Oxford Doctoral Course in Clinical Psychology

QUALITY OF LIFE, SOCIAL INTERACTION AND COGNITIVE STIMULATION THERAPY: UNDERSTANDING THE PERSPECTIVES OF PEOPLE WITH DEMENTIA AND THEIR CARERS

Amy Murphy

A thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology, validated by the University of Oxford

(Trinity Term)

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Quality of life, social interaction and Cognitive Stimulation Therapy: Understanding the perspectives of people with dementia and their carers

Amy Murphy

Harris Manchester College, University of Oxford, Doctorate in Clinical Psychology (Trinity Term 2017)

Abstract

Dementia is a progressive condition that can profoundly affect the lives of individuals and their families. With no known cure for the disease, the focus has shifted towards promoting well-being and enabling individuals to maintain an optimum quality of life. Understanding of the perspectives of both people with dementia and their carers in this area will provide greater insight into to the provision of dementia care services.

The first paper systematically reviewed the literature exploring the level of agreement between self and family-proxy ratings of patient quality of life. Twenty-six studies were identified for review. The overall level of agreement between ratings was low. Patients were found to consistently rate their quality of life as higher, compared to family-proxy ratings. A range of factors influencing this discrepancy were identified: neuropsychiatric symptoms, cognition, awareness of disease, caregiver burden and stress, relationship factors, activities of daily living and sociodemographic characteristics. The need for further interventions to address these factors is highlighted, as well as implications for future research.

The second paper aimed to explore people with dementia and their carers lived experience of social interaction and communication after attending a Cognitive Stimulation Therapy (CST) group. Interpretative Phenomenological Analysis

revealed six superordinate themes. These captured the difficulties faced by people with dementia in accessing social opportunities and the positive experience of being in the CST group. Several challenges experienced by carers were highlighted and the subsequent impact this had on their emotional well-being. Improvements for people with dementia were noticed in areas of social communication, confidence and emotional wellbeing, with no noticeable change in memory. Carers expressed a desire for on-going support and intervention following the group. These findings have important implications for future research, dementia care and increased carer support.

Acknowledgements

Firstly, I would like to thank all the participants who took part in this study. I am extremely grateful for them taking the time to meet with me and share their experiences. It was a privilege. I would also like to extend this thanks to the group facilitators and staff members who supported this project, for their enthusiasm and persistence with recruitment. Without them this would not have been possible.

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Paper A

What factors influence self and family-proxy ratings of patient quality of life in dementia?

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What factors influence self and family-proxy ratings of patient quality of life in dementia care?

A systematic review

Aging and Mental Health (see Appendix A for journal submission guidelines)

Abstract

Objectives: To review empirical literature and investigate the level of agreement between self and family-proxy ratings of patient quality of life in dementia and to identify predictive factors associated with the discrepancy between ratings.

Method: A systematic search of online databases (PsycINFO, CINAHL, EMBASE and Medline) was conducted using key words linked to ratings of quality of life provided by patients with dementia and their family-proxies.

Results: Twenty-six studies were identified for review. The overall level of agreement between self and family-proxy ratings was low. Patients were found to consistently rate their quality of life as higher, compared to family-proxy ratings. A range of predictive factors relating to this discrepancy were identified; neuropsychiatric symptoms, cognition, awareness of disease, caregiver burden and stress, relationship factors, activities of daily living and sociodemographic characteristics.

Conclusion: There are a wide range of predictive factors associated with the discrepancy in ratings, which affect the perceptions of both self and family-proxy raters. The need for further interventions to address these factors is highlighted, as well as implications for future research.

Key words: dementia, quality of life, family-proxy, self-ratings, discrepancy

Introduction

Dementia

Dementia is a term used to describe a collection of symptoms that are caused by different types of diseases of the brain. The World Health Organization (1992) describes dementia as: A syndrome usually of a chronic or progressive nature in which there is a deterioration in cognitive function beyond what might be expected from normal aging. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied and occasionally preceded, by a deterioration in emotional control, social behaviour or motivation. (p.45).

Quality of life

Quality of life (QoL) is a broad concept and there is currently no agreed definition within the literature (Rabins & Black, 2007). The World Health Organization (1995) define QoL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (p.1405).

QoL has been defined in a variety of different ways depending on the context in which it is used (McSweeney & Creer, 1995). Historically, broader models of QoL have ranged from needs based approaches such as Maslow's hierarchy of human needs (Maslow, 1954), to models based on psychological well-being, happiness and life satisfaction (Andrews & Withey, 1976; Campbell, Converse & Rodgers, 1976). The term refers to an individual's subjective rating or evaluation of their own life in

general, or various different aspects of their life, such as health, social functioning, financial, work or living situation.

QoL and dementia

Dementia can profoundly affect the lives of individuals diagnosed with the condition and as dementia progresses, several difficulties may impact on an individual's QoL. Cognitive difficulties gradually begin to impact on the individual's ability to function on a day to day basis. The individual may find it more difficult to do household tasks such as shopping and managing finances, and may require prompting with personal care. As deficits become more severe, there may be a need for assistance from a caregiver. In addition to cognitive symptoms, individuals may experience behavioural and psychological symptoms of dementia. These symptoms commonly include: agitation, anxiety, depression, apathy, delusions, sleep, appetite disturbance, elation, irritability, disinhibition and hallucinations (Cerejeira, Lagarto & Mukaetova-Ladinska, 2012). Towards the severe to advanced stages of dementia, individuals may be unable to function independently and may require assistance from caregivers in all aspects of daily living, including toileting and feeding (Draper, 2013).

With no known cure for dementia, the focus has shifted towards promoting well-being and enabling individuals to maintain an optimum QoL (Gomez-Gallego, Gomes-Amor & Gomez-Garcia, 2012). The QoL of people with dementia is now considered to be a key major outcome measure in dementia care (Ettema et al., 2005) and has become an important indicator when evaluating the effectiveness of interventions, including pharmacological, behavioural, educational and psychosocial (Banerjee et al., 2009).

QoL theoretical framework

Within the dementia literature, reports of QoL often refer to the conceptual framework by Lawton (1991). Within this framework, Lawton (1991) argues that QoL is a multidimensional concept, which should be assessed subjectively as well as objectively, and be specific to the characteristics of the population being evaluated. The framework includes both subjective and objective domains: behavioural competence, the objective environment, perceived QoL and psychological well-being. Lawton suggested that the objective domain of behavioural competence includes behavioural symptoms, agitation, depression, self-care abilities, meaningful time-use, social engagement and emotional expression. The objective-environment includes physical safety, presence of amenities, privacy and stimulation. These objective domains have been considered as predictors of perceived QoL (Mack & Whitehouse, 2001). Subjective perceived QoL includes spirituality, satisfaction with health care, family, friends, spare time and housing. Finally, psychological well-being includes affect state, happiness, morale and self-esteem.

Measuring QoL in dementia

The assessment of QoL in dementia presents a number of challenges (Rabins & Black, 2007). Several studies have shown that people with mild to moderate dementia can reliably self-report their QoL (Gomez-Gallego et al., 2012; Logsdon, Gibbons, McCurry & Teri, 2002). However, this may be more difficult for people with severe dementia (Streiner, Norman & Cairney, 2015). Varying cognitive deficits can impact on an individual's ability to understand questions or communicate their own subjective states (Logsdon, Gibbons, McCurry & Teri, 1999). Psychological and behavioural symptoms, including depression, agitation, or psychosis, may also impact

on QoL ratings (Ready, Ott, Grace & Fernandez, 2002). Furthermore, as dementia progresses, an individual's judgment about what is important to them in terms of their QoL may also change (Logsdon et al., 1999).

Typically, only patients' self-assessment of their QoL is considered the gold standard, however, the difficulties associated with dementia may lead to services considering their ratings to be less valid. In this situation, caregivers may be called upon to provide additional proxy ratings of patient QoL (pQoL[1]; Arons, Krabbe, Scholzel-Dorenbos, van der Wit & Rikkert, 2013). A proxy rating is when a caregiver communicates information (often from their perspective) on behalf of the person with dementia, either verbally to health care professionals or via a measure such as questionnaire, about the individual's needs, symptoms or effectiveness of treatment.

Self and family-proxy ratings of QoL

Proxy ratings of pQoL can be provided by different sources including family members and paid care staff. However, evidence has shown a discrepancy, as patients typically report higher levels of quality of life compared to proxy ratings, with the reliability of ratings varying according to the relationship of the proxy (Novella et al., 2001).

Proxy-ratings are more often provided by family members, as they are frequently considered to be the primary source of information (Adams, McIlvain, Geske & Porter, 2005). However, as dementia progresses, additional demands may be placed on the carer, which can bring about several stressors that may impact on their ability to accurately rate pQoL. Family caregivers of people with dementia have been found to report higher levels of stress, more depression and anxiety symptoms and

[1] pQoL – refers to 'patient quality of life' from here onwards.

lower levels of subjective well-being and self-efficacy (Pinquart & Sorensen, 2003). This therefore highlights important questions regarding the usefulness of family-proxy reports to inform treatment, as treatment decisions which are based on these reports may not produce the maximum person-centred benefits from the perspective of the person with dementia (Schulz et al., 2013).

The factors that influence self and family-proxy ratings of pQoL remain unclear. To understand these factors, several studies have investigated the influence of clinical variables related to dementia and have included individual factors relating to both the person with dementia and family carers (Conde-Sala et al., 2009; Logsdon et al., 2002). Banerjee et al. (2009) conducted a systematic review of the use of QoL measures in dementia aimed at summarising the predictive and explanatory value of these measures. The findings indicated that higher ratings by the person with dementia may be affected by their level of cognitive functioning, behavioural disturbance, depression and functional disability. In contrast, factors negatively affecting the ratings of paid care staff and family carers included high caregiver burden and depression, and high distress associated with the neuropsychiatric symptoms displayed by the person with dementia. They concluded that further research is needed in this area, including exploring the use of self and proxy ratings of pQoL.

Rationale for review

Despite a growing number of studies investigating factors associated with QoL ratings, most studies in this area have investigated either a limited number of predictive variables, an isolated feature or a specific population group from a particular setting, such as people with dementia living in residential homes, where

ratings of pQoL are often provided by paid care staff (Bosboom, Alfonso, Eaton & Almeida, 2012).

In addition to the review by Banerjee et al. (2009), previous reviews on this topic have investigated the psychometric properties of measures of QoL (Bowling et al., 2013); factors associated with QoL of people with dementia in long term care facilities (Beerens, Zwakhalen, Verbeek, Ruwaard & Hamers, 2013); QoL in different stages of the disease (Ettema et al., 2005); and the effectiveness of pharmacological interventions to improve QoL in dementia (Cooper et al., 2013). While these reviews have identified various clinical variables that may impact on self and proxy ratings of pQoL, they have also included the perspectives of paid care staff. To the author's knowledge, there have been no systematic reviews to date which have investigated factors influencing pQoL ratings, from the perspectives of self and family-proxy raters only.

This review therefore aims to critically evaluate quantitative studies which identify factors associated with the discrepancy in self and family-proxy ratings of pQoL. This review will explore the results of the studies by firstly investigating the level of agreement between self and family-proxy ratings and secondly, identifying the predictive factors associated with the discrepancy. Methodological and ethical issues relating to the studies will then be discussed, as well as implications for clinical practice, policy and research.

Method

Search method

Studies were identified by systematically searching NHS Evidence databases: PsycINFO, CINAHL, EMBASE and Medline, in November 2016 (Appendix B). The following key search terms were used and combined using Boolean operators; *patient, self, carer*, caregiver*, proxy, proxies, relative, family, spouse, daughter, son, child*adj4, "self-report", "proxy-report", rating* measur*adj5, dementia, Alzheimer*, "quality of life", QOL.* The thesaurus was used for each database to expand the search terms relating to *dementia,* which included the following terms; *"dementia with lewy bodies", "vascular dementia", Alzheimer's disease", "frontotemporal dementia", "dementia, vascular", "lewy body disease".* Secondary searches of the reference lists and full texts were conducted to identify any additional studies which were not identified in the initial literature search.

Study selection

This review included studies which met the following criteria:

- The aim of the study was to 1) explore the level of agreement between self and proxy ratings of pQoL and/or 2) explore predictive factors associated with self and proxy ratings
- Studies which used quantitative measures of QoL that were completed by both the person with dementia and a proxy rater
- Studies were included when participants were individuals who had received a diagnosis of dementia of any subtype and any severity
- Studies with participants living in community and residential settings

- Proxy-raters were non-paid family caregivers, including spouses and adult children. Other closely related family members and non-paid friends were included if they were identified as the primary unpaid caregiver and the majority of participants in the study were spouses or adult children
- Studies written in English and published in a peer-reviewed journal

Exclusion criteria

- Studies which included participants with mild cognitive impairment (MCI; patients who did not reach clinical criteria for a diagnosis of dementia or who scored 0.5 on the Clinical Dementia Rating Scale) were excluded if the majority of the sample had MCI and/or if the data was analysed as a whole group sample
- Studies investigating QoL ratings of participants with early onset dementia
- Unpublished papers, dissertations and review papers

Search outcome

The initial electronic search yielded 293 results, of which 103 were duplicates and were removed. The titles and abstracts of 190 articles were screened, which identified 49 potential articles. A further four articles were excluded as they did not meet the inclusion criteria. In addition to the electronic search, references and citations from the papers identified were reviewed manually, as well as a manual search of Google Scholar. This identified a further 17 articles.

From the electronic and manual searches, a total of 62 full text articles were reviewed. Thirty-six of these were excluded as they did not meet the inclusion criteria. A total of 26 articles met the criteria to be included in this review. See Figure 1 for the flow chart of the systematic search.

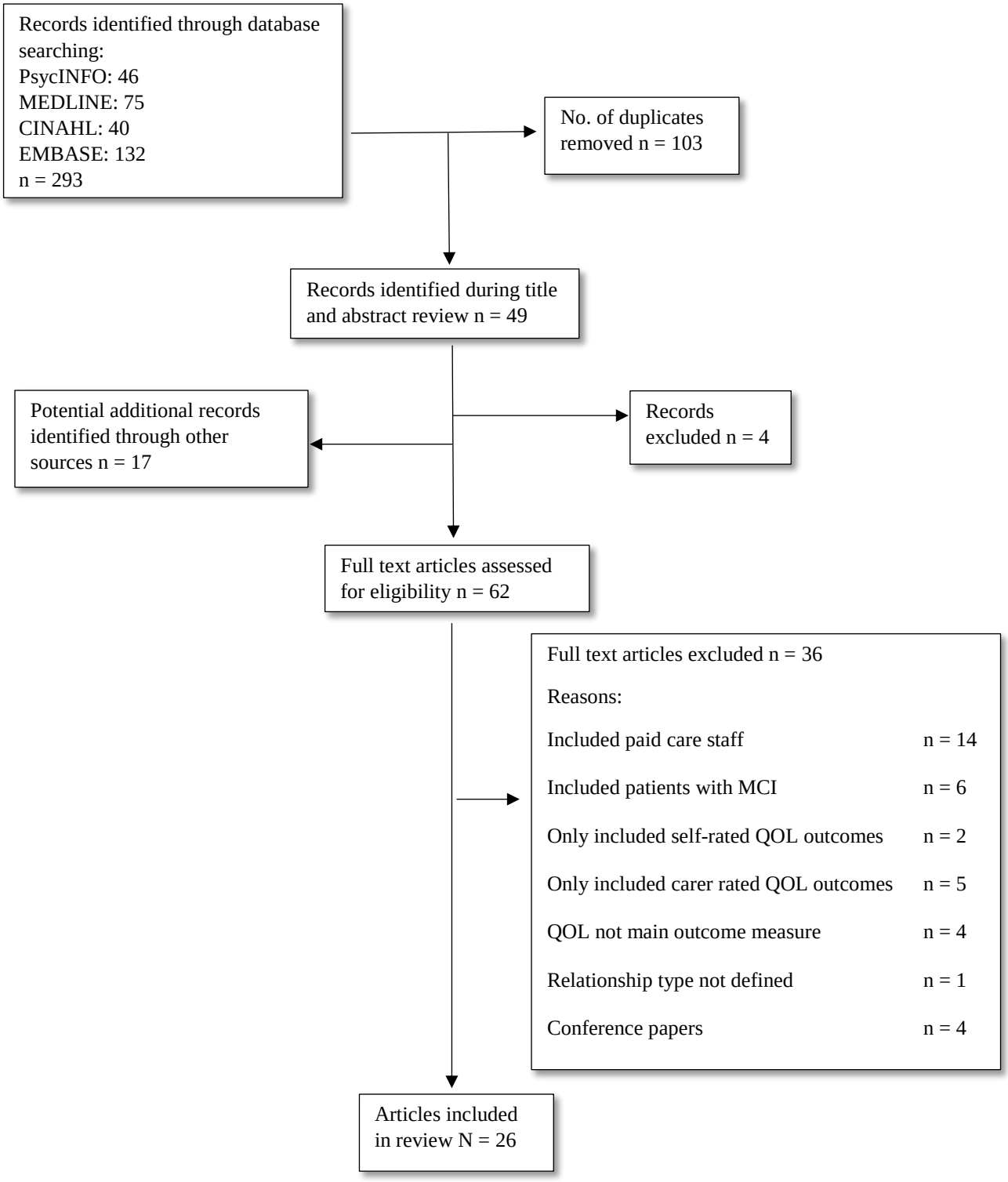

Figure 1: Flow chart of systematic literature search

Data extraction

The findings from this review are presented with consideration of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2015). The included studies were subject to data extraction using a data extraction form developed by the author (Appendix C) and were methodologically appraised using guidance from the Downs and Black checklist (1998).

Results

Overview

Among the 26 eligible studies, 18 had a cross-sectional study design and eight had a longitudinal design. The data relating to patient and family caregiver dyads was collected from 21 of the 26 studies and included 4,044 dyads. The main caregivers were spouses and adult-children, with 11 studies including other family members or friends.

Study characteristics

The characteristics of the individual studies included in this review are presented in Table 1. A summary of the main findings from each study are presented in Table 2.

Table 1. *Demographic and study information of individual studies*

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Andrieu et al. (2016) **France**	Longitudinal (2-year follow-up) Community Recruited from an RCT study	Mild to moderate AD only	574 dyads	Age (79.6 years, s.d 5.9). MMSE (19.5, s.d 3.9). 66.6% female	Age (64.1 years, s.d 13.7). 66.2% female	Spouse (47.2%), child (44.6%). 8.2% other (not stated) [a]	Looked after by a well-identified informal caregiver	QoL-AD, MMSE, ADL, IADL, NPI, MNA, ZBI
Bosboom, Alfonso, Eaton and Almeida (2012) **Australia**	Cross-sectional Community Recruited from memory clinics and media advertisements	Mild to moderate AD only	80 dyads	Age (78.3, s.d 7.9, 56-92). 65% women. 75% lived with carer. Education (10.2, s.d 2.2)	Age (66.6 years, s.d 14.5). 57.5% women	61.4% spouse, 38.6% other family member [a]	Family carer had to have regular contact with the patient - at least 3 times a week over past one year	QoL-AD (patient and from two carer perspectives - carer-carer and carer-patient). CAMCOG-R, HADS, IQCODE, GRAD, AQ, ADL, IADL, NPI
Bosboom et al. (2013) **Australia**	Longitudinal (18-month follow-up) Community Recruited from mental health and aged care services	Mild to moderate AD only	80 dyads	Age (78.3, s.d 7.9, 56-92). 65% women. 75% lived with carer. Education (10.2, s.d 2.2) 47 completed follow-up assessments	Age (66.6 years, s.d 14.5). 57.5% women. 47 completed follow-up assessments	61.4% spouse, 38.6% other family member [a]	Family carer had to have regular contact with the patient - at least 3 times a week over past one year	QoL-AD, CAMCOG-R, HADS, IQCODE, GRAD, AQ, ADL, IADL, NPI

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Bosboom and Almeida (2014) **Australia**	Longitudinal (18-month follow-up) Community Recruited from mental health and aged care services	Mild to moderate AD only	80 dyads	Baseline data from Bosboom et al. (2012;2013) Follow-up data: Age (78.7, s.d 8.2, 62-92). 72.3% female, Education (10.2, s.d 2.1)	Age (66.6 years, s.d 14.5). 57.5% women. 47 completed follow-up assessments	61.4% spouse, 38.6% other family member [a]	Family carer had to have regular contact with the patient - at least 3 times a week over past one year	QoL-AD, BNT30, CVLT, D-KEFS, Digit Span and Digit symbol coding (WAIS-III), NAB, RCFT, VAT, CAMCOG-R, AQ, HADS, IQCODE, ADL, IADL, NPI
Buckley et al. (2012) **USA**	Cross-sectional Community Recruited as part of a dementia progression study and a larger memory study	Mild to moderate	164 dyads	Age (85.60, s.d 5.7), MMSE (19.78, s.d 7.25) education (13.22, s.d 2.86), 76.1% AD, 98.4% 61.4% female	Age (67.18, s.d 14.25), education (14.20, s.d 2.42), 98.8% 75.6% female	39.8% spouse, 49.8% adult child, 10.4% other [a]	Not reported	Single item QoL scale, MMSE, DSRS, NPI, CDRS, CDR, GMHR
Conde-Sala, Garre-Olmo, Turro-Garriga, Lopez-Pousa and Vilalta-Franch (2008) **Spain**	Cross-sectional Community Recruited from a four-year observational study of patients with AD and family caregivers	Mild to severe AD only	236 dyads	Age (77.8, s.d 6.9). 79 males (33.5%) 157 women (66.5%). 32.2% mild, 65.3% moderate, 2.5% severe	Age (59.9, s.d 14.6), 70 men (29.7%) 116 women (70.3%)	43.6% spouse, 46.2% son or daughter	The person who was responsible for helping the patient with daily living activities, both basic and instrumental, as well as for supervising them at home	QoL-AD, CAM-COG-R, MMSE, DAD, NPI, SF-12, CBI

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Conde-Sala, Garre-Olmo, Vilalta-Franch and Lopez-Pousa (2010) **Spain**	Cross-sectional Community Recruited from outpatient Memory and Dementia Assessment unit- part of a four-year observational study of patients with AD and family caregivers	Mild to moderate AD only	251 dyads	Spouse group age (75.3, s.d 7.3), Adult-child group age (79.5, s.d 5.7)	Spouse - age (73.6, s.d 7.4), Adult-child group- age (49.3, s.d 7.2)	55.3% adult children, 44.6% spouse	The person responsible for helping the patient with basic and instrumental needs of daily living as well as providing supervision at home	QoL-AD, CAMDEX, CAM-COG, MMSE, DAD, NPI, SF-36, CBI
Conde-Sala et al. (2014) **Spain**	Cross-sectional Community Recruited from an outpatient Neurology service	Moderate to severe AD only	141 dyads	Age (77.6, s.d 7.2), 58% female, education 27.7% 5-8 years, 40.4% moderate severity, 32.6% moderately severe, 27% severe	Age (63.2, s.d 13.4), 71.6% female, education 40.4% >8 years, 83.7% lived with patient	53.2% spouse, 41.1% son or daughter, 5.7% other relative [a]	The person who was responsible for helping the patient with activities of daily living	QoL-AD, GDS, GDS^2, AQ, MMSE, DAD, NPI, SF-36, ZBI
Conde-Sala, Turro-Garriga, Garre-Olmo, Vilalta-Franch and Lopez-Pousa (2014) **Spain**	Longitudinal (3-year follow-up) Community. Recruited from a four-year observational study of patients with AD and family caregivers	Baseline data from 2008 study - Mild to severe AD only	119 dyads	Age (77.0, s.d 6.7), 63.9% women, education years 60.5% >6 years	Age (61.0, s.d 14.6), 68.9% female, education >6years 79.0%	Husband n=22, daughter n=40, wife n=33, son n=15	The person with main responsibility for helping the patient with activities of daily living.	QoL-AD, CAMDEX, CAMCOG, MMSE, DAD, NPI, SF12, ZBI

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Dourado et al. (2016) **Brazil**	Longitudinal (1-year follow-up) Community Recruited from outpatients	Mild AD only	69 dyads	Age (76.8 s.d 7.3). 28 males: 72 females. Education (8.2 s.d 4.0)	Age (57.5 s.d 13.5). 16 males: 84 females. Education (11.3, s.d 3.3)	Primary family caregiver	The person with the most responsibilities relating to care of patient. Met patient face to face once a week	QoL-AD, MMSE, ASPIDD, CDR, CSDD, PFAQ, NPI, ZBI
Gitlin, Hodgson, Piersol, Hess and Hauck (2014) **USA**	Cross-sectional Community Recruited through media advertisements and mailings through aging and faith based organisations	Mild to moderate	88 dyads	Age (81.7, s.d 8.0 range 56-97), MMSE (17.7 s. d 4.6, range 10-28), 52% female, 76% White	Age (65.8 s.d 12.2, range 38-89), 89% female, 77% White, education 97% >high school	55.7% spouses, 44.3% non-spouse	Caregiver self-defined as having primary care responsibilities, over 21 years old, lived with/in close proximity, provide care > 5 months or more	QoL-AD, Home Environment Assessment Protocol, Health conditions, NPI, TUG, VAS, Faces Pain Scale, PSQI, CES-D, DMS, Conflict Tactics Scale
Gomez-Gallego, Gomez-Garcia and Ato-Lozano (2015) **Spain**	Cross-sectional Community Recruited from day centres	Mild to moderate AD only	138 dyads	68.6% female, Age (72.09, s.d 6.39, range 60-85), education years (4.48, s.d 2.71), MMSE (18.51, s.d 4.29)	70.6% female, Age (58.86, s.d 15.91, range 30-85)	41.2% spouse, 50.9% child	Caregivers were people who provide daily care to the patients and supervise them at home. Non-professional caregivers	DEMQOL, MMSE, GDS^2, NPI, CIR, ZBI, HUI3, CIRS

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Hongisto et al. (2015) **Finland**	Longitudinal (5-year follow-up) Community Recruited from three hospital districts	Very mild or mild AD only	236 dyads	At baseline: 48.7% male, Age (75.6 s.d 6.5), education (7.6, SD 3.3), 54.2% very mild AD, 45.8% mild AD	At baseline: 33.5% male, Age (66.2 s.d 12.0), education (9.9, s.d 3.7)	70.3% spouse, 23.3% child, 6.4% other [a]	Not reported	The 15D, QoL-AD, EQ-VAS, CDR-SOB
Huang, Chang, Tan, Chiu and Weng (2008) **Taiwan**	Cross-sectional Community Recruited from a memory clinic and district health centres	Mild to severe	120 dyads	Age (78.4, s.d 9.13, 49-100), MMSE (18.6 s.d 6.2) 48.3% female, 35.8% college education or above	Age (61.5) >50% college education, 73% female. Mean daily time spent with patient was 15 hours	More than half were spouses	Family caregiver who lives with the patient or contacts the patient every day	QoL-AD (Chinese version), MMSE-T1 (Chinese), SCDR, DBD, WHOQOL-BREF (Taiwan Shorter Version)
Kunz (2010) **Germany**	Longitudinal (2-year follow-up) Community Data collected from a cluster randomised study	Mild to moderate	333 dyads	Age (80.2 s. d 6.7), 67.5% female, MMSE (18.6, s.d 3.8), education 67.6% primary education	Age (59.4, s.d 13.4), 73.3% female	Partner 32.2%, Parent-in-law 59.1% other 8.7 [a]	Supported by a family caregiver (informal)	EQ-5D, Barthel Index, NOSGER, MMSE, CGI-I, BSFC, Charlson Index

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Logsdon, Gibbons, McCurry and Teri (2002) **USA**	Cross-sectional Community Recruited from a patient registry	Mild to moderate AD only	177 dyads	Age (77.2, s.d 7.0), education years (13.4, s.d 3.3), MMSE (16.4, s.d 7.3), 56% male, 90% White, 94% lived with caregiver	Age (69.6, s.d 12.6), education years (13.6, s.d 2.5), 68% female	80% spouses, 9% adult children, 11% other close relative/friend who lived with and cared for patient [a]	An actively involved caregiver who lived with patient or spent every day with them	QoL-AD, MMSE, PSMS, RMBPC, GDS, PES-AD, MOS, SCB, CESD
Logsdon, Gibbons, McCurry & Teri (1999) **USA**	Cross-sectional Community Recruited from a patient registry	Mild to moderate AD only	77 dyads	Age (78.3, s.d 6.1), education (12.7 years, s.d 3.4) MMSE score (17.1, s.d 5.6) 47% female, 86% Caucasian	Age (69.8, s.d 13.8), education (13.7, s.d 2.7), 66% female	76% spouse, 10% children, 14% other close relative or friend [a]	Actively involved carer who lived or spent every day with patient	QoL-AD, MMSE, PSMS, HDRS, GDS, PES-AD
Moon, Townsend, Dilworth-Anderson and Whitlatch (2016) **USA**	Cross-sectional Community No details of recruitment method provided	Mild to moderate	200 dyads	Age (75.88, s.d 9.06, 51-97), 49.50% female, 64% White	Age (64.05 s. d 2.67, 35-91), 79% female, 64% White	56.50% Spouses	Primary family caregiver	QoL-AD, ADL and IADL, DMI, CES-D, DRSS

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Nagpal, Heid, Zarit and Whitlatch (2015) **USA**	Cross-sectional Community Recruited from two service based organisations with caregivers actively seeking help and support	Mild to moderate	111 dyads	Age (76.80, s.d 8.90, 39-90), 53% female, education years (3.20, s.d 1.50), MMSE (20.7, s.d 3.80, 13-26)	Age (61.20, s.d 14.00), 81% female	41% spouses	Primary family caregiver - person most involved in providing assistance and daily care	QoL-AD, 3 items about religiosity, MMSE, RMBPC
Orgeta, Orrell, Hounsome and Woods (2014) **UK**	Cross-sectional, Community Recruited from a study investigating reminiscence therapy	Mild to moderate	488 dyads	Age (77.6, 54-95). 49.6% female. Age leaving school (15.5)	Age (69.8, 23-91), Age leaving school (16.7 years). 67.1% female	71% spouse, 20.7% son or daughter, 8.3% friend/other relative or partner [a]	A person who had regular contact with the patient (4h per week) and was assisting the person with basic and instrumental activities	QoL-AD, CSDD, RADS, BADLS, CDR, EQ-VAS, GHQ-28, RSS
Sands, Ferreira, Stewart, Brod and Yaffe (2004) **USA**	Cross-sectional Community Recruited from previous dementia studies, Alzheimer's Association and volunteers	Mild to moderate	91 dyads	Age (78.7, s.d 7.6). 84% White. MMSE score (19.7). 63% female	No demographic details provided	Over half were spouses, one quarter were daughters	Spouse or relative who either lived with the patient or visited at least 3 times a week. Interviewed caregiver who provided the most care for the patient including ADL, finances and medical care	DQOL, MMSE, GDS, CBQ, PSMS, IADL

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Schiffczyk et al. (2010) **Germany**	Cross-sectional Community Recruited from a cohort of patients applying for a short-term in-patient treatment	Mild to severe AD or mixed dementia only	137 dyads	Age (73.0, s.d 6.7, 52-88), 69.3% male, MMSE (16.9, s.d 6.4, 3-28), 51-mild, 66-moderate, 20-severe	Age (69.6, s.d 7.6, 43-90), 70.1% female	98.6% spouses	Patients living in one household with their primary proxy	GDS, MMSE, Semantic fluency (proxies), BEHAVE-AD, Bayer-ADL, EQ-5D
Schulz et al. (2013) **USA**	Longitudinal (1-year follow-up) Community Recruited from Alzheimer's Disease Research Centre and Alzheimer's Association	Mild to moderate AD only	79 dyads	Age (76.0, s.d 8.5), MMSE (23.1, s.d 3.6), education 42% high school degree or less, 89% White, 66% male	Age (66.5, s.d 11.0), 81% female	73% spouse, 27% non-spouse	Caregiver had to be a family member/partner, 21 years or over, provide minimum of 3 months in home care, speak English and self-define as primary caregiver	QoL-AD, DEM-QOL, suffering scale, MMSE, SF-12, CES-D, ZBI, self-ratings of health
Sousa et al. (2013) **Brazil**	Cross-sectional Community Recruited as part of larger study into awareness of disease, from an AD outpatient unit	Mild AD only	41 dyads	MMSE (21.0, s.d, 3.93), Age (77.3, s.d 7.82), 65.8% female, education (7.9, s.d 4.2), disease duration (4.6, s.d 2.9)	88.8% females, Age (56.0, s.d 11.5), education (12.0, s.d 3.5)	Family caregiver. No other information provided	The individual who was the most responsible for the care of the patient	QoL-AD, MMSE, CDRS, CSDD, PFAQ, ZBI, ASPIDD

Authors, Year, Location	Study design, setting, recruitment method	Dementia Severity	Total sample size (N)	Person with dementia (mean, s.d, range)	Family caregiver (mean, SD, range)	Relationship type	Definition of relationship	Outcome measures
Tay et al. (2014) **Singapore**	Cross-sectional Community Recruited from memory clinics	Mild to moderate	165 dyads	Age (76.8, s.d 6.9), 55.2% women, 95.2% living with spouse or children, MMSE (18.4, s.d 4.2), 127 mild, 38 moderate	Age (58.1, s.d 13.5), 64.2% female 70.3% living with person with dementia	37% spouse, 56.4% adult child, 6.6% other relative [a]	Caregiver had to be primary caregiver and over 21 years of age	QoL-AD, CMMSE (Chinese version), Bristol-ADL, CSDD, NPI, CDR, ZBI, questions about interpersonal relationship
Vogel, Mortensen, Hasselbalch, Andersen and Waldermar (2006) **Denmark**	Cross-sectional Community Recruited from a memory clinic prospective research program	Mild AD only	48 dyads	Age (77.0, s.d 5.8, 62-87) Education (11.3years, s.d 2.9, 6-17years). MMSE (24.9, s.d 2.3)	No information about demographics reported (previously described in Vogel et al, 2004)	62% spouses, 33% children, 5% other family relation [a]	Not reported	EQ-5D, EQ-VAS, QoL-AD, 3-point categorical scale rating anosognosia, MMSE, GDS, DART, Category Cued Recall, FBI

Note. See Appendix D for abbreviations reference list.

[a] Other friend/relative- These studies met the inclusion criteria as they only included informal non-paid caregivers, with the majority of the sample being spouses or adult-children.

Abbreviations: AD = Alzheimer's disease; ADL = Katz Index of Activities of Daily Living (Katz, 1983); ASPIDD = The Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (Dourado et al., 2014); AQ = Anosognosia Questionnaire (Migliorelli et al., 1995); BADLS = The Bristol Activities of Daily Living Scale (Bucks, Ashworth, Wilcock & Siegfried, 1996); Bayer-ADL = The Bayer Activities of Daily Living Scale (Hindmarch, Lehfeld, Jongh & Erzigkeit, 1998); BEHAVE-AD = Behavioural Pathology in Alzheimer's Disease Rating Scale (Sclan et al., 1996); BNT30 = The Boston Naming Test (Graves, Bezeau, Fogarty & Blair, 2004); BSFC = The Burden Scale for Family Caregivers (Grabel, Chiu & Oliver, 2003); CAMDEX = Cambridge Mental Disorders of the Elderly Examination- Revised (Roth et al., 1986); CAM-COG-R= The Cambridge Cognitive Examination – Revised (Vilalta-Franch et al., 1990; Roth et al., 1999); CIR = Clinical Insight Rating Scale (Ott & Fogel, 1992); CBI = Caregiver Burden Interview (Zarit, Todd & Zarit, 1986); CBQ = Caregiver Burden Questionnaire (Zarit, Reever & Bach-Peterson, 1980); CDR = The Clinical Dementia Rating Scale (Morris, 1997); CDR-SB = The Clinical Dementia Rating Scale – Sum of Boxes (Pavlik, Doody, Massman & Chan, 2006); CES-D = Centre for Epidemiological Studies – Depression Scale (Radloff & Teri, 1986); CGI-I = The Clinical Global Impression-Involvement Scale (Guy, 2000); CIRS = Cumulative Illness Rating Scale (Miller et al., 1992); CMMSE = Chinese Mini-Mental State Examination (Sahadevan, Tan & Chan, 2000); CSDD = The Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young & Shamoian, 1988); CVLT-II = The California Verbal Learning Test (Woods, Delis, Scott, Kramer & Holdnack, 2006); DAD = Disability Assessment for Dementia (Gelinas, Gauthier, McIntyre & Gauthier, 1999); DART = Danish Adult Reading Test (Nelson & O'Connell, 1978); DBD = Dementia Behaviour Disturbance Scale (Baumgarten, Becker & Gauthier, 1990); DEMQOL = A Dementia Specific QoL Measure (Smith et al., 2005); D-KEFS = The Delis-Kaplin Executive Function System (Delis, Kaplan & Kramer, 2001); DMI = The 15-item Decision Making Involvement Scale (Menne, Tucke, Whitlatch & Feinberg, 2008); DMS = Dementia Management Scale (Hinrichsen & Niederehe, 1994); DRSS = Dyadic Relationship Strain Scale (Poulshock & Deimling, 1984); DSRS = The Dementia Severity Rating Scale (Clark & Ewbank, 1996); DQOL = The Dementia QoL Questionnaire (Brod, Stewart, Sands & Walton, 1999); EQ-5D = Euro-QoL 5 Domain (Euro QoL, 1990); EQ-VAS = Visual Analogue Scale (EuroQol, 1990); FBI = Frontal Behavioural Inventory (Kertesz, Davidson & Fox, 1998); GDS = The Geriatric Depression Scale (Yesavage et al., 1983); GDS^2 = Global Deterioration Scale (Reisberg, Ferris, de Leon & Crook, 1982); GHQ-28 = General Health Questionnaire (Goldberg & Hillier, 1979); GMHR =The General Medical Health Rating (Lyketsos et al., 1999); GRAD = Guidelines for the Rating of Awareness of Deficits (Verhey, Rozendaal, Ponds & Jolles, 1993); HADS = Hospital and Anxiety Scale (Zigmond and Snaith, 1983); HDRS = The Hamilton Depression Rating Scale (Hamilton, 1967); HUI-3 = Health Utilities Index Mark 3 (Boyle, Furlong, Feeny, Torrance & Hatcher, 1995); IADL = Instrumental Activities of Daily Living (Lawton & Brody, 1969); IQCODE = Informant Questionnaire on Cognitive Decline in the Elderly (Jorm, 1994); MMSE = The Mini-Mental State Examination (Folstein, Folstein & McHigh, 1975); MMSE-T1 = The Mini-Mental State Examination-Taiwan, Version 1 (Liu et al., 1994); MNA = The Mini Nutritional Assessment (Guigoz, Vella & Garry, 1996); MOS = Medical Outcomes Study (Stewart, Hays & Ware, 1988); NAB = The Neuropsychological Assessment Battery (Stern & White, 2003); NOSGER = The Nurses' Observation Scale for Geriatric Patients (Wahle, Haller & Spiegel, 1996); NPI = The Neuropsychiatric Inventory (Cummings, 1997); PES-AD = The Pleasant Events Schedule-AD-Short Form (Teri & Logsdon, 1991); PFAQ = The Pfeffer Functional Activities Questionnaire (Pfeffer, Kurosaki, Harrah, Chance & Filos, 1982); PSQI = Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman & Kupfer, 1989); PSMS = Physical and Instrumental Self-Maintenance Scale (Lawton & Brody, 1969); QoL-AD = The Quality of life in Alzheimer's Disease (Logsdon, Gibbons, McCurry & Teri, 1999); QoL = Quality of Life; RADS = The Rating of Anxiety in Dementia Scale (Shankar, Walker, Frost & Orrell, 1999); RCFT = Rey Complex Figure Test (Meyers & Meyers, 1995); RMBPC = The Revised Memory and Behaviour Problem Checklist (Teri et al., 1992); RSS = Relative's Stress Scale (Greene, Smith, Gardiner & Timbury, 1982); SCB = The Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker & Maiuro, 1991); SCDR = Structured Clinical Dementia Rating Scale (Chen, Chiu, Tang, Lin & Yip, 2003); SF-12 = SF-12 Health Survey (Gandek et al., 1998); SF-36 = SF-36 Health Survey (Ware & Sherbourne, 1992); TUG = Timed Up and Go Test (Podsiadlo & Richardson, 1991); The 15D = The Generic 15D (Sintonen, 2001); VAT = The Visual Association Test (Lindeboom, Schmand, Tulner, Walstra & Jonker, 2002); WAIS – III = Wechsler Adult Intelligence Scale III (Wechsler, 1997); WHOQOL-BREF = (Taiwan Shorter Version; Yao, Chung, Yu & Wang, 2002); ZBI = The Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980).

Table 2. *Main findings from included studies*

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Andrieu et al. (2016)	Caregiver reports were significantly lower than patient self-reports on QoL-AD (p<0.001). ICC were low between 0.08 and 0.49 for individual scores and 0.37 for total score on QoL-AD. Correlations for individual items (r=0.10 to 0.53) and total score (r = 0.38) was low.	Older patient age was significantly associated with overestimation by caregivers. NPI total score and higher caregiver burden associated with underestimation by caregivers. Mean patient self-reported QoL remained stable over 2-year follow-up (p=0.857), caregiver reports significantly declined (p=0.001). Cognitive impairment, number of comorbidities, use of support services or home assistance were all not significant.	Older patient age NPI score - Patient depressive symptoms and apathy Higher caregiver burden Having at least one basic ADL limitation Female patients Patient cared for by adult children
Bosboom et al. (2012)	Self-ratings were significantly higher than carer-carer ratings (p<0.001) and carer-patient perspective (p<0.001). Carer-carer ratings were lower than carer-patient perspective ratings (p<0.001). Acceptable level of agreement between ratings (within +/- 1.96 SD of mean). Patient systematically rated own QoL as lower.	Cognition was not associated with self-ratings but showed a significant positive correlation with both carer ratings. Self-ratings inversely associated with anxiety, depression, NPI and awareness of disease scores. Carer-carer ratings inversely associated with patient depression, and ADL. Carer-patient scores inversely associated with patient depression, ADL and IADL. Demographic factors apart from 'living together' not associated with ratings of pQoL.	Awareness of disease Patient depression Use of anti-dementia medication Cognition – for carer-carer ratings
Bosboom et al. (2013)	The difference between self-reported and carer-rated QoL at 18 months was significant (p=0.001).	Carer ratings significantly declined over time (p = 0.003) but not self-ratings (p = 0.427). Self-ratings inversely associated with anxiety and depression. Changes in carer ratings directly associated with cognition and patient practicing hobbies and inversely associated with awareness, NPI, patient depression and carer burden.	Patient anxiety and depression Awareness of disease Cognition – for carer ratings only Practicing hobbies Number of visits to hospital over the last six months at baseline. Carer burden
Bosboom & Almeida (2014)		There was a significant decline in carer ratings over 18 months (p = 0.003) but not in self-ratings (p =0.427). A decline in episodic memory on CVLT-II free recall was associated with stable/improved self-rated QoL (p = 0.005). But this no longer met the studies criteria for significance after adjusting for differences on the HADS scores. No other changes in cognitive scores were associated with self or carer ratings.	No effect of specific cognitive functions.

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Buckley et al. (2012)	Modest level of agreement. 44% of dyads had congruent ratings, proxy reports lower than self-report for 41% of dyads, proxy reports higher for 15% of dyads. Significant correlation between reports (p = 0.289, p<0.01).	Self-ratings predicted by; better general health, fewer neuropsychiatric symptoms, better functional ratings and higher MMSE scores. Caregiver ratings predicted by; better general health, higher education, fewer neuropsychiatric symptoms, higher MMSE and lower severity of dementia. Gender, NPI and severity scores predicted differences.	Dementia severity Medical comorbidity Cognition Neuropsychiatric symptoms ADL
Conde-Sala et al. (2008)	Patient and caregivers had significantly different perceptions of pQoL (p<0.001, d= 0.628). Patients scored higher on all items except living situation.	Higher self and caregiver ratings for male patients. Lower scores by patients and caregivers when patient scored high on NPI-depression (p<0.001), NPI-apathy, NPI-total score and had greater autonomy in ADL. Higher scores for anxiety and depression for female patients. Higher levels of carer burden associated with worse perceived QoL (r = 0.562; p<0.001). Son/daughter scores significantly lower than spouse caregivers (p=0.001, d = 0.477). Patients with son/daughter caregiver had lower scores (p<0.01, d = 0.418). Higher caregiver burden for son/daughters compared with spouses (p<0.001, d = 0.414). Spouses had poorer physical health than son/daughters (p<0.001, d= 0.715). No significant associations with education or cognitive tests.	Sociodemographic – older patient age, patient gender, married, lived with spouse, lived in own home. Patient depression and apathy Greater patient autonomy in ADL Caregiver burden and mental health Family relationship
Conde-Sala et al. (2010)	Global perception of pQoL for caregivers as a whole was worse than that of patients as a whole (p<0.001, d = 0.66). ICC absolute agreement between caregiver and patient ratings was low, although was slightly higher in the subgroup of spouse caregivers (ICC=0.34) than adult-child subgroup (0.31). ICC consistency was 0.41 and 0.37.	Spouses had more positive perceptions than adult children (p = 0.001, d = 0.46). Patient ratings were more positive in spouse group. The greatest differences were among wife (d=0.90) and daughter caregivers (d=0.67) in ratings of pQoL. Caregivers as a whole, more positive perceptions associated with higher educational level in caregiver (p<0.001), greater functional autonomy in patient (p<0.001). Negatively associated with greater burden (p<0.001), being an adult child (p= 0.015) and depression and apathy in patient (p<0.001). Negative patient ratings associated with having an adult child caregiver and patient depression (p<0.001).	Caregiver education level Relationship type Carer burden

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Conde-Sala et al. (2014)	Significant differences between patient and caregiver rating (p<0.001, d= 1.5). ICC values were low in relation to absolute agreement (ICC=0.18) and consistency (ICC=0.35).	Male caregivers gave higher ratings (p = 0.046, d= 0.38). No significant differences in kinship or living arrangements. Caregivers reported poorer QoL as severity increased, discrepancy increased in line with severity. Higher patient ratings predicted by greater anosognosia and less depression. Higher caregiver ratings predicted by less carer burden, less anosognosia and patient depression, and greater functional ability.	Dementia severity Anosognosia Patient depression Carer burden Greater functional ability
Conde-Sala et al. (2014)	Poor agreement (kappa index weighted/unweighted) for most of the 13 items on the QoL-AD <0.21 and <0.25. Items with highest agreement were mood (k=0.20/0.25) and marriage (k=0.21/0.25). The lowest were living situation (k=0.07/0.07) and memory (k=0.09/0.10). There was a significant discrepancy between patients and caregivers in terms of their scores on the QoL-AD (p<0.001, $n^2 p$ = 0.14).	Differences related to patients' gender and education. Men gave higher ratings than women of their own QoL (p=0.023). Higher ratings for more educated patients (p=0.048). Caregiver differences related to wives and sons giving lower ratings than husbands and daughters (p = 0.046). Female caregivers showed greater decline over the three years. Patient ratings remained stable over time (p = 0.439), caregiver ratings declined (p< 0.001). Patients with higher anosognosia gave higher ratings (p = 0.001), whereas caregiver ratings were lower with greater patient agitation (p <0.001), apathy (p<0.001) and functional deficits (p<0.001), greater burden (p= 0.003) and worse mental health (p = 0.003).	Sociodemographic (gender and education) Anosognosia Relationship Neuropsychiatric symptoms Functional deficits (ADL) Carer burden and mental health
Dourado et al. (2016)		Patient ratings correlated with mood and neuropsychiatric symptoms. Caregiver ratings correlated with patient mood, neuropsychiatric symptoms, and caregiver burden. At follow-up, caregiver ratings changed significantly (p=0.049, d = -0.27), no significant change in patient ratings at follow-up (p= 0.89, d = 0.09). Patient awareness of disease significantly different (p = 0.001). No significant correlations with sociodemographic characteristics, cognitive function, functionality or awareness of disease.	Patient mood Awareness of disease

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Gitlin et al. (2014)	Patient's self-rated QoL was statistically higher than caregivers (p<0.001). 45% of patients rated their QoL higher than caregivers rated it, 37% rated it similarly and only 18% rated it lower than caregivers. Patient self-rated QoL was moderately associated with caregiver ratings (r=0.47, p<0.001).	Lower patient ratings associated with having more unmet assistive/navigation needs (p = 0.028) and health conditions (p= 0.003), pain approached significance (p = 0.055). Lower caregiver ratings associated with more patient health conditions (p = 0.002), greater frequency of behaviours (p< 0.001) and greater use of negative communications (p= 0.002). No significant association with cognitive impairment by either patient or caregiver.	Unmet assistive device/navigational needs Patient health conditions Frequency of patient behaviours Negative communication
Gomes-Gallego et al. (2013)	Significant differences between patient and caregiver ratings on the DEMQOL scores (p=0.025) and in the domain of "feelings" (p=0.001). In 35.5% of dyads the difference in DEMQOL scores was positive with patients scoring higher than caregivers. In 23.18% of dyads the difference was negative with patients scoring lower.	Positive differences (patient ratings higher than caregivers) predicted by NPI Psychosis (r = 0.349), NPI Mood (r = 0.420) and ZBI (r = 0.541), NPI mood explained 30.8% of the total variance). Negative differences (patients gave lower scores) predicted by MMSE (r = -0.570) and pain (r = -0.579), both accounting for 72% of the variance. Anosognosia not found to be a significant predictor.	Patient mood Cognition Carer burden Patient reported pain
Hongisto et al. (2015)		Self-rated QoL did not change significantly over the 5-year follow-up, but the caregiver ratings did change significantly (mean change [95% CI]: -1.88 [-2.15 to -1.60]). Caregiver and self-ratings began to diverge after the CDR-SOB reached 4. The need for assistance in responding to questionnaires also began in the early stages, when CDR-SOB reached 4-6.	Dementia severity
Huang et al. (2008)	Agreement ICC was low 0.17 for whole sample. Agreement ranged from 0.06-0.45 on each item on QoL-AD.	Patient ratings significantly correlated with severity scores (r= -0.21, p = <0.05), but not with MMSE scores or dementia behaviours. Caregiver ratings negatively correlated with patients' behaviour (r = -0.39, p <0.01) and carer distress from these behaviours (r = 0.41, p <0.01). Carer ratings and the discrepancy correlated with caregivers' overall QoL (r= 0.44, p < 0.01; r = -0.29 respectively) and quality of carer-patient relationship (r = 0.34, p<0.01; r= -0.29, p<0.01 respectively). No effect of patient or caregiver age or gender.	Dementia behaviours Carer distress from behaviours Carer overall QoL Patient education level Quality of relationship

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Kunz (2010)	The exact agreement exceeded 50% in all five dimensions of the EQ-5D. The ICC between patient and carer rated EQ-5D utility scores was 0.48. Inter-rater agreement was higher in the mild dementia subgroup (ICC = 0.54) compared to the moderate dementia subgroup (ICC=0.33). In all 5 dimensions, caregivers rated pQoL significantly worse than the patients (p=<0.001).	The higher the subjective burden of caregivers, the higher the discrepancy between ratings (p = 0.03). The greater the ability of patients to perform ADL the greater the agreement (p = 0.001). No significant effect of cognition (p = 0.210). Agreement higher if carer was female and lived in same household, but R-squared was very low (R^2 = 0.09*).*	Dementia severity Carer burden Greater ability to perform ADL Female carer, living in same household
Logsdon et al. (2002)	Agreement between patient and caregiver ratings was low. ICC consistency was 0.28 and ICC absolute agreement was 0.19.	MMSE scores and education not significantly correlated with either patient or caregiver scores. Higher scores related to less impairment in behavioural competence, better psychological status, less impaired physical function and a better interpersonal environment. ADL significantly associated with both patient (r= -0.31) and carer (r = -0.37) ratings. Higher frequency of pleasant events associated with higher patient (r = 0.30) and caregiver (r = 0.44) ratings. Caregiver burden significantly associated with both ratings but more strongly with carer ratings (r = -0.52). Carer depression significantly correlated with carer ratings (r = -0.48) but not with patient ratings.	ADL Pleasant events Carer burden and depression
Logsdon et al. (1999)	Agreement on total score was adequate (r=.40, p>0.001). ICC after one-week interval (test-retest reliability) was acceptable (ICC=0.76 for patients and 0.92 for caregivers).	Self and caregiver ratings correlated with ADL scores (r = -.33, r= -.32, respectively p<0.01), but not IADL. Patient depression correlated most highly for self and carer ratings (r =-.56 and -.40 respectively, p = <0.001). Carer depression correlated with caregiver ratings (r = -.23, p<0.05) but not for patient ratings. Pleasant events correlated with self and carer ratings (r= .30, p= <0.01). Patient education level was the only demographic variable related to ratings. MMSE did not add significant predictive value.	ADL Patient depression Patient education level

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Moon et al. (2016)	Significant discrepancy between patient and caregiver ratings of pQoL (p<0.001). Caregivers reported significantly lower pQoL than the patients (p<0.001). In 36% of dyads, caregivers reported higher scores, or were congruent in responses. Less than two-thirds of caregivers reported lower QoL than patients.	Depression not a significant predictor. Higher relationship strain reported by caregivers related to higher odds of caregivers reporting lower pQoL. No background factors significantly associated with discrepancy. DMI and functional impairment were the two significant predictors. DMI incongruence and relationship strain significantly predicted the caregivers lower report of pQoL.	Functional impairment (ADL) Decision making involvement Relationship strain
Nagpal et al. (2015)	Significant differences between patient and caregiver ratings of pQoL (p = 0.00). Caregivers report lower perceptions of pQoL (M= 2.37, SD = 0.46) than self-ratings (M=2.66, SD = 0.43).	Caregiver stress significantly associated with caregiver ratings and report lower levels of pQoL. One's own report of religiosity is not predictive of one's own perception of pQoL. Significant effects of caregivers' religiosity on patients' perception of their own QoL and for patients' religiosity on caregivers' perceptions of pQoL.	Carer burden Religiosity
Orgeta et al. (2014)		People with mild dementia rated their QoL higher compared with moderate dementia. Higher self-ratings were associated with lower depression and anxiety, higher ADL ability, higher levels of family carer health, lower levels of psychological distress and stress related to caregiving. Higher carer ratings associated with greater ADL ability, lower levels of anxiety and depression.	Dementia severity Patient self-rated health Patient depression and anxiety. Higher ADL ability. Sociodemographic - younger patient age, married, lived with spouse. Caregiver stress
Sands et al. (2004)	Agreement between ratings was low to very low. ICC ranged from 0.06 to 0.33. Patients and caregivers differed significantly in their ratings of pQoL (p<0.001). Caregivers' ratings were lower than the patients.	Patient depressive symptoms (>6) were significantly associated with discrepancy between patient and caregiver ratings, correlations ranging from 0.04 to -0.34. Patients with greater depressive symptoms had lower QoL rated by themselves and caregivers. Ratings were similar for Positive Affect, Negative Affect, Feelings of Belonging and Sense of Aesthetics. When symptoms were <6, caregiver ratings were still significantly lower than patients. Level of caregiver burden significantly associated with discrepancy (p= 0.03), correlations ranging from 0.24 to 0.33. Factors not associated with the discrepancy; patient age, gender, ADL, patient behaviour, caregiver age and gender, type of relationship, living with patient, being a spouse or daughter, number of hours spent caring each week.	Patient depressive symptoms Caregiver burden

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Schiffczyk et al. (2010)		Proxy ratings decreased with increasing severity of dementia. Differences in ratings correlated with MMSE of the patient (r= 0.434, p<0.001), even if the analysis was only for patients with mild AD (r= -0.328, p = 0.019). Proxy ratings were correlated with cognitive and behavioural symptoms of the patient and with proxy mood (r = 0.317, p<0.001) and proxy cognitive abilities (r = 0.209, p <0.01).	Dementia severity Patient cognition and behaviour Proxy mood and cognition
Schulz et al. (2013)	Correlations between patient and caregiver ratings medium to low, highest correlation for the QoL-AD (r=0.354) and lowest for existential suffering scale (r=0.279). Agreement between 1-year follow-up and baseline was generally poor but was moderate for psychological suffering (r=0.340) and the QoL-AD (r=0.381).	Caregivers reported significantly higher levels of patient suffering than reported by patients (p<0.01) and significantly lower pQoL than patients on the QoL-AD (p<0.01) but not for the DEMQOL. At baseline, psychosocial wellbeing and physical health status of the carer explained nearly a quarter of the difference in ratings of suffering (R^2 = 0.226) and QoL-AD (R^2= 0.234). Household income, years living together and race/ethnicity collectively accounted for <5% of differences in ratings. After 1 year, changes in carer physical and mental health status accounted for a significant proportion of the discrepancy in ratings of suffering (R^2= 0.185) and QoL-AD (R^2= 0.153).	Carer burden Carer depression Carer physical health status Household income Years living together Race/ethnicity
Sousa et al. (2013)	Significant differences between self-reported and caregiver QoL-AD scores (p<0.05, d=0.72) for chores (d=1.17), memory (d=0.90) and energy (d=0.82). No significant differences between ratings of physical health, mood, living situation, family, marriage, money, fun, self or life as a whole.	Self-ratings were higher than the caregiver ratings. Self-ratings correlated with level of awareness of disease (r = 0.456, p= <0.001). Caregiver ratings correlated with patient depression (r = -0.513, p = <0.001) and caregiver education (r = 0.394, p <0.05). No correlation with cognitive function, functional activities, caregiver burden, gender, age, education level of patient or disease duration.	Awareness of disease Patient depressive symptoms Education level of caregiver
Tay et al. (2014)	Poor overall agreement on QoL-AD (ICC=0.22, ranging from 0.06 to 0.38) and consistency (ICC=0.27).6.1% of dyads achieved equivalent QoL-AD ratings. Patient-rated QoL was higher than caregiver ratings in 67.2% of dyads.	Patient ratings were significantly higher than carer ratings (p < 0.001). Discrepancy significantly predicted by patient education level (p= 0.03), patient depression (p<0.01) and neuropsychiatric symptoms (p<0.001), explaining 17% of the variance. Dyads with poorer self-perceived QoL scored significantly lower on QoL-AD, with more female patients (p= 0.033), a lower level of carer contribution (p = 0.038) and a trend towards being a non-spouse carer (p= 0.074).	Patient education level Patient depression Patient neuropsychiatric symptoms severity Nature of relationship

Author	Agreement between ratings	Study outcomes	Significant predictors of discrepancy
Vogel et al. (2006)	ICC between patient and informant ratings were low on both the EQ-5D Visual Analogue Scale (r=0.33) and QoL-AD (r=0.33). Significant differences found on QoL-AD (p=0.012) and EQ-VAS (p=0.012).	Caregivers reported significantly higher levels of problems on the EQ-5D across four out of five domains (all except Anxiety and Depression). On the EQ-5D and the QoL-AD, a significant association was found between self and carer ratings for patients with full insight (EQ-5D; r = 0.61, p = 0.02; QoL-AD; r = 0.52, p = 0.049), whereas no significant correlation for patients with impaired insight (EQ-5D; r = 0.26, p = 0.191; QoL-AD; r = 0.25, p = 0.22). Patient behaviour correlated with carer ratings and depression significantly correlated with self and carer ratings. Self-ratings did not correlate with MMSE score. No effect of gender or age.	Awareness of disease Patient behaviour Patient depression

Study Results

Overall level of agreement

Twenty-one studies reported findings relating to the level of agreement between self and family-proxy ratings[2] of pQoL. Eleven studies used Intraclass Correlation Coefficient values (ICC; Lee, Koh & Ong, 1989[3]) to determine the degree of agreement. Overall, the values ranged from 0.06 to 0.54, indicating a poor to fair level of agreement between self and caregiver ratings. Huang et al. (2008) found the agreement between ratings was low, regardless of whether scores on the QoL-AD (Logsdon et al., 1999) were compared for the whole group sample (ICC=0.17), by cognitive level (ICC=0.15 to 0.20) or by severity of dementia (ICC=0.13 to 0.18).

Twenty-one studies used the QoL-AD as a measure of QoL and found that patients and caregivers had significantly different perceptions of pQoL. In all 21 studies, patients rated their QoL higher than caregivers, with three studies reporting medium to high effect sizes (Conde-Sala et al., 2008; Conde-Sala et al., 2014; Sousa et al., 2013).

Two longitudinal studies (Bosboom et al., 2013; Schulz et al., 2013) found that the agreement between ratings on the QoL-AD remained generally poor to moderate after one year, with the difference still being significant at 18-month follow-up. Six studies found that self-rated QoL remained stable over time, with no significant changes, whereas caregiver ratings were found to decrease over time (Andrieu et al., 2016; Bosboom et al., 2013; Bosboom & Almeida, 2014; Conde-Sala et al., 2014; Dourado et al., 2016; Hongisto et al., 2015).

[2] Family-proxy will be referred to as 'caregiver' from here onwards

[3] ICC values for level of agreement. Less than 0.40 = Poor, between 0.40 and 0.59 = Fair, between 0.60 and 0.74 = Good, between 0.75 and 1.00 = Excellent (Lee et al., 1989).

Schulz et al. (2013) found that caregivers reported significantly lower levels of pQoL than the patients on the QoL-AD but not on the DEMQOL (Smith et al., 2005), on which no significant discrepancy between ratings was found. Similarly, Gomes-Gallego et al. (2013) found a modest level of agreement between ratings using the DEMQOL, but found that the agreement between ratings was higher for observable aspects of life such as activities of daily living and memory, compared to the domain of 'feelings', which showed a significant difference between ratings.

Predictive factors associated with the discrepancy in QoL ratings

Neuropsychiatric symptoms

Twenty studies investigated neuropsychiatric factors as a predictor of the discrepancy[4] in ratings. Sands et al. (2004) found that a high number of patient depressive symptoms on the GDS (>6 symptoms) was significantly associated with the discrepancy between ratings. Interestingly, even when patients had less than six depressive symptoms, caregiver ratings were still significantly lower for patients across all five domains on the DQOL (Brod et al., 1999).

Only one study did not find patient depression to be a significant predictor of the discrepancy (Moon et al., 2016). This may be due to their study using a different measure of depression, the CES-D (Radloff & Teri, 1986), whereas all other studies primarily used either the CSDD (Alexopoulos et al., 1988) or the GDS (Yesavage et al., 1983).

Several studies showed that neuropsychiatric symptoms had a stronger association with lower ratings by caregivers, compared to self-ratings (Andrieu et al., 2016; Buckley et al., 2012; Conde-Sala et al., 2010; Dourado et al., 2016; Gomes-Gallego et al., 2013;

[4] Discrepancy refers to the difference in the level of agreement between self and caregiver ratings of pQoL.

Sousa et al., 2013). Three studies found that patient neuropsychiatric symptoms such as agitation, anxiety, irritability, elation, aberrant motor behaviour and appetite disorder were associated with lower QoL scores by caregivers (Conde-Sala et al., 2008; Conde-Sala et al., 2014; Tay et al., 2014). Caregiver ratings were found to be significantly correlated with dementia related behaviours and their frequency (Gitlin et al., 2014; Huang et al., 2008; Vogel et al., 2006). In contrast, Sands et al. (2004) did not find aggression, attention-seeking behaviour or sexually inappropriate behaviours to be associated with the discrepancy, although this study was based on a small sample size and did not report using a validated measure of behaviours. It is also important to note that measures of patient behaviours were only completed by caregivers.

Cognition

Twenty-one studies investigated patient cognition, with mixed results being found. Patient cognition was not found be a significant predictor in 12 studies, all of which used either the MMSE (Folstein, Folstein & McHigh, 1975) or the CAM-COG-R (Roth et al., 1998) as a measure of cognition.

Four studies reported a negative association between lower caregiver ratings and greater patient cognitive impairment (Bosboom et al., 2012; Bosboom et al., 2013; Conde-Sala et al., 2014; Gomes-Gallego et al., 2015), which was significant at 18 and 36-month follow-up (Bosboom et al., 2013; Conde-Sala et al., 2014). However, these findings were not found to be associated with specific cognitive functions, such as poor episodic memory (Bosboom & Almeida, 2014).

Eight studies showed that dementia severity was associated with the discrepancy in ratings. People with mild dementia rated their QoL higher compared to those with moderate dementia (Conde-Sala et al., 2014; Kunz, 2010; Orgeta et al., 2014; Schiffczyk

et al., 2010). Self-rated QoL scores were significantly correlated with scores on the SCDR (Chen et al., 2003) but not with MMSE scores (Huang et al., 2008). Hongisto et al. (2015) found that self and caregiver ratings began to diverge from each other after the CDR-SOB reached 4, in the very mild cognitive impairment stage. Only one study found that neither cognition nor dementia severity was associated with the discrepancy (Tay et al., 2014).

Awareness of disease

Six studies identified impaired awareness of disease (also referred to anosognosia) as a predictive factor. Several studies found an inverse association between anosognosia and self-reported QoL, but not as a predictive factor for caregivers (Bosboom et al., 2012; Sousa et al., 2013; Vogel et al., 2006). Conde-Sala et al. (2014) found that higher anosognosia scores among patients were correlated with better self-perceived QoL, which increased in line with dementia severity on the GDS[2] (Reisberg et al., 1982). In contrast, caregiver ratings decreased as patient anosognosia worsened, especially in the more severe stages on the GDS[2].

Anosognosia was found to be inversely associated with patient depression among self-ratings, especially in the early stages (Conde-Sala et al., 2014). In contrast, for caregivers, there was a direct correlation between anosognosia and patient depression which only reached significance at GDS[2] stage 6. In their longitudinal study, Conde-Sala et al. (2014) found that patient anosognosia was associated with greater cognitive impairment after twelve months. They found no association between anosognosia and caregiver ratings.

Vogel et al. (2006) found the discrepancy between QoL scores for patients and caregivers to not be significantly associated with the presence of anosognosia, but this

finding may be due to the study having low statistical power, which should be considered when interpreting this result. No association was also reported by Gomes-Gallego et al. (2015).

Caregiver burden and stress

Eighteen studies investigated caregiver burden as a predictive factor. The majority of studies reported that increased caregiver burden was related to lower caregiver ratings of pQoL. Orgeta et al. (2014) found that carers who were the sole caregiver and providing more hours of care to the patient, rated their relative's QoL as lower.

Conde-Sala et al. (2010) found that wife caregivers who had a more positive perception of their own QoL, subsequently had more positive perceptions of pQoL. Caregivers with higher levels of depression, burden and poor physical health tended to over-rate patient existential suffering and down rated pQoL (Schulz et al., 2013).

Caregiver stress was also associated with lower self-ratings of QoL (Conde-Sala et al., 2010; Logsdon et al., 2002; Orgeta et al., 2014; Tay et al., 2014). Only one study found no association between caregiver burden and the discrepancy between patient and caregiver ratings (Sousa et al., 2013), however, their study was based on a very small sample size and only included patients in the mild stage of Alzheimer's disease.

Relationship factors

Nine studies explored the association between relationship factors and ratings of pQoL. Several studies found that carer-rated QoL was influenced by whether the caregiver was a spouse or adult-child. Evidence showed that adult-children tended to give lower ratings compared with spousal caregivers (Conde-Sala et al., 2008; Conde-Sala et al., 2010; Orgeta et al., 2014). These results yielded small to medium effect sizes (Conde-Sala et al., 2008; Conde-Sala et al., 2010). In addition, patients who were cared for by

their adult-children were more likely to rate their own QoL as poorer compared to those cared for by their spouses (Andrieu et al., 2016; Conde-Sala et al., 2008; Conde-Sala et al., 2010; Tay et al., 2014). Wife caregivers had the most positive perception of pQoL (*d*= 0.90), while daughter caregivers had the most negative (*d*= 0.67), with large effect sizes reported (Conde- Sala et al., 2010).

Lower caregiver ratings and the discrepancy were associated with higher caregiver and patient relationship strain (Moon et al., 2016), the quality of the carer-patient relationship (Huang et al., 2008), and a lower level of caregiver contribution (Tay et al., 2014). Two studies found no effect of relationship factors (Conde-Sala et al., 2014; Sands et al., 2004).

Activities of daily living

The higher the ability of the patient to perform ADL, the greater the agreement between self and carer ratings (Kunz, 2010; Moon et al., 2016). Having more unmet assistive and navigational needs at home was associated with lower self-rated QoL (Gitlin et al., 2016), while higher carer-ratings at 18 months were associated with the patient still practicing hobbies (Bosboom et al., 2013). Instrumental activities of daily living (i.e. shopping, transport and home management) was shown to be associated more with caregiver ratings, rather than patient ratings (Bosboom et al., 2012; Logsdon et al., 2002).

Four studies found that the correlation between degree of autonomy and QoL-AD scores was significant for both patient and caregivers, although the correlation was stronger for caregivers (Bosboom et al., 2012; Conde-Sala et al., 2008; Conde-Sala et al., 2014; Conde-Sala et al., 2014). In contrast, three studies found no association between the discrepancy in QoL ratings and ADL (Dourado et al., 2016; Sands et al., 2004; Sousa et al., 2013).

Sociodemographic characteristics

Age: The findings relating to age produced mixed results. Two studies found that younger patient age was associated with higher caregiver scores (Conde-Sala et al., 2008; Orgeta et al., 2014). In contrast, Andrieu et al. (2016) found that older patient age was significantly associated with over estimation of QoL by caregivers compared with self-ratings. Three studies found no effect of patient or caregiver age on QoL ratings (Conde-Sala et al., 2014; Huang et al., 2008; Vogel et al., 2006).

Gender*:* Six studies reported findings relating to gender. Three studies reported that female patients were often rated as having lower QoL, by both patients and caregivers (Andrieu et al., 2016; Conde-Sala et al., 2008; Tay et al., 2014). In contrast, one study found that caregivers who were female rated the patient's QoL as higher (Orgeta et al., 2014).

In their three-year follow-up study, Conde-Sala et al. (2014) found that differences in patient ratings continued to be related to gender, with men giving higher ratings than women and a trend towards female caregivers showing a greater decline in their scores over time. Two studies found no effect of patient or caregiver gender on ratings (Huang et al., 2008; Vogel et al., 2006).

Education*:* Seven studies identified education level as a predictive factor. Four studies found patient education level to be associated with the discrepancy in ratings (Conde-Sala et al., 2014; Huang et al., 2008; Logsdon et al., 1999; Tay et al., 2014). More years of education was found to be related to higher self-rated QoL (Logsdon et al., 1999), which remained significant after three-years (Conde-Sala et al., 2014). Three studies found caregiver education level to be a factor (Buckley et al., 2012; Conde-Sala et al., 2010; Sousa et al., 2013). Conde-Sala et al. (2010) found that higher education levels

among caregivers was associated with more positive perceptions of pQoL by both patients and caregivers. Two studies found no effect of education level on ratings (Conde-Sala et al., 2008; Logsdon et al., 2002).

***Health**:* Seven studies found physical health to be associated with the discrepancy between QoL ratings. Bosboom et al. (2012) found a direct association between the use of anti-dementia drugs and QoL self-ratings. Bosboom et al. (2013) found an inverse association between caregiver ratings at baseline and the use of alcohol by the patient and the number of hospital visits or admissions over the past six months.

Pain reported by the patient was also a factor found to be associated with self-ratings. Gomes-Gallego et al. (2013) found that lower patient scores were associated with patient reported pain, which explained 41.2% of the variance. Gitlin et al. (2014) found the association for pain approached statistical significance for self-ratings only (p = 0.055).

Three studies commented on the effect of caregiver physical health (Conde-Sala et al., 2008; Orgeta et al., 2014; Schulz et al., 2013). Conde-Sala et al. (2008) found that spouse caregivers suffered the effects of poor physical health more than caregivers who were sons or daughters, with this difference yielding a large effect size. However, this finding was not associated with the discrepancy between QoL ratings of patients and caregivers. In contrast, Schulz et al. (2013) found that changes in the physical and mental health status of the caregiver accounted for a significant proportion of the discrepancy between self and caregiver ratings at both baseline and one-year follow-up. Only one study which explored health found no association with the discrepancy in QoL ratings (Andrieu et al., 2016).

***Living situation**:* Four studies found that the patient and caregivers' living situation was directly associated with the discrepancy in ratings (Bosboom et al., 2012; Conde-Sala et al., 2008; Kunz, 2010; Orgeta et al., 2014).

Conde-Sala et al. (2010) found that marital status and living situation were associated with self-ratings, whilst living situation was only significant when caregivers were considered as a whole, not separately in the spouse or adult child-caregiver subgroups. On the other hand, Conde-Sala et al. (2014) found no effect of living situation in their longitudinal study.

Race, ethnicity and religiosity: Only two studies reported findings related to race, ethnicity and religiosity. Schulz et al. (2013) found that household income, years living together and race/ethnicity collectively accounted for less than 5% of the difference in ratings. Nagpal, Heid, Zarit and Whitlatch (2015) found that self and caregivers own religiosity did not predict their perception of pQoL. However, the authors did find an interdependent effect, whereby caregivers' religiosity was positively related to self-reports and patient religiosity was negatively associated with caregiver perceptions of pQoL.

Factors correlated with overall QoL ratings

Seven studies found that higher patient depression was negatively associated with poorer self and caregiver ratings (Bosboom et al., 2012; Buckley et al., 2012; Conde-Sala et al., 2008; Conde-Sala et al., 2014; Logsdon et al., 1999; Sands et al., 2014; Tay et al., 2014). The correlation between higher patient depression and poorer QoL scores has been found to occur across all stages of dementia for both patients and caregivers (Conde-Sale et al., 2014). Symptoms of apathy (Andrieu et al., 2016; Conde-Sala et al., 2008) and

anxiety (Bosboom et al., 2013; Orgeta et al., 2014) were also found to be associated with lower ratings of pQoL by both patients and caregivers.

Higher abilities in functional activities of daily living (ADL) was identified as a factor associated with higher self and caregiver ratings of pQoL (Buckley et al., 2012; Conde-Sala et al., 2010; Orgeta et al., 2014; Logsdon et al., 1999; Logsdon et al., 2002). Some studies found that self and caregiver ratings were associated with having at least one basic ADL limitation (Andrieu et al., 2016) and having a higher frequency of pleasant events (Logsdon et al., 2002).

Two studies found that lower self and caregiver ratings were associated with the patient having more medical comorbidities (Buckley et al., 2012; Gitlin et al., 2014). Higher self and caregiver ratings were found when the patient either lived with a spouse (Conde-Sala et al., 2008; Orgeta et al., 2014), lived in the same household as the carer (Bosboom et al., 2012; Kunz, 2010) or the patient and caregiver were married (Orgeta et al., 2014).

Methodological critique of research studies

Participants and demographics

Fifteen studies included participants who were diagnosed with Alzheimer's disease only. One study included participants who were diagnosed with either dementia of mixed type or Alzheimer's type (Schiffczyk et al., 2010). Only nine studies included participants with different subtypes of dementia, however no information was provided regarding the number of participants in each subgroup. Whilst Alzheimer's disease is the most common type of dementia, accounting for approximately 62% of all cases in the UK (Alzheimer's Society, 2014), these results make it difficult to generalise the findings to all subtypes of dementia.

Seventeen studies included participants who were in the mild to moderate stages of dementia. Four studies included participants in the very mild or mild stage only (Dourado et al., 2016; Hongisto et al., 2015; Sousa et al., 2013; Vogel et al., 2006). Only four studies included participants in the mild to severe stages of dementia (Conde-Sala et al., 2008; Conde-Sala et al., 2014; Huang et al., 2008; Schiffczyk et al., 2010). However, the demographic data showed that within these samples, the majority of participants were in the mild to moderate stages of dementia. The longitudinal study by Hongisto et al. (2015) initially only included participants in the very mild or mild stage, but they found that 17.8% of participants had progressed to the severe stage of dementia at the final five-year follow-up. With such small numbers of participants in the severe stage of dementia, it is difficult to generalise the findings to this population.

The majority of studies included participants who were predominantly Caucasian and female. This was evident for demographics relating to both participants with dementia and their caregivers. This therefore affects the generalisability of the findings to other ethnic groups and to males. Two studies did not report demographic details relating to the caregivers (Sands et al., 2004; Vogel et al., 2006).

All studies except three (Buckley et al., 2012; Hongisto et al., 2015; Vogel et al., 2006) provided a clear definition of the role of caregiver in their inclusion criteria. All studies except one (Buckley et al., 2012) detailed the specific diagnostic criteria used to establish eligibility. Disease severity was established using the MMSE (n=16), the CDR (n=4) and the GDS[2] (n=1).

Sampling and recruitment

Overall, there was great variation in the samples. At an individual study level, sample sizes ranged from 41 to 574 dyads, with ten studies having less than 100 dyads in

their sample. Five studies reported results from the same baseline sample of participants. Conde-Sala et al. (2008) and Conde-Sala et al. (2014) used the same baseline data which was followed-up in a longitudinal study; Bosboom et al. (2012), Bosboom et al. (2013) and Bosboom and Almeida (2014) also used the same baseline data which was subsequently analysed in the two longitudinal studies.

Only four studies reported conducting power calculations and achieving adequate statistical power at recruitment (Bosboom et al., 2012; Conde-Sala et al., 2014; Dourado et al., 2016; Huang et al., 2008). The wide range of sample sizes suggests that the studies with larger samples may have increased statistical power, with their results being more generalizable to wider populations. However, studies with smaller sample sizes may be underpowered, suggesting that potential predictors of the discrepancy in QoL ratings may not have reached statistical significance. Six longitudinal studies reported high numbers of attrition rates (Andrieu et al., 2016; Bosboom et al., 2013; Bosboom and Almeida, 2014; Conde-Sala et al., 2014; Dourado et al., 2016; Hongisto et al., 2015). All of these studies acknowledged the impact of attrition rates on statistical power and possible chance associations due to participant bias in the samples. Andrieu et al. (2016) and Conde-Sala et al. (2014) found that participants who dropped out of the studies were of older age, had greater cognitive impairment and neuropsychiatric symptoms, and decreased functional status. Attrition rates could therefore suggest overall higher ratings of pQoL reported by patients and caregivers.

All 26 studies included in this review used a community sample of participants. A limitation of this sample is that it is not considered representative of the population of people with dementia and further excludes people with more severe dementia and/or those who are living in residential care facilities, where QoL ratings are more likely to be provided by paid care staff.

Nine studies used data from a sample of participants who were initially recruited as part of a separate study. For example, Orgeta et al. (2014) used data that was collected as part of the REMCARE study, which investigated the effects of reminiscence therapy in people with dementia and their family caregivers (Woods et al., 2012). Interpretation of these results should be with caution as it is difficult to control for the effect of the trial and additional confounding variables on QoL ratings. Eleven studies recruited through clinical sources such as memory clinics, neurology outpatient departments and day centres. Eight studies recruited volunteers from a number of sources including media advertisements (Bosboom et al., 2012; Bosboom et al., 2013; Bosboom and Almeida, 2014; Gitlin et al., 2014; Sands et al., 2004), the Alzheimer's Association (Sands et al., 2004; Schulz et al., 2013) and aging and faith based organisations (Gitlin et al., 2014), using self-selecting methods which could increase the likelihood of sampling bias. Two studies recruited from existing patient registries (Logsdon et al., 1999; Logsdon et al., 2002). Two studies recruited participants who were either applying for a short-term inpatient stay (Schiffczyk et al., 2010) or seeking help and support (Nagpal et al., 2015), potentially limiting external validity. One study did not report their sampling method (Moon et al., 2016).

Study design

A cross-sectional design was used in 18 out of the 26 studies included in this review. This design does not allow for the assessment of QoL ratings over time and the authors were unable to establish directionality of the effects found. In addition, this design does not enable the use of a control group, which makes it difficult to interpret the meaning and significance of the agreement levels and the discrepancies between ratings. For example, the authors cannot determine whether the discrepancies in ratings are greater than those that would be found in the general population of healthy participants.

Eight studies utilised a longitudinal design, which improves understanding of the dynamics of QoL ratings over time and their predictors. Longitudinal designs enable perceptions to be monitored over time as severity of dementia increases and as caregivers may require greater support and resources. Follow-up time frames ranged from one year to five years. Four studies included follow-ups at only two-time points, compared to the remaining four studies which had longer follow-up times ranging from two to five years and included yearly follow-ups. Having fewer follow-ups can limit the interpretation of the linear or non-linear change in QoL ratings over time.

Measures

Twenty-one studies used the QoL-AD as a measure of self and caregiver-rated pQoL. This measure is widely used in clinical trials and clinical practice, and has been reported to have good reliability and validity (Logsdon et al., 1999; Logsdon et al., 2002). The QoL-AD is also well adapted for the use in longitudinal studies, despite patients' deterioration due to disease progression (Selwood, Thorgrimsen & Orrell, 2005). Two studies used the DEMQOL and despite having good psychometric properties (Smith et al., 2005), this measure contains numerous items relating to behavioural observations of the patient, rather than inferring internal states, which could potentially explain the inconsistent findings reported by Schulz et al. (2013) and Gomes-Gallego et al. (2015). One study used an un-validated single-item measure of QoL (Buckley et al., 2012) which threatens the internal validity of the study and limits the interpretation of results.

Nineteen studies used the MMSE as a measure of patient cognition. This measure is only a brief screening tool for cognitive impairment and is impacted by ceiling and floor effects for detecting change over time, education level, language abilities and culture, often leading to false negative results (Lezak, Howieson, Bigler & Tranel, 2012).

Only six studies used more robust measures of cognition, such as the CAM-COG-R, which could explain the inconsistent findings for cognition.

Two studies used measures which had been translated into Chinese, the MMSE (Huang et al., 2008; Tay et al., 2014) and the WHOQOL-BREF (Huang et al., 2008), increasing the internal validity of the studies.

Statistical analysis

Statistical analyses were largely appropriate across all studies. Pearson correlation was used in 16 studies to analyse continuous variables and indicate the magnitude and direction of the relationship between self and caregiver ratings. Non-parametric Spearman correlation was used in 13 studies. Eleven studies used a two-way mixed model, single measure intraclass-correlation coefficient (ICC) in addition to correlational analysis to investigate the agreement between ratings. Two studies used less conventional analyses; actor-partner interdependence multi-level model, which explored the relationship between religiosity and QoL using the dyad as the unit of analysis (Nagpal et al., 2015) and Bland-Altman plots, which provided a visualization of the level of agreement between ratings, within the ranges of 1.96 SD (Bosboom et al., 2012).

A total of 19 studies used a regression analysis approach which allowed for investigation into the effect of individual variables on the perception of QoL by patients and caregivers. Logistical regression was used in eight studies. Seven studies using a regression analysis were found to have a limited number of predictive variables, which in combination with small sample sizes, makes it difficult to interpret the strength of their results (Bosboom et al., 2013; Gitlin et al., 2014; Logsdon et al., 2002; Moon et al., 2016; Orgeta et al., 2014; Schiffczyk et al., 2010). Bosboom et al. (2013) did not explore the

potential relationship between explanatory variables due to small sample size, which could have resulted in Type II errors.

Six studies completed multiple analyses which may have produced some chance associations (Bosboom et al., 2012; Bosboom and Almeida, 2014; Dourado et al., 2016; Schulz et al., 2013; Sousa et al., 2013; Vogel et al., 2006). To control for Type I errors, only three studies applied a more stringent criterion of <0.01 (Bosboom and Almeida, 2014; Schulz et al. 2013; Vogel et al., 2006).

Only six studies reported completing tests of normality (Conde-Sala et al., 2010; Conde-Sala et al., 2014; Dourado et al., 2016; Huang et al., 2008; Schiffczyk et al., 2010; Sousa et al., 2013). The non-parametric Mann-Whitney-U and Kruskal-Wallis tests were used in seven studies. Student's t-test was used to compare the differences between self and caregiver ratings in 17 studies, or the appropriate non-parametric equivalent was used in five studies. Cohen's D was used as a measure of effect size; however, effect size was only reported in seven studies, making it difficult to determine the magnitude of the significant differences between self and caregiver ratings.

Ethical issues

Eighteen studies reported that ethical approval had been granted for their research. Sixteen studies reported that both patients and caregivers provided written informed consent, with two studies reporting that patients provided verbal assent and written consent was obtained from their carer (Gitlin et al., 2014; Tay et al., 2014). One study reported that caregivers provided proxy consent on behalf of the patient. One study outlined a protocol for if patients were considered to lack mental capacity (Schulz et al., 2013) and one study outlined a protocol if participants became distressed during the

interviews. Anonymity, confidentiality and data protection were referred to in only five studies.

Discussion

This systematic review critiqued studies which identified factors associated with, including predictive factors of, the level of agreement between self and family-proxy ratings of pQoL in dementia.

Firstly, the studies consistently reported that the level of agreement between self and family-proxy ratings was low, with ICC scores ranging from 0.06 to 0.54, indicating a poor to fair level of agreement across all studies. Patients were found to consistently rate their QoL as higher, compared to family-proxy ratings, with studies showing family proxies being more likely to underestimate pQoL. Longitudinal studies found that this level of agreement and the discrepancy between ratings, remained generally poor to moderate, even after 18 months (Bosboom et al., 2012; Schulz et al., 2013). Evidence also suggested that the agreement between ratings was higher for objective domains, such as ADLs and memory, compared to subjective domains such as feelings, which is in line with Lawton's framework of QoL (1991) and the findings that objective domains are more frequently considered as predictors of perceived pQoL (Mack & Whitehouse, 2001).

The studies report a wide range of factors associated with the discrepancy in self and family-proxy ratings. These factors included greater patient neuropsychiatric symptoms (depression, anxiety, apathy and dementia related behaviours), dementia severity, greater patient anosognosia, higher caregiver burden and stress, relationship factors, higher functional impairment in the patient and sociodemographic characteristics.

There was a widely-reported association between the level of caregiver burden and the discrepancy between ratings. Increased caregiver burden and stress was related to lower ratings of pQoL by family caregivers. It was noted that caregiver ratings were significantly influenced by caregiver physical health and emotional well-being, as well as studies showing that adult-children experienced greater levels of burden compared to spouses. One explanation for this relates to the nature of the relationship, with adult-children having more obligations outside of the caring role such as work and their own families, compared to spouses who may be closer to the patient in terms demographic factors and life stage, which may evoke a greater sense of empathy between them (Conde-Sala et al., 2008). In addition, the presence of neuropsychiatric symptoms such as higher patient depression, and higher functional impairment, may imply a greater level of overall impairment in the patient, which may result in increased caregiver burden (Garre-Olmo et al., 2002; Hughes et al., 2014). These findings are also consistent with the outcome of a recent systematic review, which identified these factors to be associated with caregiver burden in informal caregivers of people with dementia living in the community (Chiao, Wu & Hsia, 2015).

The majority of studies found no effect of patient cognition on the discrepancy between ratings, however, dementia severity was found to be significantly associated, with ratings beginning to diverge in the very mild cognitive impairment stage (Hongisto et al., 2015). In addition, longitudinal studies found that self and family-proxy ratings do not decline at the same rate over time. These findings could be due to a decrease in patient awareness, which may leave their ratings unaffected over time (Vogel et al., 2004).

Clinical and policy implications

To ensure the provision of person-centred care (Kitwood, 1997), clinicians need to be aware of the factors influencing both self and family-proxy ratings of pQoL. It is essential for clinicians to be aware of the biases in ratings, to ensure an accurate assessment of pQoL and to inform clinical decisions and appropriate treatment options. This will be particularly important as the disease progresses and patients may become unable to express their QoL in a valid way, and family-proxy ratings may be required (Arons et al., 2013).

It is important for clinicians to treat neuropsychiatric symptoms in patients with dementia, such as depression and anxiety, as these symptoms are often interrelated and can affect the QoL of not only the patient, but also their family caregiver. Clinicians should be aware of the health and wellbeing of the family caregiver and recognise that their assessments of pQoL may be negatively biased due to their own QoL being compromised. This highlights the need for further healthcare provisions and social and emotional support for family caregivers to reduce levels of burden, which may positively impact on both the caregiver and the patient. Collectively, such interventions may improve the accuracy of self and family-proxy rating of pQoL.

Finally, distinctions should be made between family relationships and whether the caregiver is a spouse or an adult-child. These groups should not be treated as a standardised group, but should be considered separately by health professionals when supporting caregivers (Conde-Sala et al., 2008).

Future research

Due to wide variations in sample sizes and questionable statistical power, more robust methodologies, with larger sample sizes should be used in future research. More

effort should be made to include different subtypes of dementia in research, such as Lewy Body dementia or Fronto-temporal dementia, as these were largely excluded from the studies in this review. Findings may present important differences between these populations, such as the nature of the psychological and behavioural challenges they face and their impact on QoL ratings. Studies should also strive to include individuals from different ethnic groups. There is a need for more longitudinal research, to explore the changes in perceptions of QoL over time, with a focus on exploring the differences across all stages of the disease, ranging from MCI to severe dementia.

Limitations of the review

One of the main limitations of this review is that studies which included participants with MCI and early onset dementia were excluded. The findings from these studies may have contributed further towards understanding factors influencing self and family-proxy ratings in the earlier stages of dementia and within a younger age group, where it remains unclear how QoL differs to later-onset dementia (Millenaar et al., 2017). This review only included one group of proxy-raters (family caregivers) and did not consider the perspectives of paid care staff, who more often provide proxy-ratings for people with dementia living in residential care (Bosboom et al., 2012). This may have expanded the research to include residential care settings and patients in the more severe stages of dementia, who were not captured within this review. Finally, this review is limited by the exclusion of the grey literature, such as unpublished data and non-peer-reviewed papers, as well as papers that were non-English.

Conclusion

This review systematically identified and critiqued the quantitative literature exploring factors associated with self and family-proxy ratings of pQoL in dementia.

Findings indicated that people with dementia and their family caregivers have different perceptions of pQoL, with patients consistently rating their QoL as higher compared to family caregivers. Numerous factors associated with this discrepancy were identified. The findings of this review have significant implications for future research, clinical practice and the provision of services for both people with dementia and family caregivers.

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Oxford Doctoral Course in Clinical Psychology

Paper B

How do people with dementia and their carers experience social interaction and communication after attending a Cognitive Stimulation Therapy group?

Amy Murphy

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How do people with dementia and their carers experience social interaction and communication after attending a Cognitive Stimulation Therapy group?

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Abstract

Objectives: The current study aimed to explore people with dementia and their carers lived experience of social interaction and communication after attending a Cognitive Stimulation Therapy (CST) group.

Method: This was an exploratory qualitative study, using semi-structured interviews. Eight dyads, including people with dementia who attended a CST group and their carers were interviewed. The interviews were triangulated and included two individual interviews and one joint interview. All interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Six superordinate themes emerged from the data. These themes related to the difficulties people with dementia experience in accessing social opportunities in the community and the positive experience of being in the CST group. Themes captured the challenges faced by carers in providing social interaction and stimulation outside of the group and the subsequent impact this had on their emotional well-being. At the end of the group, improvements for people with dementia were noticed in areas of social communication, confidence and emotional wellbeing, with no noticeable change in memory. Carers expressed a desire for on-going support and intervention following the group.

Conclusion: The findings highlight key areas for future research and have important implications for dementia care and increased carer support.

Key words: Cognitive Stimulation Therapy, social interaction, communication, people with dementia, carers.

Introduction

Dementia

Dementia is a term used to describe a collection of symptoms that are caused by different types of diseases of the brain. It is characterised by a global cognitive impairment, which leads to a progressive and irreversible decline from a previous level of functioning. Symptoms commonly include poor memory, language and reasoning skills and a deterioration in social and emotional behaviour (American Psychiatric Association, 2013).

In an aging UK population, there are approximately 815, 827 people living with dementia, with one in every 14 people over the age of 65 years receiving a diagnosis. These rates are estimated to increase to over 1 million by 2025 and over 2 million by 2051 (Alzheimer's Society, 2014). With high and increasing prevalence rates, dementia presents a challenge for society and profoundly affects the lives of people and their families. Such challenges have called for action to be taken to improve the provision of dementia care (Department of Health, 2009).

Biopsychosocial framework of dementia

Dementia has predominantly been understood in the context of the medical model, which focuses on understanding the causal mechanisms leading to neuropathological changes in the brain (Clare, 2008). Kitwood (1997) critiqued the medical model and argued that it cannot account for 'excess disability', where level of functioning is worse than the level of cognitive impairment. Kitwood (1997) proposed a dialectical model of dementia, which argues that 'malignant social psychology', such as poor social interactions and care processes that fail to take into account the person's life history and

personality, can reduce self-efficacy and potentially lead to further damaging interactions and deterioration.

Kitwood (1997) argued that if the elements of 'malignant social psychology' can be identified, appraised and overcome, then overall care can be improved and the person with dementia (PWD[5]) will achieve a greater sense of wellbeing and personhood. Kitwood (1997) defined 'personhood' as a "standing or status that is bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect and trust" (p.8). Based on this framework, the concept of 'person-centred care' came into practice, which emphasises communication and relationships, to enhance ways of working with the lived experiences of PWD (Brooker, 2007).

While Kitwood's (1997) model has transformed dementia care, Nolan, Ryan, Enderby and Reid (2002) argued that person-centred care does not fully capture the dynamics of the relationships and interdependencies that underpin caregiving relationships. Kitwood's model focusses on relationships with paid care staff, while the role of members of the wider system such as family caregivers, has been largely overlooked. Family members have been identified as the primary providers of care and support for people living with dementia in the community (Department of Health, 2009). It is therefore important to also understand the role of family caregiving.

Introducing the new concept of 'relationship-centred care', Nolan, Brown, Davies, Nolan and Keady (2006) developed the Senses Framework, which suggests that dementia care is provided within a 'triadic' relationship of giving and receiving care, and by

[5] PWD – refers to both 'person with dementia' and 'people with dementia' interchangeably

including the views of family caregivers, a greater understanding of dementia can emerge.

The impact of dementia on social roles

The quality of an adult's social relationships has been shown to be closely related to their sense of well-being and life satisfaction (Pinquart & Sorensen, 2000). Maintaining close relationships with family and friends has been shown to be important for maintaining higher levels of cognitive functioning (Beland, Zunzunegui, Alvarado, Otero & del Ser, 2005) and in contrast to this, a lack of social interaction has been linked to cognitive decline in later life (Wilson et al., 2007).

The cognitive difficulties associated with dementia can impact on an individual's ability to interact with others and over time, opportunities for social interaction may decrease (Acton, Yauk, Hopkins & Mayhew, 2007). In a qualitative study, Clare and Shakespeare (2004) explored communication between PWD and their family carers and found that PWD were less able to respond as before, and mutuality in the relationship was likely to diminish, resulting in a significant impact on didactic communication. Effective communication, both with and between PWD, has been shown to be imperative in incorporating the PWD's views, overall well-being and maintaining social identity and personhood (Ward et al., 2008).

Psychosocial interventions for people with dementia

Post-diagnostic interventions can be effective in enhancing an individual's sense of personhood and aspects of their quality of life, such as social relationships and well-being. There is currently no known cure for dementia and for services to meet the needs of people diagnosed with the condition, two categories of treatment are offered:

pharmacological treatment, which is underpinned by the biomedical model and includes medication such as acetylcholinesterase inhibitors, or psychosocial 'non-pharmacological' interventions, which reflect a more holistic person-centred approach.

While pharmacological treatments have been found to be effective in slowing cognitive decline and frequently remain the first line of treatment, they are not effective for all types of dementia (Birks, 2006). There is therefore an urgent need to provide non-pharmacological alternatives, such as psychosocial interventions, to address both the cognitive and emotional impact of dementia (O'Brien & Burns, 2011). Psychosocial interventions can positively impact on an individual's cognitive functioning, which in turn, may help to maintain social relationships after a diagnosis and improve quality of life (British Psychological Society, 2016).

Cognitive Stimulation Therapy

Cognitive Stimulation Therapy (CST) is a brief group-based intervention for PWD and is based on the principles of person-centred care (Spector et al., 2003). CST is the only non-pharmacological psychosocial intervention recommended for people with mild to moderate dementia by the National Institute for Health and Clinical Excellence guidelines (NICE, 2006). The guidelines recommend that PWD should be offered the opportunity to participate in a structured cognitive stimulation group, irrespective of pharmacological interventions prescribed to treat the cognitive symptoms.

The manualised CST programme involves 14 sessions, twice weekly, lasting for 45 minutes each. These sessions involve engagement in a range of activities and discussions, and is aimed at general enhancement of cognition, behaviour and social functioning (Clare & Woods, 2004). The key principles of the CST group include using implicit learning rather than explicit teaching and a focus on opinion rather than fact.

These principles aim to reduce the chance of failure by building on a person's strengths and confidence (further details are provided in Appendix E).

CST: The evidence base

Evidence to support the clinical effectiveness of CST has been well established. In a large multi-centred randomised controlled trial (RCT), Spector et al. (2003) found CST participants showed significant improvement on two measures of cognition, the Mini Mental State Examination (MMSE, Folstein, Folstein, & McHugh, 1975) and the Alzheimer's disease Assessment Scale-Cognition (ADAS-COG, Rosen, Mohs, & Davis, 1984), compared to a control group. They also found CST participants to show greater improvements than acetylcholinesterase medication and positive trends towards improvements in communication on the Holden Communication Scale (Holden & Woods, 1995). In addition, they found improvements in quality of life as measured by the Quality of Life-Alzheimer's Disease scale (QoL-AD, Logsdon, Gibbons, McCurry & Teri, 1999).

These findings are corroborated by a Cochrane review (Woods, Aguirre, Spector & Orrell, 2012) and a meta-analysis (Aquirre, Woods, Spector & Orrell, 2013) of RCTs investigating the effectiveness of cognitive stimulation for PWD, which found improvements in cognitive functioning and aspects of quality of life, including social interaction and communication.

Potential mechanisms of change

Spector et al. (2003) suggested a number of possible mechanisms of change. Stimulation has been proposed to improve cognition, which in turn may mediate improvements in quality of life. In addition, the group may work against the excess

disability due to the 'malignant social psychology' of a negative social environment (Kitwood, 1997) by improving self-esteem through social stimulation and encouragement. Furthermore, the group positively reinforces questioning, thinking and interaction with others, objects and the environment. These effects may extend outside the group and participants may also communicate more effectively in daily life.

To explore these potential mechanisms further, Woods, Thorgrimsen, Spector, Royan and Orrell (2006) examined whether the reported improvements in quality of life after attending CST were mediated by changes in either cognition or non-specific group factors, such as the enjoyment of group activities. They found that improvements in quality of life related to relationships, memory, energy levels, and managing chores. They found that these perceived changes were mediated by improvements in cognitive functioning and suggested that cognition-based approaches such as CST have a positive impact on quality of life.

These hypotheses of mechanisms of change are further supported by neuropsychological evidence, which suggests that people who attend CST demonstrate improvements in language domains on neuropsychological tests. Spector, Orrell and Woods (2010) found significant improvements in language after CST, compared to a control group. They found no significant changes in memory and new learning, which is consistent with the CST approach focussing on implicit learning, rather than explicit learning of information. The authors suggested that the constant encouragement of views and opinions on topics during the sessions may have encouraged people to find new ways of expressing themselves verbally. Verbal skills could have been additionally strengthened by CST tasks, such as word association, object recognition and word games.

Similar findings were reported by Hall, Orrell, Stott and Spector, (2013), who suggested that the strong emphasis that the CST group places on verbal communication, thinking and expressing opinions, could enhance the use of the neural pathways responsible for syntax, therefore preserving language as a cognitive function. Improvements in language skills have also been attributed to engagement in homework in between the sessions, which encouraged an increase in meaningful conversations with carers and family members (Chapman, Weiner, Rackley, Hyman & Zientz, 2004).

Qualitative evidence-base for CST

Using Framework Analysis, Spector, Gardner and Orrell (2011) found attending CST to benefit the lives of people with mild dementia in a number of ways. PWD reported feeling more positive, relaxed and confident after attending the group and valued meeting with others who shared common experiences. They also found it easier to talk both within and outside of the group and noticed an increase in fluency in their conversations. A third of carers (informal and paid) also noticed some improvements in verbal skills outside of the group. This provides further support to the findings that CST enhances language function (Spector et al., 2010) which has been shown to also have a positive impact on interactions between the PWD and their carers. In addition, participants also noticed improvements in other areas of cognition, including memory and attention. The study by Spector et al. (2011) is the only qualitative study to date which explores the experiences of PWD and their carers who attended group-based CST. They argue a need for further qualitative research to support the findings of RCTs.

Rationale for current study

Much of the current research on CST has focussed on its effect on cognition, with some literature starting to emerge on the subjective experiences of PWD who attend CST groups and their carers (Spector et al., 2011). The evidence base suggests that attending a CST group can positively impact on language skills and social interaction. However, to date, there has been no known qualitative research specifically exploring the relationships between PWD and their carers and how they experience social interaction and communication after attending CST. The current study therefore aims to build upon the study by Spector et al. (2011), by exploring further the lived experiences of PWD and their carers after attending a CST group.

This study used an Interpretative Phenomenological Analysis (IPA) methodology. This qualitative method focusses primarily on understanding personal lived experience and how people make sense of their experiences (Smith, Flowers & Larkin, 2009). This was considered the most appropriate design as it reflected the overall aim of the study. Gaining the experiences of carers will further enable a greater understanding of dementia in the context of social relationships. Interviewing dyads has previously been used in dementia research (Robinson, Clare & Evans, 2005; Wawrziczny, Antoine, Ducharme, Kergoat & Pasquier, 2014). Further consideration of the IPA epistemology and the rationale for choosing this design can be found in Appendix F.

Aim of study

This study aimed to explore the following research question: How do people with dementia and their carers experience social interaction and communication after attending a CST group?

Method

Design

This was an exploratory qualitative study, using semi-structured interviews to explore the experiences of PWD and their carers after attending a CST group.

Participants

Eight dyads who met the eligibility criteria were recruited. This sample size is in line with the IPA methodology (Smith et al., 2009). Details of participants are presented in the results section.

Inclusion criteria:

- Have a medical diagnosis of dementia of any subtype
- Have a named unpaid carer whom they have at least once a week face to face contact with
- Have mental capacity and be able to give informed consent to take part in the study
- At the start of the CST group, have scored above 11 on the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), or above 10 on the MMSE (Folstein et al., 1975) indicating a mild to moderate severity of dementia[6]
- Have attended more than 7 of the 14 sessions[7] of a CST group that was offered as part of routine NHS care, which had finished within the past 4 weeks
- The PWD can recall that they have attended the CST group

[6] These screening tools were utilised by the participating memory clinics to initially assess for suitability to attend the CST groups and to assess any changes in cognition prior to and after completion of the group.

[7] This criterion was determined by the researcher to ensure that participants had attended an adequate number of sessions to be able to provide a rich account of their experiences before, during and after attending the CST group.

- The PWD must be aged 65 years old and above
- No gender identity inclusion criteria were applied
- Have a sufficient understanding and expression of the English language to take part in the consent and research process
- Can express verbal language and understand verbal communication

Exclusion criteria:

- Have not regularly attended a CST group that was completed within the past 4 weeks (attended less than 7 of the 14 sessions)
- Unable to recall attending the CST group
- Have a diagnosis of a moderate to severe dementia and a score below 11 on the MoCA or below 10 on the MMSE
- Lack mental capacity and are unable to give informed consent
- Have insufficient understanding and expression of English language

Procedure

Recruitment

Participants were recruited from five NHS memory clinic sites across Oxfordshire and Berkshire. Each CST group consisted of approximately 6-12 participants and followed the 14 session CST manual (Spector et al., 2003). Group facilitators identified potential participants who met the inclusion criteria. They offered participants a study pack which contained a covering letter (Appendix G), two information sheets, one for the person attending the CST group (Appendix H) and one for the carer (Appendix I), and an expression of interest form (Appendix J). Participants opted in to the study by returning the expression of interest form to the group facilitators. Participants were then contacted

by the researcher to arrange face to face interviews. All interviews were held at the participants homes.

At the start of the interview process, information sheets were reviewed and participants were informed of their right to withdraw at any time. All participants provided written informed consent (Appendix K). All dyads completed a demographics questionnaire (Appendix L) and were interviewed using a semi-structured interview (Appendix M).

Semi-structured interview

Semi-structured interviews were used to investigate dyads' lived experiences of social interaction and communication after attending a CST group. Semi-structured interviews enabled a rich and in-depth exploration of how dyads made sense of their experiences in the context of their interpersonal relationship and interactions.

The questions were open-ended and explored the dyads shared experiences of social interaction and communication before, during and after they attended the CST group. The semi-structured interviews were triangulated, with each participant being interviewed separately and then jointly with both members of the dyad. This method of interviewing provided the opportunity for the individual and joint experiences to be heard, whilst also allowing for differing perspectives of the same experience to be expressed, with no one perspective being privileged over another. This way of interviewing dyads has been previously used by McIntyre and Reynolds (2012) who explored the experiences of falling by older PWD and their carers. The duration of each interview was approximately 20 to 30 minutes, with the total interview time for each dyad being between 60 to 90 minutes. Interviews were audio-recorded and later transcribed verbatim with all identifiable information removed.

The construction of the interview schedule was influenced by reviewing the existing literature, discussions with research supervisors and the principles of IPA (Smith et al., 2009). The interview schedule was developed to guide the researcher, with prompts to facilitate conversation and explore the participants' experiences in-depth. Further information about the interview schedule development can be found in Appendix N.

A pilot interview was completed first. This ensured the appropriateness of the schedule items by enabling feedback on the questions and their ability to facilitate in-depth discussions about the dyads' experiences. Following the interview, no changes were made to the interview schedule. A more detailed account of the pilot interview can be found in Appendix O.

Data Analysis

The dyads transcripts were analysed in line with the IPA procedure (Smith et al., 2009). As it was important to consider the experiences of both members of the dyad and dyadic processes, the collective transcripts for each dyad were considered as one data item, as described by McIntyre and Reynolds (2012).

The researcher familiarised themselves with the data by reading and re-reading the transcripts for each dyad. The coding process involved the researcher annotating the transcripts with exploratory notes about the semantic content and language use which described key objects of concern for each dyad. These were noted in one margin of the transcript. Interpretive comments were then listed in the other margin (see Appendix P for an example of coding). Objects of concerns were then clustered together into emergent themes and summarised in tabular format (Appendix Q). This coding process was repeated for each individual data item. Emergent themes across all transcripts were then compared and grouped together based on their similarities and differences to form

subordinate themes. This part of analysis also allowed for similarities and differences to be explored between the two perspectives of the dyad, to capture the unique and shared experiences. The emergent themes were then grouped together to form superordinate themes. Participants quotes were regularly revisited to ensure that the themes were representative of all dyads experiences.

Quality Measures

Reflexivity

To maximise the validity of the current study, several steps were taken to increase the transparency of the researcher's position and account for their interpretations of the subjective experiences of individual participants (Smith et al., 2009). A reflective journal was kept from the beginning of the research process, with detailed reflections after each interview and responses which arose for the researcher during the data analysis phase (see excerpts in Appendix R). The researcher also took part in a 'bracketing' interview with a fellow IPA researcher prior to the data collection, to elicit the researcher's own expectations and experiences which may have influenced the data collection process and data analysis (see Appendix S).

Credibility

A systematic audit trail was kept throughout the process to ensure the credibility of the research. The audit trail recorded initial note taking, the development of the interview schedule, service user feedback, emerging themes and the final structure of the report. The data was triangulated during the analysis phase through discussions with the researcher's supervisor, within a peer group of qualitative researchers and workshops with an IPA expert. The research supervisor independently analysed a selection of transcripts and through discussions, consensus on the superordinate and subordinate

themes was established. Further details of credibility procedures can be found in Appendix T.

Ethical Approval

This study received approval from the Oxford Institute of Clinical Psychology Training Research Sub-Committee (see Appendix U). This study was Sponsored by Oxford Health NHS Foundation Trust (see Appendix V). Full NHS ethical approval was obtained from North West- Haydock Research Ethics Committee (see Appendix W) and then local NHS trust sites (Appendix X). Ethical considerations relating to issues of consent, confidentiality, mental capacity, managing distress and risk and data protection were considered (see Appendix Y for details).

Results

Participant demographics

All eight dyads who opted into the study were eligible. Participant demographic information is presented in Table 1. The mean age of the participants who attended a CST group was 86.88 years (standard deviation (SD) = 3.39, range = 83-93). Four participants were diagnosed with Alzheimer's disease, two with mixed type dementia and two participants were unsure of the type of dementia they had been diagnosed with.

The mean age of carers was 65 years (SD = 12.27, range 49-84). All carers had known the PWD for over fifteen years. Five carers were daughters, one son, one wife and one husband. Half of the carers saw the PWD daily, with only one carer seeing them once a week.

Table 1

Summary of participant demographic information

Dyad No.	Person who attended the CST group	Age	Gender	Dementia type	Ethnicity	Length of time since diagnosis	Carer	Age of Carer	Gender	Relationship	Length of time known person with dementia	How often carer sees person with dementia	Ethnicity
1	Annette	83	Female	Alzheimer's disease	White British	>1 year ago	Alan	82	Male	Husband	>15 years	Daily	White British
2	Betty	90	Female	Unsure	White British	>18 months ago	Beth	61	Female	Daughter	>15 years	4 times a week	White British
3	Charles	84	Male	Unsure	White British	>18 months ago	Celia	84	Female	Wife	>15 years	Daily	White British
4	Doris	84	Female	Mixed dementia	White British	6 months to 1 year ago	Danielle	58	Female	Daughter	>15 years	Once a week	White British
5	Edith	88	Female	Alzheimer's disease	White British	6 months to 1 year ago	Elaine	58	Female	Daughter	>15 years	Daily	White British
6	Frank	87	Male	Mixed dementia	White British	6 months to 1 year ago	Fearne	60	Female	Daughter	>15 years	Daily	White British
7	Gladys	93	Female	Alzheimer's disease	White British	Over 1 year ago	Gina	68	Female	Daughter	>15 years	5 times a week	White British
8	Harold	86	Male	Alzheimer's disease	White British	Less than 6 months ago	Henry	49	Male	Son	>15 years	Less than 3 times a week	White British

Overview of themes

Six superordinate themes emerged from the data, each with a structure of two to three subordinate themes (see Table 2). Each superordinate theme will now be discussed and supported by verbatim quotes from all participant-dyads[8]. See Appendix Z and AA for a matrix showing how each member of the dyad contributed to the themes and further illustrative quotes.

[8] To annotate the role of the speaker, (P) will be used for the person who attended the CST group and (C) will be used for the carers, followed by the first line number of the quote.

Table 2

Superordinate and subordinate themes

Superordinate themes	Subordinate themes
1. Barriers to socialising outside of the group *"Socialising is difficult"*	1a. Diminished opportunities to socialise *"I don't meet too many people"* 1b. Physical health *"If it wasn't for my bad leg…"* 1c. Understanding the diagnosis *"Everything changed"*
2. Sharing and feeling supported in the group	2a. Sharing with similar people *"We all do it"* 2b. Support in the group to interact *"Getting people talking and thinking"* 2c. CST as a social opportunity *"To me, it was social"*
3. The family as enablers	3a. Family providing stimulation *"Being reliant on us".* 3b. Focussing on practical tasks *"Oh, that lightbulb needs fixing"*
4. The impact on the carer *"We do the best we can"*	4a. It's effortful *"It still needs an awful lot of effort from me"* 4b. CST as a *"relief"*
5. Noticeable change after CST *"He's much more keen to do things, but his memory is probably worse"*	
6. Keeping it going after CST	6a. The need for more *"It's essential we find something to replace it"* 6b. CST at home *"It would pass half an hour"*

1. *Barriers to socialising outside of the group "Socialising is difficult"*

This superordinate theme was endorsed by all members of the dyads and highlights the difficulties that PWD experience in relation to accessing opportunities to meet with other people and engage in social interaction, prior to attending the CST group.

1a. Diminished opportunities to socialise "I don't meet too many people".

Nearly all members of the dyads endorsed this subordinate theme. People who attended the group talked emotively about experiencing loss and grief, with friends either passing away or losing contact with them over time *"I didn't have very much, most of my contempories have either gone or moved or died, so I didn't have any close relationships with friends anymore"* (Doris, P, 18).

Relationships were described as *"diminished"* (Edith, P, 25), and *"Sterile"* (Doris, P, 22), which suggested that participants considered loss to be an inevitable part of the aging process and acknowledged the difficulties they were experiencing in developing new and fruitful relationships. This was further endorsed by participants describing a lack of opportunity to meet and socialise with people of a similar age:

"*Socialising here is difficult, because it is such a small town…So here, few elderly people, but now of course, everybody has got a car, so we all jump in our cars and drive off into the town, so socialising is difficult. There's not that many people, we know people, know them quite well, passing say hello, how are you? But to socialise, um…"* (Annette, P, 22).

This quote highlights how Annette was feeling isolated in her area and as a result, she felt *"pretty lonely"* (P, 244). These experiences were also described by carers prior to the group *"I think she was very lonely"* (Danielle, C, 210) and the lack

of close friendships of their own *"the only people he was meeting were my friends"* (Fearne, C, 317).

This feeling of isolation was further impeded by practical difficulties in not being able to drive and having to rely on others, which restricted opportunities to go to places where participants could interact with people *"the biggest thing that is affecting my dad is not being able to drive the car […] because he doesn't want to rely on anybody else and when he wants to go somewhere, he's not able to anymore and obviously that's a big change in lifestyle because he was always out and about somewhere, well he gets out now but he's limited to where he can go"* (Henry, C, 233).

1b. Physical health "If it wasn't for my bad leg…". Eleven participants shared a narrative about the impact of physical health difficulties and how they were stopping the PWD accessing social opportunities *"it's just unfortunate that I've got this serious severe arthritis just about the same time, which has handicapped me a lot, I'd have been much more mobile and looked-for places to go if I hadn't been limping everywhere"* (Doris, P, 27). For Doris, the arthritis was an additional problem, which led to her feeling further isolated and reducing her sense of autonomy. In addition, there was a perceived loss of confidence in abilities to engage in interactions which was endorsed by carers "*because she has ambulatory problems and because she fell and broke her elbow on one trip, it took away her confidence and so she's kind of trapped here"* (Danielle, C, 246). Being '*trapped'* was considered to portray a sense of being stuck and imprisoned at home, with access to the community being restricted for participants.

An interesting reflection by carers was the subsequent impact of physical health difficulties on memory and a further decline in cognition due to restricted

stimulation *"she's quite blind as well and of course when they were reading articles and stuff like that […] she can't read, she can't watch telly very easily anymore, so that you know has narrowed her world considerably and I swear that her memory has got worse with the lack of stimulation of not being able to read"* (Elaine, C, 189).

1c. Understanding the diagnosis "Everything changed". Ten participants endorsed this subordinate theme and spoke about how the diagnosis of dementia is viewed by others within society and within the family, and how this impacts on engagement in social interactions.

Three group members spoke about experiencing stigma and the negative reactions of others to the diagnosis:

"if you tell anybody you've got Alzheimer's, there is an immediate sort of slight backwards feel that, oh dear I'm going to have problems here, they won't be able to understand what I'm talking about or I'm going to get up and start dancing, but I don't do that. It's a thing that people don't understand" (Annette, P, 182).

In this account, Annette experienced a sense of unease and uncertainty from others, with people withdrawing from interactions with her because of their negative preconceptions about dementia and a disregard for her sense of personhood. It could also be suggested that Annette experienced a sense of shame about her diagnosis, leading her to avoid disclosing it to anyone, due to a fear of rejection in social situations.

Seven carers spoke about the struggle they had experienced understanding the diagnosis of dementia, describing it as *"quite alien"* (Gina, C, 120), indicating feelings of unfamiliarity and strangeness, with carers also tending to compare the person to how they used to be before the diagnosis *"my father still expects her to be the same person that she always was"* (Danielle, C, 223). Carers spoke about the

challenges they had faced during their interactions with the person *"you are just repeating everything all the time"* (Beth, C, 475), which could suggest feelings of impatience and frustration. Carers also spoke about the unpredictability of how the person will engage during interactions *"he has good and bad days, so some days he's as sharp as a nail and other days he can just be far in his own little world, so it's quite difficult to judge when he's socialising"* (Fearne, C, 244).

2. *Sharing and feeling supported in the group*

This superordinate theme relates to the participants' experience of being in the CST group and the opportunity they had to meet with similar people who were *"in the same boat"* (Edith, P, 58). This theme was mainly endorsed by PWD, with carer perspectives being limited to interactions they had whilst accompanying the person to the group.

2a. Sharing with similar people "We all do it". Ten participants, including seven group members, talked about the importance of being with people who shared common experiences in relation to the diagnosis of dementia *"it was sort of based around something that was common to us all"* (Edith, P, 125), which brought a sense of purpose and familiarity to the group. For several others, it was a new and valued opportunity to talk to people in a group and share their ideas, which they may not have experienced prior to the group *"Well, it was quite interesting because I've always read the paper and had a paper everyday anyway to keep up with the news, so just talking things over, what was happening, it was nice. Different ones were contributing to the talk"* (Betty, P, 69).

For people who attended the group, they felt able to talk about the symptoms of dementia with each other, which helped them feel that they were not alone in their experiences "*Whereas of course with people who have it, and can talk about it, you don't mind talking about it and you can have a laugh about something funny that*

happened" (Annette, P, 142). The use of humour in the group implied that it was acceptable to make mistakes and helped attendees to feel relaxed and comfortable sharing in a group, which was non-stigmatising.

Five PWD reported feeling accepted within the group. For Frank, he feared how the facilitators would perceive him and others in the group *"We thought "what do the people think of us?" you know, when we were asked various things and we just can't remember them, it's a bit embarrassing but, they just sort of accepted that"* (Frank, P, 104).

2b. Support in the group to interact "Getting people talking and thinking".

The role of the facilitators in supporting the group members to interact was acknowledged by three carers and six participants who attended the group. Participants reflected on the directive style of the facilitators and how this enabled the group to think for themselves and promote a sense of autonomy *"they guide us and they sort of don't teach us but they help us. They are not sort of, they prod you and make you think, which is a good thing"* (Annette, P, 203). Frank talked about the style of prompting *"sometimes they need to jog the memory "oh yes" and then we can be away"* (P, 110), and how it *"made it easier for me to think"* (P, 45). Charles talked about how in light of his difficulties communicating, *"they saw me and let me"* (P, 125) which enabled him to feel recognised as a valued member of the group, where he could be himself and was able to contribute in a way that he had not experienced outside of the group.

The benefits of this style of facilitating were acknowledged by both group members and carers. They commented on the structure of the group and how this made CST stand apart from other groups, suggesting some level of insight into the implicit learning style, which enabled group members to interact with each other more, rather than withdrawing from conversations *"I'm sure that the structured form*

of them and the fact that presumably [facilitator] was there sort of letting some people talk and then making other people bring their thoughts to the table, that probably helped her come out of herself a little bit more than if she was just in a group of people chatting and tea and biscuits, because then it's less structured" (Elaine, C, 209).

2c. CST as a social opportunity "To me, it was social". Six group members referred to CST as a social opportunity, which was considered preferential over the content of the group *"I was more interested in the people rather than what we were doing"* (Edith, P, 16), with the group being viewed as place to meet friends *"I just thought it was nice to have a lot of friends"* (Gladys, P, 47) and talk to people *"it was nice, having a little chat"* (Betty, P, 86). One participant thought being in the group was *"like sitting at a dinner party"* (Charles, P, 154), implying that it was a relaxed and enjoyable event, with the social aspect being of greater value.

3. The family as enablers

This superordinate theme was endorsed by all carers except one, and considers the roles they undertook in providing social interaction and stimulation for the PWD outside of the group. It highlights the hands-on and practical focus of their interactions and the role of CST in facilitating carers to engage in more meaningful interactions as a dyad after the group.

3a. Family providing stimulation "Being reliant on us". There was a shared narrative amongst six carers that due to limited opportunities for the PWD to interact with others outside of the group, their relationship was subsequently the main source of interaction and stimulation for the individual *"I just think that she's spending huge amounts of time on her own and when we are here it's a time when she can have stimulation and conversation"* (Danielle, C, 228). Providing cognitive stimulation during interactions was viewed amongst carers as a way to help the PWD *"I*

encourage Annette to do one or two crosswords a day, it helps" (Alan, C, 435) and potentially prevent further decline in their symptoms *"to keep your mind going"* (Henry, C, 359).

3b. Focussing on practical tasks "Oh, that lightbulb needs fixing". Seven carers spoke about the content of their interactions mainly being focussed on meeting the practical needs of the individual, as described by Betty (P) and her daughter Beth (C):

> Beth: *"often when I come up I'm sorting out all the practical things for you aren't I?"*
>
> Betty: *"Yes, doing the paperwork"* (562-565)

Following the group, some carers positively acknowledged the role of CST in helping them to recognise this pattern of interaction outside of the group and to consider engaging with the PWD in a more intentional way "*maybe I've learned something from the group that maybe I should be doing something a little bit more structured, rather than just popping in with the shopping"* (Gina, C, 305).

4. The impact on the carer "We do the best we can"

This superordinate theme relates to the struggle experienced by carers in getting the PWD to the CST group each week. It speaks to the effort and challenges faced by carers and highlights a shift in the relationship dynamics. In addition, it also captures the positive effects of attending the group and the relief that carers experienced.

4a. It's effortful "It still needs an awful lot of effort from me". Five carers spoke in depth about the challenges they faced getting the PWD to the CST group each week. Beth (C, 329) expressed that *"it was horrendous getting her ready in time and the night before was always 'oh no, I don't think I'll go tomorrow', and it was very much like that, so it was quite difficult for me as I'd ring at 7am and then get 'oh*

no, let me roll over and go back to sleep' you know, and half an hour later I would ring again and say, 'are you up?". This suggested that the process of getting her mum to the group required a great deal of energy and effort, which was quite distressing for Beth each week. This struggle was supported by Gina (C, 218) who stated, *"I felt quite a bully making her go every week, but it was fine once she was there".* This suggests that Gina was faced with the dilemma of wanting her mother to attend the CST group because she knew she benefitted from it, but also not wanting to force her or disrespect her wishes.

Interestingly, four carers who were adult-children, compared their interactions with the PWD with that of a child:

"it's just like primary school kids […] I'd pick her up and say, "how was it mummy?" and she'd say, "oh it was lovely, you know we had a chit chat" and I'd say, "what have you discussed?" […] "what was the theme" or "what did you do?", "oh I don't think we did anything particularly today". (Elaine, C, 173).

This illustrates a potential shift in the relationship dynamics and communication style, with the adult-children taking on a parental-role within their relationship and the PWD needing a great deal of encouragement and enabling from the carer, like a child, during their interactions.

In support of the carers views, all eight PWD were aware of the support they received from their carers and despite feeling very grateful for the support, they also worried about being a burden on their carers *"he's absolutely fantastic, but he worries, he worries me terribly because he's lumbered with me"* (Annette, P, 233).

4b. CST as a "relief". Despite the challenges to enable participants to attend, all eight carers described the positive impact in which CST had in providing relief and worry-free time whilst the person attended the group *"Relief I suppose, not*

having to worry about anything he's doing or what he's wanting" (Celia, C, 183). CST also provided a space for carers to engage in other relaxing hobbies and activities, and to feel not solely responsible for providing social interaction, which supported them in managing feelings of guilt *"it meant that I didn't have to have responsibility for her socialising, so I suppose from that point of view, knowing that there was something that lands on a Friday is just wonderful, I can go play golf and have no sort of concerns that she needs company"* (Gina, C, 223).

5. *Noticeable change after CST "He's much more keen to do things, but his memory is probably worse"*

All except one participant endorsed this superordinate theme, which captures participants' expectations prior to attending the CST group and the surprising benefits they noticed in areas of social interaction, confidence and emotional wellbeing after the group.

Nine participants spoke about noticing no tangible change in cognition after the group *"I don't feel that the memory classes did anything to stimulate or regress the advancement in the Alzheimer's"* (Gina, C, 193), which suggests that there was a hope amongst carers at the start of the group that there would be an improvement by the end. This view was supported by Henry who stated, *"I was hoping that he would learn some memory techniques or helping him with his condition in some way, I'm not sure how much it has"* (C, 217). This suggests that some carers may have felt disappointed at the lack of cognitive change the end of the group.

However, there were differing views amongst participants, with several noticing no changes in memory, but describing benefits in other abilities, as described by Charles *"I didn't get anything to make my memory better but I could go there and I could talk and share"* (P, 108). For Charles, to be able to engage in conversations

with others was a benefit which was of more value to him, than being able to remember the content of the group.

Four carers noticed a change in the person's ability to talk and communicate with others *"She was the same lady I took in as when I took her away, except she was talking, she wasn't talking when she went in"* (Alan, C, 582), which was attributed to an increase in confidence talking with others *"his confidence has seemed to come in his speech, he will approach people to talk to them now"* (Celia, C, 230). This was also self-reported by three people who attended the group *"gaining confidence I think, it would perhaps be said that before this I did tend to draw back from communication with people"* (Doris, P, 162).

Confidence also came in the ability of the PWD to complete the group tasks *"we all managed it"* (Frank, P, 41), which suggests that people felt a sense of achievement and reassurance in their own abilities *"you feel as though you are okay, you are going on okay"* (Betty, P, 278). There was also a noticeable change in emotional well-being during the group *"I don't know a time when I wasn't looking happily"* Charles (P, 70), with carers using words such as *"more spark"* (Danielle, C, 298) and *"buzz"* (Fearne, C, 163), which evokes a perception of enthusiasm, interest and reconnection with sense of self, in the PWD.

6. Keeping it going after CST

This superordinate theme relates to the CST group ending and the need from carers for more support and additional groups to replace it, in addition to feelings of grief and loss experienced by the PWD. The final subordinate theme speaks to the idea of carrying on CST at home as a dyad.

6a. The need for more "It's essential we find something to replace it". Six carers talked about the importance of finding another group to replace CST after it

ended. There was a shared narrative about there being a need to find another group to fill the gap in the weekly schedule, to ensure that the PWD were always occupied and doing something *"they've got something more or less every day, so now it's that I'll have to find something, find an activity to replace the clinic, because otherwise they'll just sit and do nothing"* (Fearne, C, 216).

Danielle described *"I think if we can find her an art class or something where we had someone to take her there, someone to interact with her, someone to talk to her* […] *I actually think, that we would keep her longer"* (C, 308). Her account suggests an underlying fear about her mothers' future if the interaction and stimulation stops and views it as a way to keep her alive and well for longer. Both accounts by Fearne and Danielle acknowledged a desire for others to provide the interaction, which would relieve the family from this responsibility and the difficulties faced getting PWD to the groups, as outlined in earlier themes.

In contrast, five PWD expressed a great sadness at the group ending *"I was very very sad to leave it* […]*when they come to the end of it, you go out and get on the bus to take you home and we never see each other again"* (Charles, P, 86). His account suggests feelings of grief and loss at the group ending and the termination of relationships formed.

6b. CST at home "It would pass half an hour". Nine participants endorsed this subordinate theme. Five of the carers felt that they did not have a good understanding of the content of CST and viewed the CST folder, which participants took home with them, as an opportunity to gain insight into the group content and to use it outside of the group *"I would like to [use the folder] because it will give me a better idea of what they were doing or trying to do"* (Celia, C, 342) and also use it as a prompt to enhance the stimulation provided by the carer and also enrich their

interactions with each other *"it's helpful, it's a guide, and it's something to talk about"* (Beth, C, 432).

However, four PWD were less motivated to continue with the content of CST outside of the group *"no thank you, for me it's just paper […] I don't expect to be in their company at all and I can take pleasure of when I was there, but it's ended"* (Charles, P, 340), suggesting that the content of CST was of less value to the person compared with other aspects of the attending the group, such as socialising with others.

Discussion

This study aimed to explore how PWD and their carers experience social interaction and communication after attending a CST group. Six superordinate themes emerged from the data, which will now be discussed, with a focus on current research, theory and clinical implications.

The findings of the first superordinate theme indicate that PWD are experiencing many challenges in accessing social opportunities outside of the CST group. Participants spoke about experiencing feelings of social isolation and loneliness, which is known to be a common experience amongst older adults (Nicolaisen & Thorsen, 2014). These findings link to previous research by Aartsen and Jylha (2011), who found that loss of partners and friends, increased physical disabilities and compromised functional capacity, results in reduced social networks amongst older adults and consequently, the experience of loneliness. A lack of social interaction has also been linked to cognitive decline in later life (Wilson et al., 2007), with social isolation and loneliness being further exacerbated for people who develop dementia due to cognitive and functional difficulties limiting social interaction (Haj, Jardi, Laroi & Antoine, 2016). In addition, participants experience of stigma

correlates with evidence showing how negative stereotypes can result in PWD withdrawing from social interactions (Snyder, 2007), which may lead to further social isolation and greater dependency on family members.

The findings in the second superordinate theme support earlier qualitative research by Spector et al. (2011). They also found that participants in CST groups valued being able to meet with similar people, with whom they shared a common difficulty, in a non-stigmatising and supportive environment. The supportive role of the facilitators was also acknowledged in their study and indicates that PWD may benefit from being in a more structured and facilitator-led group, which helps them to manage the memory and language difficulties associated with dementia (Toms, Clare, Nixon & Quinn, 2015). These findings coincide with theories of therapeutic group processes (Yalom & Leszcz, 2005), whereby attending a CST group may provide a sense of being 'normal' and feeling understood by others. It may also act as a forum to test out new beliefs and coping strategies and provides a safe space to talk about stigmatising experiences. Through meeting and talking with similar people, a PWD may start to feel less isolated and frightened, helping them to process and make sense of their experiences (Cheston & Gilliard, 2003).

The third superordinate theme highlights the role of family caregivers in providing opportunities for social interaction, stimulation and practical support for PWD outside of the CST group. With an aging population and increasing prevalence rates of dementia, family caregivers are more frequently providing services which are expensive for health and social care services to provide (Alzheimer's Society, 2014). This may ultimately result in an overdependence on family members to fulfil basic unmet needs, and subsequently the restructuring of well-established relationships (Schulz & Martire, 2004).

While caring for a relative with dementia can be a positive experience, this new role can also be stressful (Pinquart & Sorensen, 2003), as highlighted in the fourth superordinate theme. The challenges faced by caregivers in this theme relate to the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). This model proposes that stressful experiences as construed through person-environment transactions, which are mediated by caregivers' initial appraisal of the stressor and secondly, their capacity to manage the stress through the selection of environmental resources. In the current study, CST may be considered as an environmental resource, which was reported to be effective in providing relief from the stressful experience of caregiving. However, carers also reported experiencing stress related to getting the PWD to the CST group each week, which indicates that CST has both positive and negative connotations for carers, which clinicians should be mindful of when planning future CST groups.

Within this theme, the current study presents an interesting finding relating to PWD's perception of their carers and their awareness of the impact of caregiving. To the authors knowledge this is a new finding, which would benefit from further exploration in future research.

The findings of the fifth superordinate theme provide additional support for the study by Spector et al. (2011), with PWD feeling better able to talk and share with others in the CST group, with improvements also being noticeable outside of the group by some carers. Both PWD and their carers did not notice any specific changes in memory and new learning, which was also found by Spector et al. (2010) and is consistent with the approach of CST, which focusses on general stimulation and implicit learning rather than explicit learning of information. However, improvements in talking and subsequent social and emotional changes following the group, could be due to CST working against malignant social psychology (Kitwood, 1997) by

improving participants' self-esteem and confidence in their own abilities, through social stimulation and encouragement, which may support PWD to communicate more effectively.

The final superordinate theme relates to the carers desire for ongoing support after CST and the need to find another group to replace it. Carers' fear of further decline in the PWD corresponds with the concept of 'Use it or Lose it' (Swaab, 1991), which proposes that the activation of neurons through stimulation may have a prolonging effect on neuronal function and survival throughout aging and dementia. The finding that carers wanted to continue CST at home, to gain a better understanding of CST and enhance dyadic interactions, relates to the growing evidence base for individual CST (iCST), which is provided by carers at home for 24 weeks, following the standard CST group. Recent research by Orrell et al. (2017) found that iCST enhanced the quality of the caregiving relationship and caregivers' quality of life, however, there was no effect on cognition or quality of life for PWD. One explanation for this could be the lack of social stimulation from participating in a group context, which was found in the current study to be of greater value to PWD than the overall content of the CST group.

Strengths and limitations

This study adds to the existing CST literature and provides new insights into the subjective experiences of PWD and their caregivers. This was the first qualitative study to explore the experiences of social interaction and communication after attending a CST group. The method of triangulating the interviews enabled the perspectives of both PWD and their carers to be included, without favouring one perspective over the other. With the shift towards person-centred care, there is an acknowledgment of the importance of including PWD in research, in order to explore

their life experiences of dementia and how this can best inform the development of dementia services (Minghella, 2012).

While this research focussed on dyadic processes, rather than the ability of PWD to recall the content of the CST groups, the impact of cognitive difficulties during the interview process should be acknowledged. This raises broader questions regarding the reliability of asking people with dementia about their lived experiences, particularly those within the later stages of the disease. It is possible that reduced awareness may impact on an individual's ability to accurately comment on their own experiences and as such, their reflections may differ from objective ratings and the perspectives provided by their carers. Memory difficulties may also impact on an individual's ability to reflect on their experiences of social interaction, and they may potentially confuse this with their experiences prior to the onset of dementia.

Despite gathering a rich and detailed account from a small sample of participants, the qualitative design of this study makes it difficult to generalise the findings (Smith et al., 2009). Generalisability is further affected by the participants being exclusively White British and diagnosed with either Alzheimer's disease or Mixed type dementia, therefore the findings should be interpreted with caution when applying to other ethnic groups or to other subtypes of dementia. Further research including these groups of participants is needed.

Clinical implications

The recognition of carer burden and stress in the current study highlights the need for carers to receive support in parallel to the PWD attending CST. While evidence to support the effectiveness of carer interventions is mixed and plagued by methodological issues (Woods et al., 2012), carers may benefit from attending a carers group, which is run in conjunction with the CST group. Bailey et al. (2016)

found that running a concomitant carers group alongside CST was beneficial for carers in helping them to gain a better understanding of dementia, developing coping skills and having peer support, however more large-scale research is needed.

On-going carer-led psychosocial interventions such as iCST, may further enhance dyadic communication and the caregiving relationship after a CST group (Orrell et al., 2017). However, consideration needs to be given to the impact this may have on the carer, for example, managing other commitments such as their own families and work. This may result in additional burden and stress and subsequently impact on the quality of life of the PWD. In addition, carers may not want to take on the role of 'therapist', given the current findings that carers wanted to preserve their relationship with the PWD and engage in more meaningful interactions. Carers may therefore benefit from extra professional support and training when providing iCST (Leung, Yates, Hamidi & Orrell, 2017) as well as additional social support and respite.

Alongside on-going psychosocial interventions, the findings highlight the need for more social opportunities within the community for PWD, outside of their immediate family networks. The findings suggest that this should be offered within a structured and facilitator-led environment, which supports individuals to manage the memory and language difficulties associated with dementia. Together with initiatives such as Alzheimer Cafés and Dementia Friends, there is a need to educate the wider community about dementia, to foster awareness and a culture which could provide such support and structure in everyday life.

Conclusion

This study provides important insights into the experiences of PWD and their caregivers after attending a CST group. With a focus on social interaction and

communication, findings highlighted a number of barriers to accessing social opportunities outside of the CST group for PWD, as well as several challenges faced by carers. Attending a CST group was portrayed as a positive social experience, which provided relief for carers and noticeable benefits in areas of social communication, confidence and emotional wellbeing for the PWD. Carers expressed a desire for on-going support and intervention following the group. The findings highlight key areas for future research and have important implications for dementia care and increased carer support.

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Appendix A: Guidelines for Aging and Mental Health journal

Instructions for authors

Aging & Mental Health is an international peer-reviewed journal publishing high-quality, original research. All submitted manuscripts are subject to initial appraisal by the Editor and if found suitable for further consideration, to peer-review by independent anonymous expert referees. All peer review is double blind and submission is online via ScholarOne Manuscripts. We encourage the submission of timely review articles that summarize emerging trends in an area of mental health or aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate.

Aging & Mental Health considers all manuscripts on the strict condition that

- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript is not currently under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

Please note that *Aging & Mental Health* uses CrossCheck™ software to screen manuscripts for unoriginal material. By submitting your manuscript to *Aging & Mental Health* you are agreeing to any necessary originality checks your manuscript may have to undergo during the peer-review and production processes.

Any author who fails to adhere to the above conditions will be charged with costs which *Aging & Mental Health* incurs for their manuscript at the discretion of *Aging & Mental Health*'s Editors and Taylor & Francis, and their manuscript will be rejected.

This journal is compliant with the Research Councils UK OA policy.

Manuscript preparation

1. General guidelines

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented without quotation marks.
- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list). Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate

Funding paragraph, as follows: *For single agency grants:* This work was supported by the <Funding Agency> under Grant <number xxxx>. *For multiple agency grants:*
This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.

- Structured Abstracts of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.
- Each manuscript should have 3 to 5 keywords.
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it.
- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to SI units. Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed equations or image files within their manuscript.
- Authors conducting analysis of secondary data of public datasets should ensure that the source is accessible and fully referenced.

2. Style guidelines

Font: Times New Roman, 12 point. Use margins of at least 2.5 cm (1 inch). Further details of how to insert special characters, accents and diacritics are available here.

Title: Use bold for your article title, with an initial capital letter for any proper nouns.

Authors' names: Give the names of all contributing authors on the title page exactly as you wish them to appear in the published article.

Affiliations: List the affiliation of each author (department, university, city, country).

Correspondence details: Please provide an institutional email address for the corresponding author. Full postal details are also needed by the publisher, but will not necessarily be published.

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Appendix B: Search Strategy

Current search strategy: Paper A Nov 2016

	Database(s)	Search Term		
☐	Saved Results		View Results (23)	
☐ 1	PsycINFO	(patient OR self OR carer* OR caregiver* OR proxy OR proxies).ti,ab	View Results (677,750)	Edit
☐ 2	PsycINFO	(relative OR family OR spouse OR daughter OR son OR child*adj4).ti,ab	View Results (395,088)	Edit
☐ 3	PsycINFO	("self-report" OR "proxy-report" OR rating* OR measur*adj5).ti,ab	View Results (165,695)	Edit
☐ 4	PsycINFO	"DEMENTIA WITH LEWY BODIES"/ OR "VASCULAR DEMENTIA"/ OR "ALZHEIMER'S DISEASE"/	View Results (40,813)	Edit
☐ 5	PsycINFO	(Alzheimer*).ti,ab	View Results (47,874)	Edit
☐ 6	PsycINFO	*(4 OR 5)*	View Results (50,844)	
☐ 7	PsycINFO	("quality of life" OR QOL).ti,ab	View Results (49,332)	Edit
☐ 8	PsycINFO	*(1 AND 2 AND 3 AND 6 AND 7)*	View Results (46)	
☐ 17	CINAHL	(patient OR self OR carer* OR caregiver* OR proxy OR proxies).ti,ab	View Results (650,295)	Edit
☐ 18	CINAHL	(relative OR family OR spouse OR daughter OR son OR child*adj4).ti,ab	View Results (161,071)	Edit
☐ 19	CINAHL	("self-report" OR "proxy-report" OR rating* OR measur*adj5).ti,ab	View Results (34,332)	Edit
☐ 20	CINAHL	"FRONTOTEMPORAL DEMENTIA"/ OR DEMENTIA/ OR "DEMENTIA, VASCULAR"/ OR "LEWY BODY DISEASE"/ OR "ALZHEIMER'S DISEASE"/	View Results (37,098)	Edit
☐ 21	CINAHL	(Alzheimer*).ti,ab	View Results (13,549)	Edit
☐ 22	CINAHL	*(20 OR 21)*	View Results (38,947)	
☐ 23	CINAHL	("quality of life" OR QOL).ti,ab	View Results (46,929)	Edit
☐ 24	CINAHL	*(17 AND 18 AND 19 AND 22 AND 23)*	View Results (40)	
☐ 25	EMBASE	(patient OR self OR carer* OR caregiver* OR proxy OR proxies).ti,ab	View Results (3,140,333)	Edit
☐ 26	EMBASE	(relative OR family OR spouse OR daughter OR son OR child*adj4).ti,ab	View Results (1,592,858)	Edit
☐ 27	EMBASE	("self-report" OR "proxy-report" OR rating* OR measur*adj5).ti,ab	View Results (202,879)	Edit
☐ 28	EMBASE	DEMENTIA/ OR "FRONTOTEMPORAL DEMENTIA"/ OR "DEMENTIA WITH LEWY BODIES"/ OR "ALZHEIMER DISEASE"/	View Results (242,289)	Edit
☐ 29	EMBASE	(Alzheimer*).ti,ab	View Results (147,726)	Edit
☐ 30	EMBASE	*(28 OR 29)*	View Results (257,439)	
☐ 31	EMBASE	("quality of life" OR QOL).ti,ab	View Results (303,617)	Edit
☐ 32	EMBASE	*(25 AND 26 AND 27 AND 30 AND 31)*	View Results (132)	
☐ 33	Medline	(patient OR self OR carer* OR caregiver* OR proxy OR proxies).ti,ab	View Results (2,342,451)	Edit
☐ 34	Medline	(relative OR family OR spouse OR daughter OR son OR child*adj4).ti,ab	View Results (1,306,262)	Edit
☐ 35	Medline	("self-report" OR "proxy-report" OR rating* OR measur*adj5).ti,ab	View Results (153,639)	Edit
☐ 36	Medline	DEMENTIA/ OR "ALZHEIMER DISEASE"/ OR "DEMENTIA, VASCULAR"/ OR "LEWY BODY DISEASE"/ OR "FRONTOTEMPORAL DEMENTIA"/	View Results (111,468)	Edit
☐ 37	Medline	(Alzheimer*).ti,ab	View Results (109,229)	Edit
☐ 38	Medline	*(36 OR 37)*	View Results (153,212)	
☐ 39	Medline	("quality of life" OR QOL).ti,ab	View Results (187,793)	Edit
☐ 40	Medline	*(33 AND 34 AND 35 AND 38 AND 39)*	View Results (75)	

Appendix C: Data extraction form

Citation:
Location of study:
Aims and objectives (clearly defined)
Design
Recruitment (recruitment method, source, inclusion/exclusion criteria, sample size, attrition rates)
Dementia participants (age (mean, SD, range), gender, diagnosis, severity, medication/treatment)
Family proxies (age (mean, SD, range), gender, relationship to person with dementia (spouse, children, grandchildren)
Outcome measures (appropriateness of measures, validity and reliability)

Data analysis and results (statistical significance, appropriateness of tests, effect sizes, confidence intervals)
Conclusions and key implications (clinical research, policy)
Critical appraisal (limitations of study, ethical considerations, design, method, analysis, outcome measures, validity and reliability, conclusions)

Appendix D: Abbreviations reference list

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Appendix E- Additional information about Cognitive Stimulation Therapy

The following account is to provide the reader with additional information about Cognitive Stimulation Therapy (CST). This account will summarise the main background literature into cognitive stimulation and the development of CST as a psychosocial intervention for people with dementia. To finish, a brief outline of the content of a typical CST session will be provided.

Reality orientation

One of the first psychosocial interventions was Reality Orientation (Taulbee & Folsom, 1966), which was mainly adopted for use in long-term care settings, for people with moderate to severe dementia. Reality orientation aims to increase the person's orientation to the present situation and enhance cognitive and behavioural functioning through cognition-based activities, social interaction and discussion, alongside the use of cues and prompts to aid memory (Woods, 1999). Reality orientation can be offered either in a continuous 24-hour form or as part of a group and operates by presenting and repeating orientation information. This includes basic personal information, individual calendars and a reality orientation board showing the name of the unit, its location, the day, date, weather and current events. However, reality orientation's clinical application received some criticism during the 1980's and was considered to be applied in a manner which was too rigid and insensitive (Spector, Orrell, Davies & Woods, 2001).

A Cochrane systematic review by Spector, Davies, Wood and Orrell, (2000) evaluated six randomised controlled trials for reality orientation and concluded that reality orientation had both cognitive and behavioural benefits for people with dementia, but identified a need for further large scale multi-centred trials. Since the

development of reality orientation, there has been a growing interest in developing interventions aimed at enhancing cognitive functioning in people with dementia.

Cognitive stimulation

Within the literature, different terms are used interchangeably to describe various interventions aimed at improving cognitive functioning in people with dementia. Clare and Woods (2004) identified three main types of cognition focussed interventions and established the following definitions;

- Cognitive stimulation involves engagement in a range of activities and discussions, usually in a group setting and is aimed at general enhancement of cognition, behaviour and social functioning. This definition includes global cognitive stimulation and reality orientation.
- Cognitive training involves guided practice on a set of standard tasks designed to address particular aspects of cognitive functions, such as memory, language, attention or executive function. The tasks involve a range of difficulty levels to suit the individual's level of ability.
- Cognitive rehabilitation involves individualised interventions that are aimed at addressing personalised goals. The therapist works with the person and his/her family to devise strategies to help achieve these goals.

These definitions highlight a focus on neuropsychological and cognitive rehabilitation for people with dementia. These approaches aim to develop compensatory strategies and specific techniques to facilitate learning. The term 'Cognitive Stimulation' is now widely used to describe psychosocial interventions that encompass approaches that focus on both improving general cognition and facilitating social interactions.

Cognitive Stimulation Therapy

Cognitive Stimulation Therapy (CST) was originally developed by Spector et al. (2003) following a systematic review of the literature, where the authors identified the most beneficial elements of psychosocial approaches such as reality orientation, cognitive stimulation, reminiscence therapy and memory training, and incorporated these into a new CST programme.

The CST programme was designed with the understanding of dementia as proposed by Kitwood (1997). Kitwood highlighted the importance of dementia care and emphasised the need to value people with dementia and those who care for them, as well as treat people as individuals and provide a positive social environment, where the person living with dementia can experience relative wellbeing (Clare, 2008).

Each CST session follows the manualised programme developed by Spector et al. (2003) and runs for 14 sessions. Each session explores topics such as; sound, childhood, food, current affairs, faces/scenes, money, a variety of word, number and object games and the programme ends with a team quiz. The programme includes a reality orientation board, which states personal orientation information, including the group name, which is chosen by the group members. Each session begins with a gentle warm up activity, which is typically a soft ball game. Sessions which focus on themes such as childhood and food, facilitate the natural process of reminiscence but also acknowledge the present day. Each session incorporates multi-sensory stimulation when possible (Spector et al., 2003).

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Appendix F: Further information about Interpretative Phenomenological Analysis (IPA) and rationale for choosing the method

IPA is a qualitative methodology which provides an approach to explore in detail how people make sense of their life experiences (Smith, Flowers & Larkin, 2009). The use of IPA is based on concepts and knowledge derived from three epistemological stances:

1. Phenomenology: The study of experience and how individuals come to understand their experiences in the world.
2. Hermeneutics: This is the theory of interpretation. IPA acknowledges the position of the researcher and the engagement in a 'double hermeneutic', whereby they are trying to make sense of the participant trying to make sense of what is happening to them. As such, the analysis is subject to the researcher's interpretation of the participant's experience.
3. Idiography: This is the study of a particular experiential phenomena, rather than claims being made at the group or population level.

IPA studies are conducted using relatively small sample sizes, which are homogenous and purposively selected. This method of selecting participants enables insight into a particular perspective on the phenomenon which is being studied (Smith et al., 2009).

IPA was considered the most appropriate method for this study for the following reasons. Firstly, there was a lack of qualitative research exploring the experiences of people with dementia and their carers after attending a Cognitive Stimulation Therapy group (CST). This provided an opportunity for an exploratory research study into this area and IPA was considered the most appropriate method to

answer the following research question: How do people with dementia and their carers experience social interaction and communication after attending a CST group?

Secondly, people with dementia have largely been excluded from participating in research and their perspectives were often overlooked until the 1990's (Hubbard, Tester & Downs, 2003). The person with dementia was viewed as a 'disease entity', who was unable to contribute directly to research aiming to understand of the condition (Cotrell & Schultz 1993). Downs (1997) argued that people with dementia have the 'right' for their experiences to be explored through research, in order to understand how this can best inform dementia care. IPA was therefore considered an appropriate method to give voice to people with dementia and explore their lived experiences.

Interpretative Phenomenological Analysis was considered to reflect the aims and objectives of the current study, in comparison to other qualitative approaches such as Grounded theory, which aims to generate a theoretical explanation of a particular phenomenon. Other approaches which were not considered appropriate were; discourse analysis, which takes a social constructionist approach and explores the function and use of language to describe a particular experience, and narrative analysis which is interested in the content and structure that people use when telling their story about an experience.

References

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Appendix G: Covering letter

[Team base address]

Dear [name of CST attendee and name of their carer],

I would like to invite you to consider taking part in a study exploring the experiences of people with dementia and their carers' after attending a Cognitive Stimulation Therapy (CST) group. I am carrying out this study as part of my Doctoral degree in Clinical Psychology at the University of Oxford.

Further information has been enclosed in this pack, including an information sheet which provides full details of the study. I hope that you will read the enclosed information and consider whether you would like to participate. You are however, under no obligation to take part in the study.

If you decide that you would like to participate, please complete the 'expression of interest form' included in this pack and return it to the group facilitator **<Name of facilitators>**. With your permission, they will pass your contact details onto me and I will contact you to discuss the study further and arrange a time to meet with you both.

Thank you for your time in reading the study information and considering whether to take part.

Yours sincerely,

Amy Murphy
Trainee Clinical Psychologist

INFORMATION SHEET FOR PERSON ATTENDING CST GROUP

A study exploring the experiences of people with dementia and their carers after attending a Cognitive Stimulation Therapy (CST) group

Who is doing the study?

Amy Murphy is a Trainee Clinical Psychologist, who is studying Clinical Psychology at the University of Oxford. She is doing this research as part of her studies. Dr Jane Fossey, Associate Director of Psychological Services, is her supervisor and will be helping her with the study. The study is sponsored by Oxford Health NHS Foundation Trust.

Why are we doing this?

We want to better understand what it is like to attend a CST group and how this helps people diagnosed with dementia and those who support them, such as relatives or friends. We hope to use the information to see if care can be improved.

Why am I being asked to take part?

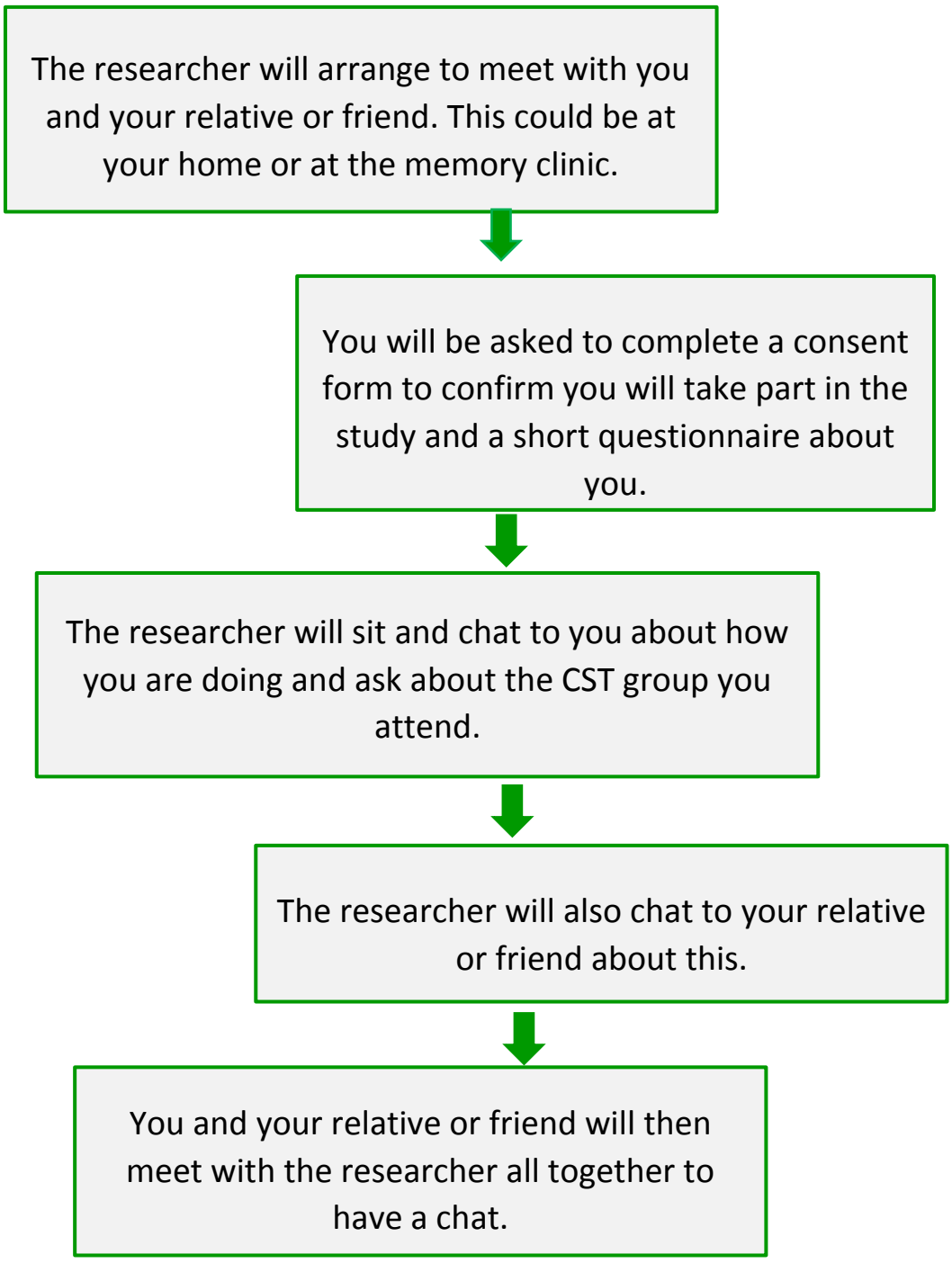
Your local memory clinic is supporting us with this study. You have been invited to take part because you are currently attending a CST group that is running at the memory clinic. You will be asked if you have a close relative or friend that may like to take part in the study with you.

Do I have to take part?

No. It is your decision whether or not you want to take part in this study. If you decide that you do not wish to take part, this will not affect the care you receive from services. If you decide to take part but then change your mind, you can withdraw from the study.

What will happen to me if I take part?

The researcher (Amy Murphy) will meet with you and someone who supports you, such as a relative or friend. You will both be asked to take part in two short interviews.



How will my information be stored?

The researcher will record the interviews and they will be written up into a report. This will include some quotes from the interviews. All quotes included in the report will be anonymised to ensure that you cannot be identified from the quotation. The tape-records will be destroyed once the interviews have been typed up.

Any information about you and your relative or friend that has your names on it, will be removed so that neither of you can be identified. Only the research team will know that it is you taking part in the study. The written report may be published in a journal. You will be asked at the interview if you wish to receive a copy of the journal article. All information will be kept safely at the Fulbrook Centre in Oxford.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and was given favourable opinion by the Research Ethics Committee (IRAS Project ID: 201654).

What do I do if there is a problem?

If you have any worries about any aspect of this study, then please contact the researcher (Amy Murphy) or their supervisor (Dr Jane Fossey - 01865 902280). If you want to make a complaint about it, there are some people who can help you with this. They are the Patient Advice and Liaison Service (PALS), who you can call on 0800 328 7971.

What do I do if I have questions?

If you would like to ask any questions about this study, you can contact Amy Murphy or you can ask the staff who run the CST group at the memory clinic/community team.

Contact details

Please feel free to contact Amy Murphy, Trainee Clinical Psychologist: amy.murphy@hmc.ox.ac.uk or by telephone: 01865 226431

Thank you for taking the time to read this information sheet.

Appendix I: Information sheet for carer

INFORMATON SHEET ABOUT THE STUDY FOR CARERS

A study exploring the experiences of people with dementia and their carers after attending a Cognitive Stimulation Therapy (CST) group

An invitation to take part in a research study

We would like to invite you to take part in a research study. Before you decide whether or not you would like to participate, we want to explain why the research is being done and what it will involve. Please read the following information sheet carefully. You are free to decide whether or not to participate. If you choose not to participate, it will not affect your relative/friend's care in any way. You might want time to discuss this with your relative/friend before you decide. Please ask us if there is anything that is not clear, or if you would like more information.

1. What is the purpose of this study?

We are interested in learning about the experiences of people who have a diagnosis of dementia and their carers after they have attended a CST group. We are inviting both people with dementia and a carer who sees them regularly, to take part in an interview with a researcher. We would like to hear about your experiences of the group and your views on how it has affected you both.

CST has been shown to be an effective treatment for people diagnosed with dementia. Research has shown that CST can lead to improvements in cognition (memory, language and other thinking skills) and a person's quality of life. However, little research has interviewed people with dementia and their carers after they have attended a group. This study aims to find out whether attending a CST group leads to any noticeable changes in cognition, in particular a person's ability to communicate and socialise with others, and how this affects the lives of people with dementia and their carers.

Conducting interviews will help us to understand more about the needs of people with dementia and their carers. This will enable us to consider ways that services and treatments could be improved to provide better support.

2. Why am I being asked to take part?

We are interested in learning more about the experiences of both people with dementia and their carers. You have been invited to take part in this study as you have been identified as someone who is providing care and support to a relative/friend who has a diagnosis of dementia. Your relative/friend is also currently attending a CST group at their local memory clinic, which is involved in this study.

3. Do I have to take part?

It is up to you whether you would like to take part in the study or not. If you agree to take part, we will ask you to sign a consent form. You can decide at any point that you do not wish to continue with the interview, up until two weeks after the interview. However, after this time your data will have been analysed and it will no longer be possible to remove this from our database, but please note that this data will not be able to identify you. If you withdraw from the study, this will not affect the standard of care that you or your relative/friend receive and any information that you have provided will be destroyed.

4. What happens if I decide not to take part?

You are under no obligation to take part in this study and you do not have to give a reason. If you decide not to take part or withdraw from the research, this decision will not have an effect on any of the services or treatment offered to you or your relative/friend.

5. What will happen if I take part?

If you choose to take part, you will be contacted by the researcher (Amy Murphy) to arrange a time most convenient for you and your relative/friend to meet. This could be either at your home or at the location of the CST group, depending on what you and your relative/friend prefer.

During this meeting, you will be asked to fill in some forms. This will include a questionnaire asking about yourself (e.g. how often you see your relative/friend) and another short form to confirm that you consent to taking part in the study. This will take approximately 10-15 minutes to complete.

You will then be invited to take part in two interviews. For the first interview, you will meet with Amy Murphy on your own and be interviewed individually. Your relative/friend will also be interviewed individually. After these interviews, you and your relative/friend will be interviewed together. It is expected that each interview will last between 20-30 minutes. The length of time for all interviews to be completed is expected to be between 1 and 1½ hours.

You will be asked questions to find out more about your relative/friend's experience of communicating and socialising with people before, during and after they attended the CST group. You will also be asked some questions about your relationship with each other and what this was like before and after the group. There are no right or wrong answers to the questions that you will be asked, we are interested in finding out more about your personal experiences.

6. What happens to the information from the interview?

The interview will be tape-recorded and following this will be typed up into a transcript (a written version) of what was talked about during the interview. Once the interviews have been transcribed, your name will be removed from all of the information so that you cannot be identified from the information. The tape-records will be destroyed once the interviews have been typed up. This will then be written up into a report and will include some quotes from the interviews. All quotes included in the report will be anonymised to ensure that you cannot be identified from the quotation. The written report may be published in a journal. You will be asked at the interview if you wish to receive a copy of the journal article. All information will be kept safely at the Fulbrook Centre in Oxford.

7. Will my taking part be kept confidential?

Any information about you and your relative/friend that has any identifying information on it, will be removed so that neither of you can be recognised from it. All information that is collected about you and your relative/friend is treated confidentially. However, if during the interviews there are concerns about risk of harm to you or another individual, confidentiality may be breached. If this situation arises, this will be discussed with you before any action is taken.

8. What are the possible benefits of taking part?

Taking part in the interviews will provide you with an opportunity to reflect on your experiences after being involved with a CST group. We cannot promise the study will help you, but the information we get from this study will be used to help improve our understanding of this experience, shape the support provided to people with dementia and their carers, and find out more about other research that might be helpful, including interventions.

9. What are the possible disadvantages and risks of taking part?

There are limited disadvantages to taking part and no risks. It is possible that some people may find it upsetting to discuss their experiences. There will be time set aside at the end of the interview to discuss how you and your relative/friend are feeling, if either of you wish to discuss it.

What if there is a problem?
If you have a concern about any aspect of this study, please speak to the researcher or their supervisor Dr Jane Fossey, Associate Director of Psychological Services (01865 738445) who will do her best to answer your query. If you remain unhappy or wish to make a formal complaint, please contact a member of the Research Team at the Oxford Doctoral Course in Clinical Psychology on 01865 226364. Alternatively, you can register your complaint via the NHS Complaints Procedure. You can also contact the Patient Advice and Liaison Service (PALS), which is a confidential service that provides information and support to patients and their families. You can contact PALS by writing to: Warneford Hospital, Warneford Lane, Oxford, OX3 7JX, by Freephone: 0800 328 7971, or by email: PALS@oxfordhealth.nhs.uk

Who is doing this study?
Amy Murphy, Trainee Clinical Psychologist, is carrying out this study as part of a doctoral degree in Clinical Psychology. The project is supervised by Dr Jane Fossey. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and was given favourable opinion by the Research Ethics Committee (IRAS Project ID: 201654). The study is sponsored by Oxford Health NHS Foundation Trust.

What do I do now?
If you wish to participate in the study, please complete the 'Expression of Interest Form' and return it to the group facilitators. With your permission, they will pass on your contact details to Amy Murphy, who will then contact you to discuss the study further and arrange a time to meet with you and your relative/friend.

Who do I contact for information or advice?
If you would like further information please feel free to contact Amy Murphy, Trainee Clinical Psychologist: amy.murphy@hmc.ox.ac.uk or by telephone: 01865 226431

Thank you for considering whether you would like to take part in this research study.

Appendix J – Expression of interest form

Expression of interest form

We are interested in taking part in the study and would like to be contacted by the researcher.

Name of person attending the CST group:

_____

Name of carer:

_____

Details (Please note the best time to contact you)

Home Telephone	
Mobile	
E-mail address	

PLEASE RETURN THIS FORM TO THE GROUP FACILITATORS

Appendix K – Consent form

Amy Murphy, Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital
Oxford, OX3 7JX
Email: amy.murphy@hmc.ox.ac.uk
Tel: 01865 226431

Participant consent form
A study exploring how people with dementia and their carers experience social interaction and communication after attending a Cognitive Stimulation Therapy (CST) group
IRAS Project ID: 201654

Please tick each box

	CST member	Carer
1. I confirm that I have read and understand the information sheet dated 9/11/2016 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 up until the interview has been typed up (two weeks after the interview) without giving any reason and without any care that I or my interview partner receive being affected.	☐	☐
3. I agree to take part in the interview for the above study and understand that the interview will be audio-taped and typed up.	☐	☐
4. I understand that quotations from the interview will be anonymised and presented in the final report.	☐	☐
5. I understand who will have access to the personal data I provide, how the data will be stored and what will happen to the data at the end of the project.	☐	☐

6. I agree to take part in this study and to be contacted by Amy Murphy, Trainee Clinical Psychologist. ☐ ☐

_____	_____	_____
Name of person attending CST	Date	Signature
_____	_____	_____
Name of carer	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

Appendix L – Demographic questionnaire

Demographic Questionnaire

It would be helpful if you could please complete the following information. This questionnaire **should be completed by both** the person attending the CST group and the person caring for them.

THIS SECTION RELATES TO THE PERSON ATTENDING THE CST GROUP

Gender: Male ☐ Female ☐ **Age:** _____

How would you describe your ethnicity? (Choose one option that best describes your ethnic group or background)

☐ White-British ☐ White- Irish ☐ White - other

☐ Asian - Indian ☐ Asian-British ☐ Asian- other

☐ Black - British ☐ Black-Caribbean ☐ Black - African

☐ Mixed- please state ☐ other - please state

_____ _____

What is your first language?

Do you have a diagnosis of dementia?

☐ Yes ☐ No ☐ Unsure

If you ticked yes, can you please confirm which type of dementia?

☐ Alzheimer's disease ☐ Vascular dementia

☐ Lewy Body dementia ☐ Frontotemporal dementia

☐ Mixed type dementia ☐ Dementia unspecified

☐ Unsure ☐ Other – please state:

When did you receive a diagnosis of dementia?

☐ Less than 6 months ago ☐ 6 months to 1 year ago

☐ Over 1 year ago ☐ over 18 months ago

THIS SECTION RELATES TO THE PERSON CARING FOR THE PERSON ATTENDING THE CST GROUP

Gender: Male ☐ Female ☐ **Age:** _____

What is your relationship to the person attending the group?

How long have you known the person attending the group?

☐ Less than 6 months ☐ less than one year ☐ 1-5 years

☐ 6-10 years ☐ 11-15 years ☐ over 15 years

How often do you see the person attending the group?

☐ Daily ☐ less than 3 times a week ☐ once a week

☐ Fortnightly ☐ once a month ☐ other

If other please state:

_____

How would you describe your ethnicity? (Choose one option that best describes your ethnic group or background)

☐ White-British ☐ White Irish ☐ White - other

☐ Asian - Indian ☐ Asian-British ☐ Asian- other

☐ Black - British ☐ Black-Caribbean ☐ Black - African

☐ Mixed- please state ☐ other - please state

_____ _____

What is your first language?

Thank you for taking the time to answer to complete this questionnaire.

Appendix M – Semi-structured interview schedule

Questions for individual interview with person who attended the CST group
I am interested in hearing about your experience of Cognitive Stimulation Therapy (CST) and also how you find talking and socialising with people. I will be asking you questions about your experiences before attending the group, as well as what it is like for you now that the group has finished.

You attended a group here <show photograph of place where CST group was held>. The group was held twice a week <say the days of the week the group was held>. I understand that you and the other group members made up a name for your group which was <say the name of the group> and you all sang a theme song together at the start of each session, which was <say name of song>. During each session, you did a variety of different activities/games together and you talked about various different topics, such as food/childhood.

1. **<u>Before</u> attending the CST group, what was it like for you talking and socialising with people?**

Prompts:

- *How did you find it?*
- *How do you think other people saw you? (Spouse, family, friends, mental health professionals, others)*
- *How did you make sense of/understand that?*
- *What did that mean to you?*
- *How did that make you feel?*

2. **What it was like attending the CST group?**

Prompts:

- *What was it like talking and interacting with the other group members?*
- *How did you feel when you were talking/interacting with the other group members?*
- *How did you make sense of/understand that?*
- *What did that mean to you?*

3. **Now that the CST group has <u>finished</u>, how do you find talking and socialising with people?**

Prompts:

- *Spouse? Family? Friends? Mental Health Professionals? Others?*
- *How do you feel when you are talking/interacting with people now?*
- *What did that mean to you?*
- *How did you make sense of/understand that?*

4. **How do you think other people find talking and socialising with you?**

Prompts:

- *Spouse? Family? Friends? Mental Health Professionals? Others?*
- *How did that make you feel?*
- *What did that mean to you?*
- *How did you make sense of/understand that?*

General prompts:

- *Can you tell me more about that…?*
- *Can you tell me what you mean by…?*
- *Can you tell me about a moment or an example of that, which stands out…?*
- *Please can you describe any examples of when…?*
- *How did that make you feel?*
- *What did that mean to you?*
- *How did you make sense of/understand that?*

- *What did you think of that…?*

Is there anything that I haven't asked about or that you think I should know in order to understand your experience better? Is there anything that you would like to ask me?

Questions for individual interview with carer

5. **From your perspective, what was it like for 'X' talking and socialising with people <u>before</u> they started attending the CST group?**

Prompts:

- *How did they find it?*
- *How do you think other people saw 'X'? (spouse, family, friends, mental health professionals, others)*
- *How did 'X'/you make sense of/understand that?*
- *What did this mean to 'X'/you?*
- *How did that make 'X'/you feel?*

6. **What was it like for 'X' attending the CST group?**

Prompts:

- *How do you think 'X' experienced talking and interacting with the other group members?*
- *How do you think 'X' felt talking/interacting with the other group members?*
- *How did 'X'/you make sense of/understand that?*
- *What did this mean to 'X'/you?*

7. **Now that the CST group has <u>finished</u>, how do you think 'X' finds talking and socialising with people?**

Prompts:

- *Spouse? Family? Friends? Mental Health Professionals? Others?*
- *How do you think 'X' feels when they are talking/interacting with people now?*
- *What did that mean to 'X'/you?*
- *How did 'X'/you make sense of/understand that?*

8. **What is it like for you and other people talking and socialising with 'X' now?**

Prompts:

- *Spouse? Family? Friends? Mental Health Professionals? Others?*
- *How do you think others find it now?*
- *How does this make 'X'/you feel?*
- *What did that mean to 'X'/you?*
- *How did 'X'/you make sense of/understand that?*

General prompts:

- *Can you tell me more about that…?*
- *Can you tell me what you mean by…..?*
- *Can you tell me about a moment or an example of that, which stands out…?*
- *Please can you describe any examples of when…?*
- *How did 'X'/you feel…?*
- *How does this make 'X'/you feel?*
- *What does this mean to 'X'/you?*
- *How did 'X'/you make sense of/understand that?*
- *What did 'X'/you think of that…?*

Is there anything that I haven't asked about or that you would like to tell me about before we finish? Is there anything you would like to ask me?

Questions for joint interview

9. **Can you tell me what your relationship was like before 'X' started attending CST?**

Prompts:

- *Can you describe what it was like day to day?*
- *What was it like talking and socialising with each other?*
- *How did you spend your time together?*
- *How did this make you both feel?*
- *What did this mean to you both?*
- *How did you both make sense of/understand that?*

10. **What is your relationship like now that the group has finished?**

Prompts:

- *Can you describe what it is like day to day at the moment?*
- *What is it like talking and socialising with each other now?*
- *How do you spend your time together now?*
- *How does this make you both feel?*
- *What did this mean to you both?*
- *How do you both make sense of/understand this?*

Prompts – if only one person responds

- *How about you?*
- *What do you think about what 'X' has just said?*
- *How do you feel about what 'X' has just said?*
- *I would be interested to hear your perspective/thoughts on this…*

General prompts for both individuals:

- *Can you tell me more about that…?*
- *Can you tell me what you mean by…?*
- *Can you tell me about a moment or an example of that, which stands out…?*
- *How do you both feel about this?*
- *What does this mean to you both?*
- *Please can you describe any examples of when…?*
- *How do you both make sense of/understand this?*

Is there anything that I haven't asked about or that you both think I should know in order to understand your experience(s) better? Is there anything that you would both like to ask me?

Appendix N – Development of the interview schedule

Semi-structured interviews are the most widely used qualitative method of data collection and enable the researcher to gather a rich and detailed account of participants' experiences, views and opinions using open-ended questions (Willig, 2013). Smith et al. (2009) recommend semi-structured interviews as a method of eliciting detailed stories, thoughts and feelings about the target phenomenon. Semi-structured interviews enable a rapport to be developed and facilitate personal discussion, which Smith et al. (2009) argues fits closely with the IPA model and the relationship between researcher and participant.

The current study chose to interview dyads (people with dementia and their carers). Interviewing dyads enables the exploration of not only the experiences of each partner, but also provides insight into their interpersonal relationship and interactions. Kendall et al. (2009) argued that multi-perspective interviews can enhance understanding of interactions and provide a rich insight into the roles of patients within their families and the way in which these maintain their identity. This relates to the current study as previous research highlights the importance of viewing the person with dementia in the context of social relationships, particularly those who provide care for them (Clare, 2008).

Using IPA and semi-structured interviews to interview dyads has been previously used in dementia research (Robinson, Clare & Evans, 2005; Wawrziczny, et al., 2014), however, several limitations to this design were identified. This included the possibility each member of the dyad influencing what each other feels willing and able to share (Clare & Shakespeare, 2004) and the person with dementia speaking less in the interviews (Wawrziczny et al., 2014). To overcome these limitations, the literature suggested triangulating the interviews by interviewing the person with dementia and their carer separately and then jointly (Quinn, Clare, McGuinness &

Woods, 2012; Robinson et al., 2005; Wawrziczny et al., 2014). This method of interviewing dyads has been used by McIntyre and Reynolds (2012) who, using IPA, explored the experiences of falling by older people with dementia and their carers. Based on the recommendations from the literature, this design was considered the most appropriate for the current study and remained in line with the IPA approach.

Smith et al. (2009) recommend developing an interview schedule that starts with a broad question that allows the participant to give a descriptive account of their experience, before moving onto more specific questions. The interview schedule was developed in advance and the questions were influenced by reviewing the existing literature, discussions with the research supervisor and Clinical Psychologists working in the field, and consideration of the research question. The final semi-structured interview consisted of ten main questions, with four questions for the participant who attended the CST group, four questions for their carer and the final two questions for the joint interview. For the joint interview, the researcher prioritised hearing the shared experiences of the dyad and the schedule consisted of directive prompts to guide the dyads interaction.

When developing the interview schedule, information sheets and consent forms, consideration was given to the format and language used. The researcher consulted guidelines published by the Dementia Engagement and Empowerment Project (DEEP, 2013). Due to participants' experiencing memory difficulties, the interviewer provided prompts and cues, including information about the location of the group, a photograph of the building where the group took place, the group's name and general information about the topics covered each week.

The interview schedule, information sheets and consent form were also presented to a member of an Age UK service representative panel for comments, reflections and amendments. This enabled the researcher to gain feedback on the

language used in the interview schedule and the length of questions. The feedback from the representative was very positive and she reinforced the idea of using prompts and cues to support the person with dementia.

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Appendix O – Pilot interview reflections

I[9] conducted a pilot interview with a 79-year-old participant who had a diagnosis of dementia and her carer who was a close friend. The participant had recently completed a 14 session CST group. However, the data from the pilot interview was not included in the final analysis due to the participant completing the CST group 6 weeks prior to the interview, which was outside of the recruitment timeframe (within 4 weeks) specified in the inclusion criteria.

Firstly, I interviewed the participant who attended the CST group, I then interviewed her carer and finished with the joint interview. In total, the interview took 57 minutes. Breaking the interview into three parts, meant that I had a short space of time in between to reflect on each interview. By the final interview, I felt that I was clearer about my position and the type of information that I needed to elicit from the dyad, i.e. descriptive versus meaning, and I also felt more comfortable and confident in my position as interviewer. I also felt that having three shorter interviews worked well with the participants and offered opportunities for breaks. For the person with dementia, I felt that having a shorter interview enabled her to maintain concentration, compared to if it had been a longer interview.

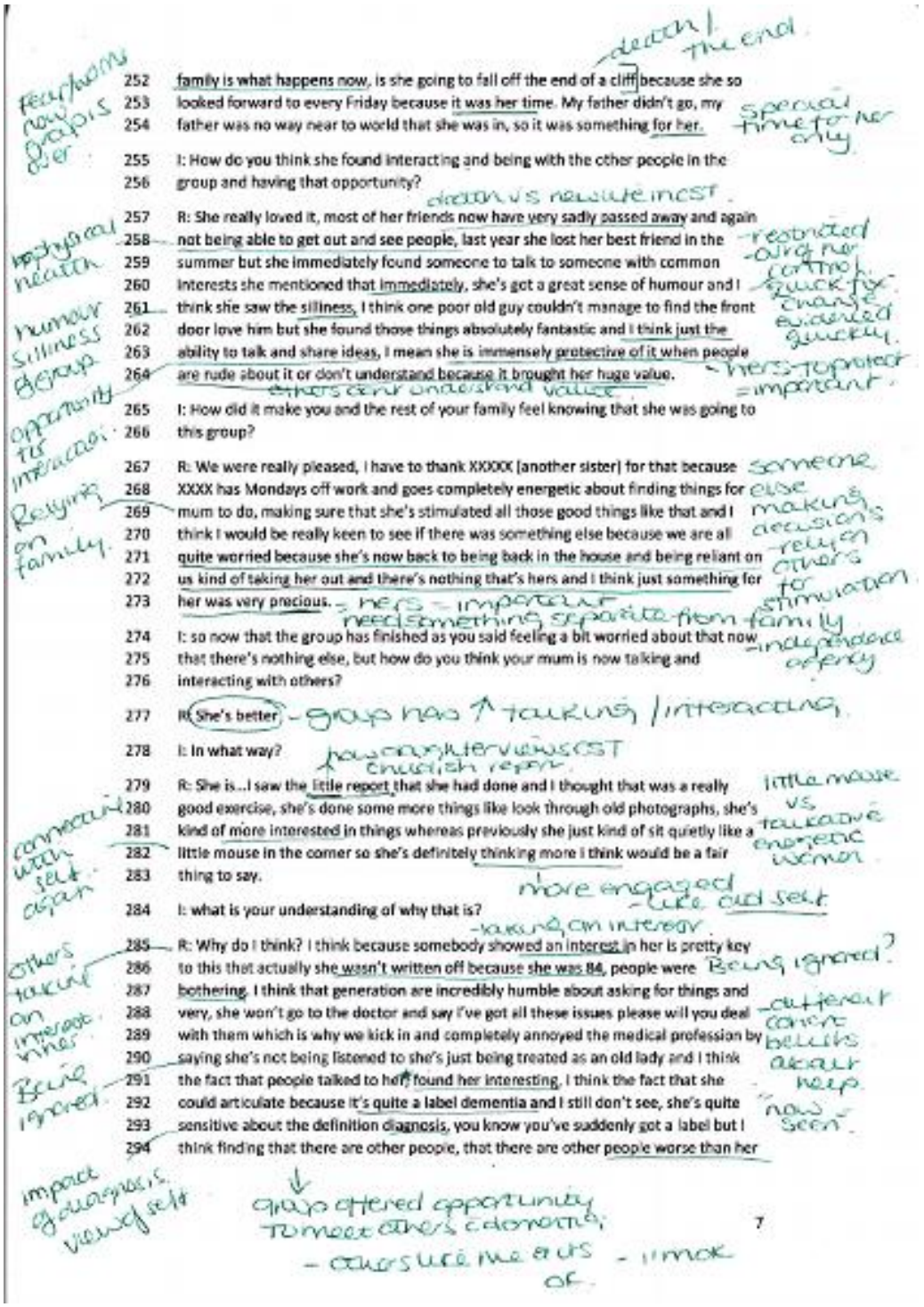
Doing this interview felt very different to any other piece of research I have done before. My experience of quantitative research acted as a voice in my head wanting me to ask questions more specifically about the CST group (i.e. what was it specifically about the group that was helpful/unhelpful, what did you do in the group that made you feel like… etc – thinking about causal factors). This was a learning curve for me. It felt different to be asking more generally about experiences but I feel that the prompts that I had developed were a useful aid in keeping me on track. I also

[9] The researcher will refer to themselves in the first person 'I' throughout this account.

felt that I was taking my time and being more thoughtful and reflective about the questions that I was asking.

I obtained feedback from the dyad at the end of the interview. They both stated that they enjoyed doing the interview. They felt that the questions I asked were easy to answer and not too intrusive or upsetting, which was important for them. In terms of the length of time if took to complete the interview, they fed back that they felt it was appropriate and did not seem to take too long. They stated that the demographic sheet and consent forms were straight forward to read and easy to answer. The feedback was overall very positive and they had no recommendations for things to change or do differently.

Appendix P – Example of annotated transcript



family is what happens now, is she going to fall off the end of a cliff because she so looked forward to every Friday because it was her time. My father didn't go, my father was no way near to world that she was in, so it was something for her.

I: How do you think she found interacting and being with the other people in the group and having that opportunity?

R: She really loved it, most of her friends now have very sadly passed away and again not being able to get out and see people, last year she lost her best friend in the summer but she immediately found someone to talk to someone with common interests she mentioned that immediately, she's got a great sense of humour and I think she saw the silliness, I think one poor old guy couldn't manage to find the front door love him but she found those things absolutely fantastic and I think just the ability to talk and share ideas, I mean she is immensely protective of it when people are rude about it or don't understand because it brought her huge value.

I: How did it make you and the rest of your family feel knowing that she was going to this group?

R: We were really pleased, I have to thank XXXXX (another sister) for that because XXXX has Mondays off work and goes completely energetic about finding things for mum to do, making sure that she's stimulated all those good things like that and I think I would be really keen to see if there was something else because we are all quite worried because she's now back to being back in the house and being reliant on us kind of taking her out and there's nothing that's hers and I think just something for her was very precious.

I: so now that the group has finished as you said feeling a bit worried about that now that there's nothing else, but how do you think your mum is now talking and interacting with others?

R: She's better

I: In what way?

R: She is...I saw the little report that she had done and I thought that was a really good exercise, she's done some more things like look through old photographs, she's kind of more interested in things whereas previously she just kind of sit quietly like a little mouse in the corner so she's definitely thinking more I think would be a fair thing to say.

I: what is your understanding of why that is?

R: Why do I think? I think because somebody showed an interest in her is pretty key to this that actually she wasn't written off because she was 84, people were bothering. I think that generation are incredibly humble about asking for things and very, she won't go to the doctor and say I've got all these issues please will you deal with them which is why we kick in and completely annoyed the medical profession by saying she's not being listened to she's just being treated as an old lady and I think the fact that people talked to her, found her interesting, I think the fact that she could articulate because it's quite a label dementia and I still don't see, she's quite sensitive about the definition diagnosis, you know you've suddenly got a label but I think finding that there are other people, that there are other people worse than her

Appendix Q – Example of case level summary

Dyad No	Objects of concern	Interpretation/meaning	Quotes
1	Stigma - Aging/ageism	Repetition of the word "not all old" – ageism, stigma making her more isolated? Feeling helpless- it's not my fault in older. "puts you off" – makes her want to avoid meeting people? Dementia an inevitable part of aging? – people not taking an interest and not wanting to talk about it or interact with her because of it – stigma a barrier to socialising? CST went against the stigma- enabled her to talk about her difficulties. Emotional impact of stigma made her feel not happy (from carer). Stigma associated with loss of relationships	PWD 32-35: and **it's not old people** all the time, it's a couple of ladies who don't work, and they're, husbands have retired so they too like a cup of tea, so it's not all women, its men and women. That's nice, I think that's a nice thing to do, locally, um, and they are **not all old,** PWD 75-78: I know that several times I have said to people that know, perhaps from U3A, they'll say "oh we haven't seen you for ages" and I'll say, "I've not been very well" and they say, "oh what's the matter" and I'll say, "well I've got Alzheimer's". **It's as if it's catching**, and I think you know hang on, am I talking to you? Am I sounding as if I'm suddenly going to run off? PWD 82-87: she was probably a locum, and she came out of the surgery and she was obviously very cross about something and she said, "I can't stand old people" and I thought oh I hope you won't become one darling. And I thought, that is not for a doctor to say in a surgery. I've not seen her since, I assume she was a locum, but never the less, it's the sort of thing that puts you off, all the time you think to yourself**, old people can't help being old.** PWD 90-95: I think they are frightened, because remember the U3A is my age, so they are in their 50's 60's and 70's going onto their 90's, there are a couple that are well over their 90's, who are perfectly sentient, well they are living by themselves truly. I think it frightens and particularly the older you get, and they really don't want to know. Nobody has ever asked me how it started or when did you think you were going barmy, nobody asked to talk about it. Which I think is sad. The only people who want to talk about it are the people who have got it. PWD 101-104: some of the meetings I've gone to, a couple of people I know, they won't go to the meetings, because they don't want to be with sick people. It's this weird sort of feeling people might have, like I might catch something or they won't be able to talk to me or they won't understand me or I won't understand them,

Appendix R – Excerpts from researcher's reflective journal

A reflective journal was kept throughout the whole research process. The aim of the journal was to develop reflexivity and elicit the researcher's own expectations, beliefs and experiences, which may have influenced the development of the study, data collection and data analysis. This account will start by situating the researcher and then provide a selection of excerpts from the reflective journal.

Situating the researcher

I[10] am a 29-year old, White British woman. My main clinical interests are neuropsychology and working with people with long-term neurological conditions and their families. My clinical experience prior to training was in the field of dementia. I worked as an assistant psychologist in a specialist dementia service. I worked in a memory clinic and two inpatient units. I gained experience working with individuals across all stages of dementia and provided carer support for family members. Throughout this experience, I developed a strong interest in working with people with dementia and supporting them and their families to maintain an optimum quality of life following their diagnosis.

Prior to starting the research, I had no experience conducting post-diagnostic interventions such as CST. I first became aware of CST working as an assistant psychologist following discussions with my clinical supervisor, who was looking to set up a CST group in the service. I remember shadowing a CST group session that was running at the day centre, which sparked an initial interest in post-diagnostic support and a desire to learn more about these interventions. I have no personal experience of dementia in my family. I was therefore aware that approaching this project, I would be mainly drawing upon my clinical experience.

[10] The researcher will now refer to themselves in the first person 'I'

Initial meetings with supervisor to discuss project ideas

During my initial meetings with Jane, we reflected on my areas of interest and previous experiences. I enjoyed my job as an assistant psychologist working with people with dementia and developed a strong interest in quality of life. Discussing CST also appealed to my interests in neuropsychology and understanding the potential mechanisms of change. We thought about the literature on CST and its evidence base showing improvements in areas of quality of life. I realised that quality of life is such a huge topic and I initially felt overwhelmed by the breadth of the concept and the literature. We discussed narrowing down the topic to focussing on particular areas of quality of life, such as relationships, social interaction and communication, which felt more manageable.

Deciding on the methodology

Exploring the literature on CST, there is a breadth of quantitative research and a clear need for further qualitative research to explore the experiences of people with dementia who attend these groups. IPA therefore appeared to be the most appropriate method as it aims to explore lived experience.

Reflecting on my experience of conducting qualitative research: As an assistant psychologist, I completed a service evaluation using questionnaires, which included open-ended questions, analysed using thematic analysis. During my adult placement in my first year of training, I interviewed people who attended a Hearing Voices group as part of a service evaluation project, which was also analysed using thematic analysis. I remember enjoying these projects and feeling much more immersed and connected to the data. The data appeared to resonate more with me compared to previous quantitative research I have done in the past.

I am new to IPA and I am in the process of trying to understand the epistemology. I find myself comparing IPA to thematic analysis, which I am much more comfortable and experienced with. I am struck by the position of the researcher in IPA and initially I feel overwhelmed by the subjective nature of the interpretation and feel slightly under pressure to produce "good" reflections.

Interview schedule development

Considering the focus of the research, Jane and I discussed the importance of viewing the person with dementia in the context of social relationships, with those who provide care for them. This lead onto discussions about the idea of interviewing dyads including people with dementia who attended CST groups and their carers, to explore social interaction and communication within these relationships.

During this process, I came to realise how passionate I am about including people with dementia in research and giving them a voice. Jane and I initially discussed interviewing dyads together in a joint interview. We explored some of the difficulties I might face interviewing participants together i.e. the person with dementia may speak less and not contribute as much to the interview, one perspective may be favoured over another, participants may not feel they can be honest, in case they upset the other person, etc. This spoke volumes to me, as the thought of the person with dementia possibly losing their voice in the research was discouraging.

After reviewing the literature, I found that most of the research which interviews dyads recommends a method of triangulation, whereby the person with dementia and their carer are interviewed separately and then interviewed jointly together. I was relieved to find this method and to see it has been previously used with people with dementia and their carers. After agreeing on the method with Jane, I

am feeling excited about using this new and different method of interviewing and I hope this will add a new scope to my research project.

Recruitment

Early December 2016: I have received three responses from teams regarding recruitment. The first was from a team who unfortunately are not currently running CST groups due to limited resources and staffing issues. When I received this e-mail, I felt quite anxious and I did not feel it was a great start to the recruitment process! I was worried that I would not recruit any participants! I then received an e-mail from a service who were coming to the end of running a CST group, it was their final week. I felt very excited about the possibility of finally recruiting some participants! I noticed I was quick to respond and deliver information packs to the service the next day. The facilitator was an Occupational Therapist and she was very keen to help with the project. The final team replied saying they were hoping to run a group in the next year – February/March, which is good timing for my project. We agreed that we will discuss this further in the new year. I am now feeling more hopeful that I will be able to recruit participants.

15th December 2016: I received an e-mail from a group facilitator informing me that a dyad had returned the expression of interest form and would like to take part in my research. I am feeling relieved. I telephone the dyad and arranged a time to meet with them to complete the interviews. I am feeling slightly nervous. It has been a few years since I have done a qualitative interview and I am wondering how the schedule will flow and the quality of the data I will gather from the interviews.

Interview 1

My first interview is complete! I really liked the participant who had attended the group, she was very warm and friendly and clearly enjoyed talking and socialising

with others. She talked openly about living in a quiet area and not having many close friends around her. This made me think about my visit that day and whether I offered an opportunity for social interaction, which she may have had very little of since attending the CST group. At times, I felt sad during the interview when she talked about feeling lonely, and as a result, I feel I focussed on this aspect more in the interview and wanted to know more about what that meant to her and how it made her feel. She appeared to remember the group well and was very forthcoming in her answers. I felt that she needed little prompting to give examples.

I noticed that the responses focussed on the experience of having a diagnosis of dementia and I found myself quite drawn to this topic. This could be because of my previous experience working in a memory clinic. I wonder if this topic will come up again in future interviews? I was struck when both the participant and carer spoke about stigma and how others viewed her and chose to interact with her. This prompted an in-depth conversation about social interaction and elicited a greater understanding of their feelings and what it meant to them.

For the carer, I felt that he had a slightly different agenda that he wanted to talk about i.e. his views on current services, which made it difficult at times to keep the interview on track. I wondered if this was a weakness of the interview schedule and whether the questions were too broad, but then I realised it was important for him to talk openly about his experiences and viewpoints. With prompts, he was able to reflect more generally on his views of cognitive stimulation and how important he felt it was for his wife to continue with stimulation after the group.

Interview 2

During the interview with the participant who attended the group, I felt that I was asking more specific prompts to try to elicit information. By half way through the interview, I had the thought "this is her experience right now" and I needed to listen

to that, rather than trying to fish for a perfect answer to my question, that I would consider desirable. She kept repeating "it was nice" and "I enjoyed it" – this made me think about how people with dementia might not be able to remember the facts and specifics of an event or what happened, but they might remember a sense, an emotion or how it made them feel. I felt that this was what this lady was connecting more with and expressing during the interview.

From the perspective of the carer, I was struck by the theme of carer burden and how the group offered a safe place for her mum to go to. When asked how she thought her mum found being in the group, she immediately spoke about it not being traumatising or being of any concern. This made me think about there being a sense of reassurance and relief that her mum was going somewhere where she was looked after, brought there and back home again and that her mum was happy there. This seemed to be the most important aspect of the group for the carer.

Interview 3

During this interview, I was struck when the gentleman who attended the group said he could talk naturally in the group and that the facilitators allowed for this. However, outside of the group, talking to people continued to be difficult. I'm wondering if within the group there was permission for him to be himself and to not be pressured or judged for his difficulties. Perhaps the more he was understood and able to participate, the better his mood was and his confidence improved? There appeared to be noticeable changes in his confidence speaking, rather than his actual speech quality. This links with the literature on increased confidence following the group and the debate about whether this is a change in language skills per se, or overall confidence and quality of life and relationships.

Again, the theme of carer stress came up, with his wife often feeling impatient or worrying about him. I was disheartened to hear that she was prescribed anti-depressant medication by her GP rather than being offered emotional support.

The CST folder was discussed and interestingly, like other participants, they have not spent much time looking through the folder that was given to them. They spoke about wanting to but not having done so. This makes me think that the social interaction and opportunity to meet with others in the group is valued more than the stimulation aspect? I was really surprised when the person who attended the group said, "it's just paper". In contrast, the carer was more interested in doing it, which again is similar to other interviews. Maybe they feel it is a way of doing something together and being able to help their loved one?

Interview 4

Over the course of the interviews I have done so far, I have learned that each person has a different name for the CST group, either the 'cognitive group', 'the think tank group' or the 'memory group'. This is something I am now mindful of asking about at the start of my interviews and making sure that I use the participant's language. I think this has helped them to recall their experiences of the group. For this participant, it was interesting to hear that she found the group easy. It was nice to hear that she made a close friend in the group, but at the same time it was sad that the friendship did not carry on afterwards. Like other participants, she did not notice any change in cognition, but she reported increased confidence in attending further groups, which was the main change she had noticed.

Interview 5

This was another participant who had a diminished circle of friends prior to starting the group and someone who was more interested in meeting people in the group rather than doing the activities. For this lady, I was struck by the importance of

family and how much this lady relied on her family for support. Again, the theme of sadness that the group had finished, a sense of loss – something to look forward to each week, but also feeling like she didn't lose something that was essential to her life. This indicated that she valued seeing her family and this was possibly enough stimulation and opportunity to socialise for her.

I was struck when her daughter referred to their interactions being like "primary school kids" - somebody who needed a lot of guidance and support. This made me think of a switch in roles and the carer now being in a more parental position rather than a child? A sense of loss from the daughter and possibly sadness at what her mother is no longer able to do? Again, the theme of the facilitators supporting the people in the group to talk came up– encouragement that could increase confidence to take part in conversations in the group?

The theme of carer burden emerged again and this sense of being in a role whereby they are responsible for the more day to day things, which then impacts on their ability to spend quality time together. A sense of struggle at not being able to cope on a day to day basis, but also conflict, whereby the daughter wants her mother close by so she can check in on her and make sure she is okay. The strain of trying to get her mother to eat, again comes back to the parental role that the daughter has now taken on and the ongoing difficulties she faces. The carer seeing the role of the group as providing stimulation and a way to get her mum to go out to see people and not stay at home all day – taking the responsibility off her?

Interview 6

For the person with dementia, there was a sense that he worries about what other people think of him "embarrassing". In the group, he found some tasks difficult but with help from the facilitators, he was able to take part and do the tasks. This

made it easier for him and enabled him to have a sense of achievement. Again, the theme of not feeling judged in the group was evident and the non-stigmatising nature of the group. He never felt that the group was too hard that he couldn't do the tasks. Key role of facilitators in supporting the group members to interact and engage.

Interview 7

I am starting to notice many occurring themes, i.e. CST providing stimulation for person with dementia and giving relief for family members. The theme of effort, getting person with dementia to the group came up again for the carers, as well as the concept of doing CST at home. However, this appeared to be more important for the carer than it was for the person who attended the group. Again, no obvious change in cognition was noticed after attending the group.

Interview 8

For the gentleman who attended the group, I was struck by how much he remembered about the people who attended and how much he enjoyed the opportunity to meet with a mix of people from different cultures and genders. It was nice to hear that he met a person who used to work in the same place as him many years ago- again this links to meeting with similar people but I wonder if the main reason he kept going back was to see his friend? They developed a routine getting the bus home together, I wonder if this was more important to him than the stimulation?

He saw the group as more of a social event rather than seeing it as a way to improve his memory. Driving was a big loss for this gentleman and was also acknowledged by the carer. Losing his licence limited his ability to access social opportunities – a loss of independence?

Data analysis

The initial stages of data analysis focussed on coding the transcripts individually and identifying subordinate themes. These were then presented in table format for each individual dyad. This was a long process but as I progressed through the task, I began to notice themes emerging from the transcripts and several differences between the perspective for people who attended the CST group compared to their carers.

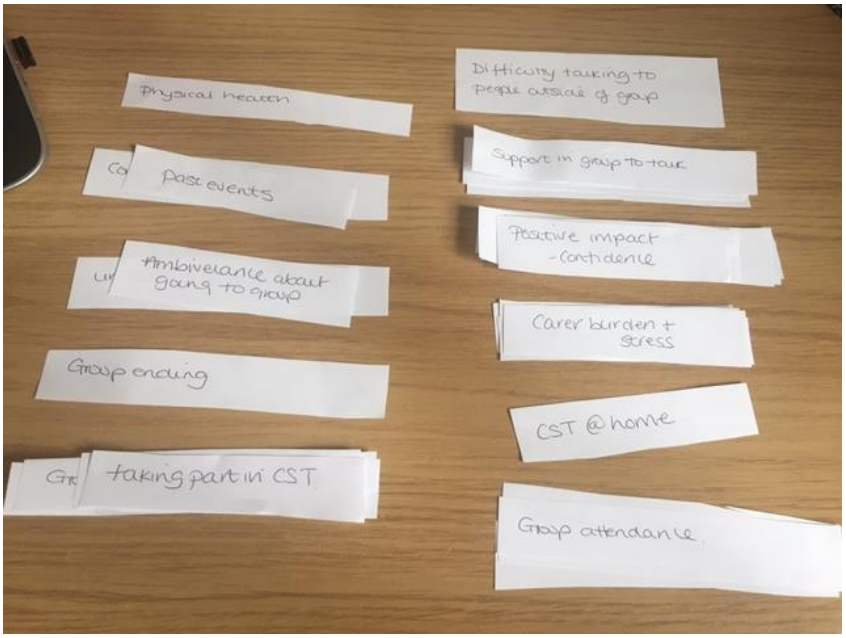
I chose to start analysing dyad 4. I chose this interview first because it was an interview which stuck out in my mind and I remember there being a detailed amount of content and it being an interview that I enjoyed. When thinking about why I enjoyed it, I recall I was pleased to hear the patient had such a positive experience of CST and it evoked a lot of reflections following the interview. When thinking about doing the analysis, I am feeling nervous and slightly overwhelmed by the whole process. This is the first time I am using IPA and I feel the need to 'do it right'.

To refamiliarize myself with the analysis process, I have re-read chapter 5 in the book by Smith, Flowers and Larking (2009). In this book, they talk about the 'novice' IPA researcher who may benefit from a step-by-step process but they also stress that there is no 'right way' of doing IPA. I am going into this analysis considering the steps outlined in the chapter but also reflecting on my previous conversations with IPA researchers about how they 'do' IPA. It seems that everyone has their own individual way of analysing the data in line with the principles of IPA. When my supervisor analyses transcripts, she said she likes to sit in a comfy chair, with nice pens. I think this is where I will start.

I have finished making my exploratory notes down one column. I found this harder than I thought I would and at times I was struggling to identify the object of

concern or thinking of how to label the codes. As I went through the transcript, I started to notice emerging themes, i.e. the role of the family in providing stimulation and noticing the striking impact of her physical health difficulties on her ability to access the community and social opportunities.

The following photo illustrates an example of the process of grouping together key objects of concern into subordinate themes at an individual case level. These themes were then transformed into a table with illustrative quotes.



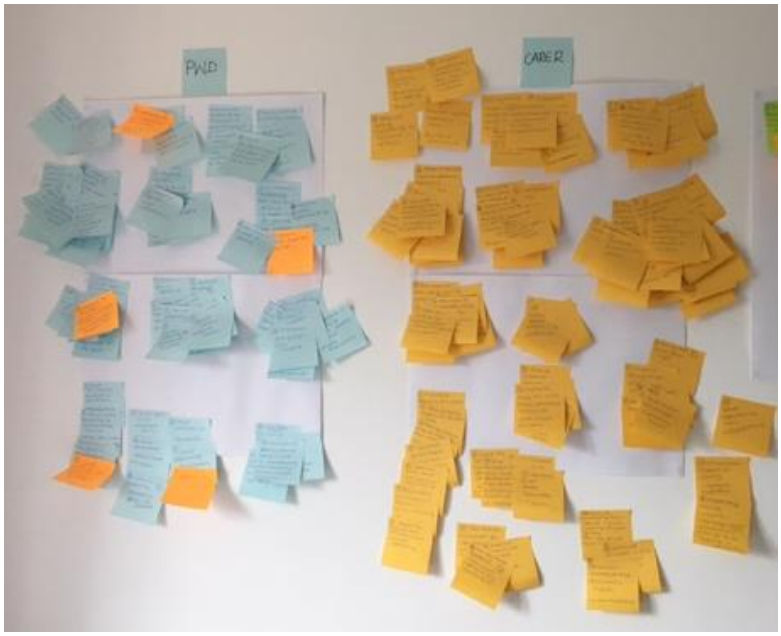
Meeting with supervisor to discuss themes

I met with Jane to start discussing the process of looking for themes across all cases. This is feeling like such a huge task and I am feeling overwhelmed by the size of it. In the meeting, we talked about my method of interviewing and because I interviewed participants separately and jointly, it will be important in my analysis to consider the shared experiences as well as the experiences of the person with dementia and the carer. This will help to identify any similarities and differences in perspectives. This advice was also recommended to me by Michael Larking (IPA expert) in our workshop. I now feel that instead of having 8 participants, I actually have 16!!

I reflected on the differences I have noticed so far. People who attended the group mainly viewed it as a social event and the opportunity to make friends and meet similar people, and many had little desire to continue with the content of CST at home. In comparison, continuing CST at home was very strong for the carers and also the need to replace CST with another group.

Initial sorting of themes– looking at the different perspectives

For this part of the analysis, I looked back through the individual tables and wrote down on different coloured post-it notes summaries of themes that emerged for both the person with dementia and the carer. Using a large wall, I then started to cluster themes together relating to either the person with dementia or their carer (see photograph).



Over time, I could see the themes starting to group together and I was very pleased to have so many themes emerging for the person with dementia. I was worried that the carers voice would be over powering in the themes but this does not appear to be the case. I feel that I have captured the voice of the person with dementia well.

Bringing it all together

The next part focussed on looking across the two perspectives to look for similarities and differences and bringing the themes together into superordinate and subordinate themes. During this process, it was apparent that there were themes which were strongly weighted towards either the perspective of the person with dementia or the carer, with some themes including both perspectives. This made me think about the findings in my Paper A, which showed that there are differences between people with dementia and their carers ratings of patient quality of life. This has highlighted how important it was to capture both perspectives in this study and identify the shared and separate perceptions of each member of the dyad.

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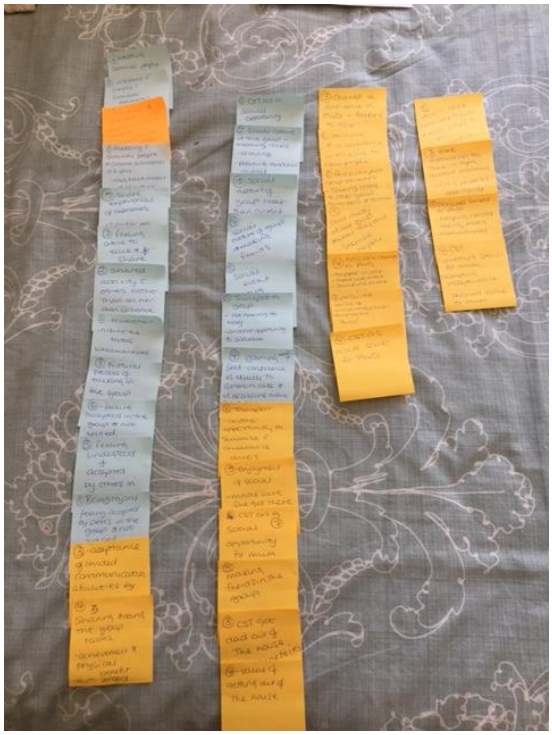


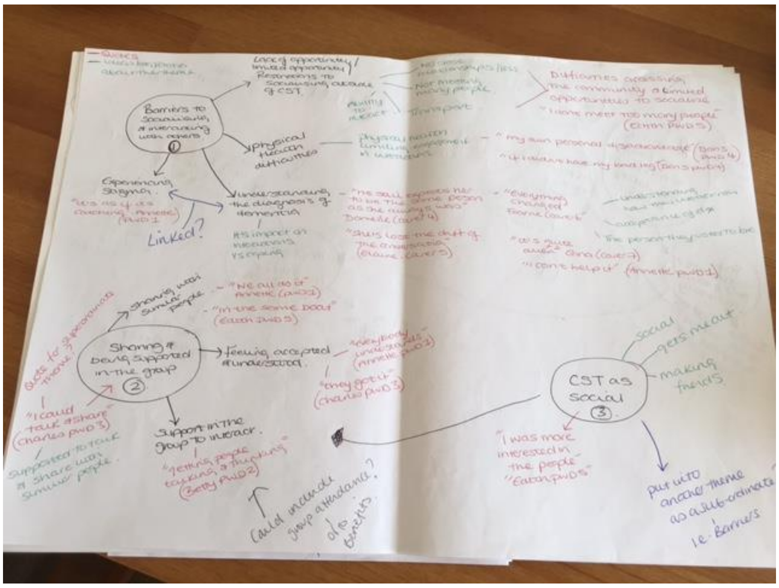
This photo represents the perspectives of participants who attended the CST groups (blue) and carers (orange) being grouped together into subordinate themes. Each vertical column represents a subordinate theme. The subordinate themes were then grouped together into larger superordinate themes.

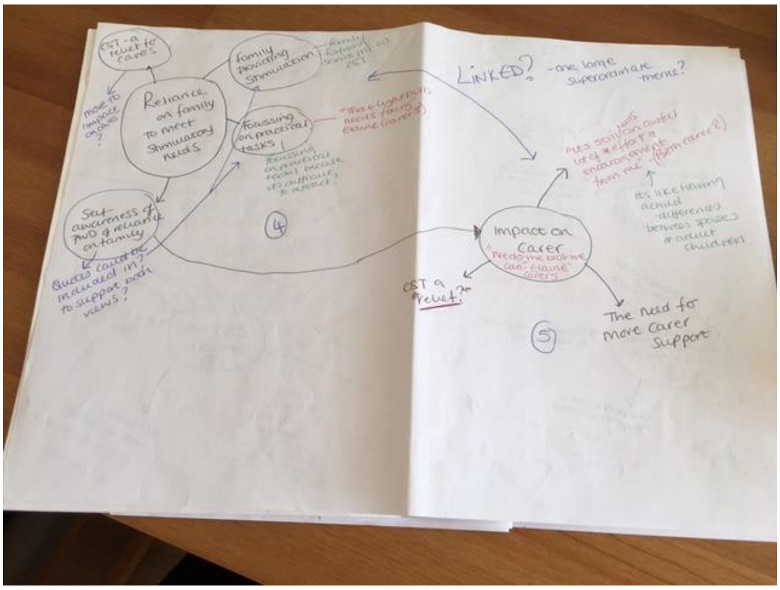
Throughout the process of analysis, I was surprised by how the themes have 'jumped out' at me. It felt like a very natural process and I noticed a very powerful story which has started to emerge. In my head, I had convinced myself that this would take a long time to do and I find myself wondering if I have done it right?! On the other hand, I felt very immersed and connected to the data.

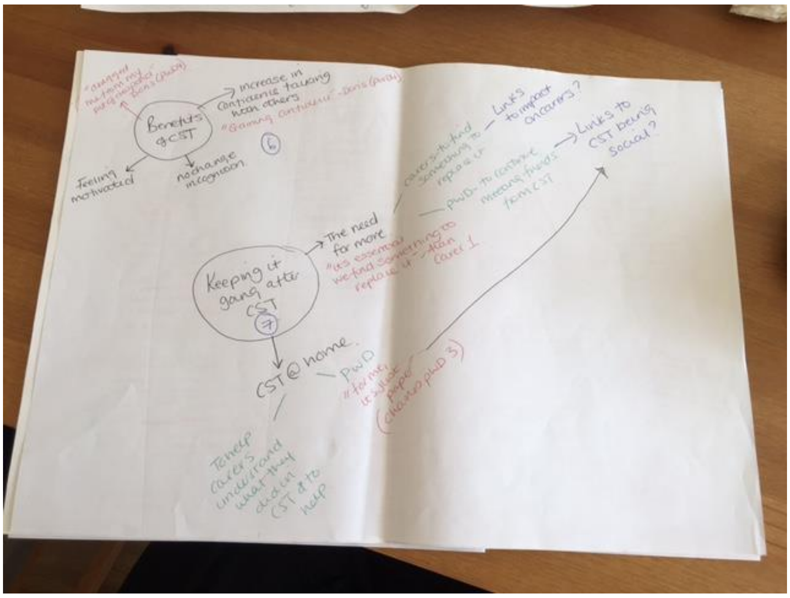
The next stage is to draw the quotes out from the transcripts and place them under each theme. This will enable me to see whether the theme is representative of all dyads experiences and from within that, start to think about the headings of each theme and how I can use the language of the participants, which captures their experiences. Then, I will look through the quotes and select which quotes I would like to include in the final report. This feels like another huge task and I am overwhelmed by the amount of data that I have. At the moment, it feels like my process is very prescriptive, rather than interpretive.

Meeting with supervisor to discuss final themes

Prior to this meeting, I created mind-maps to illustrate each superordinate theme. This helped to clarify my thinking and reconnect with the meanings of each theme. Jane and I then added to these maps during the meeting (see photographs).


Barriers to socialising & interacting with others
1
Physical health difficulties
Experiencing stigma
Linked?
Sharing & being supported in the group
2
Feeling accepted & understood
Support in the group to interact
CST as social
3
"I was more interested in the people"
put into another theme as a sub-ordinate ie. Barriers


Reliance on family to meet stimulatory needs
CST - a relief to carers
family providing stimulation
Focusing on practical tasks
Self-awareness of PwD of reliance on family
4
LINKED? - one large superordinate theme?
Impact on carer
CST a "relief?"
The need for more carer support
5


Benefits of CST
6
increase in confidence talking with others
Feeling motivated
no change in cognition
Keeping it going after CST
7
The need for more
CST @ home
PwD
Links to CST being social?
Links to impact on carers?

Jane and I agreed on the majority of the themes and she helped me to see how some of the themes might be linked even further. For example, I had a standalone superordinate theme "CST as a social opportunity" and I wondered if this would form part of another superordinate theme as a subordinate theme. We discussed how this could link with the superordinate theme "sharing and being supported in the group", as group members have the opportunity to meet with others in similar situations and share, which occurs in a social context.

In total, I have 6 superordinate themes, each with additional subordinate themes. I hope they capture the experiences of all the dyads.

Writing up

At first, I found it quite hard to select which quotes to include in the final report. I found that I was selecting too many quotes and as a result, my first draft was too descriptive. However, I felt that this helped to shape my thinking, as I was then able to take a step back and consider the meanings in relation to the whole sample, rather than each dyad or member of the dyad.

Appendix S – Bracketing interview transcribed

Bracketing Interview – completed on 21st November 2016

Interviewer: A fellow qualitative researcher

Amy, I would be really interested to hear what got you interested in this area of research?

Well, I always wanted to do my dissertation with people with dementia, because I'd worked previously as an assistant psychologist with people with dementia. I worked in a memory clinic and on inpatient wards as well, so I was working with people at all stages of their journey and I became particularly interested in dementia. As an assistant, I also did a service evaluation that was a piece of qualitative work. I used thematic analysis and I really enjoyed it. I felt like I really connected with the research and I felt it was much more meaningful, I felt much more connected to the research, much more than say a quantitative piece of research I have done previously, so I think for me that's why I really wanted to do qualitative as well.

So, there are two elements, there is the really liking dementia but also liking the methodology. If you have worked with people throughout the whole journey before, what kind of lead you to focus on this aspect of their journey and looking at CST?

Initially I set out with the idea of wanting to do research in neuropsychology and dementia. With there being no cure for dementia, the research is focussing on psychosocial interventions, so I kind of feel like that is where a lot of the research is going and I feel it is a really important area to focus on. Um, but I think CST…some of the research looks at the neuropsychological mechanisms but there is also another side to it as well, in terms of the impact that it can have on people's relationships and more generally their quality of life, so I kind of felt like it really lent itself to both aspects of my interests quite nicely, so that's why I focussed on it.

And have you got any thoughts about how your previous work might impact on the way that you approach this research, considering you have worked with the population quite extensively?

I feel very passionately about giving people with dementia a voice, because clinically from my experience, I felt like the person's voice was lost a lot of the time. I think clinically a lot of proxy reports are usually preferred from family members, even throughout all stages of the disease, so I think personally I felt very strongly about that. Also, within research it's often considered that people with dementia, they can't give reliable information and they are often excluded from research and again proxy carers are more likely to be included, and this is why I wanted to focus on this area and I felt that qualitative research really lent itself quite nicely to that.

That's really nice that you're driving force is that you are really passionate about getting their voice heard and I guess qualitative research is all about grounding it in their experience. Have you had any personal experience of dementia that you feel may or may not impact on your qualitative methodology?

I haven't no, I don't have any personal experience, anyone close to me that has had a diagnosis of dementia, so that is potentially something that might impact on the research. I think I will be drawing upon my clinical experience and using that as my route into the research rather than any personal experience.

Yeah, that makes sense. So, do you foresee any difficulties with the research?

I think because I feel quite passionately about giving people with dementia a voice, I think that is something I am going to be very mindful of because I'm interviewing dyads. Initially I was going to interview them both jointly together, in one interview, but looking through the literature I found that a lot of the research that had done this had commented that the person with dementia didn't speak very much, it was mainly the carers' perspective and that was one of the limitations, which kind of went against the reasons why I wanted to do the research. That's why I came up with a different design and interviewing both individuals separately and then doing a shorter joint interview, but I think that is something that is always going to be at the back of my mind, particularly in the joint interview, making sure that I can gather both perspectives. I think that was something that I really thought about with my prompts as well, so if one person is speaking more just having a prompt like "so, what do you think about that or do you agree with that", really thinking about how I can get both people's perspectives. I think just making sure that I really try to learn the interview schedule as well, I think that might help the interview to be more of a natural process, I want it to feel more like a conversation.

And why is that important to you that it's more of a conversation and a natural process?

I suppose to help the individual to feel comfortable during the interview and to build up a rapport as well, so that they feel that it is a safe place, where they can talk about their experiences, but also it comes back to the reasons why I really liked qualitative research because it comes back to that personal connection that you can have with somebody and it's such a privilege to be in a position where you can hear about somebody's personal experiences. For me, I think I just want it to be as comfortable and as natural as possible.

And, thinking a bit further forward and analysing your data, do you think you have any preconceptions about the themes that might come up, that you might have to watch yourself about or do you feel like you are very open?

The analysis process and the coding process, I'm generally feeling quite nervous about because I have never used IPA before and it is a completely new method. I wonder if because I feel so passionately about giving the person with dementia a voice, if that is the part of the interview that I will really focus on, particularly in drawing out themes. So, I think that will be something to be mindful of during the research and ensuring that I'm getting a balance between both perspectives, so they can both be captured.

And, have you got in mind the audience where you would like your results to go to, how do you want the research, what do you want it to inform in the future?

I think I would like the research to be open to all health professionals, not just clinical psychologists because CST is a group that is not only run by psychologists,

but also occupational therapists, nurses, a wide range of health professionals, and I think I want it to be really accessible to those. I want professionals to look at the broader impact of CST on individual's quality of life and see it as being a really meaningful and important intervention. I think that would be my hope for the end of the research.

That is a good motivating factor.

I am really looking forward to getting started. It's such a long process going through ethics, but even now I'm still feeling really excited to get going and I'm really looking forward to doing the interviews.

Anything else you feel might impact the research?

I suppose the emotional impact of the work, particularly hearing two different peoples' perspectives, they could be completely different perspectives. I'm aware that caring for someone with dementia can be highly stressful, so it will be important to acknowledge this and be empathic in the interview if this comes up and also be mindful of my own emotions and what it brings up for me.

How do you think you will manage that? What will you put in place to manage your own emotions?

I think having good supervision will be very important, knowing that there are people that I can talk to about it if there are any particular difficulties that come up, but also having a reflective journal and writing in this after the interviews will be incredibly important. As soon as I conduct the interviews, I'm planning to reflect on the experience, my emotions and the process of doing the interview and what it brought up for me and anything from that bringing it to supervision and talking it through. If I feel like I need any support in the interim, I think my supervisor is very open to being contacted and other members of the research team, so that's quite important to think about.

And with that idea that you might come across quite difficult emotions in the room and you will want to show that CST is a valuable intervention, but you might actually find that people say it didn't really do anything for me, how do you think you might manage that?

I think I'm going into the interviews thinking that people will say it's great and that it has helped them and been really beneficial and that they have enjoyed the experience, and that they've noticed a change in their language and communication and their relationships! It's important to think that actually they might not, and that's okay, as well. And again, it's not about searching for that within the interview, just acknowledging that's their experience and not trying to influence it in any way and searching for a positive.

Do you think your reflective log and supervision will help you to do that?

Yes, and I know using the interview schedule is very much a guide and I think in that situation, if I notice myself doing that, just knowing that I've got the guide and structure to come back to, as a way of refocusing the interview, but I think just having that awareness in the moment as well, which can be quite difficult. Again, it might be

that after the interview I reflect on it which will hopefully be helpful for the next interview and hopefully it will build up. I just think it's important to be aware of it, which might be quite tough in the moment.

I guess, is there anything about your supervisor's background that might influence the research in any way?

My supervisor has got a lot of experience in this area, working with people with dementia, carers, research into quality of life and qualitative research. She's very knowledgeable and very experienced in all of these areas, which I think will be brilliant for me as somebody who is very new to using IPA. I think her guidance in that respect will be very important. Um, any influence…. Probably in the encoding and interpretation stage, because my supervisor will be looking at a few of the transcripts and we'll be comparing our interpretations and I think that might be a point where we might have different interpretations, so it will be important to be open about where those interpretations are coming from. I'm guessing for her it might be her extensive experience in this field whereas it might be very different for me.

I was just wondering about her position, I'm aware she is a clinician and whether she is running CST groups and whether there might be a benefit to her finding that CST works?

She is not actually involved in running any CST groups, but as head of psychological services I suppose she is quite an influential person and there are certainly people within her team, clinical psychologists, research assistants, assistant psychologists, who are involved in planning the CST groups and looking at the outcome data, so from that perspective it could be quite beneficial. I think they are all very passionate about CST and about the research which is great.

Is there anything else you want to say?

I don't think so, I think we've covered a lot in terms of the emotional aspects, the reasons why I'm doing it, any expectations that I have and any influences, other people's expectations and influences. No, that's been good, thank you.

Appendix T – Credibility procedures

Several steps were taken by the researcher to maximise the credibility of the research. These are described below:

1. ***Feedback on developing ideas***

In the early stages of development, the research project was presented to a group of colleagues and a service user representative. The researcher also had general discussions with Clinical Psychologists working in the field. The research ideas were reconsidered and refined based on feedback from the presentation and discussions.

2. ***Feedback on study documents and interview schedule***

All study documents and the interview schedule were presented to an Age UK service user representative, who was a carer for her husband who had a diagnosis of dementia. The interview schedule was also piloted with a participant who had previously attended a CST group and their carer. This ensured the appropriateness of the schedule items by enabling feedback on the questions and their ability to facilitate in-depth discussions about the dyads' experiences.

3. ***Qualitative peer reflection group***

The researcher met regularly with a qualitative peer reflection group, which consisted of IPA and other qualitative researchers. The meetings were to discuss the IPA method and epistemology, the use of reflexivity, to share and review interview schedules and to conduct bracketing interviews. During the data analysis phase, time was dedicated to coding a selection of each other's

transcripts. This involved discussing emerging themes for each participant, as well as any differing views and interpretations.

4. ***Seminar with an IPA expert***

During the data collection and data analysis phase, the researcher attended two seminars with an IPA expert. The researcher brought a selection of transcripts to the seminars to check the coding process and sought advice for analysing data from dyads. There were also discussions about the development of emergent superordinate and subordinate themes and the presentation of the final report.

5. ***Meetings with research supervisor***

The researcher met regularly with their supervisor to discuss issues relating to recruitment, data collection and to consider emerging themes. The research supervisor independently analysed four transcripts and through discussions, consensus on the superordinate and subordinate themes was established.

6. ***Audit trail***

An audit trail was kept throughout the whole research process to demonstrate the researcher's decision making throughout the data analysis and write up stages. This included coded transcripts, emergent themes for each individual transcript in tabular format, notes about the process of developing the superordinate and subordinate themes and a table of illustrative quotes supporting each theme.

Appendix U – Letter of approval from Oxford Institute of Clinical Psychology Training Research Sub-Committee

Oxford Health NHS
NHS Foundation Trust

The Oxford Institute of Clinical Psychology Training

UNIVERSITY OF OXFORD

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
Tel: +44(0)1865 226431
Website: www.oxicpt.co.uk

27th May, 2016

Amy Murphy
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital

Dear Amy,

Thank you very much for submitting your dissertation proposal to the Research Sub Committee. You now have full approval for your project.

We wish you all the very best with your research.

Yours sincerely,

Myra

Dr Myra Cooper
Chair, Research Sub-Committee

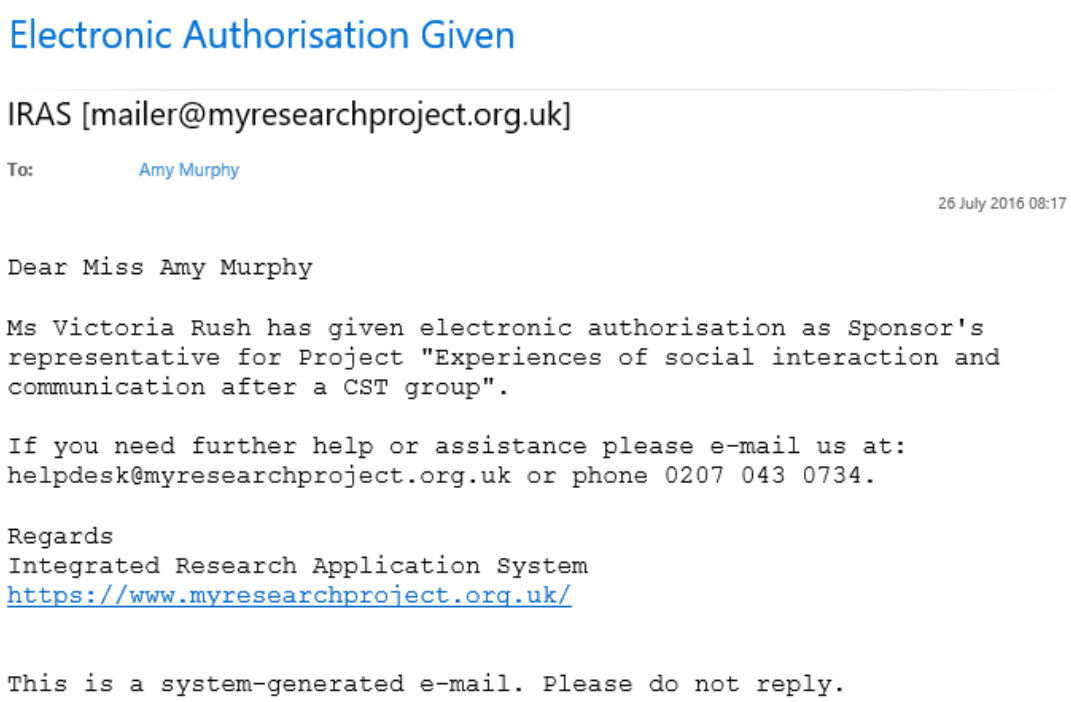
c.c. Susie Hales
Jane Fossey

Senior Research Tutor: Dr Myra Cooper, M.A. (Hons)., M.Phil., D.Phil., C.Psychol. Tel: (01865) 226375
myra.cooper@hmc.ox.ac.uk

amurphydissapp

Appendix V – Confirmation of Sponsorship

This study was sponsored by Oxford Health NHS Foundation Trust. Confirmation of Sponsorship was provided via electronic authorisation by Victoria Rush (Research Governance Manager). The e-mail below was generated through the online NHS Integrated Research Application System.



Electronic Authorisation Given

IRAS [mailer@myresearchproject.org.uk]

To: Amy Murphy

26 July 2016 08:17

Dear Miss Amy Murphy

Ms Victoria Rush has given electronic authorisation as Sponsor's representative for Project "Experiences of social interaction and communication after a CST group".

If you need further help or assistance please e-mail us at: helpdesk@myresearchproject.org.uk or phone 0207 043 0734.

Regards
Integrated Research Application System
https://www.myresearchproject.org.uk/

This is a system-generated e-mail. Please do not reply.

Appendix W – NHS ethics approval letter

NHS
Health Research Authority

Miss Amy Murphy
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
The Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Email: hra.approval@nhs.net

09 November 2016

Dear Miss Murphy,

Study title:	**How do people with dementia and their carers experience social interaction and communication after attending a Cognitive Stimulation Therapy group?**
IRAS project ID:	**201654**
Protocol number:	**N/A**
REC reference:	**16/NW/0615**
Sponsor	**Oxford Health NHS Foundation Trust**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you

have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training
We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **201654**. Please quote this on all correspondence.

Yours sincerely

Catherine Adams
Senior Assessor
Email: hra.approval@nhs.net

Copy to: *Mrs Victoria Rush, Oxford Health NHS Foundation Trust*

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview schedule]	1	04 July 2016
IRAS Application Form [IRAS_Form_27072016]		27 July 2016
Other [Expression of interest form]	1	13 July 2016
Other [HRA Statement of Activities]	1	2 November 2016
Other [HRA Schedule of Events]	1	2 November 2016
Participant consent form [Consent form]	2	9 November 2016
Participant information sheet (PIS) [Information Sheet - Carer]	2	9 November 2016
Participant information sheet (PIS) [Information sheet - person with dementia]	2	9 November 2016
Research protocol or project proposal [Oxford Health NHS Foundation Trust Sponsorship protocol]	3	14 July 2016

Appendix X – Local NHS site approval letters

Oxford Health NHS
NHS Foundation Trust

Caring, Safe and Excellent

Professor John Geddes
Director of R&D
Warneford Hospital
Oxford
OX3 7JX
Tel: 01865 226451

Our Ref: OHFT PID 1234/MB

16th November 2016

Miss Amy Murphy
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
The Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Dear Amy,

RE: **CONFIRMATION OF CAPACITY AND CAPABILITY (GREEN LIGHT)**
Study Title: **How do people with dementia and their carers experience social interaction and communication after attending a Cognitive Stimulation Therapy group?**

IRAS Project ID: **201654**

I am pleased to confirm that Oxford Health NHS Foundation Trust (OHFT) has the capacity and capability to undertake the above named research study, as described in your Statement of Activities report. This confirmation is dependent on formal approval from the HRA, which includes a favourable ethical opinion from a National Research Ethics Service Committee if applicable. The HRA approved documents should be provided to us, and where appropriate, all localised patient facing documents.

Oxford Health NHS Foundation Trust agrees to start this study on 16th November 2016 as previously discussed with you. This confirmation of capacity and capability is dependent on you and the sponsor commencing the study within 3 months from the date of this letter. If the study does not commence by 16th February 2017 then please notify the R&D office as the Trust position may have changed and this confirmation of capacity and capability may need to be reassessed.

Recruitment

NHS Trusts are required to meet and report on performance standards set against national recruitment targets, one of which is first participant recruited to a study. I can confirm that your first participant target recruitment date is 24th January 2017. In addition to this, a study is expected to recruit its target sample size within a pre-specified recruitment period. In the

Statement of Activities you state that the Trust's involvement in your study will end on 30th September 2017 and that a target recruitment of 8 participants is required. If you feel that you may not meet these targets please notify the R&D department immediately.

Access to NHS for Research Purposes

Completion of a Research Passport Application may be required for researchers who do not hold a substantive or honorary contract with an NHS organisation. Research activity should not take place at this site until either a Letter of Access or Honorary Research Contract has been issued for individuals where this applies. Please contact the R&D office to check if this is required.

Governance & Compliance

It is the Trust's expectation that the study will comply with all applicable and relevant laws, such as the Data Protection Act (1998), the Human Tissue Act (2004), the Mental Capacity Act (2005) and adheres to the Research Governance Framework (RGF), the principles of (ICH) Good Clinical Practice (GCP) and the NHS Confidentiality Code of Practice (Nov 2003) and if applicable the Clinical Trial regulations.

Oxford Health Foundation Trust R&D Website

In order to comply with the Research Governance Framework and your ethical approval we will list of your study on our Trust's website.

Please note that the Trust, as host organisation, is required to monitor research to ensure compliance with the RGF and other legal and/or regulatory requirements and you may be asked to provide access to authorised individuals from the R&D office for monitoring or audit purposes.

In working with the Trust there is an expectation that the following are provided to the R&D office in a timely manner;

- date of first participant recruited
- ongoing recruitment figures
- copy of reports to the HRA/REC
- any substantial or non-substantial changes relevant to the OHFT
- final report on completion of the study
- any publications arising from the study
- immediate notification of changes in involvement of key site personnel

If you wish to discuss this further, please do not hesitate to contact the R&D Office.

Kind regards

Professor John Geddes Director of R&D

Healthcare from the heart of your community

Berkshire Healthcare NHS
NHS Foundation Trust

Amy Murphy
The Oxford Institute of Clinical Psychology Training
Isis Education Centre
Warneford Hospital
Oxford, OX3 7JX

Research & Development
Fitzwilliam House · Skimped Hill Lane
Bracknell · Berkshire · RG12 1BQ
t: **01344 415825**
f: **01344 415666**
e: **research@berkshire.nhs.uk**

7th March 2017

Dear Amy Murphy

Re: Letter of Access for Research - How do people with dementia and their carers experience social interaction and communication after attending a Cognitive Stimulation Therapy group?

Berkshire Healthcare NHS Foundation Trust confirms your right of access to conduct research through the organisation for the purpose and on the terms and conditions set out below. This right of access commences on 08.03.2017 and ends on 22.09.2017 unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with this NHS Trust. We are satisfied that the research activities that you will undertake in Berkshire Healthcare NHS Foundation Trust are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisation. Evidence of checks should be available on request to Oxford Health NHS Foundation Trust.

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

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

While undertaking research through Berkshire Healthcare NHS Foundation Trust, you will remain accountable to your employer Oxford Health NHS Foundation Trust but you are required to follow the reasonable instructions of your nominated manager Stephen Zingwe in this NHS Trust or those given on his behalf in relation to the terms of this right of access.

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

You must act in accordance with Berkshire Healthcare NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Berkshire Healthcare NHS Foundation Trust in discharging its duties under the Health and Safety at Work Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Berkshire Healthcare NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and Berkshire Healthcare NHS Foundation Trust prior to commencing your research role at this site.

You are required to ensure that all information regarding patients or staff remains secure and **strictly confidential** at all times. You must ensure that you understand and comply with the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

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

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS Trust accepts no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS Trust or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Research & Development

Appendix Y – Ethical considerations

The following account summarises the ethical issues considered throughout the research process. These considerations were reviewed and approved by the NHS Research Ethics Committee.

Informed consent

Informed consent was required by both the person with dementia and their carer to participate in the research. As participants were in the mild to moderate range of dementia, it was expected that they had the mental capacity to give informed consent to taking part in the study. This was initially assessed by the group facilitators and if participants had capacity then their details were passed onto the researcher. Consent was obtained at the start of the interview process and mental capacity was assessed by the researcher each time they met with the participant. The researcher adhered to the principles of the Mental Capacity Act (2005) when assessing capacity and ensured that the person with dementia could a) understand the information relevant to the research study, b) retain the information for long enough to make a decision, c) weigh the pros and cons of taking part in the research and d) communicate their decision regarding participation. If the person with dementia was considered to lack capacity, they would be excluded from taking part in the study and the group facilitators would be notified by the researcher.

Participants were asked to give informed consent for the interviews to be audio-recorded and later transcribed. They were asked to consent to verbatim quotes being published in the final report. It was outlined in the information sheet and verbally that all names and identifiable information would be removed or changed to ensure anonymity of all participants.

Of note, all participants were considered able to provide informed consent.

Coercion

The risk of coercion was controlled for by providing participants with information about the study and asking them to opt-in by expressing an interest to the group facilitators and giving consent for their contact details to be passed onto the researcher. The researcher provided further information about the study to participants when they contacted them via telephone. This enabled both the person with dementia and their carer to individually ask the researcher questions about the study before arranging the interview. Participants were given a minimum of 24 hours to read and consider the information sheet before the researcher obtained informed consent and conducted the interviews. Furthermore, in order to address possible power imbalances between the dyads, the information sheets were firstly given to the person attending the group, rather than to their named carer. This was to encourage a sense of autonomy in the individual and to enable them to make an informed choice about whether to participate.

Right to withdraw

Participants were informed that they had the right to withdraw their data from the research within 2 weeks of the interview being completed. After this time point, the data was written up for the purpose of the study, making it difficult for their data to be withdrawn, as all identifiable information had been removed. If they chose to withdraw within this timeframe, they would have been informed that this would not affected the care that they received from the service. This was communicated on the participant information sheet and at the start of the interview process. The researcher's contact details were provided on the participant information sheet.

Of note, no participants requested to withdraw from the study after completing the interviews.

Managing distress and risk

Due to the potentially sensitive nature of the research, participant's well-being was verbally assessed during and at the end of the interview. Participants were made aware of the limits of confidentiality. This was also communicated on the participant information sheet and at the beginning of the interview process. If there were any concerns about the welfare of the person with dementia or their carer, the researcher would encourage them to discuss this with the group facilitator or their GP if they had been discharged from the memory service. If there were concerns regarding risk, the researcher planned to adhere to NHS safeguarding procedures. Details of available services that provided emotional and practical support were made available by the researcher, including PALS, crisis telephone numbers and dementia advisers.

Of note, no risk issues were raised during the interviews.

Confidentiality and data

The interviews were audio-recorded on an encrypted Dictaphone. All transcribed material was anonymised and stored securely on an NHS password protected computer. After study completion, all transcripts and recordings are being stored at a secure NHS base.

If the interviews were conducted at participants' homes, the researcher adhered to Oxford Health NHS Foundation Trust's Lone Worker Policy.

References

Mental Capacity Act. (2005). Code of practice. Department for Constitutional Affairs. London: TSO.

Appendix Z: Matrix of participants who endorsed the superordinate and subordinate themes

Super-ordinate themes	Subordinate themes	Dyads																Total
		1			2		3		4		5		6		7		8	
		Annette	Alan	Betty	Beth	Charles	Celia	Doris	Danielle	Edith	Elaine	Frank	Fearne	Gladys	Gina	Harold	Henry	
1. Barriers to socialising outside of the group	(1a) Diminished opportunities to socialise	*	*	*	*	*	*	*	*	*	*		*	*		*	*	14
	(1b) Physical health			*	*	*		*	*	*	*	*	*		*		*	11
	(1c) Understanding the diagnosis	*	*		*			*	*		*		*		*	*	*	10
2. Sharing and feeling supported in the group	(2a) Sharing with similar people	*	*	*		*	*	*	*	*		*				*		10
	(2b) Support in the group to interact	*	*	*	*	*	*	*			*	*	*			*		11
	(2c) CST as a social opportunity	*	*	*		*				*			*	*	*	*	*	10
3. The family as enablers	(3a) Family providing stimulation		*		*			*	*		*				*		*	7

Super-ordinate themes	Subordinate themes	Dyads																Total
		1		2		3		4		5		6		7		8		
		Annette	Alan	Betty	Beth	Charles	Celia	Doris	Danielle	Edith	Elaine	Frank	Fearne	Gladys	Gina	Harold	Henry	
	(3b) Focussing on practical tasks		*		*		*	*	*		*				*	*	*	9
4. The impact on carer	(4a) It's effortful	*		*	*	*	*	*		*	*	*	*	*	*	*		13
	(4b) CST as a 'relief'		*		*		*		*		*		*		*		*	8
5. Noticeable change after CST		*	*	*	*	*	*	*	*	*	*	*	*		*	*	*	15
6. Keeping it going after CST	(6a) The need for more	*	*		*	*	*	*	*	*	*		*	*			*	12
	(6b) CST at home			*	*	*	*				*		*	*	*	*	*	10

Appendix AA – A selection of illustrative quotes

Superordinate themes	Subordinate themes	Illustrative quotes – participant, quote and line number
Barriers to socialising outside of the group *"Socialising is difficult"*	Diminished opportunities to socialise *"I don't meet too many people"*	**Annette (PWD 1)** 257-258: I used to have a car and be able to drive up and see them and spend the day with them, but now I can't do that. **Betty (PWD 2)** 307-308: being picked up and taken home was lovely and not having to worry about transport, it was all very nice. **Celia (Carer 3)** 295: we don't do those things to that extent we used to **Gladys (PWD 7)** 26: Not a lot since I've been here **Harold (PWD 8)** 15: I don't sort of go out anywhere else **Danielle (Carer 4)** 257-259: most of her friends now have very sadly passed away and again not being able to get out and see people, last year she lost her best friend in the summer **Doris (PWD 4)** 398-399: I don't have many people now to communicate with, they've all gone.
	Physical health *"If it wasn't for my bad leg…"*	**Betty (PWD 2)** 587-589: I went to answer the phone and went flying over it and then of course the metal part was up like that, chrome, and I went down and my full weight went down on the chrome and of course it started them off **Beth (Carer 2)** 575-577: last year mum had the ulcers on her legs which were horrendous um, and now that they are a lot better, hopefully we'll be able to get out for some little walks just around and about. 354-358: And because she's got hearing problems and eyesight problems and memory it's hard for her to take the initiative to say, "yes I will go to a social group" and she feels very inadequate, so that's why I was really amazed that she enjoyed the group as much as she did. **Charles (PWD 3)**121: the possession of that are the effect of the seizure **Doris (PWD 4)** 48: And now I've got this croaky throat and I can't talk properly. 82-83: and she said that I could get to that on the bus, if I didn't have my bad leg 102-103: Um, well mainly I think because XXXX (another group member) was the one I communicated with, although difficult because of the hearing problems **Danielle (Carer 4)** 213-217: I think particularly because her hearing is not good she found it quite hard. I notice when have family groups I notice that it's quite hard for her to keep up unless you put her somewhere in the middle because big noisy family, there is too much going on really for her to participate **Edith (PWD 5)** 33-34: And since my sight is going I lose track of them because I can't recognise them always

		Elaine (Carer 5) 293-295: so, she can do it but she's lost a lot of confidence as well because then she says, "I can't see the money in my purse, can you pay", so she's lost a lot of confidence about what she can do **Frank (PWD 6)** 68-71: I've got a problem with my eyes so I had to give up driving all together and I'm still waiting for a guy, they want to clear this each side, because anything sad I'll have tears running down my face, which is embarrassing at times. **Fearne (Carer 6)** 132-134: he is hard of hearing and I never know whether it's because he hasn't heard or whether he hears but he can't actually process the information., **Gina (Carer 7)** 125-126: I think it's hearing as much as anything, I think people with hearing loss lose a lot of confidence
	Understanding the diagnosis *"Everything changed"*	**Annette (PWD 1)** 101-104: some of the meetings I've gone to, a couple of people I know, they won't go to the meetings, because they don't want to be with sick people. It's this weird sort of feeling people might have, like I might catch something or they won't be able to talk to me or they won't understand me or I won't understand them **Alan (Carer 1)** 324-325: In fact, she misses it, because there is a stigma attached to it, she misses those people that she used to see on a regular basis. We are trying to overcome that. **Doris (PWD 4)** 133-139: I must say, the only time I've really socialised is that big dinner dance that we have that I told you about and that nice lady said they are all a bit mental, that was a bit of a push back, had I been courageous I'd have said "I'm an inmate" but I didn't I was a coward, I didn't say anything. **Danielle (Carer 4)** 285-287: I think because somebody showed an interest in her is pretty key to this that actually she wasn't written off because she was 84, people were bothering. 289-290: we kick in and completely annoyed the medical profession by saying she's not being listened to she's just being treated as an old lady **Beth (Carer 2)** 471-476: Sometimes I'm amazed at what she remembers, little things. Sometimes I'm amazed at what she doesn't remember, and you can have a conversation on the phone, like when we came back just earlier this week, "yep your back, your back safe and sound, where are you now? How's XXX, and you say and then two minutes later "so where are you, where are you darling, are you alright?". **Danielle (Carer 4)** 292-293: it's quite a label dementia and I still don't see, she's quite sensitive about the definition diagnosis, you know you've suddenly got a label

		Gina (Carer 7) 120-121: I don't know because it's quite alien, you know, as we were growing up mum was very confident, so I think it's the memory loss that probably makes her more uncertain 145-146: yes, it can be quite upsetting knowing the mum that we knew all our lives and the mum who's now got Alzheimer's. **Doris (PWD 4)** 146-149: I think it helped me over this initial stage where one is not quite sure what dementia is and you sort of have to pick up points from people as to what it is and…I can't think of any other ways to describe it, as seeking knowledge to know what it is we are walking into. **Harold (PWD 8)** 120-123: it's a bit worrying because my mother had very bad dementia and she didn't even know who I was before she died but um, I presume I've got some of her genes that's why I'm the way I am I don't know, I hope to goodness that I don't end up like her but you don't know do you? **Henry (Carer 8)** Carer 203-207: well I guess it made him feel a bit nervous, obviously he didn't really know what the group was, what would happen during the sessions and I guess whenever you go into a clinical environment you look at other people and think, I mean I've been in hospital with physical things and you think "hmm, am I going to end up like that or like that" so I imagine there's a certain amount of concern I guess
Sharing and feeling supported in the group	Sharing with similar people *"We all do it"*	**Alan (Carer 1)** 395-296: Because they all got friendly. They all got friendly. They all had the same problems in different degrees and they all understood one another. **Annette (PWD 1)** 145-147: But, it is an interesting moment there, I have to say because you hear other people talking about what they feel, and they understand, everybody understands. **Betty (PWD 2)** 162: It was nice sharing, I quite enjoyed it. **Doris (PWD 4)** 103-105: she was very similar to me, same absolutely we could have been twins, same education same everything. **Danielle (Carer 4)** 262-263: I think just the ability to talk and share ideas 259-260: she immediately found someone to talk to someone with common interests she mentioned that immediately **Frank (PWD 6)** 62-64: I think we all had something wrong with us, **Charles (PWD 3)** 103-104: In this situation, here I know the people I can talk to, they will do it well. Everybody out there, family and friends and um, I just go. **Celia (Carer 3)** 206-208: He didn't tell me he'd been bad speech wise, um, I think they all made allowances for one another I don't know what sort of situation the other people were in

	Support in the group to interact *"Getting people talking and thinking"*	**Annette (PWD 1)** 208-209: I thought to myself, oh that is good. You are not telling us but you are sort of giving us little clues that will sort of knock us and letting us look at each other and go "ummm" **Betty (PWD 2)** 305-307: there was a young man there and he used to write on the board the things that we were talking about, it was very, um, very pleasant, just getting people talking and thinking about things **Harold (PWD 8)**137-145: and then there was another lady there, I can't remember what her name was, she was very jolly school girl type of person and then she livened things up anyway, made us all welcome, you know, we were cheered up really, I'm sure
	CST as a social opportunity *"To me, it was social"*	**Annette (PWD 1)** 667-669: To me it was social, I like social, you know, I'll talk to anybody, anywhere, and it was nice to be able to listen to other people and hear what they have done and been doing **Charles (PWD 3)** 134: I liked to see the people that I know, going to meet with people **Gina (Carer 7)** 176-179: we were just pleased that she had another social activity, she doesn't do anything on a Monday **Harold (PWD 8)** 89-90: it's like a social event really, you know, you meet someone twice a week who you've never seen before and you got to become friends with them 130: I took it as a social event, to be honest with you **Henry (Carer 8)** 193: he made a friend there which helped I think
The family as enablers	Family providing stimulation *"Being reliant on us"*	**Beth (Carer 2)** 490-492: you don't know whether to say to wake her up and say "come on mother you're with us at the moment, have a little bit of stimulation" **Betty (PWD 2)** 191: I see the family and everything, it's nice, it keeps you alert. **Henry (Carer 8)** 339-340: We've been doing a few puzzles and things haven't we, we've tried a few models and do things together **Danielle (Carer 4)** 267-269: We were really pleased, I have to thank XXXXX (another sister) for that because XXXX has Mondays off work and goes completely energetic about finding things for mum to do, making sure that she's stimulated all those good things like that 271-272: she's now back to being back in the house and being reliant on us kind of taking her out 414-420: And I know XXXXX (other daughter) is fantastic, XXXX is forever arranging amazing holidays to take you but she's kind of doing the same thing for you…to make sure you're always doing something, that you've always got a beautiful view to look at, you know something that's just a bit different, different walls and environment, different food

		Elaine (Carer 5) 296-299: unless I'm around or my husband is around to say "we're going out XXXX will you come with us" for a little walk to the shops or whatever, but otherwise she tends to stay in and sit on her sofa and listen to books all day, so I like her to go out. 312-315: we have her over here for dinner every evening, which is nice because then she interacts with us here, the family, the girls and as I say there's a great deal of chit chatting and she forgets it all but that's fine but at least there is that interaction.
	Focussing on practical tasks *"Oh, that lightbulb needs fixing".*	**Beth (Carer 2)** 458-461: I like to smooth her arm and that, while she's watching TV and I can make sure she eats properly. **Celia (Carer 3)** 260-261: I'm on escort duty for dentist and doctors **Elaine (Carer 5)** 241-243: when I pop in it will be queries about "oh that bulb needs fixing" and then two minutes later "that bulb", "yes mummy I know that bulb needs fixing I'll get it sorted out" **Henry (Carer 8)** 278-279: I'm trying to do more practical things yeah, 307: Heating, sorted the heating so you could put a new bathroom in **Danielle (Carer 4)** 352-355: Well we've got the Ready Bus in XXXX and we've got so many facilities where we could have her picked up and I think it will take us to give her a hand to do these things… we can do that for her easily.
The impact on the carer *"we do the best we can"*	It's effortful *"It still needs an awful lot of effort from me"*	**Beth (Carer 2)** 376-382: it takes an awful lot of energy from me, to get mum motivated, to get her ready to get her to do things and then there's things like um, you have to remember things like that she goes to the toilet, because if she leaves it too long, you know then there's problems, it like having a child really and sometimes when the sermon finishes I'm like "right mum, let's get to the loo before there's a long line", and then "oh no no, I'm fine darling", "well let's just try", you know if you don't try then I have to end up dealing with that little situation. 384: Lots to manage 402-405: once you make the effort mum, you know you will be pleased you did, um but again, it still needs an awful lot of effort and encouragement from me. 449-450: it's a lot of stress and strain worrying about mum. **Celia (Carer 3)** 241-245: Well to start with I went to the doctor because I was getting so um, uptight with impatience…irritable that's the word and he gave me some tablets which…they won't give me a sleeping tablet,

		they're to help me calm down I suppose, which made things better and now I can sleep all night which I wasn't doing. **Elaine (Carer 5)** 270: So, you know I have that little battle with her **Fearne (Carer 6)** 142: I had to sell it to him **Gina (Carer 7)** 132-140: Erm, quite, quite, it was quite difficult because we knew…everything is full circle it's like treating your children, we knew once she was there she'll be absolutely fine so there was a fine line between bullying her into going somewhere and not. As an example, we were going to take her to my sisters who lives in XXXXX, she comes through every week, to stay for a few days over Christmas and I got here and she'd dressed and everything ready to go and I said right we're taking you to XXX, "oh no I don't want to go", so there, do you sort of say well you're going, but we couldn't, so it has been quite upsetting at times, and there are times when I can say "yeah come on mum", like the Monday sessions. **Doris (PWD 4)** 387-388: Well she's a very busy lady, as you must have found out, she spends as much time as she possibly can, helping me which is much appreciated **Charles (PWD 3)** 362: I tell you she's my staff **Edith (PWD 5)** 76-77: to be living next door to my daughter, she's my lifeline now, 91-92: I'm so happy to be next door to my daughter, I hope I am not too much of a bother to her.
	CST as a *"relief"*	**Alan (Carer 1)** 368-370: But it means that somebody else is keeping a watch on her, not that she has done anything crazy before, but I don't really like leaving her for a long time. 662-664: Well, suddenly Annette was not in my care, by that I mean someone else was looking after her, who I trusted, who was in the right place if anything went wrong she was in the hospital, so that was fine. **Beth (Carer 2)** 348: Absolutely, oh, brilliant, because um…. everything is on my shoulders **Celia (Carer 3)** 179-181: I suppose it was only about an hour because the time he went and coming back um, really, I just had a lazy and just sat down and not worry about anything for a while. **Elaine (Carer 5)** 285-286: I like her going to groups, because otherwise she stays in a lot, she doesn't go anywhere **Fearne (Carer 6)** 191-193: Well I was really pleased, I mean being perfectly honest, the first thing is that they've got an activity and it fills out part of the day, so it gives me a break, because I'm with them 24/7. 225: Well it's a relief really, you know, so that they, um…to start off with it was hard

		Gina (Carer 7) 176-179: she doesn't do anything on a Monday so, in a way it kind of, oh this sounds awful, released us from feeling like we ought to take her out or we ought to sort of, because you know, socialising is so important isn't it **Henry (Carer 8)** 224: Well I guess I was pleased that he was doing something
Noticeable change after CST *"He's much more keen to do things, but his memory is probably worse"*		**Alan (Carer 1)** 384-385: Well, it was amazing how after a period of time, she was chatting quite, she's a friendly soul in any case, but they were all chatting together and that's the point, everyone talking together. 480-481: Because at the end, they were all talking. There was no one who didn't participate, throw themselves into a thing that they all seemed to enjoy. **Annette (PWD 1)** 600: It was nice to be able to tell him what I had been doing, so he knows what's going on. **Celia (Carer 3)** 212-213: when he'd done something, he came home some days he was more full of it than others 254-257: Well just body language I suppose…he looks a lot happier that's the only thing I can say, when he's talking to people. **Doris (PWD 4)** 123-124: It made me feel better. Yes. It made me feel that I haven't lost everything yet. 173-175: I'd have probably gone miserable, if I hadn't gone to that course I'd have found it much more difficult to join one of the outside luncheon clubs or things, and I'd give it a very big plus. 410: you dragged me from my pit of despond **Danielle (Carer 4)** 236-237: I think that group was just a real life-saver for her. 239: She loved it, absolutely, we saw the difference her immediately. 280-283: she's kind of more interested in things whereas previously she just kind of sit quietly like a little mouse in the corner 322: She is better, she is most definitely better and she's happier in herself 298: She's got more spark, I really think she's got more spark **Fearne (Carer 6)** 160-163: I think dad used to think that if he could answer the questions or put his hand up then he must do it very well and he must be better than everybody else so I think he got a bit of a buzz from sort of going. 279-283: it doesn't matter who they are, dad is always pleased to speak to them and that is probably more, more confident in speaking to them I would say than potentially before, so before, he would only talk to the people probably that he knew, now whether he thinks I'm not sure if I know you or not so I'll just speak to you anyway, he'll speak to anybody.

		323: it's just given him confidence **Henry (Carer 8)** 207-209: he was quite chatty about what they had done and the songs they had sung or memories that they've talked about, he seemed reasonably happy. **Beth (Carer 2)** 402: I think, if I'm honest, things haven't really changed, **Harold (PWD 8)** 88-89: I don't think it was to make my memory any better because I don't think it did **Henry (Carer 8)** 185: I wouldn't say that anything has changed particularly. **Gina (Carer 7)** 190: I don't see any difference at all, neither positively nor negatively 319-320: As I say, I certainly haven't felt there was any improvement as a result of the 14 weeks but you went **Elaine (Carer 5)** 178-179: So I don't' think, I'm not sure that it affected her cognitive reception particularly
Keeping it going after CST	The need for more *"It's essential we find something to replace it"*	**Alan (Carer 1)** 609-610: Well Thursdays spare, unless you fill it with something else. So it's either up to me or the group. We have to find something else. 485-488: 10 weeks, it was over 10 weeks and by the time we finished we thought, ah, it's like leaving home. You think oh my god, what are we going to do now? Every Monday was booked up, for how many weeks, about 9 or 10 weeks. **Beth (Carer 2)** 535-538: I wish there was something else we could get her to on a sort of similar sort of basis um, that would start a bit later in the day 541-543: Um, so something like that, I think because she is now familiar with (place of CST) and the routine, I think she would happily go back to something again, if there was anything. **Celia (Carer 3)** 318: It means you don't go off twice a week **Danielle (Carer 4)** 251-252: I think my fear is the fear of the rest of the family is what happens now, is she going to fall off the end of a cliff 421: there must be something as well as a follow-up **Elaine (Carer 5)** 179-182: I say they really enjoyed it and I say XXXX another lady who mummy became quite friendly with and they both said they were going to miss it terribly, so we'll have to find some other little group that I can take her to. 277-283: No, as I say it was a great success, in a way I wish it could go on but I understand that there are many people waiting to join the group, so I know there are some other, lots of other memory things, there is one at the nature reserve down the road here on a Monday morning and there is one at the corner exchange once a month, so I'll try those depending on how I can fit it in around my work, I'll try and get her to some of those, but they might

		not be as regular as the CST group, which somehow I always seemed to be free on Thursdays, um, so we'll just take it from there really. **Henry (Carer 8)** 251-252: There's a couple of things I've encouraged him he might want to do 255-259: I saw something on the news where there's, he's a member of a boat club so he does have some social time with them but I saw something on the news about like a shared workshop for old men and if that existed locally that would be perfect for him, because he's obviously got a lot of knowledge from building things his entire life. **Gladys (PWD 7)** 64: What a shame **Edith (PWD 5)** 70: I'm sorry that the group stopped in the end. **Annette (PWD 1)** 127: We were all sorry when it stopped, all of us. **Doris (PWD 4)** 75-76: on the whole, it's fourteen weeks that I really enjoyed and I wish there was another one
	CST at home *"It would pass half an hour"*	**Gina (Carer 7)** 299-303: You would do sort of different activities within the group when you went to your classes and maybe I hadn't really thought about doing something like that with you but perhaps we could or get the memory books out **Beth (Carer 2)** 405 I was just looking through the information that was had contained in the folder for activities and things and I have marked up some, **Celia (Carer 3)** 331-332: We did look through it, I looked through it because I saw there was a lot of blank sheets so we're going to sit and do those **Gladys (PWD 7)** 315: it would pass half an hour **Betty (PWD 2)** 617: well I don't really think about it do you? we just read through…. 145-148: I just feel relaxed and happy, if I do, and if I don't then I'm quite happy with the paper and the television.