlay, 2002). Below I will briefly outline my key beliefs and attitudes in relation to the current research.

I have been consciously aware of my firm belief that people can and do live well with dementia since the early stages of developing the research, acknowledging my perception that the stigma associated with dementia is a key factor behind the negative impact a diagnosis can have on a persons' wellbeing. Due to this, I am aware of my desire to ensure that I do not contribute to the negative literature base prevalent in dementia research, and so fuel this stigma.

Undoubtedly, this drove my selection of the research question and epistemological position adopted within the research. Furthermore, the positive focus of the research was explicit in the title of the study and so will have affected the participants recruited as well meanings made within the double hermeneutic.

I am also aware of my initial preconceptions about the perceptions psychiatrists would have about wellbeing in dementia. On reflection, I initially held the view that people coming from a medical background would be largely influenced by reductionist biomedical perceptions of wellbeing in dementia. Subsequently, I felt that they would view medical interventions as the most important factor in supporting a person to live well and place little value in providing psychological support to a person with dementia. As is recognised within IPA, my own subjective meaning made about the phenomenon in question has both driven my exploration of this phenomenology, and changed as a consequence of my own-lived experiences of the research process (Smith et al. 2009).

Undoubtedly, the experience of engaging in the research has been key in shifting these pre-conceptions. However, I think I would be naïve to assume that it is only my research experience that has influenced this. Through the two-

years since the initial development of the research project I have also developed both as a clinician myself and as a person, and as such, the lived-experiences upon which my understanding are based have changed dramatically and so influenced my own hermeneutic process.

It was also important to consider the impact of my position in relation to my research participants, as I am of a different professional group, level of experience and age to my participants (as well as gender for male participants). Prior to starting data-collection I expected these differences to hinder data-collection, expecting that participants would feel the need to 'teach' me due to my age or be unwilling to open-up due to my perceived out-group status. Interestingly, although I initially considered myself to be an out-group member due to my role as a trainee clinical psychologist, my own opinion of this has also shifted through the course of the research. Not only were my preconceptions about the impact of my position largely not supported by my experiences, I have also developed as a clinician and so am now more comfortable in identifying as a health-care professional myself. Furthermore, my own understanding of what constitutes an in-group and out-group has shifted throughout my training. I now perceive my own status in relation to my participants (at least in terms of professional group) as occupying the space between, which highlights the existence of both shared and unique experiences (Dwyer and Buckle, 2009).

I took a number of steps to ensure that I remained reflexive, as far as possible, throughout the research process. Through the use of regular

supervision, IPA group, reflective practice group and my own reflective journal, I took steps to bring my own opinions, values and beliefs into awareness and as such, allow consideration of them throughout the research process. In addition, descriptive codes of transcripts were second-rated as a credibility (not validity) check to ensure that codes were grounded in verbatim quotes rather than my own assertions (Madhill, Jordan and Shirley, 2000).

Conclusion

This statement provides a brief overview of the epistemological and ontological position adopted by the current research and a brief reflexive statement. Due to the nature of the research questions and my own position as a researcher, qualitative methodology based upon the constructivist-interpretivist position was adopted. IPA was selected due to its focus on ideography, phenomenology, hermeneutics and consideration of reflexivity. Furthermore, IPA's use of interviews to collect data reflects my clinical skills.

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Appendix I: Semi-structured interview schedule

NHS Trust Banner has been removed from the document to protect the anonymity of participants

Name of Researcher: **Adrienne Vince**

SEMI-STRUCTURED INTERVIEW SCHEDULE

An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis.

I would like to ask you some questions about your understanding of positive wellbeing and living well in dementia, and your experiences of discussing this with people when sharing a diagnosis of dementia. Although there is no unanimously accepted definition of what this means in practice. I am interested to find out what your personal understanding of this is. When answering questions, I would like you to talk about and reflect on your experiences with an older adult patient group specifically. I am interested in your understanding and experiences with all types of dementia.

Subjective understanding

Question 1 “What does the term ‘positive wellbeing with dementia’ mean to you?”

Prompts:

- What is your understanding of the term positive wellbeing in relation to dementia?

- In your own language, how would you define positive wellbeing in dementia?
- How does one live well with dementia?

Development of understanding

Question 2 “What factors shape your understanding of this?”

Prompts:

- What clinical/ professional/ organizational/ personal factors influence this understanding?¹⁷
- Has this understanding changed over your professional career? If so, what factors have influenced these changes?

So now we have talked about what positive wellbeing might mean, with all that we have discussed in mind,

Experience

Question 3 “Can you tell me about your experiences of discussing positive wellbeing and living well with dementia when sharing a diagnosis of dementia?”

¹⁷ Identified as factors that influence the disclosure process as a whole:

Koch, T. & Iliffe, S. (2010). Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Family Practice*, 11(52), 1471-2296.

Werner, P., Karnieli-Miller, O. & Eidelman, S. (2013). Current Knowledge and future directions about the disclosure of dementia: A systematic review of the first decade of the 21st century. *Alzheimer's & Dementia*, 9, e74-e88.

Prompts:

- Would you say that you regularly engage in discussions about positive wellbeing when sharing a diagnosis of dementia?
- How easy or difficult do you find engaging in discussions about positive wellbeing when sharing a diagnosis?

Factors that help/hinder

Question 4 “Are there any factors that influence the extent to which you engage in discussions about positive wellbeing when sharing a diagnosis?”

Prompts:

- What clinical/ professional/ organizational/ personal factors influence this?²
- What would help to make this discussion easier?
- What is your experience of discussing positive wellbeing and living well in the absence of sharing a formal diagnosis?”

Role of diagnostic disclosure in shaping positive wellbeing

Question 5 “What role does the diagnostic disclosure have in shaping positive wellbeing? Do you think that diagnostic disclosure influences positive wellbeing?”

Prompts:

- Do you think positive wellbeing is influenced by how the diagnostic disclosure is given and received?

Other

Question 6 “Would you want to be told if you had dementia?”

Prompts:

- If not, why not?
- If yes, how would you like this information to be shared? Would you like the disclosing clinician to discuss positive wellbeing with you?

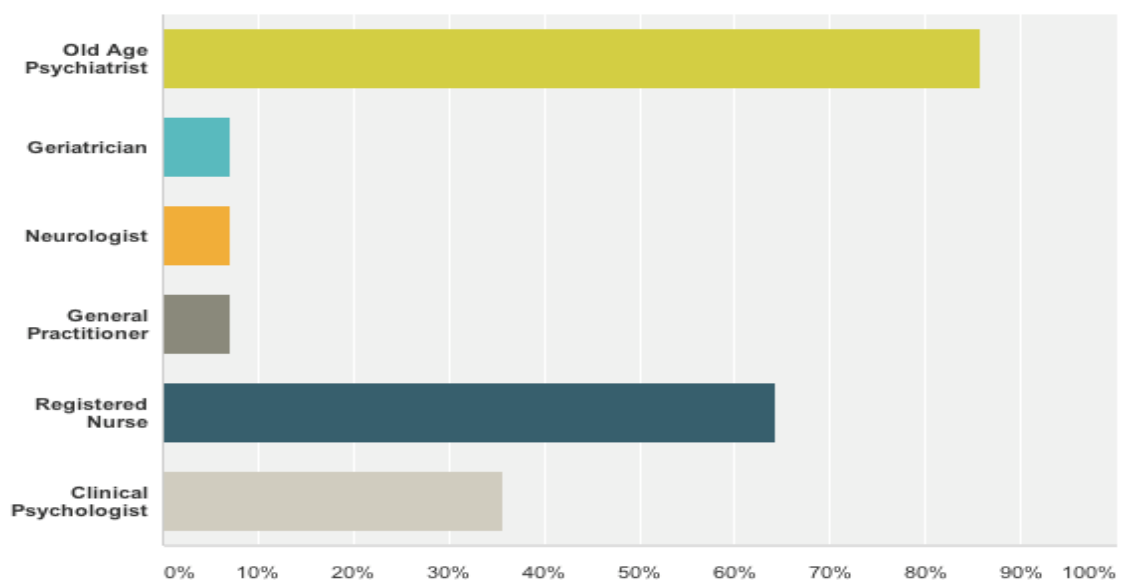
Finally “Is there anything else that you would like to say/ it would be helpful for me to know?”

Thank you for your time.

Appendix J: MSNAP survey

A survey of accredited memory services was conducted to inform and validate the design of the research and gain insight into the level and nature of training in diagnostic disclosure and/or wellbeing in dementia professionals had received. Services were identified and contacted via the Memory Service National Accreditation Program. Data was collected via online survey.

Figure 1: Professional groups frequently involved in the diagnostic disclosure of dementia



Of the data received:

- 42 % had received specific training about wellbeing in dementia
- 27% had received training about directly discussing issues relating to wellbeing as part of the diagnostic disclosure process.

Appendix K: Documentation for Ethical Approval



Miss Adrienne Vince
Department of Psychological Health and Wellbeing
University of Hull
Cottingham Road
Hull
HU6 7RX

FACULTY OF HEALTH AND
SOCIAL CARE RESEARCH
ETHICS COMMITTEE
T: 01482 464680
E: j.dyson@hull.ac.uk

OUR REF: 141
29 April 2014

Dear Adrienne

Re: An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis

Thank you for submitting the above proposal to the Faculty Research Ethics Committee, which was considered at a Committee meeting on 28 April 2014. The committee have asked me to commend you on your high quality application which clearly considers relevant ethical issues.

I am pleased to inform you that ethical approval is granted, subject to submission and approval by Chair's action of the recruitment poster to which you refer.

Please note that should you choose to disseminate the results of your study you may need to be particularly careful to ensure anonymity is maintained as you have a small number of participants with very specific professional roles and area of work (psychiatrists working locally in older adult services).

I look forward to receiving a copy of the poster.

Yours sincerely

Dr Judith Dyson
Chair, Research Ethics Committee
cc: file/supervisors



Miss Adrienne Vince
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Wellbeing
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**FACULTY OF
HEALTH AND
SOCIAL CARE**
T: 01482 464530
E: j.kelly@hull.ac.uk

OUR REF: 141
29 May 2014

Dear Adrienne

**Re: An exploration into psychiatrists' understanding
of what it means to live well with dementia, and
experiences of engaging in discussions about positive
wellbeing when sharing a diagnosis**

Thank you for your responses to the Ethics Committee. I
am pleased to inform you that ethical approval is granted,
as per the Committee's Terms of Reference.

I wish you every success with your research.

Yours sincerely

Dr Janet Kelly
Acting Chair, Research Ethics Committee
cc: file/supervisors

Appendix L: Participant Information Leaflet

NHS Trust Banner has been removed from the document to protect the anonymity of participants

Name of Researcher: **Adrienne Vince**

PARTICIPANT INFORMATION SHEET

An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis.

We would like to invite you to participate in our research: An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis.

Before you decide, we would like to explain the purpose and aims of the research, and what participant would involve for you.

The researcher will answer any questions or concerns you may have. The researcher may be contacted via contact details provided below.

What is the purpose of the research?

NICE states that it is best practice to disclose a dementia diagnosis (capacity permitting). Furthermore, best practice guidelines have highlighted the

importance of discussing the implications of the diagnosis and living positively when sharing a diagnosis of dementia. Despite its inclusion in best practice guidance, there is no research to date exploring the experience of engaging in discussions about positive wellbeing when sharing a diagnosis of dementia. Therefore, there is little understanding of the factors that can help or hinder a clinician who is regularly required to engaging in conversations of this nature.

The current study will use a qualitative design to explore psychiatrists' own understanding of positive wellbeing with dementia, and their experience of discussing this when sharing a diagnosis. A clear understanding of this is crucial in order to enhance the experience of the disclosure meeting for people with dementia, their carers and the clinicians themselves. Furthermore, current literature exploring disclosure practices focuses heavily on GP's. This research aims to bridge this gap by exploring the experience of other professions regularly required to engage in the diagnostic disclosure of dementia.

Why have I been selected for participation?

This information sheet has been given to practicing psychiatrists, regularly involved in the diagnostic disclosure of dementia since 2009. A named point of contact at various locations in the North East of England has disseminated the leaflet to individuals who fulfil these criteria, as they may be interested in participating in the research.

Participation is voluntary

You are **not** obliged to participate in this research. Should you wish to participate, the researcher will go through this information in person, giving further opportunity to clarify information and ask questions, before requesting your written consent to participate. You are free to withdraw from the research at any point until the process of data-analysis begins. This will be approximately one month after your research interview but may be subject to change.

Withdrawing from the research will not affect your professional or legal rights.

What is the procedure if I agree to participate?

If you are interested in participating in this research please contact the researcher directly using the contact information provided on page 3. The researcher will provide further information about the research and answer any questions you may have before you decide whether you wish to participate in the research. This should take no longer than 15 minutes and may be done via telephone, email or in person depending on your preference. We advise you to take time to consider whether you wish to participate in the research. Should you agree to participate in the research, you will be requested to contact the researcher directly. At this point, a research meeting will be arranged. This will be at a date, time and location of your convenience.

Research interviews will take approximately one hour. You will be asked some brief questions about your job role and training experience. The researcher will then ask a number of open questions, which will explore your understanding and experience of positive wellbeing in dementia in further depth. This should

take no longer than 45 minutes. The researcher will audiotape the discussion using a dictaphone.

What are the possible disadvantages and risks of participation?

Participating in this research will require up to 90 minutes of your time; this includes time taken to provide further information about the research and clarify queries, as well as the 60-minute research meeting. This will be time taken out of the working day. It is possible that some people may find discussing issues of breaking bad news or diagnostic disclosure distressing, or that it may highlight difficulties with the requirements of the job role or burnout. Should this happen the researcher will offer support, and direct you to further sources of support. It is important to reiterate that the research interview can be stopped at any point.

What are the possible benefits of participation?

We cannot promise that you will have any direct benefits from participating in this research. However, participating in research does count towards a medical professionals continued professional development (CPD) appraisal. It is hoped drawing on psychiatrists' understanding and experience of positive wellbeing with dementia will help to identify factors that help and hinder engaging in discussions of this nature when sharing a diagnosis. Furthermore, it is also possible that discussing your personal understanding and experiences of living well with dementia may provide a helpful opportunity to reflect on your practice.

Complaints procedure

If you have any concerns about any aspect of this study, you can contact the researcher or their research supervisors, who will do their best to answer your questions.

Confidentiality

All personal information that you provide will be kept strictly confidential. In accordance with ethical and legal practice, all information about you will be held in confidence. Individuals who agree to participate will be allocated a unique participant number to protect their anonymity. Identifiable data will be held on an encrypted memory stick, and information linking data and personal information will be securely stored in a separate secure location at the University of Hull. All identifiable data will be destroyed on completion of the research; anonymised data will be stored securely for 10 years. During the course of the research meeting, it is possible that participants may disclose unethical practice. Upon such a disclosure, should it be deemed necessary and appropriate, the researcher would have a duty of care to share this information with research supervisors and your service manager.

Dissemination of results

You will be offered a summary copy of the final research upon its completion. We will also invite you to comment upon the results should you wish. Results will be condensed and submitted for publication in an academic journal and

presented at conferences and professional development events. This may contain direct quotations from your research meeting, however any information that may be used to identify you will **not** be included.

Organising and funding

This research is being undertaken as part of a doctoral thesis in clinical psychology. The research is funded and regulated through the University of Hull. Some sections of data collected during the study that are relevant to participation may be assessed by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the research?

The research was reviewed by The Faculty of Health and Social Care Research Ethics Committee based at the University of Hull and received a favourable review. This protects the interests of research participants.

If you have any further questions, comments or queries please do not hesitate to contact Adrienne Vince (principle investigator).

If you would like to participate in this research, please contact Adrienne Vince directly, using the contact details provided.

Thank you for taking the time to read this information.

Yours Sincerely,

Adrienne Vince

Trainee Clinical Psychologist

Supervised by:

Dr. Christopher Clarke

Clinical Psychologist

Dr. Emma Wolverson

Clinical Psychologist

Appendix M: Participant consent form

NHS Trust Banner has been removed from the document to protect the anonymity of participants

Patient Identification Number:

Name of Researcher: **Adrienne Vince**

CONSENT FORM

An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis.

Please initial all
boxes

1. I confirm that I have read and understand the information sheet dated 4/03/14 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any point before the data-analysis process, without giving a reason. If I withdraw from the study my professional and legal rights will not be affected.

3. I understand that the research interview will be audio-recorded. It has been explained that anonymised verbatim quotations may be used in the research report.

4. I understand that my data will remain confidential. It has been explained that in the event of disclosure of unethical practice, confidentiality will be breached; and my service manager and the research project supervisors informed of the details of the disclosure. I understand that I will be informed if this procedure is followed.

5. I agree to take part in the above study.

6. I agree to allow the named researcher to contact me using the contact details I provide to inform me of the results of this research. Or I wish to be contact by the researcher with the results of the study upon completion of the research.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix N: Participant Demographic Questionnaire

NHS Trust Banner has been removed from the document to protect the anonymity of participants

Patient Identification Number:

Name of Researcher: **Adrienne Vince**

Version:3

Demographic Questions

An exploration into psychiatrists' understanding of what it means to live well with dementia, and experiences of engaging in discussions about positive wellbeing when sharing a diagnosis.

I would like to start by asking some questions about your professional role and the training you have received. Do not worry about providing exact dates or details, however please try to be as accurate as possible.

1. What is your full job title and grade or NHS band?

.....

2. How many years have you been practicing as a psychiatrist?

.....

3. Have you received any specific training about positive wellbeing or living well with dementia? If so, when?

.....

3.1 What was the nature of this training? Please provide details on course title, method of delivery, length of training, whether training was mandatory or voluntary and the name of the training provider (if available).

.....

.....

.....

4. Have you received any specific training about breaking bad news?
Please provide details of course/module title, method of delivery, length of training, whether training was pre-qualification or post-qualification, whether training was mandatory or voluntary and the name of the training provider (if available).

.....

.....

.....

4.1 What was the nature of this training?

.....

.....

.....

Thank you very much for your time.

<p>Keeping a sense of who they are</p>	<p>all and end all and some people don't wanna [sic] go to half- you know they don't they don't [sic] want to engage with that. You know some people just wanna go off and g-get on with it really.</p>	<p>8. There's more to living well than activity/ groups</p> <p>9. some people just wanna go off and get on with it.</p> <p>10. Coping styles</p>
	<p>I: Mm. And d-do you think not engaging with that impacts on their wellbeing or?</p>	
<p>Keeping a sense of who they are</p>	<p>P: I don't I don't [sic] think not necessarily no I don't. I think it erm I mean in some it possibly could but I think you've gotta [sic] really, people, you know this is part of it isn't it they need to make their own decisions. People have got capacity to consent to things and make their decisions and actually sort of saying "well we think this is best for you" kind of sort of feeds into all of that and actually t-to sort of say "well you're still an autonomous being who can make decisions and it's about you and about what you're preferences are and you know. You might never have been a</p>	<p>11. Not engaging with groups does not necessarily impact on wellbeing</p> <p>12. Groups are part of it but people need to make their own decisions.</p> <p>13. Saying "we know what's best" feeds into all of that.</p> <p>14. Paternalistic care damages wellbeing</p> <p>15. You're still an autonomous being who can make decisions. Have your own preferences.</p> <p>16. Living well is being an autonomous being</p> <p>17. Living well is continuing as before</p>

	<p>person that like to go groups, so you're not gunna wanna go[sic]" You know</p>	
	<p>I: Yeah</p>	
<p>Keeping a sense of who they are</p>	<p>P: So you can't [stutters]. There's always a lot of people, cause we all come to things with our own ideas don't we and family members thinking "well we, this is what we think will be best." And that maybe for 'us', but actually it's not about 'us' it's about that person</p>	<p>18. We all come to things with our own ideas of what's best</p> <p>19. Families may think what's best for them 'us'</p> <p>20. Difficult to remember it is about the person when we come with our own ideas- term 'us' but talking about families, does this extend to health care professionals and her? Links to my understanding about schema and social constructionist that every person see's through their own lens, regardless of their relationship to the person.</p> <p>21. PWD gets lost under other people's views and ideas</p>

Appendix P: Reflective statement

In this statement will reflect on the key stages of the process, trying to highlight my reactions and decisions throughout.

Developing the Study

Although I considered a number of different projects in the first instance, I quickly decided that I wanted to explore wellbeing in dementia for my thesis. Prior to starting the course I had gained much of my experience working with people with dementia and as such, have always had an interest in how people with dementia can be supported to live well. I have also always had an interest in the interaction between biological and psychological paradigms, and so was drawn to exploring how concepts that stem from positive psychologically are understood within a traditionally reductionist condition when the two may, on the face of it, be perceived as conflicting ideas.

My particular interest in exploring the understandings and experiences of medical professionals was initially sparked when observing a nurse in a dementia assessment. During her introductory statement to her patient, the nurse told the gentleman and his wife that if he were to receive a diagnosis of dementia then the doctor could prescribe medication that would 'get him back to normal' so they needn't worry. I remember feeling disturbed by this, due to the inaccuracy of the information the nurse had provided, and was interested in the processes that may have underpinned clinical encounters such as this.

In developing my specific research questions, I spent a long time considering exploring both the subjective understandings and experiences of participants, and how this may interact with disclosure practices (e.g. by video taping and analysing diagnostic disclosure meetings). After many months of considering how these questions would best be answered with my supervisors, we agreed that exploring both the understanding and experiences of participants as well as the relationship between this and their clinical practice, would be a extensive piece of research and beyond the scope of the current study. Both were felt to be valid and relevant research studies in their own right, however an exploration into the subjective understandings and experiences of psychiatrists discussing wellbeing was considered the natural starting point in researching such an under-developed literature base.

After deciding on the specific aims of the study we then had to chose and appropriate methodology. From the beginning of the course I was keen to gain some experience conducting qualitative research. Although credited as a 'qualitative friendly' University, I had never really considered qualitative methodology for my dissertation during undergraduate degree nor had I felt encouraged to do so. However, having learned more about it during the early stages of teaching I was conscious of my desire to use qualitative methodology within my thesis, both to increase my skills base and because it better matches my own epistemological stance. Through supervision, we concluded that IPA

would be the most appropriate methodology due to its focus on the lived experience of an individual.

Throughout the process of the research I have often reflected on my desire to use qualitative methodology for my thesis given my propensity for struggling with finding the 'right' language. On reflection, I think that the importance I place on the language used is the very reason why I chose both the methodology and the research question in the first place. I have a deeply held belief that the way we express ourselves is very meaningful, and that the conversations we have can have significant impact upon our lived-experiences. As such, the very reason why I have, at times, struggled with the methodology I selected is the very reason why I chose to research the area I did in the way that I did.

Recruitment and Interviews

I think recruitment is an aspect of research that every trainee approaches with trepidation. It is one of everyone's biggest fears that you will spend so much time and energy developing a project only to learn that others do not share your enthusiasm for your project and so the study falls through. Recruitment was an area that I was particularly concerned about considering the participants I was targeting, the methodology I was using (which many participants were unfamiliar with) and the considerable time pressures in the NHS. However, I am very grateful to say that fortunately my concerns were not realised, and

recruitment was one of the aspects of the research that ran most smoothly. I remember feeling surprised at this, and taken aback when one participant shared her enthusiasm that a researcher was actually interested in her experiences. I also think that much of the ease in recruitment was attributable to the excellent suggestions of the focus group I held during the development of the research. I wonder that if I had not followed their recommendations about how best to recruit and the length of interviews, whether the study would have received the interest that it did. I am also grateful for their suggestion of recruiting over multiple NHS Trusts, which I now consider to be one of the real strengths of the study.

I clearly remember during an interview one participant saying “when somebody steps into my room I see it as a privilege and an adventure”. Despite my initial anxiety, I feel that the above statement perfectly captures my experience of the research interviews. Looking back, I think that during my early interviews I was so cautious of doing something wrong that I was less active in the conversation than I naturally would have been. I think that this anxiety was a reflection of my unfamiliarity with the data-collection method, as well as my own tendency to be a bit of a perfectionist (which is a trait I have only really discovered throughout the research process). Although I do not believe that this affected the quality or the depth of the data collected during early interviews, with hindsight, I would have embraced my role in the double hermeneutic sooner which would then have allowed me to enjoy the experience of interviewing earlier into the process.

Throughout data collection I was surprised to learn that often my participants' level of anxiety appeared to match or exceed my own. We had discussed this possibility during supervision because of the exposing nature of the research and the participants' unfamiliarity with the methodology, but I had maintained the belief that my participants would not be intimidated by the process or by me. However, it quickly became apparent that most of my participants were initially extremely nervous about the interviews. I think much of this was a reflection of my perceived out-group status. On reflection, I think that at times I perceived my out-group status to be less significant than my participants did, as they may have been unaware of the nature of our training, and so did not expect this to cause them anxiety. However, I am confident that I used my clinical skills to appropriately negate my participants' anxiety and so increase their acceptance of me as a perceived out-group researcher, as evidenced in the richness of data collected.

Although I have never questioned the importance of the field I am researching, through the interview process I remember oscillating between feeling that my research questions were stupid/ obvious and being really proud of the study that I had co-created. On reflection, I think this was because within the process of our conversations my participants were creating their subjective understandings as they spoke and that, as is consistent with IPA, their lived-experiences were being constructed within conversations. As a consequence, the tensions and conflicts experienced by participants were reflected in our

conversations, which were often filled with contradictions and so difficult for me to follow at times. At a deeper level, I have also reflected on the difficulties inherent in the nature of the questions I had asked my participants. Ultimately, not only was the root of my research questions asking participants to share their understanding of what they perceived made a good life, but I was also asking them about their perceptions of this for a group of other people.

Like many of my friends also conducting IPA, at points in the interview process I struggled with my role as a researcher rather than as a trainee clinical psychologist. As discussed, I had not expected the level of affect participants shared with me and as such I do not think that I gave enough consideration to the impact this may have on me (considering my dual role) in the early stages of the research. I was very fortunate and grateful that participants were so open in sharing their difficult experiences with me. At points I felt the need to go into 'therapist mode' by thought challenging and reframing, but was mindful that the participants had consented to research and not therapy, and so was conscious to remain within the researcher role. In future research endeavors, I will always give consideration to this dynamic within the research regardless of whether I perceive it to be significant to that particular context or not.

Analysis and write-up

With hindsight, data analysis was definitely the most enjoyable part of the research for me, as well as the most stressful! I thoroughly enjoyed the process of interpreting the data and discovering meaningful themes and sub-themes as they emerged, however remember feeling that there was not enough time to immerse myself in the data as I would wish. Fortunately, my concerns about a lack of time were not accurate, and in fact the process naturally reached write-up without feeling premature or rushed. However, the experience has caused me to reflect upon my own perfectionism, which I honestly did not know ran quite so deeply!

By my nature as a novice qualitative researcher, I was unfamiliar with most of the unique aspects and terminology of the methodology until I encountered it within my own research. As such, I have been acutely aware that throughout the whole research process I have had a sense that I have not really known what I was doing until I had done it. At points, I was uncomfortable with this uncertainty and became extremely thorough in my work as a way of trying to manage this. Looking back I am grateful for the high quality supervision my supervisors offered me as this contained my anxiety and the time and has subsequently allowed me the distance to see that this is actually the essence of both qualitative research and systematic literature reviews.

Throughout the process of data collection and analysis I became aware of the number of parallel process playing out within the research. Firstly, participants' accounts of feeling isolated and let down by services in the impending threat of dementia mirrors the literature base regarding the lived experiences of people with dementia themselves. Furthermore, I interpret my own anxiety about finding the right words as reflective of my desire to do my participants accounts justice within my write-up. This desire to find the right words and as such 'do right by them', may be argued to mirror participants' accounts of wanting to find the right words and do right by their patients, demonstrating another parallel process within the research.

Systematic Literature review

I undoubtedly found this the most challenging aspect of the thesis. Initially I was very excited about a number of review questions, only to find that there was not sufficient literature in these fields upon which to conduct a review. With recommendations from my supervisors and after many literature searches, I finally landed on a research question that was appropriate for a review.

Although I was at times frustrated about the quality of literature within the field (and sneaky data-dredging that many papers were guilty of) I was grateful that the process of data extraction and quality assessment ran relatively smoothly.

However, the development of my final question ended up being an on-going struggle that was resolved until well into the write up process. I remember

feeling immensely frustrated when I learned that a meta-analysis was not viable due to the lack of available data after all of the time and effort I had spent on understanding and developing the analysis. I was further disheartened when I had to reconsider the aims of my review by deleting one review question after I had extracted, analysed and written up the findings. I know that this was the right decision as overall, the review was more useful and less confusing (and considerably less lengthy) without the inclusion of the final question, but this was definitely one of the least enjoyable aspects of the research experience for me. However, through this experience I have learned an important skill in being succinct, which will undoubtedly be invaluable as I progress in my career as a clinician and a researcher.

Final Reflections

At this stage in the research I am able to look back over the project as a whole and see how much I have developed as a researcher. With the distance this offers me I can clearly see the amount I have enjoyed conducting the research despite its many challenges, and how immensely proud I am of what I have achieved. The experience of presenting my initial findings at an international conference, and having other professionals genuinely interested in what I had found, has developed my confidence and supported my on-going enthusiasm for the research. I am pleased to have found that I am still just as passionate and interested in my project as I was at the beginning of the process, and

because of the research, have accrued a knowledge base and skill set that will be invaluable as I progress into my career as a clinical psychologist.

I have also learned a lot about myself throughout the process, namely my secret perfectionism and discomfort with uncertainty at times of stress. Through the research process (and the course in general) I have come to understand that there will always be unknowns within research, and to accept that it is identifying and acknowledging these unknowns as far as is possible that makes us good researchers. I have also learned to become more self-compassionate and less self-critical, and that value is to be found in being confident but constructively critical of the work we have done.

Now we are nearing the end of the research process I am surprised to feel myself becoming quite nostalgic about the end of the course. On reflection, I think this is because although it has obviously been a very challenging process, I feel comfortable within a learning environment and ultimately do really enjoy learning. Therefore although I am (I think understandably) apprehensive about shutting the door on my student role, I am looking to the future with an overriding sense of optimism and excitement.