Does a Post-Diagnostic Dementia Group Increase Relationship Satisfaction in Couplehood?

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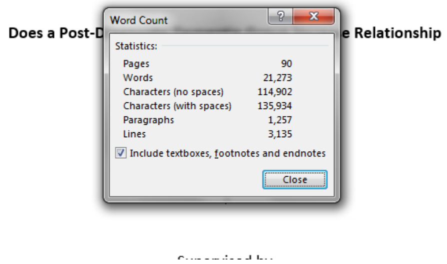

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Introductory Chapter: Thesis Overview

There is growing interest in the research literature towards relationships in the context of dementia care. This thesis focuses upon the relationship between spouses when one has a diagnosis of dementia, called here the ‘care-dyad’. Group interventions that may benefit both spouses amidst the inherent challenges of the diagnosis are explored. This thesis is divided into two chapters.

Chapter one presents a systematic review of the available evidence for group interventions that have been designed for both spouses, where one spouse has a diagnosis of dementia. The review synthesises the evidence from available research, highlighting the limited efficacy of group interventions and suggests a need for more empirical testing to understand the processes that occur within dyadic interventions. Limitations of the empirical evidence suggest a lack of theoretical underpinning of the interventions tested and the inconsistent use of outcome measures that have been recommended for dementia research.

Findings demonstrating few significant benefits to care dyads and some negative consequences to carers raises significant ethical considerations when empirically evaluating such interventions within practice settings. Therefore, in considering dyadic group intervention research within dementia, the possible benefits and costs to the participants must be weighed up (Woods et al, 2012). Of note, previous studies have limitations, in which this study aimed to build upon. As such, Chapter 2 evaluates the efficacy of a dyadic post-diagnostic group intervention that is delivered within routine older adult health care services.

The study described in Chapter 2, builds upon previous limitations in three ways. First, this study uses an entirely spousal sample, as previous dyadic intervention study samples included people with dementia and their carers, including spouses and family members. This is important as the needs, roles and emotional reactions to family members with dementia differs between spouses and adult children (Braun et al., 2009). Second, a number of outcome measures have been recommended by expert consensus for use with dementia studies, however, previous studies have not consistently used these outcome measures. As such, this study uses recommended outcome measures for use in dementia research. Third, this post-diagnostic group draws upon the couplehood literature and equity theory, which is novel in comparison with previous studies, which have not described their theoretical framework, a limitation previously highlighted by Braun et al. (2009).

Preliminary unpublished qualitative data evaluating this post diagnostic group, previous to this study, has demonstrated that participants report benefits in improving their ability to cope and their knowledge of dementia, as well as considering the intervention to be both appropriate and satisfying. Previous participants have not expressed negative consequences of the intervention and furthermore, retention rates for the intervention have traditionally been high, which supports the supposition that the intervention appears acceptable for participants. This post-diagnostic group however, had not been studied using validated quantitative measures. Given that the present study aimed to build upon previous limitations described above, and that participants have previously reported positive qualitative experiences of this post-diagnostic group, the decision was made to explore the potential efficacy and effectiveness of this intervention using standardised quantitative measures.

The second chapter presents an empirical study of whether a post-diagnostic dyadic group intervention, which is theoretically informed by the 'couplehood' literature, increases relationship quality for spousal dyads, where one spouse has a diagnosis of dementia. The findings are explored and discussed within a theoretical context.

The chapters in this thesis have been formatted to the guidelines set out by *Dementia*, the international journal of social research and practice, which adheres to SAGE style and APA referencing. The guidance provided by *Dementia* has been summarised in Appendix 7.

Chapter 1:

Dyadic group interventions for spouses in dementia: A systematic review[1]

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[1] Article prepared for submission to *Dementia*

Abstract

The efficacy of dyadic group interventions for couples, where one spouse has dementia, remains unclear. This paper aims to systematically review the efficacy of group interventions for spousal-dyads within the dementia literature. A search of all studies from Psychinfo, SCOPUS, EBSCO, Medline, and Web of Knowledge was conducted in November 2013. Studies were included if they met the criteria of assessing a dyadic group intervention for spousal dyads. Six studies were quality assessed and reviewed. One reported significant improvements in quality of life and depression for people with dementia, whilst another reported significant improvements for carer's preparedness for the future, preparedness in maintaining cognitive activities and perceived effectiveness. These findings were either modest or limited by non-standardised measurement, and some evidence suggested that carers may experience more distress following intervention. The review highlights that, to date, there is little quantitative evidence to suggest whether group interventions are beneficial for care-dyads.

Keywords

Dementia, dyads, spouses, intervention efficacy

Introduction

With the ageing population, the number of people with dementia across the European Union (EU) is set to rise. The economic and social cost of dementia with an ever growing population represents a huge challenge, with the European Commission (2009) estimating a cost of €130 billion a year to the EU. In the UK alone, it is estimated there are 800,000 people living with dementia, which is predicted to rise to 1.4 million people over the next 30 years with an estimated cost of up to £50 billion a year for the provision of care (Alzheimer's Society, 2012).

In response to a growing population of people with dementia, the European Dementia Research Agenda (International Longevity Centre-UK, 2011) highlighted the need to prioritise dementia within the current health, social and research policy across the EU. More recently in December 2013, countries from the G8 summit agreed to substantially increase funding for dementia research. Their aim was to increase the number of people involved in dementia studies and to develop an international, shared action plan for research (Department of Health, 2013). The involvement of people with dementia in research is an important consideration as in the UK, less than 1% of people with dementia are involved in intervention studies (International Longevity Centre-UK, 2011). People in the early stages of dementia however, are often as aware of the implications and difficulties associated with dementia as their caregivers (Whitlach, Feinberg, & Tucke, 2005). Furthermore, they are able to report their experience in the early stages and can still maintain their sense of self into the later stages of the illness (Adams, 2006; Menne & Whitlatch, 2007; Whitlatch et al., 2005).

With regards to social policy, over the last 10 years, the UK government have continually aimed to improve dementia care (e.g. Forget me not, Audit Commission, 2002; National Dementia Strategy, Department of Health, 2009; Prime Minister's challenge on dementia, Department of Health, 2012). Whilst providing good quality care presents an economic challenge to the UK and EU economies, it is informal carers including spouses and family members who bare much of the costs (Camden, Livingston, & Cooper, 2011; Montgomery & Williams, 2001). Consequently, national policy has given carers a formal identity and carers have been increasingly moved towards being part of the 'care team', which Szmukler and Holloway (2001) argue, provides an environment conducive to progress (2001). This professionalisation of informal carers (Henderson & Forbat, 2002) encourages the provision of care to take place primarily within one's own home (Challis et al., 2009).

Whilst informal carers provide the foundations of dementia care, empirical research has consistently demonstrated the physical and psychological impact that carers experience, including increased stress and depression, and deterioration in well-being, physical health, and self-efficacy (Brodaty, Green, & Koschera, 2003; Pinquart & Sörensen, 2003; Chein et al., 2011; Elvish, Lever, Johnstone, Cawley, & Keady, 2012).

Recognising the fundamental role of informal carers and their need for support, the European Dementia Research Agenda (International Longevity Centre-UK, 2011) recommended more carer-centred research. This research tends to focus upon ameliorating carer distress (Braun et al., 2009), with the majority of interventions delivered in a group format. Meta-analyses' have reported mixed results regarding the effectiveness of these carer interventions with some demonstrating no effects on perceived burden (e.g. Acton & Kang, 2001; Brodaty et al., 2003) and some finding small but meaningful effects for psychological morbidity, caregiver knowledge and levels of well-being (Brodaty et al., 2003; Chein et al., 2011; Elvish et al., 2012; Pinquart & Sörensen, 2006).

In aiming to meet the needs of both the person with dementia and their carer, referred to here as the care-dyad, a range of interventions have been developed. These interventions are highly heterogeneous ranging from inpatient admissions (e.g. Bakker et al., 2011) to home visits (e.g. Gitlin et al., 2001). Some interventions utilise multiple components including home visits, telephone calls and groups (e.g. Eloniemi-Sulkava et al., 2009), whilst others are uni-modal, such as singular group interventions (e.g. Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

A series of reviews have been conducted to synthesise the effectiveness of these heterogeneous interventions. For example, Smits et al. (2007) reviewed 25 studies of 22 intervention programmes, which varied in design, intervention format and duration. They concluded that dyadic psychosocial intervention programmes yielded evidence of improved mental health for people with dementia and their carer, although the effects on most other functional and behavioural domains were moderate or inconsistent.

Building on the work of Smits et al. (2007), Van't Leven et al. (2013) conducted a further systematic review of care-dyad interventions. Again, the interventions were varied in treatment length and intensity and included groups, couples counselling, long-term multi-modal care and home interventions. The authors report that dyadic interventions increased the quality of life (QoL) for the care-dyad as well as reducing the dependency of people with dementia on their carer and improving the carers' sense of competence. Eleven of the 23 studies included in the review showed significant positive effects for both members of the dyad; however outcomes were inconsistent across studies, with some showing significant improvements in mood and functioning and others showing no effect.

In addition, Moon & Betts Adams (2012) reviewed 12 intervention studies published between 2000 and 2011, all including care-dyads. Interventions were largely heterogeneous, both in terms of the intervention type (e.g. cognitive stimulation, counselling, supportive seminar, day care, support group, or skills training) and duration. They concluded that intervention programmes for care-dyads in the early stages of dementia were feasible and well accepted. A combination of quantitative and qualitative findings indicated that both spouses in the care-dyad benefitted from these dyadic interventions, particularly in terms of improved cognitive functioning for the people with dementia and improved social relations for carers. Most of the studies presented evidence that spouses experienced improvement in the dyadic relationships, overall QoL and knowledge of dementia.

Overall, the interventions described in these three reviews tended to be multi-modal, with home visits, individual education and some group based elements (Moon & Betts Adams, 2012; Smits et al., 2007; Van't Leven et al., 2013). However, given the heterogeneity of the interventions reviewed, as well as the inconsistent findings between studies, it is not clear which intervention components are effective for care-dyads.

Another consideration is that most intervention studies reviewed did not distinguish between spousal caregivers and other caregivers, such as offspring, which is a limitation recognised within the dementia literature (Braun et al., 2009). This is important as spouses and other family carers have been shown to have different emotional experiences of caring, with adult children reporting feelings of grief, anger and frustration, compared to sadness as reported by spouses (Meuser & Marwit, 2001). Furthermore, spousal caregivers are at higher risk of physical and emotional difficulties within their caring role, compared with adult children (Barnes, Given & Given, 1992; Pinquart & Soerenen, 2003). This suggests that different carers have different experiences of caring and therefore, using mixed samples may increase the probability of Type I or II errors when measuring intervention efficacy.

In addition, the majority of interventions for the person with dementia and their carer were carried out separately. Care, however, occurs within a relationship (Henderson & Forbat, 2002) and there has been an increasing interest in the literature towards 'relational centred' caring (Nolan, Lundh, Grant, & Keady, 2004), with a growing rationale for intervention research to adopt a joint, dyadic approach (Abitt, Jones, & Meurs, 2009; Thompson & Walker, 1982). For example, Post (2001) suggests that rather than investigating QoL, research should focus on the 'quality of lives' of both parties within ———the care-dyad. There is also empirical evidence indicating improved carer mental health following interventions that have included people with dementia (Brodaty et al., 2003; Smits et al., 2007).

The current review aims to systematically review the efficacy of dyadic group interventions for spousal care-dyads where one has a diagnosis of dementia. The focus on a homogenous intervention and a spouse sample aims to provide a clearer synthesis of the efficacy of these interventions for care-dyads.

Method

Eligibility criteria

Quantitative and qualitative studies evaluating a group intervention where the person with dementia and their spouse attended together were eligible for inclusion in the review.

Eligible studies included group interventions which were fully dyadic, where people with dementia and their spouse attended the group jointly, or partially dyadic, where people with dementia and their spouse attended jointly, before moving into separate groups. Studies were included if the carers sample consisted of at least 60% of spousal caregivers and if the aim of the intervention was to reduce distress for one or both members of the dyad. Studies were excluded if the care-dyad received multiple psychological interventions e.g. group, individual or couples therapy, or where the people with dementia and their spouse only attended groups separately. Studies were not restricted by year of publication, but only studies published in English were eligible for review.

Information sources

Only online resources were accessed, namely Psychinfo, SCOPUS, EBSCO, Medline, and Web of Knowledge. The search was conducted in November 2013.

Search strategy

The following keywords were used; (coupl* OR dyad* OR spous* OR partner) AND (effic* OR effec*) AND (group) AND (support OR programme* OR intervention) AND (Alzheimer* OR dementia). Mesh or Emtree terms were also used to ensure the search was as complete as possible (Higgins & Green, 2011). The reference lists from the papers that met the inclusion criteria were screened to find additional studies that met the inclusion criteria.

Study selection

Initially, study titles and abstracts were screened and studies that were not relevant to dementia, or that clearly did not meet the inclusion criteria were excluded. Abstracts, methodology and demographic information of the remaining publications were then assessed to ensure they met the inclusion criteria. Duplicates were removed. Final publications eligible for review were read in full, with two reviewers independently providing a quality assessment.

Quality assessment

Methodological quality was assessed using the Quality Assessment Tool for Studies of Diverse Design (QATSDD; Sirriyeh, Lawton, Gardner & Armitage, 2012), which covers 14 domains with scores are on a 4-point Likert scale, ranging from "*no mention at all*" of a particularly domain, through to "*very slightly*" and "*moderately*" to "*complete*". The measure provides useful qualitative descriptors of each score to increase reliability and validity (see Appendix 1 for the quality assessment table), and accommodates varied methodological designs.

The QATSDD has good face validity and appropriate inter-rater reliability (k=.71). For the current review, the inter-rater reliability was within acceptable limits (k=.75). Quality assessment tools are not recommended as gold standard measures to evaluate papers (Higgins & Altman, 2008) given their low psychometric properties (Juni, Witschi, Bloch, & Egger, 1999). Therefore the quality assessment process was used only to provide an indicator of the strengths and limitations of studies. As such, studies were not excluded on the basis of the quality rating.

Results

Study selection

The study selection process is summarised in Figure 1. The search criteria yielded 773 records. Eight records were identified through screening the reference lists of papers that met the inclusion criteria. After duplicates were removed, 339 records remained. The removal of titles not meeting the inclusion criteria left 41 studies. On reading the abstract and method, a further 35 were removed as they did not meet the inclusion criteria: 31 due to intervention type and three due to the population sample. One study, Logsden et al. (2007), was removed as they presented preliminary data, which was reported again in a later study that has been included in the review (Logsden et al., 2010). Another study (Synder, Quayhagen, Sheperd, & Bower, 1995) was also removed as their data were used in a later study by Quayhagen et al. (2000), which has also been included in the review. This avoided the possibility of duplicated findings and biasing the review process. In total, six studies were identified as meeting the inclusion criteria for review.

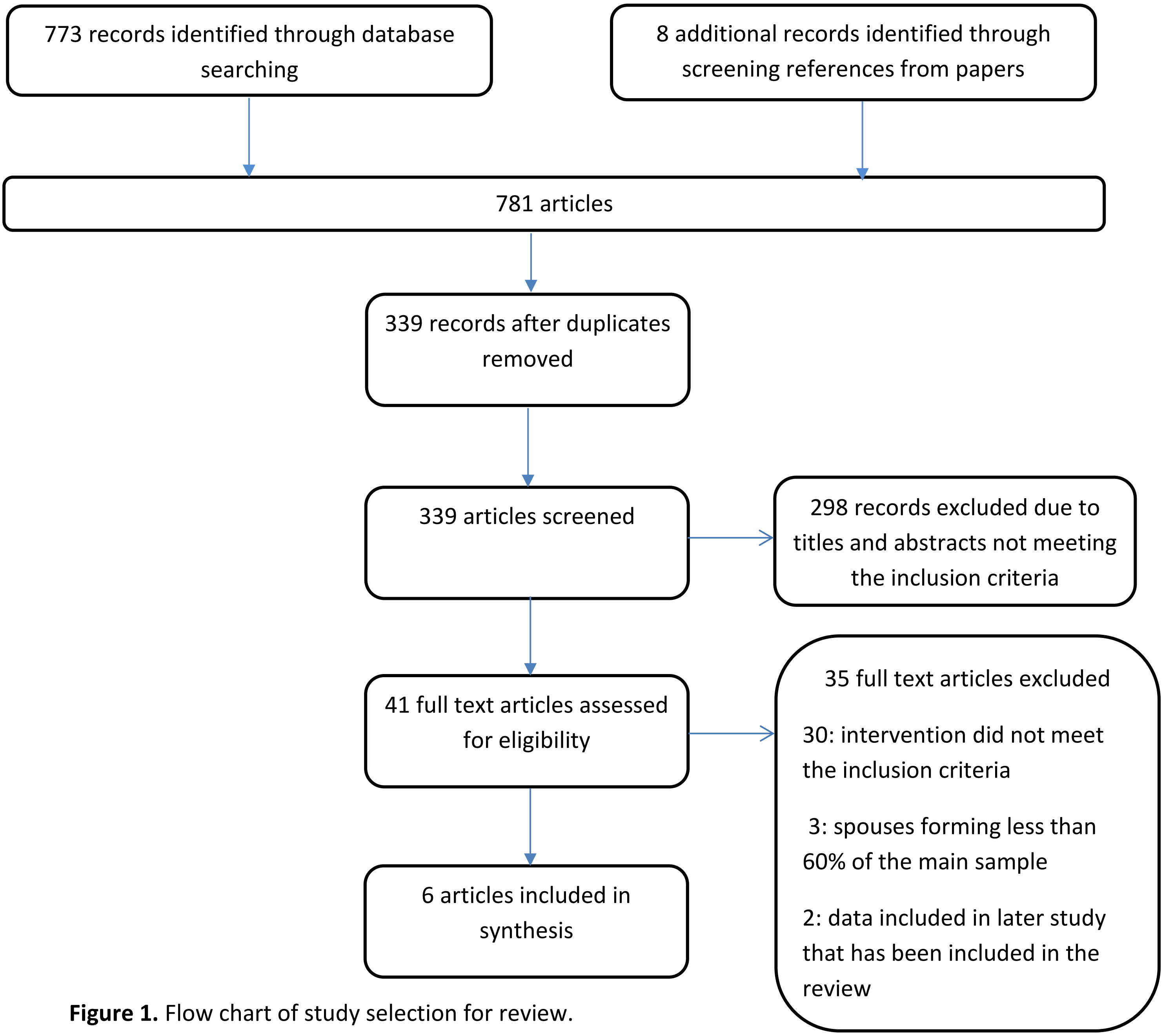

Figure 1. Flow chart of study selection for review.

Study characteristics

Three studies were randomised controlled trials (RCT; Logsden et al., 2010; Quayhagen et al., 2000; Woods et al., 2012) and three studies were single group designs; one evaluated the group following the intervention (Zarit et al., 2004) and two used repeated measures design (Gaugler et al., 2011; Roberts & Silverio, 2007). A summary of the included studies is reported in Table 1.

Group interventions tended to have a number of aims, but shared aims across studies were providing and sharing information (Gaugler et al., 2011; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009) and future planning (Gaugler et al., 2011; Logsdon et al., 2010; Quayhagen et al., 2000).

Two studies, Roberts & Silverio (2009) and Quayhagen et al. (2000), were fully dyadic programmes, in that care-dyads were together throughout the entire intervention. Four group interventions included combined groups for both spouses and split groups where carers and people with dementia met separately (Gaugler et al., 2011; Logsdon et al., 2010; Woods et al., 2012; Zarit et al., 2004)

Five of the groups were between 8-12 sessions long, whilst one study (Roberts & Silverio, 2009), was only four sessions. All group sessions lasted between 1.5-2 hours. The sample sizes varied, from 22 dyads - 488 dyads. Two studies were between 23-36 dyads (Quayhagen et al., 2000; Zarit et al., 2004), three studies were between 63-104 dyads (Gaugler et al., 2011; Logsdon et al., 2010; Roberts & Silverio, 2009) and one study included 488 dyads (Woods et al., 2012).

The majority of carers were female. In terms of the relationship between care-dyads, only one study (Quayhagen et al., 2000) had a total sample of spouses. All other studies had a spousal sample ranging between 66% - 80%. Five studies were conducted in the USA (Gaugler et al., 2011; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Zarit et al., 2004), whilst one study was conducted in the UK (Woods et al., 2012).

Table 1. Summary of study characteristics

Authors	Design	Intervention	Sample	Aim of Intervention	Outcome Measure	Main Findings	Quality Score
Quayhagen et al., 2000	RCT	8x90min sessions Joint group 30mins, separate groups 60mins	Experimental group, *n*=22 dyads. Control group, *n*=15 dyads. 100% spousal sample. Mild-moderate dementia.	Collaborative planning for the future	**Primary Outcomes** Spousal coping with dementia	Non-significant on all measures	24/42
					Secondary Outcomes Stress, coping, & support	Non-significant on all measures	
					Programme evaluation	Qualitative: rated positively	
Logsden et al., 2010	RCT	9x90min sessions Joint group 30mins, separate groups 60mins	Experimental Group, n=96 dyads. Control group, *n*=46 dyads. 80% spousal sample. Mean MMSE =23.4	Collaborative planning for the future	**Primary Outcomes** QoL for people with dementia	Significant increase in QoL for people with dementia	26.5/42
					Secondary Outcomes Mood, family communication & self-efficacy	Significant decrease in depression for people with dementia	
Woods et al., 2012	RCT	12x2hr sessions & 7 monthly sessions Joint and separate groups	Experimental group, *n*= 265 dyads. Control group, *n*= 220 dyads. 70% spousal Sample. Mild-moderate dementia.	To facilitate the recall of past experiences Improve well-being	**Primary Outcome** QoL for people with dementia Carer distress	Non-significant on all measures	36/42
					Secondary Outcome Autobiographical memory Quality of the Relationship for dyad	Non-significant on all measures	
					Depression and Anxiety for dyad	Significant increase in carer anxiety	

Zarit et al., 2004	Single group evaluation	10 session programme, fortnightly. Joint and separate groups	*N*=23 dyads and 1 person with dementia. 66.6% spousal sample. Majority MMSE<25	Strengthen dyad, to improve communication & maintain positive aspects of relationship Collaborative planning for the future Reach out to other family members	**Primary Outcome** Interview & questionnaire	Qualitative: participants satisfied with the group	14.5/42
Roberts & Silverio, 2009	Single group, repeated measures	4x2hr sessions Joint Sessions	*N*=74 dyads. "Vast majority" Spousal sample Mean MMSE - 23.8, mild range.	Provide information Provide support in coping with stresses To empower participants to take an active role in coping and seeking out support and education	**Primary Outcomes** Knowledge of Alzheimer’s Coping & adjustment to illness Caregiver strain AD related behaviours	Non-significant for all measures	24.5/42
					Secondary Outcomes Participant satisfaction	All participants highly satisfied Qualitative: dyads described positive changes in behaviours	
Gaugler et al., 2011	Single group, repeated measures	10-13 sessions 90-120 minutes Joint and separate groups	*N*=61 dyads, & 2 people with dementia <80% Spousal Sample MMSE - Mild range	Increase Information Improve Relationship & Communication Improve confidence in future planning Enhance feelings of support through reaching out to family members	**Primary Outcomes** Stress & depression Person with dementia effectiveness	Non-significant on all measures	18.5/42
					Carer effectiveness	Significant increase	
					Dependency on carer for activities of daily living	Significant increase	
					Secondary Outcomes Satisfaction	High Satisfaction for carers, moderate satisfaction for people with dementia	

Abbreviations: RCT, Randomised Control Trial; QoL, Quality of Life; MMSE, mini mental state examination (Folstein, Folstein & McHugh, 1975); AD, Alzheimer’s Disease

Quality assessment

Overall most of the studies were described well with clear aims and most using outcome measures that had appropriate psychometric properties. Generally however, the studies as rated by the QATSDD (Sirriyeh et al., 2012) scored quite low (see table 2).

Table 2. *The mean scores of each domain of the QATSDD for the six studies included in the review*

	Quayhagen et al. 2000	Logsden et al. 2010	Woods et al. 2012	Zarit et al. 2004	Roberts & Silverio,	Gaugler et al. 2011
Explicit theoretical framework	0	1	1	1	1	0
Statement of aims in main body of report	2	2	3	.5	3	3
Clear description of research setting	2	2.5	3	3	2	3
Evidence of sample size	1	1	3	1	1	1
Representative sample of target group of a reasonable size	2	2	3	2.5	2	2.5
Description of procedure for data collection	3	3	3	2	1.5	1.5
Rationale of choice of data collection tool	3	3	3	0	3	1
Detailed recruitment data	1	2.5	3	3	1.5	1.5
Statistical assessment of reliability and validity of measurement tools	3	3	3	0	2.5	1
Fit between stated research question and method of data collection	3	3	3	.5	3	2
Good justification for analytical method selected	2	2.5	3	0	1.5	1
Evidence of user involvement in design	0	0	2	0	0	0
Strengths and limitations critically discussed	2	1	3	1	2.5	1
Total	**24**	**26.5**	**36**	**14.5**	**24.5**	**18.5**

The studies often failed to describe the theoretical underpinning of the intervention they used, which is a limitation previously highlighted within the literature (Braun et al., 2009). Furthermore, studies often failed to provide detailed information regarding their recruitment process and failed to justify their sample size in relation to appropriate power needed to conduct statistical analysis. Generally studies tended to lack diverse populations and only one study (Woods et al., 2012) had involved service users in their design. In addition, these limitations were often not critically discussed within the studies, with some studies presenting their findings without the context of their methodological limitations.

Whilst most studies reviewed here used outcome measures with appropriate psychometric properties, there are 22 outcome measures that have been endorsed by experienced clinicians in dementia for use in dementia research (Moniz-Cook et al., 2008). They based their recommendations on the psychometric properties, usability and previous use in clinical and research settings of commonly used outcome measures and whilst they did not review all outcome measures, their review provides a useful guide for the use of outcome measures in dementia.

Of the 11 measures used by Quayhagen et al. (2000) none were recommended by Moniz-Cook and colleagues (2008). Logsden et al. (2010) used six measures and three of these were recommended measures: the Quality of Life in Alzheimer’s Disease (Logsdon, Gibbons, McCurry, & Teri, 1999) was used as the primary outcome measure, and the Geriatric Depression Scale (Yesavage et al., 1983) and the Medical Outcome Study short form (Stewart, Hays, & Ware, 1988) were used as secondary outcome measures. Woods et al. (2012) used 11 measures with five being recommended, including the Quality of Life in Alzheimer’s Disease (Logsdon et al., 1999) and the General Health Questionnaire (Goldberg

& Hillier, 1979) for primary outcomes measures, and the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the European Quality of Life-5 Dimensions (The EuroQol Group, 1990) as secondary outcome measures. Roberts & Silverio (2009) used four measures, none however, were recommended by Moniz-Cook et al. (2008) and Gaugler et al. (2011) used nine measures, with one recommended measure, the Geriatric Depression Scale-15 (Yesavage et al., 1983) used as a primary outcome measure. Table 1 includes the total quality scores for each study (See Appendix 1 for full quality assessment scores).

Results of individual studies

Randomised controlled trials. Quayhagen et al. (2000) investigated four non-pharmacologic treatments for care-dyads. They randomly assigned 103 care-dyads to cognitive stimulation, dyadic counselling, dual-supportive group seminar, early stage day care, or a waiting list control condition. Only the dual-supportive seminar group is reported here as this was the only group intervention. Twenty-two dyads were assigned to this group and participants with dementia were in the mild-moderate stages of dementia. The intervention comprised of eight, 90 minute, weekly sessions and was based on the ‘supportive seminar group’ developed by Synder et al. (1994), which was originally developed to independently meet the needs of care-dyads when one had dementia. The supportive seminar group aimed to provide a forum for enhancing communication and sharing through education and support. Qualitatively they found that the group was rated positively, however they did not find any significant quantitative findings. The authors noted that carer morale and depression both deteriorated, although these were not significant.

Logsdon et al. (2010) randomly assigned 142 care-dyads to an early-stage memory loss support group intervention (*n*= 96) or to a waiting list control (*n*= 46). Participants with dementia were in the mild-moderate stages, with a mean Mini-Mental State Examination (MMSE, Folstein, Folstein, & McHugh, 1975) of 23.2 (*SD*=4.7). The group was nine sessions long, lasting 90 minutes each and was also based on the work of Synder et al. (1995). Here however, the group was primarily intended to meet the needs of the people with dementia and the inclusion of care-dyads was only to support the people with dementia. The study found significantly improved QoL (*p*<.001) and lower levels of depression (*p*<.01) for the people with dementia (Logsdon et al*.,* 2010). On further analysis, the significant findings are due to the very slight improvements in the intervention group and slight deterioration in the control group and the authors noted that these improvements were modest.

To evaluate the effectiveness of manualised reminiscence groups for care-dyads, Woods et al. (2012) conducted a large, multicentre randomised controlled trial. They allocated 488 care-dyads to either a reminiscence intervention group or to a treatment as usual control group. Participants with dementia were in the mild-moderate stages of dementia. The intervention consisted of 12 joint reminiscence sessions that lasted 2 hours, followed by monthly maintenance sessions for a further 7 months. They found no significant differences on any measures except for the anxiety scores of carers, which significantly increased at the 10-month end point (*p* = .04).

Evaluation studies. Zarit et al. (2004) reported outcomes from an evaluation study of the 10 session ‘Memory Club’ programme, for 23 care-dyads. They report that the majority of participants with dementia had an MMSE (Folstein et al., 1975) score of 25 or higher (SD not reported), reflecting mild stages of dementia. Each session lasted 90 minutes and was held fortnightly. The aim of the study was to evaluate the group intervention, to identify its strengths and areas for development. They used qualitative methodology and reported that participants were satisfied with the group.

In an evaluative study, 36 care-dyads completed the ‘Taking Control of Alzheimer’s Disease programme’ (Roberts & Silverio, 2009). Participants with dementia were in the mild stages, with a mean MMSE (Folstein et al., 1975) score of 23.8 (3.9). The intervention was a 4 session group programme, with each session lasting 2 hours. The aim of the group was to empower dyads to 'take control' and to manage effectively with dementia. The qualitative results demonstrated that participants were satisfied with the group and described positive changes in behaviours. Quantitative data yielded no significant findings.

A different group called ‘*The* Memory Club’ was evaluated by Gaugler et al. (2011). Sixty-one care-dyads and two further people with dementia participated in the Memory Club across three sites. Participants with dementia were in the mild stages of dementia, with a mean MMSE (Folstein et al., 1975) score of 24.6 (3.26). The intervention was 10 -13 sessions with each session lasting 90 minutes. The aim of the group was to decrease distress, enhance preparation for care, and improve feelings of confidence in managing dementia symptoms. The authors found that the dependency of people with dementia on their carers for activities of daily living significantly increased (p=.04), but interestingly carers felt significantly more effective in dealing with care tasks (p=.02). Carers were also significantly more prepared in conducting activities to maintain the people with dementia cognitive abilities (p=.00) as well as preparing for the future (p=.04). The measures in these domains however, were non-standardised and appeared to have been constructed by the researchers themselves to capture domain specific effects. The standardised measures of depression and stress however, yielded no significant changes.

Synthesis of results

Quality of life. Of the two studies that measured QoL, the findings are contradictory. Logsden et al. (2010) reported that QoL was significantly better for people with dementia in the intervention group when compared to the control group. In examining the moderating effects of the intervention on QoL, effects were greater for the participants who experienced more distress at baseline, resulting in increased improvement following the intervention. In contrast, Woods et al. (2012), who used the same measure, the Quality of Life in Alzheimer's disease (Logsdon et al., 1999), did not find any significant improvements in quality of life for people with dementia.

Depression. Whilst Logsdon et al. (2010) found modest improvements in depression for people with dementia, Gaugler et al. (2011), Quayhagen et al. (2000), and Woods et al. (2012) found no evidence that dyadic groups reduce depression for people with dementia or their caregiver.

Carer role. Gaugler et al. (2011) reported a significant increase in dependency of people with dementia to carry out activities of daily living. Whilst this may have potentially exacerbated carer stress, the authors found that the carer's sense of effectiveness increased. In addition, their ability to conduct activities that maintain cognitive stimulation for people with dementia and their preparedness in dealing with care tasks significantly increased. These findings are, however, difficult to generalise as the measures used in these domains were non-standardised and are only reported in one study.

Carer strain. No studies demonstrated any significant improvements of carer strain. Other related constructs including self-efficacy (Logsdon et al., 2010), problem solving, coping (Quayhagen et al., 2000), adjustment to illness, coping self-efficacy (Roberts & Silverio, 2009), and general quality of life (Woods et al., 2012) were also non-significant. Furthermore, Quayhagen et al. (2000) found a trend that carers' morale and depression deteriorated following the supportive seminar group. The authors hypothesised that this was possibly due to the discussions of dementia symptoms and disease progression that occurred in the group. Furthermore, Woods et al. (2012) found that carers in the intervention group reported a significant increase in anxiety, which was further supported by the finding of a dose effect; that carers attending more groups showed increased anxiety.

Relationship quality. The interventions evaluated by Gaugler et al. (2011), Logsdon et al. (2010), Roberts and Silverio (2009), Quayhagen et al. (2000), and Woods et al. (2012), all measured the quality of the care-dyad relationship as well as other social relationships. No significant differences in relationship functioning or quality were found across the studies.

Qualitative findings. Gaugler et al. (2011), Roberts and Silverio (2009), Zarit et al. (2004) and Quayhagen et al. (2000) all reported that participants found the groups satisfying. Further qualitative information from Quayhagen et al. (2000) showed that caregivers reported better insight, enhanced communication, and better participant caregiver relationships. Roberts and Silverio (2009) reported that care-dyads found the groups helpful and that they felt more supported. They also conducted interviews at three-month follow up and people with dementia reported increased physical activity and improved diet and nutrition. Care-dyads reported increased financial, legal and medical care planning, and a significant proportion had enrolled in an Alzheimer's support group.

Discussion

Previous literature reviews have indicated positive conclusions about the efficacy of a wide range of heterogeneous interventions for people with dementia and their carer. This review aimed specifically to examine the efficacy of dyadic group interventions. Only six studies were identified and overall, this review found little evidence to suggest that dyadic group interventions alone are beneficial to care-dyads.

Of the 41 measures used across the six studies there were seven significant findings, five of which indicated improvements. These included significant improvements in QoL and depression for people with dementia (Logsdon et al., 2010). For carers, these were improved perception of effectiveness, maintaining cognitive stimulation and preparing for the future (Gaugler et al., 2011). Two results however, indicated deterioration; for people with dementia, this included the increased dependency for carrying out activities of daily living (Gaugler et al., 2011) and for carers this included increased anxiety (Woods et al., 2012).The overall lack of significant findings across studies is consistent with dyadic interventions for people with mild cognitive impairment (Joosten-Weyn Banningh et al., 2008; 2011; 2013), suggesting that level of cognitive impairment is not a contributing factor to the null findings.

Carer stress

No evidence was found that dyadic group interventions benefit carers. In contrast, the anxiety of carers deteriorated (Woods et al., 2012). Furthermore, Quayhagen et al. (2000) indicated deterioration in carer morale and depression and suggested that this may reflect discussions within the group that highlight the reality of dementia and its progress. In support of this hypothesis, qualitative findings from Quayhagen et al. (2001) highlighted improved communication between care-dyad and higher communication quality has been associated with carer stress (Woods, Wills, Higginson, Hobbins, & Whitby, 2003). Therefore, it is possible that encouraging care-dyads to discuss the significant, shared impact that a diagnosis of dementia can bring (Hutchinson, Leger-Krall & Wilson, 1997; MacRae, 2010; Steeman et al., 2007) may be a natural, although stressful part of accepting the diagnosis (Graham & Bassatt, 2006). Whilst this would require empirical testing, it draws attention to the care-dyad relationship and how this changes over time (Nolan, Lundh, Grant, & Keady, 2004).

Whilst most of the interventions reviewed anticipated increases in the quality of the care-dyad relationship, no evidence for this was found. This is perhaps understandable as none of the interventions reviewed described a theoretical framework that related to couples. There are a number of theoretical frameworks that could inform future interventions, for example equity theory (Walster, Walster, & Berscheid, 1978) has been applied to the understanding carer distress in care-dyads (Martin, Peter-Wight, Braun, Horung, & Scholz, 2009; Quinn et al., 2009). Furthermore, there is growing literature around couplehood (Hellstrom, Nolan, & Lundh, 2007; Kaplan, 2001), which refers to how couples find new meaning in their relationship, whilst maintaining the sense of feeling married. The use of these theoretically informed frameworks may facilitate the development of efficacious dyadic interventions, as well as indicating which care-dyads would benefit or not benefit from intervention.

Measuring change

The overall null findings reported in the studies reviewed here are perhaps due to the limited use of potentially useful psychometric measures as recommended through

European consensus (Moniz-Cook et al., 2008). Utilising these recommended measures however, yielded inconsistent results as Logsden et al. (2010) yielded two significant results using the Quality of Life in Alzheimer's Disease (Logsdon et al., 1999) and the Geriatric Depression scale (Yesavage et al., 1983), but neither finding was replicated (Gaugler et al., 2011; Woods et al., 2012). The general inconsistency in the use of potentially useful outcome measures across the studies however, precludes further comparisons.

The lack of significant results and the inconsistent findings may reflect that a number of outcome measures used in dementia research, including recommended measures, do not appear sensitive to change (Moniz-Cook et al., 2008). Despite these limited quantitative findings, the qualitative data demonstrates that care-dyads highly regard group interventions and some even report positive behavioural changes (Quayhagen et al., 2000; Roberts & Silverio, 2009). Therefore it is possible that measuring actual behavioural changes following group interventions may be more meaningful for care-dyads and furthermore, the studies reviewed here may not have measured the constructs that mediate psychological change.

Limitations

An important consideration with regard to empirical research is the methodological strengths of the study themselves. The studies generally scored low on the quality assessment. Furthermore, whilst there is a paucity of measures specifically developed for people with dementia (Joosten-Weyn Banningh et al., 2008; Roberts & Silverio, 2009), and the measures that have been recommended in dementia intervention research were inconsistently used. From this review, there may be growing evidence that outcome measures in dementia research are not fit for purpose.

A further limitation is the lack of theoretical description underpinning the interventions evaluated, which makes the findings for each study difficult to interpret, a point previously raised by Braun et al. (2009). Overall, it seems there is a real need for dyadic dementia research to have a strong theoretical foundation if the research is going to contribute to clinical practice.

One limitation of this review is the exclusion of non-English written studies, which limits the cultural variation of the findings. Furthermore, of the six studies reviewed here, four were previously reviewed by Moon and Betts (2012; Logsdon et al., [2010]; Quayhagen et al., [2000]; Roberts & Silverio [2009]; Zarit et al. [2004]) and one was reviewed by Van't Leven et al. (2013; Logsden et al. [2010]). As these reviews included studies with highly heterogeneous interventions, the specific findings of these group interventions were difficult to ascertain. This review therefore builds on the literature, considering a homogeneous sample of studies reviewed, as the interventions were of similar length, all contained a dyadic group format and each sample was mostly spousal dyads.

Conclusion

Few studies have empirically evaluated dyadic group interventions for dementia, and there is no robust, consistent evidence for the efficacy of dyadic group interventions for people with dementia and their spousal caregiver. There is some evidence to suggest that carer distress may increase following these interventions, which requires further empirical exploration. This is important as the burden of care can be significant for carers (Brodaty et al., 2003), and with the increasing demands placed upon carers through national policy and local services, this may increase further (Henderson & Forbat, 2002). Future intervention studies will have to balance the possible benefits to people with dementia with the possible costs to carers. The provision of a theoretical framework for care-dyads, such as couplehood (Kaplan, 2001) could develop the empirical understanding of the dynamics within care-dyads and may support clinicians in distinguishing between care-dyads who may benefit from dyadic interventions and who may not.

The G8 summit (Department of Health, 2013) and the European Dementia Research Agenda (International Longevity Centre-UK, 2011) highlighted the need to develop shared, collaborative research across Europe. This review found only one European study, although there was a paucity of interventions studies generally. Furthermore, the inconsistent use of recommended standardised measures within the studies reviewed here should provide caution to the development of further European studies. As such, future studies should use consistent, standardised measures across studies, which would allow collaboration and meaningful comparison. There may also be a need for the development of robust, sensitive outcome measures developed for dementia that have ecological validity. This may support the measurement of meaningful constructs for care-dyads that underpin psychological change. In addition, this review has highlighted a need for high quality intervention studies within dyadic research as most of the intervention studies reviewed here would have benefitted from more detailed methodological procedures and theoretical descriptions of the interventions they tested.

In order for the aims of European research to be realised (Department of Health, 2013; International Longevity Centre-UK, 2011), shared, collaborative research needs to be high quality, theoretically informed, with the consistent use of sensitive outcome measures. This would permit meaningful comparisons to be drawn across studies.

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Chapter 2:

Evaluating relationship quality in dementia following a post diagnostic support group[2]

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[2] Article prepared for submission to *Dementia*

Abstract

Dementia within the context of a spousal of relationship can have a significant and detrimental effect on the relationship quality. The primary aim of this study was to investigate whether a post-diagnostic group for care-dyads would increase relationship quality. A single group, repeated measures design was used, with care-dyads completing outcome measures at three time points. Sixteen care-dyads participated in the study. Results found a modest decrease in depression scores for participants with dementia. In acknowledging the small sample as a limitation, the findings are consistent with other studies. Overall, there is little evidence to support the efficacy of dyadic group interventions alone. Relationship equity and quality for care-dyads are promising constructs to understand the changing needs of care-dyads.

Keywords
Dementia, dyad, intervention, relationship satisfaction

Introduction

The initial impact of receiving a diagnosis of dementia can often be upsetting and shocking (Lee, Roen, & Thornton, 2014; Pratt & Wilksinson, 2003), with people feeling anger and uncertainty (Bun et al., 2012) and experiencing a sense of loss related to their changing cognitive abilities (Lee et al., 2014). Dementia also has a significant impact on spouses who often have to make changes to the spousal relationship (Harris & Keady, 2004; Todres & Galvin, 2006) as well as providing the majority of the care for their spouse (Montgomery & Williams, 2001). As dementia progresses, the relationship between the person with dementia and their spouse, referred to here as the care-dyad, becomes increasingly characterised by the need and provision of care (Perry, 2002). These changes within the care-dyad relationship have often been neglected within the research literature, which predominantly focuses on the needs of people with dementia and their spousal carers separately (Montgomery & Williams, 2001).

More recently, there has been growing recognition within the dementia literature of the importance of the care-dyad relationship and how relationship quality changes over time (Braun et al., 2009; Keady & Nolan, 2003; O'Connor, 1999; Quinn, Clare, & Woods, 2009). Relationship quality refers to the feeling of emotional closeness (Lawrence, Tennstedt, & Assman, 1998) and has been conceptualised as the measure of similarity and quality within the care-dyad (Perrin & May, 2000). For 'healthy' couples, relationship quality is strongly associated with wellbeing (Proulx, Helms, & Buehler, 2007) and in dementia, the quality of the care-dyad relationship has a fundamental role in the provision of care by the spouse. Specifically, poorer relationship quality is associated with caregivers desire to relinquish the caring role (Winter, Gitlin, & Dennis, 2011), and the breakdown of the care-dyad relationship increases the likelihood of the person with dementia being placed in institutional care (Montgomery & Williams, 2001). This has significant implications for people with dementia, who often express a preference to remain in their own home (Aggarwal et al., 2003).

A theoretical approach

Previous interventions and theoretical frameworks within dementia research have been criticised for negating the relationship of the care-dyad (Montgomery & Williams, 2001). As such, theoretical approaches could benefit from exploring the dyadic nature of relationships, with a specific focus on dyadic exchange (Martin et al., 2009). This would acknowledge the nature of exchange that is inherent within relationships and how this changes within the context of dementia. As such, equity theory provides major concepts of dyadic exchange, which is consistent with the movement towards exploring the needs of the dyad as a unit of analysis (Walster, Walster, & Berscheid, 1978). Furthermore, the wide use of equity theory within the dementia literature supports the usefulness of this theoretical framework within dementia (Baikie, 2002; Braun et al., 2009; Martin et al, 2009; Quinn et al., 2009; Woods et al, 2012).

Equity theory proposes that the perceived balance between investment and reward within a relationship is essential for well-being, whereas perceived inequity places stress upon the individuals in the relationship (Dainton, 2003). Relationships that are equitable can tolerate temporary inequity if individuals are able to change their behaviour or their cognitive perceptions to restore perceived equity (Stafford & Canary, 2006; Walster et al., 1978). If inequity is sustained however, the relationship may become burdensome and intolerable (Call, Finch, Huck, & Kane, 1999).

Threats to equity

The ability for the person with dementia to reciprocate and maintain equity within the marriage as they traditionally did before the diagnosis appears to decrease over time (Evans & Lee, 2014). Given this, equity theory would predict that relationship quality would deteriorate and evidence that support this has been found in studies that have shown that care-givers report lower marital satisfaction (DeVugt et al., 2003; Eloniemi-Sulkava, Notkola, Hamalainen, & Rahkonen, 2002; Horowitz & Shindelman, 1983; Knop, Buergman-Evans, & McCabe, 1998; Morris, Morris, & Britton, 1988; Simonelli et al., 2008; Wright, 1991), less affection (Wright, 1998) less intimacy (Blieszner & Shifflett, 1990; Morris et al., 1988), less sexual intimacy (Simonelli et al., 2008; Zeiss, Davies, Wood, & Tinklenberg, 1990;), less reciprocity (Eloniemi-Sulkava, et al., 2002; Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001; Murray, Schneider, Banerjee, & Mann, 1999) less communication (DeVugt et al., 2003; Murray et al., 1999; Savundranayagam, Hummert, & Montgomery, 2005) and less empathic reciprocation (Nelis et al., 2011).

The increasingly complex needs of people with dementia that demand even more physical and psychological investment from carers have been associated with decreases in relationship quality. For example, increased dependency of the person with dementia in carrying out activities of daily living predicted reductions in satisfaction with intimacy (Svetlik et al., 2005). Furthermore, increased dependency is also associated with a faster progression to institutionalised care for the person with dementia (Gaugler, Kane, Kane, Clay, & Newcomer, 2003).

In addition, behavioural disturbances of people with dementia have been associated with lower relationship quality (DeVugt et al., 2003), whereas fewer behavioural disturbances have been associated with higher relationship quality (Spruytte, Van Audenhove, Lammertyn & Storms, 2002) and higher intimacy (Morris et al., 1988). Behavioural disturbances related to dementia have also been identified as the most prevalent risk factor for increased institutionalisation across Europe (Afram et al., 2014).

The impact that dementia can have on relationship quality can be significant and carers who report lower relationship quality, both prior and following the onset of dementia, report greater depression and distress (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Knop et al., 1998; Kramer, 1993; Morris et al., 1988; Rankin, Haut, & Keefover, 2001; Williamson & Schulz, 1990) and greater subjective burden (Fitzpatrick & Vacha-Haase, 2010; Robinson, 1990; Steadman, Tremont, & Davis, 2007; Williamson & Schulz, 1990). Conversely, carers who report high pre-caring relationship quality also report high care relationship quality (Steadman, Tremont and Davis, 2007). For people with dementia, there is little evidence regarding the impact of relationship quality on their wellbeing (Quinn et al., 2009). Wright (1991) however, demonstrated that people with dementia report significantly higher relationship quality than their spouses, which may reflect the increased investment from spouses into the relationship.

Facilitating Couplehood

Whilst the evidence supports the premise that loss of equity, characterised by cognitive decline, exacerbates relationship quality, some care-dyads show stable levels of well-being (Martin, Peter-Wight, Braun, Horung, & Scholz, 2009). Equity theory would predict these care-dyads have been able to adapt their cognitive beliefs and behaviours in order to restore perceived equity (Stafford & Canary, 2006). This process may be linked to how care-dyads find new meaning and maintain a sense of ‘couplehood’, the extent to which they feel married (Kaplan, 2001). Finding new meaning in their relationship could indeed be the process where couples jointly adapt their cognitive perceptions to accommodate the *new* balance of equity and to *find* equity in novel, nuanced ways (Graham & Bassat, 2006).

Finding new meaning in the care-dyad relationship has been associated with higher relationship quality (Quinn, Clare, Mcguiness, & Woods, 2012) and a number of qualitative studies have explored this complex dynamic process (Graham & Bassett, 2006; Hellstrom, Nolan & Lundh, 2007; Molyneux, Butchard, Simpson, & Murray, 2011; Robinson, Clare, & Evans, 2005). These highlight that changes in reciprocity and equity contribute to perceptions of loss in the relationship (Evans & Lee, 2014). In response to changing equity, some couples struggle to find new meaning in the relationship, which can be characterised by conflict, detachment and lack of compassion (Graham & Bassat, 2006). They appear to 'work apart', or 'work alone' (Keady and Nolan, 2003), which may reflect the challenges carers face in restoring perceived equity. If a couple's pre-diagnosis understanding and expectations of the person with dementia persist, their ability to find equity in more nuanced ways is significantly reduced (Bassat & Graham, 2006).

For other couples, maintaining their perceived sense of equity by adapting their behaviours and cognitive expectations seems to benefit their relationship. These care-dyads appear to 'work together' (Keady and Nolan, 2003) to sustain couplehood, with carers increasing their investment to promote shared well-being (Hellstrom et al., 2007), encourage shared activities and to live as they lived before (Molyneux et al., 2011). The increased costs to the carer in maintaining couplehood however, may reflect the findings that carers can report both positive and negative experiences of caring (Narayan, Lewis, Tornatore, Hepburn, & Corcoran-Perry, 2001) and that although the relationship may deteriorate, couples may still feel close (DeVugt et al., 2003).

Interventions

Whilst interventions historically have focussed on the needs of carers, empirical evidence suggests the inclusion of people with dementia in interventions improves carer mental health (Brodaty, Green, & Koschera, 2003; Smits et al., 2007). Furthermore, a number of dyadic interventions that aim to benefit both people with dementia and their carer have been developed (see Van't Leven et al., 2013), with groups being the most prevalent method of intervention (Moon & Betts Adams, 2013). These group interventions for care-dyads have yielded mixed findings and their efficacy for improving relationship quality appears limited (Gaugler et al., 2011; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Woods et al., 2012). These intervention studies often lack a theoretical framework, which may have contributed to the null findings. Other findings have shown improved QoL and depression for people with dementia (Logsdon et al., 2010) and increased preparedness and perceived effectiveness for carers (Gaugler et al., 2011). These findings however, have not been replicated (Quayhagen et al., 2000; Roberts & Silverio, 2009; Woods et al., 2012) with results also indicating deterioration in carer morale, depression (Quayhagen et al., 2000), and anxiety (Woods et al., 2012).

Moving Research Forward

Given that previous research within the area has found few significant benefits to care-dyads and some negative effects of dyadic interventions, careful consideration must be given to interventions within this area and how they are constructed and evaluated. The qualitative data around care-dyads experiences of dyadic group interventions contrast with the quantitative data. Consistent with unpublished findings from the intervention under study here, Gaugler et al. (2011), Roberts and Silverio (2009), Zarit et al. (2004) and Quayhagen et al. (2000) all reported that participants found the groups satisfying. Quayhagen et al. (2000) showed that caregivers reported better insight, enhanced communication, and better participant caregiver relationships. Roberts and Silverio (2009) reported that care-dyads found the groups helpful and they expressed positive changes within the care-dyad. These studies also had high retention rates, which further supports the qualitative data.

In considering the positive and beneficial qualitative experiences of participants of dyadic interventions, it seems that studies within this area can be ethical and appropriate. As such, there is a need to explore the psychological components that underpin the benefits and possible negative consequences of these interventions, to inform both future clinical and research work. Furthermore, there is a need to build upon the limitations of previous intervention studies to enhance intervention efficacy, whilst maintaining rigorous scrutiny. The current study aims to do this, by evaluating a dyadic group intervention, where the content is informed by the needs of care-dyads, under the theoretical framework of the couplehood literature and equity theory.

Content & theoretical framework of the post-diagnostic group

In considering the content of dyadic group interventions, previous interventions that have demonstrated little benefit, or some negative consequences have used reminiscence therapy (Woods et al., 2012) or psycho-education and support methods to discuss areas of common concern and difficulty (Gaugler et al, 2011; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Zarit et al., 2004). The intervention under investigation here, also utilises education and support on topics of concern, which reflect some similarities with two previous interventions (Roberts & Silvario, 2009; Zarit et al, 2010). Both of these studies did not indicate negative consequences of the intervention and both highlighted positive qualitative data from participants. This is consistent with previous unpublished qualitative data of this intervention demonstrated that the content was beneficial for care-dyads, as they described being satisfied and described increased knowledge of dementia and increased ability to cope following the intervention.

Furthermore, previous dyadic support group interventions have not been conducted within the UK. As such, this intervention draws upon areas of concern that were identified within the UK National Dementia Strategy (2009), and so the intervention topic areas were anticipated to have value for UK participants. The National Dementia Strategy also promotes the early provision of education and support to care-dyads, which is consistent with the aims of the group intervention.

In addition to the specific content of this post-diagnostic group, the intervention itself is theoretically underpinned. Specifically, this post-diagnostic group postulates through equity theory and the couplehood literature, that new knowledge and understanding of dementia can help spouses generate new expectations of investment and reward within their relationship. Within dementia, care-dyads with lower relationship satisfaction sometimes maintain their pre-diagnosis attitudes and expectations of each other and therefore experience the relationship as inequitable and distressing (Graham & Bassat, 2006). For example, carers may still expect their partner with dementia to maintain their full domestic duties, when they are cognitively unable to do so. As such, equity theory predicts that the relationship will experience stress as one spouse feels as though they are investing much more than the other. Equity theory posits that attitudes and expectations within the relationship can therefore be adapted to accommodate the new context of dementia and to adjust the expectations of spouses within the relationship. This cognitive adaption can restore perceived equity within the relationship, thus promoting relational wellbeing. Therefore it is hypothesized that knowledge of dementia and the changes that occur would enable spouses to generate new expectations of each other, to restore perceived equity and enhance wellbeing. Within the group discussion, spouses could explore each other's perspective on their experiences and attitudes, therefore opening a dialogue that may not have occurred before.

Given the content and theoretical framework of the group, it is hypothesised that following intervention people with dementia and their spouses will report increased relationship quality. The secondary hypotheses are fourfold; that anxiety and depression symptom scores for people with dementia and their carers would decrease, QoL for the person with dementia would increase, and perceived burnout for the carer would decrease.

Method

Participant characteristics

Participants met the inclusion criteria if they were couples (married or unmarried), and one partner had a diagnosis of dementia. Participants were included if they were in the mild-moderate stages of dementia and able to communicate to a level where they could complete the outcome measures with support. This was screened by a clinician before participants were approached regarding the study. Participants were eligible for the study if they had consented to attend the post-diagnostic dyadic group intervention at a local older people's service. Participants were excluded if they had mild cognitive impairment and if one member of the dyad was not a partner (e.g. family member or friend).

In total, 16 care-dyads were recruited from an older people's community service between September 2013 and May 2014. All care-dyads were male-female partners with an average age of 76 years old, ranging between 50-90 years old (males *M*= 77, *SD*= 8.1; females *M* = 75, *SD*=9.9). People with dementia consisted of 10 males and 6 females and had a mean age of 75 years (*SD*=9.9, range =50-90), and carers had a mean age of 76 years (*SD*=8.8, range=50-90). The mean length of the care-dyad relationship was 48.6 years (*SD*=18.0, range =8-68) and the mean duration of diagnosis was 2.4 years (*SD*=1.5, range= .5-6 years). All participants were heterosexual and white British.

Sampling procedure

Following sponsorship from the University of Liverpool and favourable ethical review from Preston Research Ethics Committee and Mersey Care NHS Trust, participants were recruited from a local older people's service. Thirty-eight couples met the eligibility criteria for the study and were contacted by the researcher (see Figure 1 for participant flow chart). A total of 12 dyads declined and the researcher was unable to arrange home visits for five dyads who were subsequently excluded from the study. In total, 20 couples (51%) were eligible and consented to participate. Of the remaining 20 dyads, three dropped out of the study as they did not attend any intervention session and one dyad dropped out as they were unavailable to complete the measures at T3. This gave a modest uptake rate of 53% and a high retention rate of 80% (see Appendix 2 for more information). The attendance rate of the intervention was also high with a mean attendance rate of 6.7 sessions, with 14 dyads attending all sessions.

Written informed consent was obtained for all participants who wished to participate (see Appendix 3 for a copy of the consent form). In accordance with the Mental Capacity Act 2005, and given that participants with dementia were in the mild-moderate stages of dementia, it was expected that participants would be able to give informed consent for participation, unless they demonstrated otherwise. The researcher provided appropriate explanations of the research with sufficient time of two weeks for participants to reach a decision. Current guidance from the British Psychological Society (BPS, 2008) was followed to evaluate capacity, viewing capacity as a continuing process and willingness to continue in the study was reviewed at each time point. Data were collected at the participant’s home and then subsequently at the local older people’s service, where the intervention group was conducted.

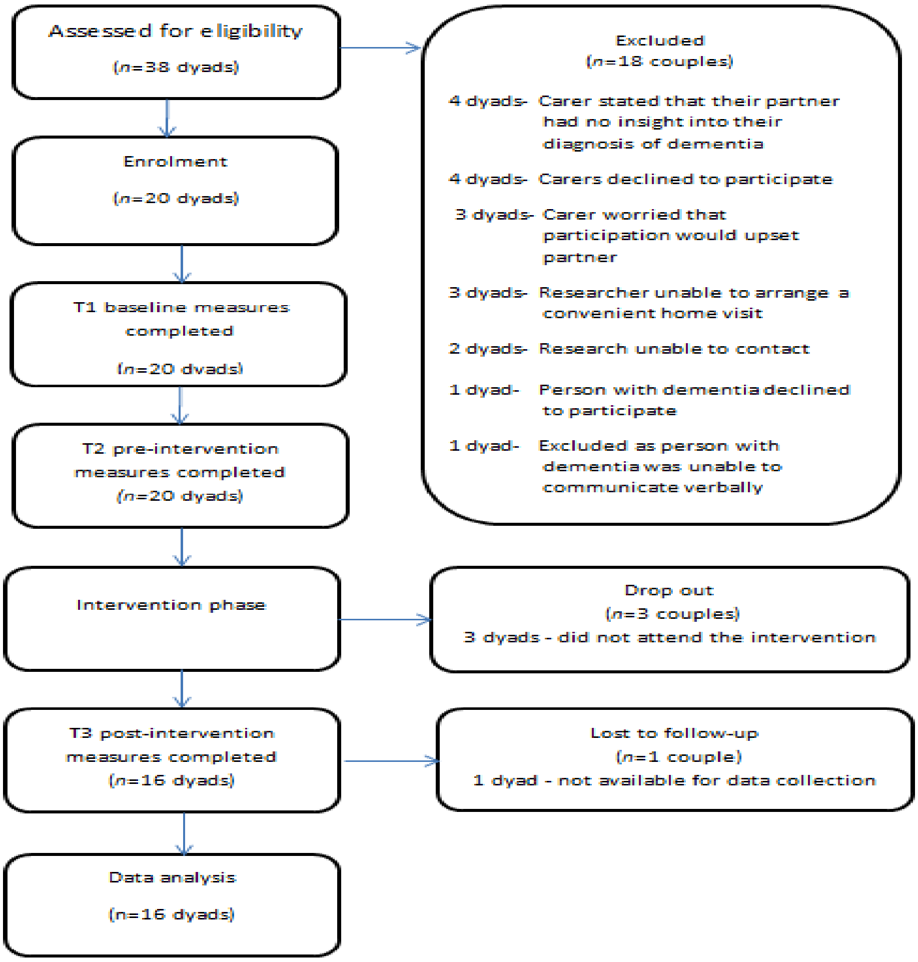

Figure 1. Participant flow chart

Sample size and power

G-power (Faul, Erdfelder, Lang & Buchner 2007) calculations for a medium effect size (f= .25) with an alpha of .05 and power of .80, collecting measures at three time points indicated a required sample size of 28 to detect a main within-between effect. Post hoc power analyses for all outcome measures, detecting a medium effect size (f= .25) with an alpha of .05 indicated a power of .53. A medium effect size was thought to be appropriate as this is the effect size cited by Losgden et al. (2010), which represents an independent interest (O'Keefe, 2007).

Measures

All measures can be found in Appendix 4. The *Quality of the Caregiver/Patient Relationship* (QCGR; Spruytte et al., 2002) was used to measure relationship quality and was completed by the person with dementia and their carer. It is a 14 item measure with two subscales, warmth and conflict, with high scores indicating more positive relationships. Responses are on a 5-point Likert scale, ranging from "*totally disagree*" to "*totally agree*". Although originally developed in Belgium, it has been used in the UK, demonstrating good internal consistency for carers (α = 0.85) and people with dementia (α = 0.80; Woods et al., 2012), which was replicated in this study (α =.78).

The Positive Affect Index (PAI; Bengtson & Schrader, 1982) assesses the extent of positive affect that the respondent has for another person and was used as a supplementary measure for relationship quality. It was completed by the person with dementia and their carer. It is a five item measure with responses on a 6-point Likert scale, ranging from "*not well*" to "*extremely well*" and responses are summed for a total score. This scale has previously been used with people with dementia showing good internal consistency (α=0.81) and re-test reliability over a 12-week period (*r*=0.66; Woods, 2009). The internal consistency in the current sample was within acceptable limits (α =.76; Kline, 1999).

The *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983) was used to measure anxiety and depression and was completed by participants with dementia and their carer. The measure has 14 items, with seven items each for anxiety and depression. Responses are on a 4-point Likert scale, for example, ranging from "*not at all"* to "*most of the time".* Despite few carer intervention studies using the HADS, it has been used both clinically and for research (Bjelland, Dahl, Haug, & Neckelmann, 2002). Furthermore, it has demonstrated good potential for use with carers of people of dementia, with its main strength being its brevity and capacity to measure both anxiety and depression (Moniz-cook et al., 2008). It has demonstrated good internal consistency on the anxiety (α =.84) and depression sub-scale (α = .83; Dagnan, Chadwick, & Trower, 2000). For this study, the internal consistency was within acceptable limits for anxiety (α =.82) and depression (α =.74).

The Quality of Life in Alzheimer 's Disease (QoL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999) was used to assess the QoL and was only completed by participants with dementia. It has 13 items, rated on a 4-point scale, ranging from "*poor*" to "*excellent*". It is reliable and valid for people with mild and moderate degrees of dementia and remains the measure of choice in dementia research (Moniz-cook et al., 2008). It has demonstrated sensitivity to change (Spector et al., 2003) and has been used by people with Mini Mental State Examination scores as low as three (Hoe, Katona, Roch, & Livingston, 2005; Thorgrimsen et al., 2003). It has also demonstrated good internal consistency (α =.81; Orgeta et al., 2014), which was replicated in this study (α =.90).

The *Zarit Burden Interview* (ZBI; Zarit, Reever, & Bach-Peterson, 1980) was used to measure carer burnout and was only completed by carers. It has 22 items examining personal strain and role strain, rated on a 5-point Likert scale, ranging from "*Never*" to "*Nearly Always*". It is the most widely used burnout measure in caregiver research (Moniz-Cook et al., 2008) and was further validated by Hérbert, Bravo and Préville (2000), demonstrating that the measure had good internal consistency (α = .92), which was replicated in this study (α =.83).

Design

A repeated measures, within-group design was used, with participants completing outcome measures at three time points. Measures were completed at baseline, seven weeks before the intervention (T1), at the first session of the intervention (T2), and seven weeks later at the final session of the intervention (T3). It was hypothesised that there would be no significant differences in outcome measures between T1-T2, which allowed for control scores (T1-T2) to be compared with post intervention outcomes (T3).

Intervention

This post-diagnostic intervention consists of seven weekly sessions, lasting 2 hours, with a maximum of seven dyads per group. In total, seven group interventions were delivered from September 2013 to May 2014, with participants being recruited across this time period. The groups were delivered by a Clinical Psychologist, and either an Occupational Therapist, an Advanced Practitioner in Dementia Care, or a Nurse Specialist at a local older people's service. Non-research participants were able to attend the groups and included people with dementia and their partner or other family member. The group had a structured format with a combination of information giving and discussion. Both spouses attended the group in its entirety, together. The format of the group sessions is as follows:

Table 1: *Session topics of the post-diagnostic group*

Session	Topic & Activity
1. Facts and Myths of Dementia	True and false quiz looking at Facts and Myths about dementia Different Types & causes of dementia Introduction of the biopsychosocial model
2. Memory	How the memory system works What changes in the brain in dementia How these changes impact on daily life and a person's reality
3. Still me?	The emotional impact of receiving a diagnosis of dementia Social networks and roles and how these changes
4. Practical Solutions to Memory Problems	Introduction to independence and dementia Group exercises about activities of daily living and potential barriers of completing them effectively Introduction to available technology to support people with dementia
5. Communication & Wellbeing	How dementia impacts on a person's wellbeing The links between dementia, anxiety and depression How communication needs change in dementia Tips for communication effectively
6. Future Plans	Driving and dementia Mental Capacity Act and how it relates to dementia Power of Attorney Other financial issues

	Description of local service provision
7. Resources	Talk from a past member of the group, currently living with dementia, to explain links they have made and what has helped them

Each week focuses on the different topics described above and so it promotes knowledge and education. It was hypothesised that knowledge of dementia and the cognitive, social and relational changes that typically occur would enable spouses to generate new expectations of each other thus promoting relationship satisfaction. Alongside the use of information and teaching, open discussion allowed the exploration of participants' experiences, particularly with regards to how they relate to one another and their perceptions of investment and reward within the relationship. Couples were encouraged to assimilate the new knowledge around dementia and to generate new, shared meaning within their relationship. For example, for care-dyads who maintain their pre-diagnosis attitudes and expectations of each other may experience the relationship as inequitable and distressing. Therefore, the group discussion allows care-dyads to share and offer alternative perspective.

It was hypothesised that alternative perspectives that facilitate the development of shared expectations and attitudes around mutual exchange within the relationship would improve relationship satisfaction. As such, equity theory was not an explicit topic and was not explicitly discussed within the sessions. It was however, inherent within the ethos of the group and how the facilitators promoted knowledge and understanding of dementia to inform the development of new relationships.

Procedure

Clinicians from the older people's service invited couples to the post-diagnostic group and informed couples that a research study was also taking place. Couples who expressed an interest to take part in the study were visited at their home by the researcher who provided full information about the study (see Appendix 5). Eligible couples who consented to participate completed T1 measures at their home during the same home visit, unless couples required more time to consider consenting to participate. Couples completed the measures separately and confidentiality. For the participants with dementia, the researcher read aloud the items from the outcome measures whilst the participant read each item. To ensure confidentiality, participants with dementia completed the measures in separate rooms, where their partners would be unable to hear their responses. The carers completed measures independently, unless they required support in completing them. At T2 and T3 participants completed the measures separately during the group at the first and final session, respectively. During completion of the measures, the researcher and members of the clinical team who were not involved in the delivery of the group supported participants to complete the questionnaires. The researcher checked for missed item responses and on two occasions, asked a participant to complete a missed item, unless they objected. Neither participant objected.

Data Analysis

Data analyses were conducted using SPSS v.21 (IBM, 2012). There were no individual items of missing data. Scores on the QCGR and the PAI could not be compared between participants with dementia and their carers as the scores were presumed to be non-independent, given that the small sample size was inadequately powered to empirically test this (Kenny, Kashy & Cook, 2006). To investigate the participants with dementia and their carers together on the QCGR and the PAI, each dyad was treated as the unit of analysis,

A between-dyads variable was created on the warmth and conflict subscales of the QCGR as well as the total QCGR and PAI scores (Kenny, Kashy, & Cook, 2006). This was calculated by subtracting the individual carer scores from the individual participant with dementia scores. This created a single score for each dyad, which allowed the analysis to measure the congruency between the dyads on each of these domains (Kenny, Kashy & Cook, 2006). As expected, the QCGR and PAI dyad scores were significantly correlated at T1, r=.667, p=.005, at T2, r =.766, p=.001, and at T3, r=.688, p=.003 as both measured relationship quality.

When analysing within differences on the QCGR and the PAI for participants with dementia and carers separately, the individual scores were used. The QCGR and the PAI data were non-independent for the dyadic analysis and neither met the assumptions of normality, required for parametric testing (see Appendix 6 for further details). Therefore Friedman's ANOVAs were conducted to analyse this data and Kendall's W was used as an estimate of the effect sizes.

Data from the HADS and the QoL-AD were independent, but the data were not normally distributed and so did not meet the assumptions for parametric testing. They were analysed using a Friedman's ANOVA and Wilcoxon signed-ranks test for post hoc analysis. The ZBI did meet parametric assumptions and so was analysed using a repeated measures ANOVA.

Results

Baseline assessment demonstrated no significant differences between carers and participants with dementia with regards to age and sex. The length of relationship did not co-vary with the QCGR or the PAI. Table 1 reports overall means for the primary and secondary measures.

Table 2. Medians and ranges for outcome measures at all three time points

		Mean Rank (Range)					
		T1		T2		T3	
Primary Measures							
QCGR	Participant with dementia	2.06	(44-67)	1.88	(46-67)	2.06	(48-70)
	Carer	2.25	(40-69)	2.09	(50-64)	1.66	(40-67)
	Dyad Score	1.81	(-3 – 10)	1.81	(-6-9)	2.38	(-3-10)
Warmth	Participant with dementia	2.34	(31-40)	1.63	(28-40)	2.03	(29-40)
	Carer	2.22	(28-40)	2.22	(31-39)	1.56	(27-39)
	Dyad Score	2.06	(-3-10)	1.78	(-6–9)	2.16	(-3-10)
Conflict	Participant with dementia	1.97	(16-28)	2.00	(18-28)	2.03	(10-30)
	Carer	2.03	(12-29)	1.94	(18-26)	2.03	(11-28)
	Dyad Score	1.81	(-7-13)	1.91	(-5-7)	2.28	(-12-11)
PAI	Participant with dementia	2.00	(12-29)	1.59	(15-29)	2.41*	(15-30)
	Carer	2.22	(16-28)	1.84	(13-28)	1.94	(11-30)
	Dyad Score	1.78	(-11-17)	1.88	(-10-14)	2.34	(-7-10)
Secondary Measures							
HADS	Participant with dementia	1.91	(0-23)	2.44	(0-24)	1.66	(0-23)
	Carer	2.28	(6-23)	1.94	(3-25)	1.78	(4-19)
Anxiety	Participant with dementia	1.9	(0-11)	2.34	(0-14)	1.75	(0-13)
	Carer	2.22	(1-11)	2.00	(3-10)	1.78	(2-10)
Depression	Participant with dementia	2.28	(0-12)	2.22	(0-14)	1.50*	(0-10)
	Carer	2.31	(2-12)	1.97	(0-15)	1.72	(0-9)
QoL-AD	Participant with dementia	1.75	(15-48)	1.97	(26-45)	2.28	(24-52)
ZBI	Carer	n/a	26.3 (9.1)	n/a	26.3 (12.2)	n/a	27.9 (10.4)

$p < .05$

Abbreviations: QCGR, Quality of the care giving relationship; PAI, Positive Affect Index; HADS, Hospital Anxiety and Depression Scale; QoL-AD, Quality of Life in Alzheimer's Disease; ZBI, Zarit Burnout Interview

Primary Analysis

Friedman's ANOVAs were conducted using the dyad scores for the QCGR and the PAI to evaluate differences in medians of relationship satisfaction at T1, T2 and T3. The differences in the dyad scores were not significant for the QCGR dyad score, χ^2 (2, *N* = 16) =3.484, *p*=.175, Kendall's W= .175, or the PAI dyad score, χ^2 (2, *N* = 16) =3.207, *p*=.201, Kendall's W=.100. On exploring the dyad scores on the QCGR subscales of warmth and conflict, no significant differences were found for warmth χ^2 (2, *N* = 16) =1.472, *p* = .479, Kendall's W= .046, or for conflict, χ^2 (2, *N* = 16) =2.1, *p* =.350, Kendall's W=.066.

Friedman's ANOVAs were conducted on the individual scores of participants with dementia and carers on the QCGR subscales of warmth and conflict as well as the total score. For participants with dementia, no significant differences over T1, T2, or T3 were found for warmth, χ^2 (2, *N* = 16) =4.926, *p* =.085, Kendall's W= .154, conflict, χ^2 (2, *N* = 16) =.033, *p* = .983, Kendall's W= .001, or for the overall score, χ^2 (2, *N* = 16) =.407, *p* =.816, Kendall's W= .013. For carers, there was also no significant differences between T1, T2, or T3 for warmth, χ^2 (2, *N* = 16) =5.25, *p* =.072, Kendall's W= .164, conflict χ^2 (2, *N* = 15) =.97, *p*= .953, Kendall's W= .003, or for the overall total score χ^2 (2, *N* = 16) =3.18, *p* = .204, Kendall's W= .099.

Friedman's ANOVAs were conducted on the individual scores of participants with dementia and carers on the PAI. For participants with dementia, the analysis yielded χ^2 (2, *N* = 16) =5.930, *p* = .052, Kendall's W= .185. Although the effect size was small, given that the Friedman's ANOVA was near the significance value *p*<.05, a follow-up, pairwise comparison using a Wilcoxon signed-ranks test was performed. This indicated a significant difference in the medians between T2-T3, *T*= -2.029, *p*=.042, *r*=-0.62, indicating improvement. There was no significant difference for carers across the three time points, χ^2 (2, *N* = 16) =1.393, *p* = .498, Kendall's W= .044.

Secondary Analysis

Friedman's ANOVAs were conducted on the HADS total scores and the anxiety and depression subscales, to evaluate differences in medians for participants with dementia and carers separately. For participants with dementia, there was no significant difference in the total HADS score, χ^2 (2, *N* = 16) =5.525, *p*= .063, Kendall's W= .173 or the anxiety subscale, χ^2 (2, *N* = 16) =3.66, *p* = .160, Kendall's W=.114. Depression scores of participants with dementia significantly changed over the three time-points χ^2 (2, *N* = 16) =7.569, *p* < .023, with Kendall's W= .237, indicating a modest effect size. Follow-up pairwise comparisons using a Wilcoxon signed-rank test yielded a significant decrease in depression scores between T1 -T3, *T*= -2.399, *p*=.016, *r*=-0.62 and T2 - T3, *T*=-2.683, *p*=.007, *r*=-.69.

For carers, there was no significant difference between T1, T2 and T3 in the medians of the total HADS score, χ^2 (2, *N* = 16) =2.393, *p* = .302, Kendall's W= .075, anxiety subscale, χ^2 (2, *N* =16) =1.782, *p* =.410, Kendall's W= .056, or depression subscale, χ^2 (2, *N* = 16) =3.64, *p* = .162, Kendall's W= .114.

A Friedman test was conducted using the QoL-AD to evaluate differences in medians for participants with dementia in quality of life. The QoL scores did not significantly change over the three time-points χ^2 (2, *N* = 16) =2.475, *p* = .290, Kendall's W= .077. A repeated measures ANOVA was conducted on the ZBI, to evaluate carer burnout at T1, T2, and T3. The test yielded a non-significant result, *F*(2)= .692 *,* *p*= .508. $N_p{}^2$ = .044.

Discussion

The objective of this study was to explore whether a post-diagnostic group designed for care-dyads increased relationship quality. The primary hypothesis was that a dyadic post-diagnosis group intervention would increase relationship quality for people with dementia and their partner. The overall findings from this study do not support this hypothesis. Whilst there was some evidence to suggest that participants with dementia experienced increased relationship quality on the PAI, these findings were not replicated on the QCGR measure. Furthermore, the effect size was modest and there was no significant difference between T1 and T3, indicating the relationship quality did not change following the group. The finding possibly reflects a Type I error, given the small sample and appears to have little clinical significance.

Overall, there were no significant differences in dyadic relationship quality over the three time points, which is consistent with previous findings (Gaugler et al., 2011; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Woods et al., 2012). There was also no evidence to support the secondary hypotheses' that the quality of life for participants with dementia would increase and carers perceived burnout would decrease. The hypothesis that anxiety and depression scores would decrease for participants with dementia and their carer was partially supported. For participants with dementia, there was no significant difference in anxiety, however the finding that their depression scores significantly decreased is consistent with the findings of Logsden et al. (2010). It is noted however, that the effect size was modest and the depression scores at all three time points were below clinical threshold and so the clinical relevance of this reduction is limited.

For carers, there were no significant differences in anxiety and depression scores across the three time points. Although these are null findings, previous findings have found that carer's depression (Logsden et al., 2010) and anxiety (Woods et al., 2012) can actually increase following the intervention. Therefore the intervention in the study did not appear to be contraindicated for carers.

Whilst it is recognised that the study is underpowered, the null findings are consistent with previous studies and there is a need within the dementia literature to understand this further. There are a number of possible areas to explore in attempting to understand these findings.

Dyad Characteristics

It is possible that ceiling and floor effects precluded the beneficial impact of the intervention. Specifically, at all time points throughout the study, relationship quality was consistently high, depression and anxiety scores were sub-clinical, carer burnout scores were in the mild range and the mean QoL-AD remained high. Interestingly, mean scores were similar with those observed at baseline, in the REMCARE study (Woods et al., 2012) on the QCGR, (Participants with dementia, mean =57.83, SD =.42; carers mean =53.45, SD= 8.76), HADS (carer anxiety mean=6.43, SD=4.33; carer depression mean =4.34 SD=3.5) and the QoL- AD (Participants with dementia mean=37.48, SD=5.32). The REMCARE study had a much larger sample, but also demonstrated no significant changes.

Overall, it seems that participants in the current study were not particularly distressed in any measured domain. The literature does demonstrate that some care-dyads cope well (Martin et al., 2009) and it is possible that these dyads are more likely to participate in research and in dyadic group interventions. Therefore interventions may be more effective for distressed care-dyads, which is consistent with previous findings (Logsden et al., 2010). As such, Van't Leven et al., (2013) highlighted that key characteristics of the care-dyad need to be assessed in order to indicate the most appropriate form of intervention. Assessment would include the severity of distress on the psychological construct of interest (Coon, Thompson, Steffen, Sorocco & Gallagher-Thompson, 2003), which could include the current relationship quality. In addition, assessing the quality of the pre-caring relationship may also be beneficial, as this has been associated with relationship quality post-diagnosis (Steadman, Tremont and Davis, 2007). The assessment of these constructs may allow predictions to be made regarding who would benefit from dyadic interventions.

Quality of outcome measures

It is also possible that these ceiling and floor effects reflect limitations in the sensitivity of the outcome measures used. A limitation of previous research is the use of measures that have not been recommended or constructed for dementia research. This study however, either used measures that were recommended by European consensus (QoL-AD, HADS , ZBI; Moniz-Cook et al., 2008), were developed for people with dementia (QCGR), or had been used in previous dementia research (PAI; Woods, 2009). Furthermore, all measures yielded comparable consistency with the study sample.

Within the empirical literature, qualitative methods have consistently shown that group interventions are highly regarded and care-dyads have reported better insight, enhanced communication, and better caregiver relationships (Brodaty et al., 2003; Gaugler et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). Despite the availability of recommended outcome measures, these findings are yet to be replicated using quantitative methods. It is possible that more sensitive standardised outcome measures are required or that empirical research needs to investigate other psychological constructs that may underpin psychological change.

Equity and relationship quality show promise for empirical exploration, yet these concepts are dynamic as dementia progresses and care-dyads continually attempt to find new meaning in their relationship. The measures used in this study, although recommended, are cross-sectional, for example, the QCGR focuses on the current relationship experience, rather than the changes that may have occurred within the relationship. Therefore, outcome measures may benefit from exploring what has *changed* in the relationship, rather than the current status of the relationship. It may be the case that qualitative studies, which allow an in-depth examination of the complex dynamic nature of dyadic relationships, are used to further our understanding in this area.

Mode of intervention

Given that the current findings are consistent with other studies, it is possible that dyadic group interventions alone are not effective. The finding that they do not improve relationship quality is consistent with previous findings (Gaugler et al., 2011; Logsdon et al., 2010; Roberts and Silverio, 2009; Quayhagen et al., 2000; Woods et al., 2012).

When examining the dementia carer literature, Brodaty and Arasaratnam (2012) noted that effective interventions were tailored to a specific domain and used multiple components, including home visits, individual and group telephone sessions. Furthermore, the interventions ranged in length, from 3–6 months. Additionally, effective dyadic interventions described by Smits et al. (2007) and Van’t Leven et al. (2013) were often multi-modal although the authors did not directly evaluate this. Therefore it is possible that effective interventions require multi-modal components, which include individual, dyadic and group interventions.

Tailored Interventions

Tailored carer interventions are effective (Brodaty & Arasaratnam, 2012) and these findings may also translate to dyadic interventions. Given the temporal impact of dementia, the needs of care-dyads change over time (Gallagher-Thompson & Coon, 2007) and caregivers may require different skills at different phases of dementia care, to maintain their well-being (Martin et al., 2009). The intervention under evaluation here was tailored to the needs of care-dyads at the early stages of dementia, however the mean duration of diagnosis was 2.4 years, with a range of six months to six years. It is possible that the temporal phases of the care-dyads were too heterogeneous and therefore a more homogeneous sample may have been more beneficial for care-dyads. Unfortunately, the small sample size precludes statistical analysis to explore this.

An interesting finding within the literature that provides further support for equity theory is that targeted interventions for behavioural symptoms and activities of daily living, which reflect increasing relational inequity, have yielded more promising outcomes for carers and care-dyads (Brodaty & Arasaratnam, 2012; Van't Leven et al., 2013). Therefore effective interventions may need to target domains of inequity, which impact on relationship quality. It is possible the null findings reported here reflect that whilst the intervention focused on key areas of couplehood, it did not target specific domains of inequity, which may have been more pertinent to the construct of relationship quality.

Limitations

The study has a number of limitations. The small sample size results in the study being underpowered and therefore we are unable to generalise from the results. The findings do, however, show a trend that is consistent with other dyadic group intervention studies. The study design used the time points of T1-T2 as control data, however the lack of a matched control group to compare to the intervention group is a further limitation of the study design. The heterogeneity of the participants with dementia is also a limitation, as the intervention was designed for people with early stage dementia and although some participants were cognitively able to participate, they had received their diagnosis up to six years ago. The sample also lacks diversity as all participants lived in a single geographical area and were all white British. The carer sample however, used only partners, both spouses and unmarried partners, whilst previous studies have used mixed carer samples, including spouses and other caregivers. Given the number of differences identified between spouses and other caregivers this is a strength of the study.

Recommendations

Future research should aim to develop our understanding of the different domains in which care-dyads perceive inequity, as whilst the experiences of carers have been explored, there is little evidence to demonstrate the experiences of people with dementia. This may also generate a further understanding about the needs of care-dyads, particularly at the different stages of dementia, as our understanding is currently relatively limited (Davies & Gregory, 2007).

There is a need for psychometrically strong and sensitive measures that target specific psychological domains. This may involve exploring the perceptions of how care-dyads experience changes in the relationship, including changes in equity. It appears that cross-sectional measures can ignore the temporal processes of how care-dyads find new meaning in their relationship.

Clinical implications

The findings reported here support the premise that dyadic group interventions need to be part of a carefully considered wider package of care that carer-dyads receive. This study indicated some small benefits to people with dementia and no measured benefits for their spouses. It is therefore possible that clinical packages of care need to tailor multi-modal interventions so there is a balance between the benefits for people with dementia whilst ensuring that we do not place further burden on informal carers (Montgomery & Williams, 2001; Woods et al., 2012).

The results of this study show that not all care-dyads experience the negative consequences associated with dementia. “Some family members thrive, some simply survive, and others suffer severe consequences” (Montgomery & Williams, 2001, p31) and therefore, the task of clinical services is to adequately assess the needs of care-dyads. Specifically, services should pay particular attention to the nature of the care-dyad relationship and how they find, or struggle to find, new meaning in their relationship. The perception of significant inequity within the relationship, especially in relation to activities of daily living and behavioural symptoms of dementia, should also be assessed to highlight the need for intervention within these particular areas.

Conclusions

The findings of this study supplement the literature demonstrating that dyadic group interventions alone do not seem beneficial for care-dyads and they do not improve care-dyad relationship quality. Dyadic interventions that are multi-modal may prove more effective for care-dyads within dementia. Relationship equity and quality are promising constructs to understand the changing needs of care-dyads.

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Appendices

Appendix 1. Recruitment issues

The researchers noted at the first stage of recruitment that uptake was lower than had been expected. Furthermore, as the group intervention was accessible to family members as well as partners, this reduced the potential sample pool from which to recruit. On average, between one and two care-dyads per group were non-partner dyads and included siblings and adult children. Given this, the researchers agreed to deliver two further intervention groups, to increase the probability of achieving the required sample size of 28 care-dyads. As such, seven phases of the intervention were run. Unfortunately, uptake of the intervention remained lower than expected with a further four couples dropping out of the study. It is noted that these four couples stopped attending the intervention and as such, were unable to continue taking part in the study. Therefore, this did not appear to be a reflection of the study. Furthermore, of those couples who consented to participate in the study, none withdrew from the study or declined to complete the outcome measures.

Appendix 2. Participant Consent Form

Participant Consent Form

Title of Research Project: Does a Post-Diagnostic Dementia Group Increase Relationship Satisfaction in Couplehood?

Researcher(s): Mark Walton, Dr Sarah Butchard, Dr Catrin Eames

Please initial box

1. I confirm that I have read and have understood the information sheet dated .... (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data from the questionnaires I complete will be part of this study without giving my name or disclosing my identity. ☐
4. I understand that no information from my completed questionnaires will be shared with any other participant in the study. ☐
5. I agree that anonymised data from the study may be used in future ethically approved studies ☐
6. I understand that data from the study may be looked at by regulatory authorities and by persons from the Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data ☐

______________________	________	______________
Name of participant	Date	Signature
______________________	________	______________
Name of researcher	Date	Signature

The contact details of the researcher that will be carrying out the research are:

Appendix 3. Battery of outcome measures used in the study

- *3.1 Quality of the Caregiving/Receiving Relationship*
- *3.2 Positive Affect Index*
- *3.3 Hospital Anxiety and Depression Scale (HADS)*
- *3.4 Zarit Burnout Interview*
- *3.5 Quality of Life in Alzheimer's disease (QoL-AD).*

3.1. Quality of the Caregiving/Receiving Relationship

Instructions for the care giver:

Please think about your relationship with the person you are caring for and answer the following questions by circling your responses.

Instructions for the care receiver:

Please think about your relationship with the person who is caring for you and answer the following questions.

1. My relative and I often spend time together in an enjoyable way

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

2. My relative and I often disagree

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

3. There is a big distance in the relationship between my relative and myself

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

4. My relative and I accept each other as we are

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

5. If there are problems my relative and I can usually resolve these easily

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

6. I get on well with my relative

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

7. My relative and I are tender towards each other

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

8. My relative often annoys me

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

9. I feel very good if I am with my relative

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

10. My relative and I often try to impose our opinions on each other

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

11. I blame my relative for the cause of my problems

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

12. My relative and I appreciate each other as people.

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

13. My relative does not appreciate enough what I do for him/her

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

14. I am always glad to see him/her if I have not seen him/her for some time.

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

Scoring

Positive subscale concerning warmth and affection:

Items 1-4-5-6-7-9-12-14

Negative subscale concerning conflict and criticism:

Items: 2-3-8-10-11-13

The scoring for these items need to be reversed (to give score for ‘absence of criticism’)

3.2. Positive Affect Index

1. Taking everything into consideration, how close do you feel in your relationship with…………?

Not close at all	Not too close	Quite close	Close	Very close	Extremely close
1	2	3	4	5	6

2. How is communication between yourself and……….how well can you exchange ideas or talk about things that really concern you?

Not well at all	Not too well	Quite well	Well	Very well	Extremely well
1	2	3	4	5	6

3. In general, how similar are your views about life to those of…………?

Not similar at all	Not too similar	Quite similar	Similar	Very similar	Extremely similar
1	2	3	4	5	6

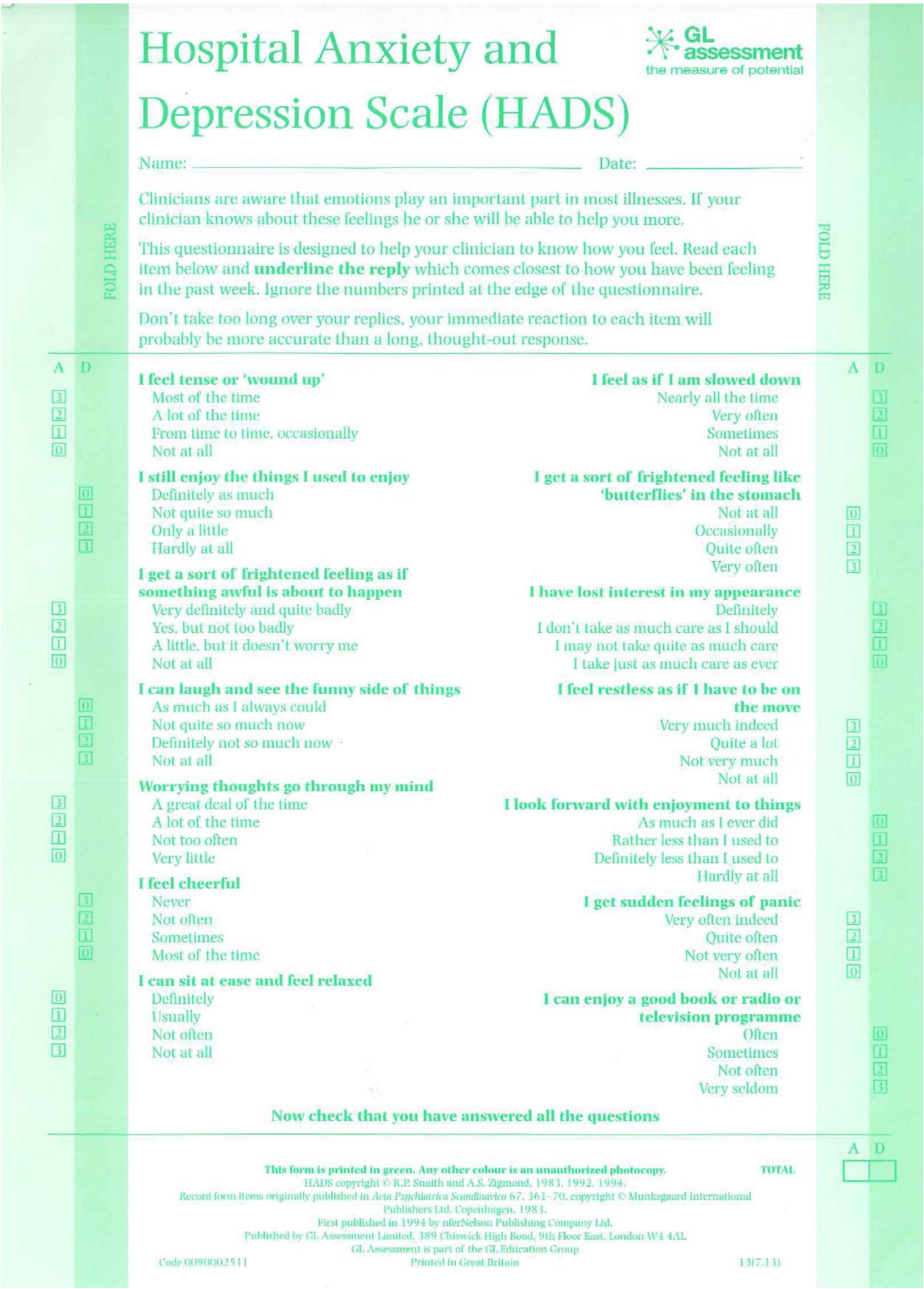
4. How often do you do things together?

Never	Very rarely	Rarely	Occasionally	Frequently	Very frequently
1	2	3	4	5	6

5. Generally how well do you and……….get along together?

Not well at all	Not too well	Quite well	Well	Very well	Extremely well
1	2	3	4	5	6

3.3. Hospital Anxiety and Depression Scale



Hospital Anxiety and Depression Scale (HADS)

GL assessment
the measure of potential

Name: ______________________ Date: __________

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

FOLD HERE

	A	D
I feel tense or 'wound up'		
Most of the time	3	
A lot of the time	2	
From time to time, occasionally	1	
Not at all	0	
I still enjoy the things I used to enjoy		
Definitely as much		0
Not quite so much		1
Only a little		2
Hardly at all		3
I get a sort of frightened feeling as if something awful is about to happen		
Very definitely and quite badly	3	
Yes, but not too badly	2	
A little, but it doesn't worry me	1	
Not at all	0	
I can laugh and see the funny side of things		
As much as I always could		0
Not quite so much now		1
Definitely not so much now		2
Not at all		3
Worrying thoughts go through my mind		
A great deal of the time	3	
A lot of the time	2	
Not too often	1	
Very little	0	
I feel cheerful		
Never		3
Not often		2
Sometimes		1
Most of the time		0
I can sit at ease and feel relaxed		
Definitely	0	
Usually	1	
Not often	2	
Not at all	3	

	A	D
I feel as if I am slowed down		
Nearly all the time		3
Very often		2
Sometimes		1
Not at all		0
I get a sort of frightened feeling like 'butterflies' in the stomach		
Not at all	0	
Occasionally	1	
Quite often	2	
Very often	3	
I have lost interest in my appearance		
Definitely		3
I don't take as much care as I should		2
I may not take quite as much care		1
I take just as much care as ever		0
I feel restless as if I have to be on the move		
Very much indeed	3	
Quite a lot	2	
Not very much	1	
Not at all	0	
I look forward with enjoyment to things		
As much as I ever did		0
Rather less than I used to		1
Definitely less than I used to		2
Hardly at all		3
I get sudden feelings of panic		
Very often indeed	3	
Quite often	2	
Not very often	1	
Not at all	0	
I can enjoy a good book or radio or television programme		
Often		0
Sometimes		1
Not often		2
Very seldom		3

Now check that you have answered all the questions

	A	D
TOTAL		

This form is printed in green. Any other colour is an unauthorized photocopy.

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3.4. Quality of Life in Alzheimer's Disease

Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below.

The interview is carried out with the subject and/or an informant. The subject should be interviewed alone.

Hand the form to the participant, so that he or she may look at it as you give the following instructions

(instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response.

Each of the four possible responses should be presented, and the participant should pick one of the four. If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. **First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.**

2. **How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?**

4. **How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?**

5. **How about your memory? Would you say it is poor, fair, good, or excellent?**

6. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

7. **How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. It there is no one appropriate, or the participant is unsure, score the item as missing.

8. **How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**

9. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?**

10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?**

11. **How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?**

12. **How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent?** If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.

13. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?**

Scoring instructions for QOL-AD: Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4. The total score is the sum of all 13 items.

3.5. The Zarit Burden Interview

Please circle the response the best describes how you feel. Never	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life	0	1	2	3	4

has suffered because you are caring for your relative?					
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative’s illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
Total Score (out of 88)					

Interpretation of Score:
0 – 21 little or no burden
21 – 40 mild to moderate burden
41 – 60 moderate to severe burden
61 – 88 severe burden

Appendix 4. Participant Information Sheet

UNIVERSITY OF
LIVERPOOL

Does a Post-Diagnostic Dementia Group Increase Relationship Satisfaction in Couplehood?

PARTICIPANT INFORMATION SHEET

Thank you for taking the time to consider participating in this research project. Please take time to read the following information carefully. This information sheet explains the purpose of the study and what will happen if you take part. If there is anything that is not clear or if you would like more information before you make a decision, please ask the researcher.

What is the purpose of the study?

People with dementia and their partners face a range of challenges as they come to terms with a diagnosis of dementia and this can put a strain on couples. Given these challenges, few studies have investigated whether it is helpful to provide support for people with dementia and their partner together. Given that both the person with dementia and their partner go through the process of dementia together it seems clear that we need to know if it is better to help people with dementia and their partner together or separately.

Therefore we wondered whether the post diagnostic group that supports couples together is helpful for couples and whether it would help in their relationship with each other.

Why have I been asked to take part?

You have been asked to take part because you and your partner have been asked to participate in the Post-Diagnostic Dementia Group.

Do I have to take part?

No. You can decide not to take part in the study. Your participation is entirely voluntary and you or your partner can stop taking part at any point without giving a reason. The results you have given up to the point you decide to withdraw may be used unless you request that they are destroyed. Your decision to take part or not will have no detrimental effect on the service you will receive from the Older People's Service.

What would it involve?

If you agree to take part you will be asked to complete four short questionnaires at three points in time. These may be different depending on whether you are the person with dementia or their partner.

Participation is expected to take about thirty minutes per set of questionnaires. If you decide to take part you can complete the first set of questionnaires at your home. Then you will complete them at the group at the beginning of the first session and at the end of the last session.

Will my taking part in the study be kept confidential?

Yes. All information you provide will be kept completely confidential. All personal information (e.g. your name, the name of the service) or anything else which might identify you will be removed so that no-one will know who you are. The information that you provide will **not** be shared with anyone in the service. No names will be used in any reports that are written.

The only exception to confidentiality is if the information that you provides suggests that you or someone else may be at risk of harm. In the extremely rare circumstances when this does happen the researcher will make every effort to discuss this with you first.

What are the possible benefits of taking part?

You will not benefit from taking part in the study. However, any information that you give us can help us to improve clinical guidance about how to help people and their families when living with dementia.

Are there any risks/disadvantages to helping with this research?

There are no known risks to taking part in this research the only disadvantage to you will be the time it takes to participate which is estimated to be about 30 minutes per set of questionnaires. Help will also be available from the researcher and from the group facilitators in completing the questionnaires.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by Preston North West Research Ethics Committee.

Who has funded this study?

This study has been funded by the Northwest Strategic Health Authority via the Doctorate of Clinical Psychology Programme, Division of Clinical Psychology, University of Liverpool.

What will happen to the results of the study?

The results of this study will be written up as a thesis which is in partial fulfilment of the principal researcher’s qualification of Doctor of Clinical Psychology. In addition, it is hoped that it will be written up as publication in a relevant scientific journal and presented at a conference. However, you will not be identifiable in any publication that is produced.

At the end of your participation the researcher will ask you whether you would like to be sent a summary of the results when the research has been completed. If you would like a copy of the results she will take an address from you.

What if I am unhappy or if there is a problem?

If you are unhappy, or have a problem during the research, please contact Mark Walton on (mwalton@liverpool.ac.uk) and he will try his best to answer your questions. If you remain unhappy you can contact Dr Catrin Eames (Mark Walton's research supervisor) via 0151 794 5534. If you remain unhappy and wish to complain formally, you can do this through the Patient Advice and Liaison Service (PALS). PALS can assist in resolving issues and concerns that may arise during your contact with the Trust. PALS can be contacted on 0800 328 2941.

Who can I contact if I have further questions?

Please contact Mark Walton via phone (0151 794 5534) or email (mwalton@liverpool.ac.uk) if you have any further questions.

Appendix 5: Normality Analysis

Analysis: Dyads as the unit of analysis. When analysing the overall data for relationship satisfaction and positive affect, scores of participants with dementia and their carers could not be compared as they were considered non-independent. This was because Kenny, Kashy & Cook (2006), state that 35 dyads are required for adequate power to be achieved to test for non-independence, if this is not achieved, as is the case here, non-independence is presumed. For the current evaluation, the difference between spousal scores was calculated to create a single dyad score, which allowed for data analysis that captured data using the dyad as the unit of analysis. Participants with dementia and their carer's scores were also analysed individually to capture any significant differences.

On exploring assumptions of normality, the QCGR indicated modest negative skew at T1 and T2, and at T3. It also indicated modest negative kurtosis at T1 and T3 and positive kurtosis at T2. The test of normality demonstrated a non-significant variation from a normal distribution at T1, D(16) = .108 p>.05, T2 D(16)=.156, p>.05. and T3, D(16)=.170, p>.05.

The PAI demonstrated significantly negatively skewed data and significantly positive Kurtosis at T1. At T2, there was modest negative skew and positive kurtosis and at T3 there was modest negative skew and kurtosis. The test of normality demonstrated a significant variation from a normal distribution at T1, D(16) = .195 p<.05 and a non-significant variation from a normal distribution at T2 D(16)=.109, p>.05 and at T3, D(16)=.170, p>.05. Neither the QCGR or the PAI met the assumption of normality for parametric testing.

Individuals as the unit of analysis. Data from the HADS was deemed to be non-independent given the nature of the psychometric measure and the correlation between participants with dementia and carers was non-significant.

Anxiety subscale. At T1 and T2 the HADS demonstrated modest negative skew and negative kurtosis, for participants with dementia and carers, whilst T3 was characterised by positive skew and negative kurtosis for both sets of data.

At T1, the data for participants with dementia was normally distributed, T1, D(16) = .159, p>.05, although the carers data significantly varied from a normal distribution; D(17) = .214, p<.05. At T2, data for participants with dementia T2, D(16) = .109, p>.05 and carers D(17) = .111, p>.05, did not significantly vary from a normal distribution. At T3, The data for participants with dementia did not vary significantly from a normal distribution, D (15) = .218, p>.05, although carers differed significantly, D (16) = .149, p<.05.

Depression subscale. At T1 and T3, modest positive skew and negative kurtosis was noted on the data for participants with dementia and carers, whilst at T2, both sets of data were characterised by modest positive skew and positive kurtosis. At T1, the data for participants with dementia was normally distributed, D(16) = .127, p>.05, although the carers data significantly varied from a normal distribution, D(17) = .208, p<.05. At T2, the data for participants with dementia significantly differed from normal distribution, D(16) = .223,p<.05, although the carers data did not significantly vary from a normal distribution; carers D(17) = .171, p>.05. At T3, neither the data from the participants with dementia, D (15) = .218, p>.05, or carers, D (16) = .149, p>.05, differed significantly from a normal distribution.

The homogeneity of variances for participants with dementia and carers on both subscales were non-significant at all time points and therefore met the assumption for equal variances across the two groups. Overall, the HADS did not fully meet the assumptions for parametric testing and a Friedman's ANOVA was used to analyse this data.

QoL-AD. At T1, the QoL-AD demonstrated modest negative skew and positive kurtosis, though the data were normally distributed, D(16) = .178, p<.05. At T2 the data demonstrated modest negative skew and negative kurtosis, and testing yielded a significant, non-normal distribution, D(17) = .226, p<.05. At T3, the data yielded a modest positive skew and negative kurtosis and did not vary from a normal distribution, D(16) = .106, p>.05. Given that the QoL-AD did not meet the assumptions for parametric testing, a Friedman's ANOVA was conducted and Wilcoxon signed ranks was used for post hoc analysis.

ZBI. At T1 and T2, the ZBI demonstrated modest positive skew and negative kurtosis. Neither groups demonstrated significant variation from a normal distribution, T1, D(16) = .107, p>.05; T2, D(16) = .116, p>.05. At T3, the data yielded modest negative skew and positive kurtosis, but did not vary significantly from a normal distribution, D(16)=.152, p>.05. The ZBI met parametric assumptions and so was analysed using a repeated measures ANOVA.

Appendix 6: Journal Guidelines

Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Journal Style

Dementia conforms to the SAGE house style.

Article title

Please format with an initial capital only and remaining words lower case, unless proper names. Italics can be included where necessary (e.g. genus name). Run on subtitle after colon, with initial capital after colon.

Abstract and keywords

Abstract should appear in bold without a colon, text should start on the next line, with no indent.

Keywords (all one word) should appear in bold without a colon. The keywords should start on the next line, separated by commas only, not semi-colons. The first keyword should have an initial cap.

Headings

1. Headings should have an initial capital with everything else lowercase, unless proper names.
2. Italics can be included in A heads (H1) if needed, e.g. mathematical symbol or genus name.
3. Headings are unnumbered and formatted as below.
4. Where headings are referred to in the text use section names, as headings are not numbered.

A head (H1) (bold with initial cap, all the rest lowercase)

B head (H2) (italic with initial cap, all the rest lowercase)

C head (H3) (same as B head, but set as first line of paragraph, full out; italic with initial cap, all the rest lowercase, followed by a full stop. Following text runs on)

Headings for Abstract, Keywords, Funding, Acknowledgements, Conflict of interest (in that order), References, and Appendices are same as A head but smaller font size.

General note: Paragraphs following a heading should not be indented. All paragraphs subsequent to the first paragraph should have an indent. T*ext following Figures, Tables, and equations does not need to be full out with no indent. If the next block of text after any of these items is a new paragraph, then this may be indented.*

Figures

1. STM: All figures should have a key line (i.e. be enclosed in a box). HSS: figures have no key line.
2. Figures should be appropriately sized (done by the TS). They do not need to be a full column width or page width.
3. Figure permissions: any figures reproduced from another publication need permission. In cases where those publishers listed on the STM permission Guidelines page (http://www.stm-assoc.org/permissions-guidelines/), permission is not required and only the reference number need by present in the caption. Some publishers ask for certain text, e.g. Elsevier.
4. Source: in cases where permission is required and has been obtained, this should appear below the caption in the following form: Source: reproduced with permission from publisher, year, reference number (Vancouver), author, date (Harvard).
5. Any abbreviations needing to be spelled out should be listed after the caption, starting on the next line, in the following format: IC: internal combustion; PID: proportional–integral–derivative).
6. Captions are positioned below the figures and left aligned.
7. Captions should start, for example, **Figure 1.** (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but should be aligned left.
8. Where figures have multiple parts, these should be labelled as (a), (b), (c), etc. (not A, B, C). Captions should contain subheadings for all parts if not present in the figure itself.
9. All figures should be numbered consecutively and cited in the text as Figure 1, Figure 2 etc. (Figure should be spelled out in full, not abbreviated).

10. Text citations: figures should be referenced in the text as follows: Figure 1, or Figures 1 and 2, or Figures 2 to 4, or Figure 1(a) and (b), or Figure 2(a) to (c). Where the figure citation is not part of the sentence it should be placed in parentheses.

Tables

1. Tables do not need to be a full column width or page width, but should be the appropriate width for the content.
2. Table headings should be left aligned, even when they relate to multiple columns, unless this creates confusion.
3. Tables should only have minimal horizontal rules for clarity, and no vertical rules (done by TS, no need for CE to format).
4. All tables should be numbered consecutively and cited in the text as Table 1, Table 2 etc. (Table should be spelled out in full, not abbreviated).
9. Footnotes should be represented in the table by superscript letters a, b, c, etc., and appear below the Table (smaller font, TS will format). Each footnote should start a new line and end with a full stop. These notes should precede the source for the table, if included.
11. Captions should start, for example, **Table 1.** (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but aligned left.
13. Normal text in columns should always be left aligned. Data in tables should be aligned on units if all the data in that column take the same units. Otherwise, the data should be left aligned. Units in table headings should be enclosed by parentheses, not square brackets (if any brackets are required at all).

Lists

1. For lists where items are not full sentences, use (a), (b), (c) etc. or bullet points (whichever is more appropriate) and separate items with semi-colons. Start list with a preceding colon and end list with a full stop.
2. For lists where items are full sentences or multiple sentences, use 1. 2. 3. Start list with a preceding full stop or semi-colon (whichever is more appropriate), and end list with a full stop.
3. List numbering/bullets should be full out and left aligned, with text indented and aligned. Lists should be separated from preceding/following text with a line space.

4. Where list items include headings, that heading should be italic, same size as text and end in a full stop. The following text should run on.

Appendices

1. Where present, notation should appear as Appendix 1, following the references. The heading *Notation* should be a B-head (not Notations; it is not plural).
2. Abbreviations list should be separated from mathematical notation under a separate B-head *Abbreviations.*

Money

For currency use the common symbol or abbreviation: £, US$, AUD$, etc. – where the quantity is stated, but not when the unit of currency is being referred to in general terms, examples follow:

- The price of oil rose to US$25 per barrel.
- £150m, *not* millions or mlns.

Units in the text

1. Where units are referred to in the text in general terms, they should be written out in full.
2. Where a specific quantity is used, the abbreviated form of the unit must be used; e.g. the nails were several centimetres long; the nails were each 2 cm in length.
3. Always use numerals with the abbreviated unit and use abbreviated units wherever possible – in lists of statistics, in tables and line artwork.
4. Numeral and units should be separated by a thin space, i.e. 100 km, not 100km (this does not need to be indicated by the CE, the TS will format, PR/PE to check). NOTE: exception to the thin space rule applies for percent and degree symbols, i.e. 90% and 35.7o
5. Abbreviations of units are the same for singular and plural (do not add an s); they do not take a full point. E.g. 25 min, 55 s
6. Use SI units wherever possible (see specific Journal webpages for more specific notes).

Numbers

1. Spell out numbers one to nine; for numbers 10 and over use numerals, except at the beginning of a sentence. Re-work the sentence if necessary.
2. Use numerals with percentages (use the % symbol, not per cent or percent), with units, in statistical passages, in tables, etc.

3. Spell out and hyphenate one-half, two-thirds, etc.
4. Do not use a comma in 4-digit numbers (thousands) but do use one in 5-digit numbers (tens of thousands) and above, e.g. 5643; 1298; 14,600; 342,885; 1,000,001. Do *not* use a thin space.
5. Do not contract number ranges, e.g. page ranges and dates; i.e. use pp. 24–29, 13–15 October, 1981–1999 etc.
6. Decimal points are never raised off the line.
7. Do not mix spelled-out numerals and units: 6 cm not six cm.

Abbreviations

1. Do not use abbreviations in the title of a paper, in the abstract, or keywords, unless the full version is very long and clumsy or the abbreviation is better known than the full term (e.g. DNA). Abbreviations may be used in headings and subheadings if they has already been defined previously in the paper at first usage. If in doubt, spell out.
2. Define an abbreviation the first time that it is used (except in the Abstract): write the term out in full followed by the abbreviation in parentheses. Use the abbreviation consistently thereafter, including at the start of sentences.
3. If abbreviations are used in a figure or table, they must all be defined in the caption or in a Table note/footnote even if they are also defined in the text.
4. Abbreviations consisting of capital letters, and acronyms and contractions, should not take full points, e.g. USA, UK, MA, UN, WHO, PhD, NATO (or Nato), UNESCO (or Unesco), AD, BC
5. Unfamiliar (but generally accepted) abbreviations should always be written out in full when first mentioned, with the abbreviated form following in parentheses, e.g. “The Confederación Española de Derechas Autónomas (CEDA) was formed”. Thereafter use the abbreviation.
6. 11. No comma after e.g., i.e. or cf. Etc. has a full stop and is usually preceded by a comma in a list. They may be used in lists or figure or table legends, and within parentheses.

STM abbreviations: some abbreviations of terms that we do not define in full are listed here (follow style given):

- SD = standard deviation
- SEM = standard error of the mean
- NS = not significant
- a.m. in the morning (but use 24-hour clock if possible)
- p.m. in the afternoon
- N/A = not applicable
- Chemical symbols (H2O, H2SO4) may be used without definition. However, write in full unless this is inappropriate (e.g. ‘Water consists of hydrogen and oxygen’; ‘Nitric oxide is also found in peripheral nerves’). Refer to *Scientific terminology* notes for further guidance.

Word Limit

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

Reference Style

Dementia adheres to the APA reference style.

APA reference style

1. If the author’s name is in the text, follow with year in parentheses:
   ... Author Last Name (year) has argued ...
1. If author’s name is not in the text, insert last name, comma and year:
   ... several works (Author Last Name, year) have described ...
2. For direct quotations, the page number follows the year, preceded by ‘p.’ (not a colon): ... it has been noted (Author Last Name, year, p. XXX) that ...
3. Where there are two authors, always cite both names, joined by ‘and’ if within running text and outside of parentheses; joined by an ampersand (&) if within parenthetical material, in tables and in captions, and in the reference list: …Author Last Name and Author Last Name stated that… ...
4. When a work has three, four, or five authors, cite all authors the first time the citation occurs; in subsequent citations, include only the surname of the first author

followed by ‘et al.’ (not italicized and with a period after ‘al’) and the year if it is the first citation of the reference within a paragraph

5. When a work has six or more authors, cite only the surname of the first author followed by ‘et al.’ (not italicized and followed by a period after ‘al’) and the year for the first and subsequent citations.
6. If two or more references by the same author are cited together, separate the dates with a comma (in chronological order): ... the author has stated this in several studies (Author Last Name, 2000, 2001, 2002, 2006) ...
7. If there is more than one reference to the same author (or by the same two or more authors in the same order) and year, insert the suffixes ‘a’, ‘b’, ‘c’, etc. after the year of publication and repeat the year. The suffixes are assigned in the reference list, where these kinds of references are ordered alphabetically by title (of the article, chapter, or complete work): ... it was described (Author Last Name, 2000a, 2000b, 2000c) ...
8. When names of groups (e.g. government agencies, universities, etc.) serve as authors, these are usually spelled out each time they appear in a text citation. However, some group authors can be spelled out in the first citation and abbreviated thereafter:
9. First text citation:
   (National Institute of Mental Health [NIMH], 2000) ...
   Subsequent text citation: ... (NIMH, 2000) ...