When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given e.g. Bolsover, Fay E. (2017) Psychological interventions and dyadic coping in couples living with dementia. D.Clin.Psych. thesis, Canterbury Christ Church University.

FAY E. BOLSOVER MA (Hons)

PSYCHOLOGICAL INTERVENTIONS AND DYADIC COPING IN COUPLES LIVING WITH DEMENTIA.

Section A:

A review of psychological interventions for couples living with dementia: To what extent are they dyadic?

Word Count: 7,981 (plus 29 additional words)

Section B:

An exploration of dyadic coping in couples living with dementia.

Word Count: 8,146 (plus 184 additional words)

Overall Word Count: 16,127 (plus 213 additional words)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

MAY 2017

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

I would like to express my gratitude to the couple participants. It was a privilege to hear their experiences and I was moved by their honesty, love, and courage.

Thank you to my supervisors, Kate Foxwell and Paula Redmond, for their enthusiasm and guidance.

I would like to thank my family and friends, particularly Heidi, for their support and encouragement, and Subreena and Hannah, for supporting my mind and body.

Finally, to my Mum, Denise, for always being there for me, and to my fiancé, John, for his endless love and support; I could not have done this without you.

Summary of the MRP portfolio

Section A

A review of the literature on psychological interventions for couples living with dementia. Findings indicated significant variation in interventions, with a lack of focus upon couple dyads~~,~~ and theoretical or empirical basis. There was also significant variation in outcome measures, with a lack of focus upon dyadic relationship constructs. Interventions were found to have positive effects upon both individual and dyadic relationship outcomes, including mood, quality of life, communication, and coping. Future research could explore how couples cope together living with dementia, to further understanding of how interventions could be developed to meet their needs.

Section B

A qualitative study which explored dyadic coping in couples living with dementia. Nine spouse couple dyads were interviewed together. Framework analysis of the data identified six main themes. Findings offered an understanding of ways in which couples cope with living with dementia, involving both individual and shared dyadic appraisals of stress and coping, discussed within the context of theoretical models of dyadic coping. Themes also suggested factors that may influence dyadic coping. This study significantly adds to a paucity of research investigating dyadic coping in couples living with dementia, and has implications for future research and clinical practice.

Section C

Appendix of supporting material.

Table of contents

Page number

Acknowledgements i

Summary of the MRP portfolio ii

Table of contents iii

List of tables viii

List of figures viii

List of appendices ix

Section A

Abstract 1

Introduction 2

- The psychological impact of dementia 3
- The relational impact of dementia 3
- The impact of dementia on spouse partners 4
- The impact of dementia upon couple relationships 4
- Conceptualisations of coping with dementia 5
- Psychosocial interventions for people with dementia and their caregivers 6
- Previous reviews of psychosocial interventions for dyads of people with dementia and their family caregivers 7
- Rationale for current review 8

Methodology 9

Literature search 9

Data extraction and analysis 12

Review 20

Review structure 20

To what extent are psychological interventions for couple dyads living with dementia dyadic (in terms of intervening with couples as a dyad and considering dyadic relationship factors)? 20

Variation in type and aims of interventions: Lack of focus upon the couple dyad 20

Variation in length and content of interventions: Lack of theoretical or empirical basis 22

How have psychological interventions for couple dyads living with dementia been found to impact both individual outcomes (for each person in the dyad) and relationship outcomes (for couple dyads), such as adjustment and coping? 24

Variation in outcome measures: Lack of focus upon the dyadic relationship 24

Positive impacts of interventions upon individual outcomes 28

Neutral or negative impacts of interventions upon individual outcomes 29

Positive impacts of interventions upon dyadic relationship outcomes 31

Neutral or negative impacts of interventions upon dyadic relationship outcomes 32

Discussion 34

Summary of review findings 34

Clinical implications 36

Research recommendations 38

References 40

Section B

Abstract 1

Introduction 2

The relational impact of dementia 2

The impact of dementia upon couple relationships 2

Models of coping 3

Models of coping with dementia 4

Dyadic coping 5

Dyadic coping in couples living with dementia 7

Method 8

Design 8

Qualitative methodology: Description and rationale 9

Epistemological position 9

Participants 9

Procedure 13

Ethical approval and guidelines 13

Study procedures, including measures and ethical considerations 13

Quality assurance 14

Results 15

Data analysis 15

Dementia awareness and ownership 15

Dementia diagnostic process 16

Acceptance versus denial 17

Emotional closeness 18

Closeness and coping together 18

Distance and coping apart 20

Responsibility 20

Partners supporting their partner with dementia 21

Loss of shared responsibility 22

Loss of shared concerns 23

Individual needs and difficulties 24

Individual impact of dementia 24

Partners of people with dementia's own needs and difficulties 25

Individual coping by people with dementia 26

Wider social context 27

Relationships and support 27

A ‘dementia friendly’ society 28

Discussion 29

Practice implications 33

Limitations 34

Sample 34

Design 34

Future research 35

Conclusions 36

References 37

List of tables

Page number

Section A

Table 1. Inclusion and exclusion criteria of papers for the review. 10

Table 2. Papers included and reviewed. 13

Section B

Table 3. Participants’ demographic information. 11

Table 4. Final thematic framework. 16

List of figures

Page number

Section A

Figure 1. Studies identified, screened, included and excluded for the review 11

Section B

Figure 2. The developmental-contextual model of dyadic coping in couples coping with chronic illness (Berg & Upchurch, 2007). 6

Figure 3. Dyadic coping, appraisal and adjustment within the developmental-contextual model of dyadic coping in couples coping with chronic illness (Berg & Upchurch, 2007). 6

List of appendices

Page number

Section A

A. Data extraction form 1

Section B

B. Clinical Dementia Rating scale [CDR] (Morris, 1993) 2
C. Study information booklet 12
D. Study recruitment poster 16
E. Ethics panel approval letter 17
F. Participant briefing prior to interview 18
G. Study consent form 19
H. Participant demographic information form 20
I. Interview schedule 21
J. Example of written information on sources of support provided to participants 23
K. Participant follow-up telephone call 24
L. Abridged research diary 25
M. Example of a coded transcript 28
N. Initial thematic framework 66
O. Working analytical framework (including codebook) 68
P. Example of a framework matrix 83
Q. Final thematic framework theme descriptions 88
R. End of study letter to the ethics panel including summary report for participants 92
S. Journal for submission’s notes for contributors 95

Section A

A review of psychological interventions for couples living with dementia:

To what extent are they dyadic?

Word count: 7,981 (plus 29 additional words)

Fay Emily Bolsover

Salomons Centre for Applied Psychology

Canterbury Christ Church University

MAY 2017

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

Abstract

Dementia is not experienced in isolation, with difficulties often initially identified by the system around the person. There is increasing recognition of the need for psychosocial support following diagnosis, both for those receiving the diagnosis and those close to them. However, the majority of interventions have focused upon caregivers individually, with people with dementia often excluded. Nevertheless, a growing number of studies have provided interventions for both people with dementia and their family caregivers. This review aimed to explore the literature on psychological interventions for couple dyads living with dementia. A systematic search of six electronic databases and relevant reference lists identified 17 papers. There was significant variation in interventions, with a lack of both focus upon the couple dyad and theoretical or empirical basis. There was also significant variation in outcome measures, with a lack of focus upon dyadic relationship constructs. Interventions were found to have positive effects upon both individual and dyadic relationship outcomes, including mood, communication, relationships, and coping. It may be important for future research to further explore how couples cope together living with dementia, to further understanding of how interventions could be developed to meet their needs.

Keywords: couple dyad, dementia, psychological intervention.

Introduction

The term dementia describes a syndrome (a group of associated symptoms) resulting from usually progressive or chronic brain damage caused by certain diseases. The most common cause of dementia is Alzheimer’s disease (accounting for 62% of dementia diagnoses) (Alzheimer’s Society, 2013). However, there are a number of other subtypes, including vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Prince et al., 2014). Symptoms of dementia vary between individuals and subtypes, but often include decline in cognitive functioning (including memory, executive functioning, language and orientation), and changes in mood (such as sadness, anxiety or frustration), behaviour (such as an increase in unusual or repetitive behaviours) and physical functioning, including sleep and appetite (Alzheimer’s Society, 2013).

The prevalence of dementia in the overall UK population is 1.3%, rising to 7.1% for people aged 65 and over (Prince et al., 2014). By 2025, the number of people with dementia in the UK is predicted to be over one million (Prince et al., 2014). Dementia is one of the main causes of disability amongst older people, and is a priority for global public health (World Health Organisation, 2012). Although there is currently no cure for dementia, the National Dementia Strategy (NDS) suggested that early diagnosis can be helpful in providing people with care and support, enabling them to ‘live well with dementia’ (Department of Health [DoH], 2009). A number of models of dementia have been used to inform understanding, with the dominant medical model characterised by neurological deterioration. However, this has been criticised for neglecting the personal and interpersonal, including psychological and social factors (Kitwood & Bredin, 1992).

The psychological impact of dementia

Making a diagnosis of dementia can be seen as a social process which places the person within a new stigmatised social group (Husband, 1999). The loss and stigma associated with a diagnosis of dementia may result in experiences of apathy, shame, loss of self-efficacy, social isolation and withdrawal (Bender & Cheston, 1997; Bond & Corner, 2001; Gwyther, 1997; Harman & Clare, 2006; Husband, 2000; Katsuno, 2005). Emotional responses to receiving a diagnosis of dementia may include denial and lack of insight (manifested by avoidance strategies), grief reactions and emotional crises (manifested by the expression of anger, fear, sadness or despair), or positive coping (manifested by optimism and maximising opportunities) (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). People with dementia may experience psychological distress related to life changes and losses, including frustration, worry, anxiety and depression (Logsdon et al., 2010). However, personal meanings of dementia are likely to be influenced by the social system surrounding the person with dementia (Bond & Corner, 2001).

The relational impact of dementia

Dementia is not experienced in isolation, with difficulties often initially identified by the system around the person (Kitwood & Bredin, 1992). Due to the often progressive nature of dementia, people affected typically become increasingly dependent upon support from those around them, with many people with dementia living at home with partners or other family members (Alzheimer’s Society, 2013). According to the NDS, over 500,000 family members care for a person with dementia in England (DoH, 2009). Some family caregivers describe positive aspects of caring for someone with dementia, such as feelings of accomplishment, which may increase wellbeing (Carbonneau, Caron, & Desrosiers, 2010). However, family caregivers of people with dementia may face a number of challenges, including changes in their relationship with the person with dementia, which may result in feelings of grief and the development of new roles (Almberg, Grafström, & Winblad, 1997; Kneebone & Martin, 2003). Many studies have documented high levels of stress, depression, anxiety and physical illness in family carers of people with dementia (Gallagher-Thompson et al., 2000).

The impact of dementia on spouse partners

The impact of dementia may be even more prominent when the person providing care is the spouse or partner of the person with dementia, due to a loss of intimacy, companionship and shared meanings (Rankin, Haut, & Keefover, 2001). Spouse partners may, therefore, experience more relationship strain due to caregiving than other types of carer such as adult children (Pinquart & Sörensen, 2011). Spouses' experiences have involved feelings of loss, and a dichotomy of connectedness and separateness, where partners still see themselves as a member of the couple and perceive continuity in the relationship, but also experience an increasing sense of separateness from their partner due to a loss of shared activities and understanding (Almberg et al., 1997; Kneebone & Martin, 2003; O'Shaughnessy, Lee, & Lintern, 2010).

The impact of dementia upon couple relationships

A growing literature on the impact of dementia on couple relationships has described a reduction in reciprocity, intimacy, shared activities and emotional support, associated with decline in verbal communication and a negative effect upon couples' experiences, including feelings of hopelessness and loneliness (Baikie, 2002; Balfour, 2014; Svanström & Dahlberg, 2004). A greater loss of intimacy and communication has been associated with less interaction, and quicker movement into residential care and death for the person with dementia (Balfour, 2014). However, it has been suggested that some relational aspects may be preserved, such as affection and closeness (Ablitt, Jones, & Muers, 2009).

The concept in the literature of ‘couplehood’ suggests that couple dyads may be motivated to work together to sustain their relationship, described as ‘sustaining couplehood’ and ‘maintaining involvement’ (Hellström, Nolan, & Lundh, 2007; Merrick, Camic, & O’Shaughnessy, 2016). Couples may develop strategies to sustain their lives together, such as mutuality, normalising, sharing and reframing experiences (Ablitt et al., 2009; Molyneaux, Butchard, Simpson, & Murray, 2012; Wadham, Simpson, Rust, & Murray, 2016). Furthermore, focusing upon these strength and relationship-based concepts may be useful in the development of psychosocial interventions to support couples’ adjustment and coping (Molyneaux et al., 2012; Wadham et al., 2016).

Conceptualisations of coping with dementia

Coping with dementia has generally been conceptualised at an individual rather than a relational level, primarily focused upon caregivers, with the voices of those with dementia often unheard (Braun et al., 2009; Molyneaux et al., 2012). Models of coping with dementia have mainly focused upon caregiver stress in spouse partners, and individual coping, based on a transactional model suggesting that stress arises from the transaction between an individual and their environment (Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990; Tremont, 2011). Although some models consider couple relationships in the context of coping with dementia, these have been seen as strains to be managed individually, rather than as something shared by couple dyads (Judge, Menne, & Whitlatch, 2010).

Sociologists have used the term dyad to mean a group of two people, with the term dyadic referring to their interaction (Simmel, 1950). Sociological theorists have suggested that dyadic relationships qualitatively differ from other types of groups as dyads are distinct units, with each element or person dependent upon and responsible to the other (Simmel, 1950). The concept of dyadic coping, a stress communication process involving couples' shared appraisals of stress and coping has recently been explored, including in couples coping with chronic illness (Berg & Upchurch, 2007; Bodenmann, 2005; Foxwell & Scott, 2011; Regan et al., 2014). It has been suggested that, as dementia is often associated with progressive cognitive decline, dyadic coping theories may not be applicable to couple dyads living with dementia (Martin, Peter-Wight, Braun, Hornung, & Scholz, 2009). It is therefore important for future research to explore coping in couples living with dementia, within the context of theoretical models of dyadic coping (Braun et al., 2009). This may inform the development of psychosocial interventions to support and enhance couples' adjustment and coping.

Psychosocial interventions for people with dementia and their caregivers

There is increasing recognition of the need for psychosocial support following such a life changing diagnosis, with people with dementia emphasising the value of social support (Bunn et al., 2012; Whitehouse, Frisoni, & Post, 2004). The pioneering work of Kitwood (Kitwood & Bredin, 1992) introduced the concept of 'personhood', the principles of person-centred care that recognise people with dementias' value, individuality, perspective, relationships, and interactions with others. Currently, these principles underpin best practice guidelines for supporting people with dementia and their caregivers in health and social care settings (National Institute for Health and Care Excellence (NICE), 2006). BPS guidelines (2016) suggest psychological interventions should be provided to people with dementia and family members, including systemic couple or family therapy, to promote adjustment and coping.

However, empirical literature on interventions for people with dementia and their caregivers has mainly focused upon caregivers individually, particularly on ways to relieve their stress and burden, such as support groups, whilst excluding people with dementia (Pinquart & Sörensen, 2006; Whitlatch, Judge, Zarit, & Femia, 2006). Therefore, NICE evidence-based guidelines (2006) recommend access to psychological interventions for ‘carers’, but suggest limited involvement of people with dementia. Where interventions have been offered to people with dementia, the majority have been pharmacological, intended to delay the progress of dementia (Leifer, 2003). Nevertheless, a growing number of studies have investigated psychosocial interventions for dyads of both people with dementia and their family caregivers (Whitlatch et al., 2006).

Previous reviews of psychosocial interventions for dyads of people with dementia and their family caregivers

Three previous reviews have explored psychosocial interventions for dyads of people with dementia and their family caregivers (Moon & Adams, 2013; Rausch, Caljouw, & van der Ploeg, 2017; Van’t Leven et al., 2013). All reviews suggested that psychosocial interventions for people with dementia and their caregivers may have positive benefits, but highlighted the overall poor quality of studies (Moon & Adams, 2013; Rausch et al., 2017; Van’t Leven et al., 2013). Both Moon & Adams (2013) and Van’t Leven et al. (2013) included a broad range of interventions, including cognitive stimulation, skills training, nursing case management and occupational therapy. Rausch et al. (2017) included psychosocial interventions for people with dementia and their caregivers; however, the review only included clinical trials, narrowing the scope for exploring participants’ experiences of psychosocial interventions (Rausch et al., 2017). Furthermore, all previous reviews made no specific selection of the type of dyad included in the review, such as spouse partners or adult children of participants with dementia, with Rausch et al. (2017) suggesting this be taken into consideration in future research.

Rationale for current review

The literature suggests that psychosocial interventions for dyads of people with dementia and their family caregivers may be beneficial. However, the scope of psychosocial interventions included in previous reviews was very wide, resulting in a lack of clarity as to which may provide positive benefit. Furthermore, little attention has been paid to potential differences between different types of family caregiver dyads, such as spouse partners or adult children, despite it being known that their experiences of coping with living with dementia differ (Pinquart & Sörensen, 2011; Rankin et al., 2001). There is therefore a need for a more focused review, both in terms of the type of intervention and type of dyad included. Furthermore, it is currently unclear to what extent interventions are dyadic.

This review thus aimed to explore psychological interventions for couple dyads living with dementia, including studies which provided interventions to both members of the dyad, whether together or separately. Throughout this review, the term ‘couple dyad’ will be used to refer to people with dementia and their spouse or partner, and the term ‘partner’ will be used to refer to spouses or partners of people with dementia.

This review aimed to answer the following research questions:

1. To what extent are psychological interventions for couple dyads living with dementia dyadic (in terms of intervening with couples as a dyad and considering dyadic relationship factors)?

2. How have psychological interventions for couple dyads living with dementia been found to impact both individual outcomes (for each person in the dyad) and relationship outcomes (for couple dyads), such as adjustment and coping?

Methodology

A traditional literature review was conducted to narratively synthesise findings regarding psychological interventions for couple dyads living with dementia.

Literature search

Systematic literature searches were performed to identify relevant papers written in the English language and published in a peer-reviewed journal from any date up to October 2016 using the following electronic databases: CINAHL, Cochrane Library, Medline, PsycINFO, Science Direct and Web of Science. The following search terms were combined: (dementia OR Alzheimer) AND (intervention OR training OR therapy OR support OR counselling) AND (couple OR dyad OR spouse OR husband OR wife OR wives OR partner OR married). Reference lists of relevant papers were examined to identify any additional relevant papers.

The literature search yielded a total of 1542 papers once duplicates were removed. The titles and abstracts were examined to see if the article was related to the topic of the literature review. For relevant papers, or those papers where it was not clear from the title and/or abstract whether the study met the review inclusion criteria (in Table 1), articles were obtained in full. In accordance with the Cochrane Handbook for Systematic Reviews of Interventions, multiple reports of the same study were included and linked together (Cochrane Collaboration, 2011). Full-text articles were obtained for 164 papers, of which 17 met the inclusion criteria (in Table 1).

Table 1

Inclusion and exclusion criteria of papers for the review

Inclusion criteria	Exclusion criteria
1) Participants consisted of dyads containing pairs of individuals of any age comprising one person who had received a diagnosis of dementia (of any type and length of time since diagnosis) and their spouse or partner (married or unmarried, heterosexual or homosexual). In studies where other types of dyadic relationship were also represented (e.g. people with dementia and their child as caregiver), more than 70% of the sample needed to consist of spouse/partner dyads to be included.	1) Participants consisted of dyads containing pairs of individuals where neither person had received a diagnosis of dementia, or, where one person had received a diagnosis of dementia, but less than 70% of their study partners were their spouse or partner, such as their children or other relatives, or where the type of dyad was not stated.
2) A dyadic intervention was provided - designed for and delivered to both members of each couple dyad, either together or separately, with both people active participants in the intervention.	2) Interventions were provided to both members of the couple, but the main evaluated intervention was designed for and delivered to one member of the dyad only (usually study partners of participants with dementia), and/or where the other member of the dyad (usually participants with dementia) was delivered an intervention (such as a music or exercise activity) solely to provide respite to their study partners who received their intervention at the same time.
3) Interventions were evaluated through data collection and analysis (using either quantitative or qualitative methodology) for both members of each dyad.	3) Interventions were simply described in terms of their process without any form of data collection and analysis (quantitative or qualitative).
4) The intervention used a psychological, psychotherapeutic or counselling approach (for multi-component interventions this must apply to at least one component), including psycho-educational and/or psycho-social support groups.	4) Interventions used approaches other than psychological, psychotherapeutic or counselling as the sole component, including: cognitive rehabilitation/stimulation, multi-disciplinary case management, occupational therapy, art, music or exercise.

The study selection process, including numbers of studies identified, screened, included and excluded can be found in Figure 1.

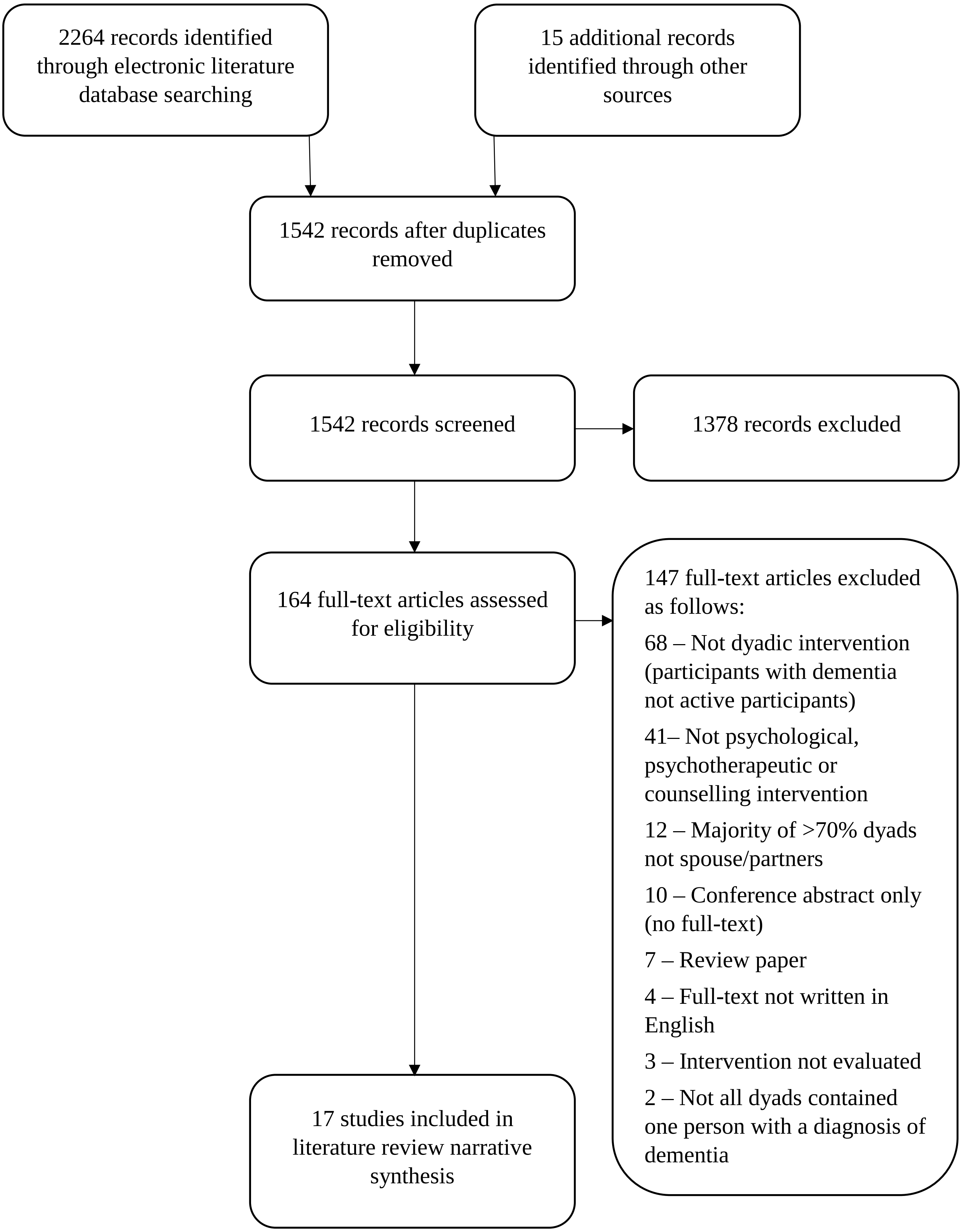


Figure 1. Studies identified, screened, included and excluded for the review

Data extraction and analysis

The quality of the 17 included papers was analysed through the creation of a ‘data extraction’ form (in Appendix A), based on a checklist for data extraction in the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Collaboration, 2011). This considered the following areas: source, methods, participants, interventions, outcomes, results and miscellaneous. Included papers and data extracted from them can be found in Table 2.

Of the 17 papers that met the inclusion criteria for the review, one was a mixed methods study (randomised controlled trial (RCT) and qualitative), ten were quantitative studies (six RCTs and four quasi-experimental) and six were qualitative studies. In accordance with the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Collaboration, 2011), all included studies were not scored using scales but were critiqued according to published criteria: the Critical Appraisal Skills Programme (CASP) (2014) checklists, the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Collaboration, 2011), the NICE (2012) quality appraisal checklist for quantitative intervention studies, and Mays and Pope (2000) criteria for assessing quality in qualitative research.

Table 2

Papers included and reviewed

Author, year & country	Design, methodology, analysis and outcomes	Sample size and characteristics	Intervention (kind; type; brief description and setting; facilitator)	Main findings
Alm, Hellzen, and Norbergh, (2014). Sweden.	- Qualitative – single case study design - Semi-structured interviews (joint and individual) - Content analysis	- 4 spouse couple dyads (N=8) - PWD - age range 73–78; 75% male; mild dementia on MMSE (100% Alzheimer's) - Spouses – 100% living with PWD; no demographic information	- Dyad together - Psycho-educational and psycho-social support group, twice monthly, 90-120 minute sessions at municipal support centre, 9 months to 4 years attendance - Cognitive rehabilitation and reminiscence - Social workers trained in dementia care	Four categories described couples' experiences: 1. Knowledge about the disease 2. Sense of comfort and support (Affected by length of time in the group) 3. Kinship through shared experiences 4. Longing for kinship
Berger et al., (2004). Germany.	- Quantitative – between groups pre- post treatment design - Outcome measures: cognitive function (MMSE), dementia severity (GLDS), behavioural & psychological symptoms of dementia (BEHAVE-AD), activities of daily living (IADL/PSMS), carer burden (ZCBI) and carer depression (GDS/BDI) - Control group - treatment as usual	- 36 PWD and carer dyads (18 intervention 18 control) (N=72) (77.8% spouses) - Intervention group PWD – mean age = 70.8; 50% male; mild – moderate dementia on GLDS (81% Alzheimer's) - Intervention group carers – mean age = 64; 33% male; 83% living with PWD - Matched control group	- Dyad separately - Three interventions: 1. Cognitive stimulation - theme-related discussion and exercises 2. Music therapy - singing, playing & listening 3. Psychotherapeutic group (carers) - supportive sharing of experiences, stress management and coping skills - Weekly, 1 hour sessions at a memory clinic for two years - Two psychologists, one music therapist	No significant differences between treatment and control groups Data trends included: - Poorer cognitive and functional outcomes over time for the treatment group - Decrease in activities of daily living over time in both groups - Higher levels of caregiver burden and depression in the control group at 12 months and in the treatment group at 24 months
Brodaty and Gresham (1989). Australia.	- Quantitative – mixed model RCT (between groups and repeated measures) pre-post treatment design - Outcome measures: cognitive function (MMSE/OIMCS/TDS), dementia severity (CDR), behaviour (PBC), activities of daily living (IADL/ADLS), mood (GDS/HRSD/GHQ/ZDS) administered at baseline, 6 and 12 months post-intervention	- 96 PWD and carer dyads (N=192) (93% spouses); Three matched intervention groups: 1. Carers and PWD groups (33 dyads); 2. PWD only group with carer respite (31 dyads); 3. Waiting list control group (32 dyads) - PWD – mean age = 70.2, 52% male, mild-moderate dementia on CDR (73% Alzheimer's) - Carers – mean age = 67.7, 46% male - Matched intervention groups	- Dyad separately - PWD - cognitive stimulation groups - cognitive rehabilitation and reminiscence therapy - Carers - support groups - psychoeducation, group therapy, behavioural therapy, assertiveness and coping skills training. 12 months of regular follow up group telephone calls - Residential groups in a hospital for 10 days - Facilitators not stated	At 12 months post-intervention: - Carers' anxiety and depression scores significantly lower post-intervention compared to pre-intervention, and in the carer intervention condition compared to the carer respite condition - Poorer cognitive and functional outcomes over time for PWD - PWD's depression scores remained stable over time and below a clinical threshold

Brodaty and Low (2004). Australia.	- Quantitative repeated measures pre-post treatment design - Outcome measures: quality of life (EQ-5D) and mental health (GHQ), PWD's memory & behaviour (RMBPC) and cognitive functioning (MMSE), and carer's depression (BDI) administered pre and post treatment and 24 months follow-up	- 24 spouse couple dyads (N=48) - PWD – mean age = 70.9, 75% male, mild dementia on MMSE - Carers – mean age = 67, 25% male, living with PWD	- Dyads separately and together - PWD - cognitive rehabilitation groups - Spouses - psychoeducation groups - Groups for 2 hours weekly, for 8 weeks. Intervention settings not stated - One couples counselling session and 1 diversional therapy (leisure based activity) session at 4 weeks - PWD subsequently attended 10 weekly behavioural activity groups - Counsellor and Diversional Therapist	- Mental health of PWD significantly improved over time - Carer reported distress significantly changed over time, decreasing at 3 months and then increasing again at 6 months - No significant differences in carer mental health or depression over time. - Non-significant trend towards improvement in carer quality of life
Epstein, Auclair, and Mittelman (2006). USA. & Auclair, Epstein, and Mittelman (2009). USA.	- Qualitative – single case study design (described as being part of an RCT – findings not published)	- Seven spouse couple dyads (N=14) used as case studies across two papers to illustrate findings from larger sample - Sample characteristics only described for larger sample of 42 spouse couple dyads (N=84), aged 61-90 PWD – mild dementia on GLDS (100% Alzheimer's)	- Dyad together - Couples counselling; Psychotherapy including elements of cognitive behavioural therapy, psychodynamic and Gestalt therapies, transactional analysis and other short-term therapies, adapted to couple's needs and goals - Six sessions within two months, at a university research centre - Counsellors knowledgeable about couples and Alzheimer's disease	The intervention was reported to have: - Helped couples achieve their goals - Reiterated couples' sense of togetherness and highlighted both reasons for being together and long-term positive patterns of relating to each other - Given the couple a sense of optimism and increased collaboration, enabling the PWD to feel more assertive and confident and allowing their partner to focus upon their strengths and abilities - Allowed couples to express their feelings over changes in roles and to participate as equals, assuming accepting and non-blaming positions
Gaugler et al., (2011). USA.	- Quantitative repeated measures pre-post treatment design - Outcome measures: couple's depression (GDS) and satisfaction with the group, carer's: stress (ZCBI), perceived effectiveness in caring, perceived preparedness for future caring and perceived activities of daily living of the PWD (IADL), PWD's : perceived effectiveness in completing activities	- 61 PWD and carer dyads (N=122) (85.2% spouses) - PWD – mean age = 74.25, 47.5% male, mild dementia on MMSE - Carers – mean age = 69.16, 41.5% male, 82% living with PWD	- Dyad together and separately - Psychosocial support groups - designed to improve knowledge, communication & confidence, and to strengthen relationship and ways of coping together - 10-13 sessions of 90-120 minutes with a joint interaction period, separate group sessions, and joint concluding session -Three concurrent groups run in community centres (content varied) - Each group facilitated by two moderators, no further detail provided	- Significant increases over time in carers: perceived effectiveness, perceived effectiveness in caring and perceived preparedness for future caring - No significant differences in PWD's scores - PWD with milder dementia severity pre-treatment more likely to indicate increased perceived effectiveness in completing activities pre to post-intervention, however, carers reported activities of daily living in PWD by carers to have decreased

Ingersoll-Dayton et al., (2013). USA. & Ingersoll-Dayton, Spencer, Campbell, Kurokowa and Ito (2016). Japan & USA.	- Qualitative – single case study design - 2013 study – content analysis using data from participants' completed open-ended questionnaires post-intervention - 2016 study – thematic analysis using data from cases	- 29 spouse couple dyads (N=58; N=40 USA, N=18 Japan) - USA PWD – mean age = 74, 70% male, mild-moderate dementia on MMSE - USA spouse partners – mean age = 72.2, 35% male (one same-sex couple), 100% living with PWD - Japan PWD – mean age = 77.4, 78% male, mild-severe dementia on MMSE - Japan spouse partners – mean age = 76.4, 22% male, (all heterosexual, 56% arranged marriages), 100% living with PWD	- Dyad together - Narrative therapy 'Couples life story approach' - structured life reminiscence questions, creation of a life story book based on discussions of significant memories from their shared past, teaching communication skills to facilitate engagement with each other. Reminiscence and communication skills practice between sessions - Five weekly one hour standardised sessions, usually conducted at the couple's or a family member's home - Social workers with a degree in social work, trained in dementia-related issues and the approach	Positive aspects of the intervention: - Partner affirmation, encouragement and highlighting strengths - Couples' improved meaningful and significant engagement with each other - Couples' increased awareness of the continued positive aspects of their relationship. - Couples' communicating about their ability to cope with losses over their lives - Adaptable in cross-cultural contexts - Communication tips were helpful but difficult for PWD to remember - Helpful for the PWD's memory - Sharing the life story book with others Negative aspects of the intervention: - Highlighted gaps in the PWD's memory and losses and changes
Laakkonen et al., (2016). Finland.	- Quantitative – mixed model RCT (between groups and repeated measures) pre-post treatment design - Outcome measures: PWD and carers' health-related quality of life (HRQoL) (15D/RAND-36), PWDs' cognitive function (VF/CDT) and carers' sense of competence (SCQ) and level of mastery (PMS), administered pre-intervention, 3 & 9 months post-intervention. Control group – treatment as usual plus nutrition & exercise advice	- 136 spouse couple dyads (N=272) (67 dyads treatment group, 69 dyads control group) - PWD - mean age = 77.3, 42% male, dementia severity - 16% <mild, 25% mild, 23% moderate, 3% severe on CDR - Carers - mean age = 75.9, 24% male	- Dyad separately - Psychosocial rehabilitation and self-management group - sharing information and support, aiming to increase knowledge, improve self-efficacy and problem-solving and make social connections - Eight weekly, 4 hour closed groups of 10 people held in memory clinics - Trained and supervised gerontology professionals (nurses, occupational therapists and physiotherapists)	Significant findings were: - Increase on the physical component of HRQoL for carers between pre-intervention and 9 months post-intervention - At 9 months post-intervention, improvement in PWD in the intervention group's cognitive function (on verbal fluency and clock drawing), compared to PWD in the control group, despite the intervention group being at more advanced stages of dementia at baseline than the control group
Logsdon et al., (2010). USA.	- Quantitative – mixed model RCT (between groups & repeated measures) pre-post treatment design - Outcome measures: HRQoL (SF-36, QoL-AD), mood (GDS), relationships (FAM), stress (PSS), self-efficacy (SES), memory and behaviour (RMBPC).	- 142 PWD and carer dyads (N=184) (81% spouses) (96 dyads treatment group, 46 dyads waiting list control group) - PWD - mean age = 77.1, 52% male, mild dementia on MMSE - Carers - mean age = 70.5, 32% male, 69% living with PWD	- Dyad separately and together - Manualised support groups – aiming to provide emotional, educational & social support (partly joint and partly separate) - Nine weekly, 90 minute, sessions held in community centres - Experienced and trained MSc level professionals	- PWD significantly improved pre to post intervention in quality of life and mood - Participants whose quality of life improved pre to post intervention reported significantly improvement in: mood, communication, interpersonal relationships and self-efficacy

Prick, de Lange, Twisk and Pot, (2015). Netherlands & Prick, de Lange, Scherder, Twisk and Pot, (2016). Netherlands.	- Quantitative – between groups RCT - Outcome measures: cognitive function (MMSE/GLDS), depression (GDS/CSDD/DRS/CES-D), general health (SIP/SF-36), behaviour in PWD (RMBPC) and caregiver burden (SPICC) administered post-intervention and at six months follow up - Control group received comparison intervention of monthly written information about dementia and monthly ten minute listening emotional support telephone calls	- 111 (N=222) (90% spouses) (57 dyads treatment group, 54 dyads control comparison intervention group) - PWD – mean age = 77, 63% male, mild dementia on MMSE (70% Alzheimer's) - Carers – mean age = 72, 30% male	- Dyad together - Intervention group – couples visited at home for eight one hour sessions, weekly then PWD and carer dyads fortnightly over three months - Psychological aspect of intervention: psychoeducation about dementia and its impact, communication skills training to enhance problem solving, planning pleasant activities - Physical aspect of intervention - 30 minutes of exercise at least three times a week, initially taught by the facilitator - MSc Clinical Psychology students, trained and supervised by a Psychologist	- On the ITT analysis, there were no significant improvements in outcome over time, from pre to post intervention - On the compliance analysis, there was no benefit of increased compliance with the intervention on any outcomes
Quayhagen et al., (2000). USA.	- Mixed methods. - Quantitative – mixed model RCT (between groups and repeated measures) design - Outcome measures: PWD's: cognitive function (memory (WMS-R), verbal fluency (VF) and problem solving (GCS)), and behaviour (MBPC), and spouse carer's: marital satisfaction (MNSS), mood (depression, anger and anxiety) (BSI), morale (subjective wellbeing) (GCMS), physical health (HAS), carer stress (MBPC), coping strategies (CSI-R) and social support (SSQ) administered pre and 3 months post- intervention - Qualitative – open ended semi-structured post-intervention questionnaire data analysed using content analysis	- 103 spouse couple dyads (N=206) randomised to one of four intervention groups or a waiting list control group, matched for age, education and ethnicity - PWD - mean age = 74.51, 63% male, mild -moderate dementia on MDRS - Carers - mean age = 71.83, 37% male	- Dyad together and separately - Four different eight week interventions 1. Cognitive stimulation – memory, problem solving and verbal fluency activities practised for an hour daily for 5 days each week by each dyad at home 2. Dyadic counselling – 90 minute weekly couples therapy sessions for each dyad at home, using systems and cognitive behavioural therapy approaches 3. Dual supportive seminar groups – 90 minute weekly support groups at a community centre, with both separate groups for PWD and spouse carers and joint large discussion groups 4. Early-stage day-care – weekly 4 hour structured sessions at a community centre, involving: social events, discussion, activities, physical exercise and community outings for PWD, and respite & monthly support groups for carers - Graduate students and clinicians from psychology, social work and nursing professions, trained and supervised	- Quantitative data outcomes from pre to post intervention: - Outcomes for PWD: - Those in the cognitive stimulation group significantly improved in: delayed memory, problem solving and verbal fluency - Outcomes for carers: - Those in the early-stage day-care group showed a significant decrease in hostility - Those in the cognitive stimulation group, showed a significant improvement in depression scores - Those in the dual supportive seminar group showed significant decreases in: morale and the use of negative emotion-focused coping - Qualitative data themes for group benefits were: enhancing communication and interaction, providing mental stimulation, acquiring insight and information, building caregiver relationships and enhancing emotional involvement

Roberts & Silverio, (2009). USA.	- Quantitative repeated measures pre-post treatment design - Outcome measures: participant satisfaction, knowledge about dementia (FKAT), coping with dementia (coping self-efficacy (ICSE), psychosocial adjustment to illness (PAIS) and caregiver strain (MBCSI) administered pre & post intervention and at 3 months follow-up - Joint interviews conducted pre & post intervention to assess attitudes and behaviours, with data analysed quantitatively	- 37 PWD and carer dyads (N=74) (81% spouse partners of PWD) - PWD - mean age = 74.4, 73% male, mild dementia on MMSE (89% Alzheimer's) - Carers – mean age = 24% male, 92% living with PWD	- Dyad together and separately - Psycho-education and support groups of 6-10 dyads. Didactic and interactive activities in both large groups and smaller discussion groups for the PWD and their care partners separately, including the provision of written information, with the aim of including the PWD, improving active coping and the use of supportive and educational resources - Four weekly two-hour sessions held at community centres - Alzheimer's Association employees trained and experienced in dementia care	- Coping with dementia - no significant differences pre to post intervention in: levels of coping, self-efficacy, psychosocial adjustment to illness or caregiver strain - Participant satisfaction: 99% of participants found the intervention helpful and 76% felt more supported - Knowledge about dementia: no significant difference pre-post intervention - Attitudes & Behaviours: positive changes in self-reported behaviours of PWD, including: regular physical exercise, healthier eating and future planning - Participants reported feeling more in control (66%) and more accepting (69%) of living with dementia
Sørensen, Waldorff and Waldemar, (2008). Denmark.	- Qualitative – semi-structured interviews were conducted with PWD and their spouses separately, pre and post intervention, to explore their personal experiences - A 'template organising' style of interpretation, which appeared to be a form of thematic analysis, was used to analyse the data	- 10 spouse couple dyads (N=20) - PWD - mean age = 73.4, 50% male, mild dementia on MMSE score - Carers - mean age = 73.4, 50% male, 100% living with PWD	- Dyad together and separately - 6 month multi-component intervention programme at community centres 1. Counselling – two couple sessions, two separate individual sessions each for the PWD and spouse and one session for the couple and family system 2. Education groups for PWD - five sessions of verbal & written information about dementia, and support group activities 3. Education groups for spouse partners with five sessions of a more formal education course, written information about dementia, and support group activities 4. Telephone counselling 5. Log books kept separately by the PWD and their spouse partner - Facilitated by project co-ordinators – no further information provided	- Exploration of participants' experiences of the intervention, using template organising categories: - Recognition of the changes before and after the intervention, including range of awareness of the changes caused by the disease - Reactions to the impacts of the changes caused by the disease before and after the intervention, in everyday life, communication, role patterns and social relations

Woods et al., (2012). UK.	- Quantitative – RCT - Outcome measures: mood (HADS/CSDD/RAID/GHQ), relationship quality (QCPR and rated videotaped interactions); self-reported quality of life (QoL-AD), autobiographical memory (AMI), cognitive function (MMSE) and activities of daily living (BADL) for PWD; and psychological distress for carers (RSS) administered at baseline (pre-intervention), 3 months (during intervention) and 10 months (immediately post-intervention) - Control group - treatment as usual	- 350 PWD and carer dyads (N=700) (71% spouses) - PWD - mean age = 77.5, 50% male, mild-moderate dementia on the CDR (58% Alzheimer's) - Carers - mean age = 69.65, 33% male (one same-sex couple)	- Dyad together - Joint reminiscence therapy groups following a treatment manual, with each session focused upon a different theme, for example childhood, marriage, holidays, journeys, with large and small group work and activities including art and music - Groups of up to 12 dyads attended 12, two hour, weekly sessions followed by 7 monthly sessions, held in social community settings, including community centres and museums - Trained professionals including: clinical psychologists, occupational therapists, mental health nurses, arts workers and community support workers	- ITT analysis: - No significant differences in outcome between the intervention and control groups on any measure - Post-hoc analysis: - 10 months post-intervention, there was a significant difference between groups for psychological distress, with carers in the intervention group reporting significantly increased anxiety - Compliance analysis - attending an increased number of sessions was associated with: - Higher autobiographical memory performance, relationship quality and quality of life in PWD - Increased stress in carers

Key: PWD=participant(s) with dementia; MMSE=Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975); GLDS=Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982); BEHAVE-AD = Behavioural Abnormalities in Alzheimer's Disease Rating Scale (Reisberg et al., 1987); IADL=Instrumental Activities of Daily Living Scale & PSMS=Physical Self Maintenance Scale (Lawton & Brodie, 1969); ZCBI=Zarit Caregiver Burden Interview (Zarit, Reever, & Bach-Peterson, 1980); GDS=Geriatric Depression Scale (Yesavage et al., 1982); BDI= Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961); RCT=Randomised Controlled Trial; OIMCS=Orientation, Information, Memory & Concentration Scale & TDS=The Dementia Scale (Blessed, Tomlinson, & Roth, 1968); CDR=Clinical Dementia Rating scale (Morris, 1993); PBC=Problem Behaviour Checklist (Gilleard, Boyd, & Watt, 1982); ADLS=Activities of Daily Living Scale (Katz & Akpom, 1976); HRSD=Hamilton Rating Scale for Depression (Hamilton, 1960); GHQ=General Health Questionnaire (Goldberg, 1972); ZDS=Zung Depression Scale (Zung, 1967); EQ-5D=European Quality of Life Scale (Williams, 1990); RMBPC=Revised Memory & Behaviour Problem Checklist (Teri et al., 1992); HRQoL=Health related quality of life; 15D (Sintonen, 2001); RAND-36 (Hays & Morales, 2001); VF=Verbal Fluency Test (Morris et al., 1989); CDT=Clock Drawing Test (Sunderland et al., 1989); SCQ=Sense of Competence Questionnaire (Vernooij-Dassen, Persoon, & Felling, 1996); PMS=Pearlin Mastery Scale (Pearlin & Schooler, 1978); QoL-AD=Quality of Life-Alzheimer's Disease (Logsdon, Gibbons, McCurry, & Teri, 2002); SF-36=Medical Outcome Study-Short Form (Ware & Sherbourne, 1992); FAM=Family Assessment Measure (Skinner, Steinhauer, & Santa-Barbara, 1983); PSS=Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983); SES=The Self-Efficacy Scale (Seeman, McAvay, Merrill, Albert & Rodin, 1996); CSDD=Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988); DRS=Depression Rating Scale (Morris et al., 1999); CES-D (Radloff, 1977); SIP=Sickness Impact Profile (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976); SPICC=Self-Perceived Pressure from Family Care (Pot, Van Dyck, & Deeg, 1995); ITT=Intention to treat; WMS-R=Wechsler Memory Scale-Revised (Wechsler, 1987); GCS=Geriatric Coping Schedule (Quayhagen & Chiriboga, 1976); MBPC=The Memory and Behaviour Problems Checklist (Zarit, Orr, & Zarit, 1985); MNSS=Marital Needs Satisfaction Scale (Stinnett, Collins, & Montgomery, 1970); BSI=Brief Symptom Inventory (Derogatis & Spencer, 1982); GCMS=Geriatric Center Morale Scale (Lawton, Moss, Fulcomer, & Kleban, 1982); HAS=Health Assessment Scale (Rosencranz & Pihlblad, 1970); CSI-R=Coping Strategies Inventory-Revised (Quayhagen & Quayhagen, 1988); SSQ=Social Support Questionnaire (Schaefer, Coyne, & Lazarus, 1981); MDRS=Mattis Dementia Rating Scale (Mattis, 1988); FKAT=Family Knowledge of Alzheimer's Disease Test (Maas, 1990); ICSE=Illness Coping Self-Efficacy (Merluzzi & Martinez Sanchez, 1997); PAIS=Psychosocial Adjustment to Illness Scale (Derogatis, 1986); MBCSI=Margaret Blenkner Research Center Caregiver Strain Instrument (Bass, McClendon, Deimling, & Mukherjee, 1994); HADS=Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); RAID=Rating Anxiety in Dementia scale (Shankar, Walker, Frost, & Orrell, 1999); QCPR=Quality of Caregiver/Patient Relationship (Spruytte, Van Audenhove, Lammertyn, & Storms, 2002); AMI=Autobiographical Memory Interview (Kopelman, Wilson, & Baddeley, 1990); BADL=Bristol Activities of Daily Living scale (Bucks, Ashworth, Wilcock, & Siegfried, 1996); RSS=Relatives' Stress Scale (Greene, Smith, Gardiner, & Timbury, 1982).

Review

Review structure

In exploring psychological interventions for couple dyads living with dementia, this review has been divided into sections relating to the different questions under investigation, with relevant review findings organised by thematic content, including critiques of studies using published criteria. This is followed by a discussion, including a summary of the review findings and consideration of clinical and research implications.

To what extent are psychological interventions for couple dyads living with dementia dyadic (in terms of intervening with couples as a dyad and considering dyadic relationship factors)?

Variation in type and aims of interventions: Lack of focus upon the couple dyad. There was significant variation in intervention type across studies. Seven studies involved more than one type of intervention and there was a notable lack of focus upon the couple dyad. Of the 17 included studies, only nine involved couple-based psychological interventions for couple dyads together - specifically involving a therapist providing an intervention with each couple, rather than in groups with other couples (Auclair, Epstein, & Mittelman, 2009; Brodaty & Low, 2004; Epstein, Auclair, & Mittelman, 2006; Ingersoll-Dayton et al., 2013; Ingersoll-Dayton, Spencer, Campbell, Kurokowa, & Ito, 2016; Prick, de Lange, Twisk, & Pot, 2015; Prick, de Lange, Scherder, Twisk, & Pot, 2016; Quayhagen et al., 2000; Sørensen, Waldorff, & Waldemar, 2008). Of the 11 studies that involved group interventions, only two involved couple dyads being together throughout the group sessions (Alm, Hellzen, & Norbergh, 2014; Woods et al., 2012).

Of the remaining group-based studies, four involved group interventions for couple dyads both together and separately - where couple dyads spent part of the session together in joint groups and part of the session in separate groups for either partners or people with dementia only (Gaugler et al., 2011; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009). Five studies included group interventions where couple dyads received interventions separately from each other. Two involved separate groups of partners and people with dementia receiving the same intervention as each other but delivered separately (Laakkonen et al., 2016; Sørensen et al., 2008) and three involved separate groups of partners and people with dementia receiving a different intervention from each other delivered separately (Berger et al., 2004; Brodaty & Gresham, 1989; Brodaty & Low, 2004).

Studies also varied in terms of intervention aims. Many studies stated that the aims of their intervention were either to reduce psychological distress, including depression and stress, or to promote mental health and wellbeing for each member of the couple, but often focused more upon the partner (Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000; Woods et al., 2012). Furthermore, whereas some studies stated that their aims were to support coping and self-efficacy, this was for each member of the couple individually rather than for couple dyads together (Laakkonen et al., 2016; Logsdon et al., 2010; Roberts & Silverio, 2009; Sørensen et al., 2008). Although some studies described an aim of their intervention was to reduce or prevent social isolation, or improve social relations, this was in terms of the wider social system and therefore again was not focused upon the couple dyad (Berger et al., 2004; Logsdon et al., 2010; Sørensen et al., 2008). Only six studies specifically stated aims involving the dyadic relationship, which included, to support and maintain the couple's relationship, including each person's sense of self within the relationship context (Auclair et al., 2009; Epstein et al., 2006), to strengthen couples' relationships by improving ways of coping together and communication (Gaugler et al., 2011), to help couples review their lives together and improve dyadic communication (Ingersoll-Dayton et al., 2013; Ingersoll-Dayton et al., 2016), and to improve couples' interaction (Quayhagen et al., 2000).

Furthermore, in most studies, interventions were not tailored to couple dyads' specific needs or goals, with the exception of four studies (Auclair et al., 2009; Epstein et al., 2006; (Ingersoll-Dayton et al., 2013; Ingersoll-Dayton et al., 2016).

Overall, in considering interventions provided across studies, there appeared to be a general lack of focus upon the couple dyad, both in terms of the type and aims of interventions provided, with both a lack of couple-based psychological interventions for individual couple dyads and a lack of study aims involving the dyadic relationship. Furthermore, interventions were generally not tailored to couple dyads' specific needs or goals.

Variation in length and content of interventions: Lack of theoretical or empirical basis. There was also significant variation in the length of interventions across studies. In studies including couple-based interventions, the number of sessions provided ranged from one to eight, with a mean of six sessions (Auclair et al., 2009; Brodaty & Low, 2004; Epstein et al., 2006; Ingersoll-Dayton et al., 2013; Ingersoll-Dayton et al., 2016; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000; Sørensen et al., 2008).

In most group-based interventions, the number of sessions ranged from four to 22, with a mean of 12 sessions (Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Laakkonen et al., 2016; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Sørensen et al., 2008; Woods et al., 2012). Two group interventions were significantly longer than this, which lasted for between two and four years (Alm et al., 2014;

Berger et al., 2004). In contrast to the other group interventions, the group provided by Alm et al. (2014) was open, allowing members to leave and join, with membership of the group varying between nine months and four years. Groups also varied in how structured they were, with some groups described as being flexible in terms of having varied content (Gaugler et al., 2011), whereas other groups were stated to follow a manualised treatment programme (Logsdon et al., 2010; Woods et al., 2012).

In the 11 studies including group-based interventions, these were generally only broadly described. Interventions often consisted of multiple components, including psycho-educational (which provided participants with information and guidance, including anger or stress management, coping strategies, and skills training, such as communication or assertiveness), psychotherapeutic or psychosocial (which involved a confidential and supportive therapeutic or social group context, sometimes described as peer support or counselling), cognitive stimulation/rehabilitation, and reminiscence (Alm et al., 2014; Berger et al., 2004; Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Laakkonen et al., 2016; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Sørensen et al., 2008; Woods et al., 2012).

Seven studies included couple-based interventions stated to involve specific types of psychological therapy (Auclair et al., 2009; Epstein et al., 2006; Ingersoll-Dayton et al., 2013; Ingersoll-Dayton et al., 2016; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000). Auclair et al. (2009) and Epstein et al. (2006) suggested that their intervention involved an integration of psychotherapeutic approaches, including cognitive behavioural therapy (CBT), psychodynamic and Gestalt therapies, transactional analysis and other short-term therapies. The intervention provided by Ingersoll-Dayton et al. (2013) and Ingersoll-Dayton et al. (2016) was described as being mainly based upon a narrative therapy approach, plus aspects of reminiscence therapy, described as a 'couples' life story approach'. Prick et al. (2015) and Prick et al. (2016) suggested their intervention involved aspects of CBT, including psycho-education, behavioural activation (involving the planning of pleasant activities), and communication skills training to enhance problem solving. The couple therapy intervention provided by Quayhagen et al. (2000) was described as an integration of systemic and CBT approaches, including identifying problems or conflicts that reduced couples' interaction, stress reduction and anger management, and communication building and conflict resolution, designed to increase problem solving skills.

Overall, across studies, there was a notable lack of any theoretical or empirical basis for the length or content of interventions provided, either from psychological theory or from the research literature. Exceptions to this were the interventions provided by Auclair et al. (2009) and Epstein et al. (2006), who described basing their psychotherapeutic intervention upon specific psychological theories such as transactional analysis and psychoanalytic theories, and Ingersoll-Dayton et al. (2013) and Ingersoll-Dayton et al. (2016), who specifically considered the literature on the impact of dementia upon the couple relationship, such as the concept of 'couplehood' (Hellström et al., 2007), in the design of their intervention.

How have psychological interventions for couple dyads living with dementia been found to impact both individual outcomes (for each person in the dyad) and relationship outcomes (for couple dyads), such as adjustment and coping?

Variation in outcome measures: Lack of focus upon the dyadic relationship. All 11 mixed method and quantitative studies evaluated interventions by administering outcome measures immediately before and after interventions (Berger et al., 2004; Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Laakkonen et al., 2016; Logsdon et al., 2010; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000; Roberts & Silverio, 2009; Woods et al., 2012). However, due to the previously noted significant differences in intervention length, this period covered significantly different time spans across studies. Six studies also administered outcome measures after a post-intervention follow up period, however, this period varied between 3 months and 2 years (Brodaty & Low, 2004; Laakkonen et al., 2016; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000; Roberts & Silverio, 2009).

Furthermore, there was significant variation across studies in outcome measures used, both in terms of the constructs measured and the specific questionnaires used, making it difficult to compare findings. In terms of measures of dementia severity or symptoms, all studies included at least one measure of cognitive functioning and/or dementia severity, with 10 studies using the Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975) as a measure of general cognitive functioning (Berger et al., 2004; Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Laakkonen et al., 2016; Logsdon et al., 2010; Prick et al., 2015; Prick et al., 2016; Roberts & Silverio, 2009; Woods et al., 2012). Seven studies measured behavioural and psychological symptoms and four studies measured activities of daily living for participants with dementia (Berger et al., 2004; Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Logsdon et al., 2010; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000; Woods et al., 2012).

However, measures of dementia symptoms or severity may not be valid or appropriate intervention outcome measures. Particularly for samples of participants with early stage dementia, for example, ‘behavioural symptoms’ may not have been apparent, which may have led to ceiling effects and a lack of validity of measures. In addition, due to the often degenerative nature of dementia, measures of dementia symptoms or severity, such as cognitive functioning, are likely to decline over time with disease progression, and therefore may not be amenable to intervention. Thus, they may not be appropriate intervention outcome measures, particularly over longer time periods. Furthermore, study participants varied across studies in terms of dementia type and severity, which, due to the known differences between symptoms in different types of dementia, as well as the often degenerative nature of dementia, may have influenced findings.

In terms of measures of mood and quality of life, nine studies included 12 different measures of mood, mainly assessing depression, but with some also assessing anxiety, anger, stress and overall mental health, in both participants with dementia and partners (Berger et al., 2004; Brodaty & Gresham, 1989; Brodaty & Low, 2004; Gaugler et al., 2011; Logsdon et al., 2010; Prick et al., 2015; Prick et al., 2016; Quayhagen et al., 2000; Woods et al., 2012). Seven studies specifically assessed caring burden or stress (Berger et al., 2004; Gaugler et al., 2011; Logsdon et al., 2010; Prick et al., 2015; Quayhagen et al., 2000; Roberts & Silverio, 2009; Woods et al., 2012). Four studies measured quality of life, for both participants with dementia and partners, two of which also measured health related quality of life for participants with dementia (Brodaty & Low, 2004; Laakkonen et al., 2016; Logsdon et al., 2010; Woods et al., 2012).

However, participants’ mood also varied across studies, in terms of self-rated depression and anxiety. Whereas some studies stated that their interventions were more suited to those participants without clinically significant levels of anxiety and depression, other studies had inclusion criteria for participants to have some depression symptoms pre-intervention. This variation in participants’ mood across studies is likely to have influenced the varying effectiveness of interventions.

In terms of measures of coping and adjustment, five studies also included measures of coping, self-efficacy, sense of competence, mastery, morale, and psychosocial adjustment to illness (Laakkonen et al., 2016; Logsdon et al., 2010; Quayhagen et al., 2000; Roberts & Silverio, 2009; Woods et al., 2012). However, it is notable that all measures of coping and adjustment were focused upon the individual rather than the couple dyad. Furthermore, there was a notable lack of interventions being based upon, or authors having considered, any theoretical models of coping, or any reference being made to the literature on coping with dementia.

Only three quantitative studies included measures of dyadic relationship constructs, including communication and interpersonal relationships, marital satisfaction, and relationship quality (Logsdon et al., 2010; Quayhagen et al., 2000; Woods et al., 2012). Woods et al. (2012) also stated that they assessed relationship quality by rating two videotaped sessions of structured interaction between each participant with dementia and their partner. However, findings of these assessments were not reported.

In terms of evaluating the outcomes of qualitative studies, two studies used semi-structured interviews and one used questionnaires to collect post-intervention data (Alm et al., 2014; Ingersoll-Dayton et al., 2013; Sørensen et al., 2008). However, whereas Sørensen et al. (2008) conducted separate individual interviews with each member of each couple dyad, Ingersoll-Dayton et al. (2013) administered open ended questionnaires to couple dyads together and Alm et al. (2014) conducted joint interviews with couple dyads together. It has been suggested that it is only possible to gain a dyadic perspective by gathering data jointly from couple dyads together (Braun et al., 2009).

The quality of included qualitative studies was assessed using published criteria, including the CASP (2014) checklist for qualitative research and Mays and Pope (2000) guidance for assessing quality in qualitative research. Overall, the quality of included qualitative studies was poor. In all qualitative studies, there were no clear descriptions of particular qualitative methodologies or researchers’ epistemological positions. Furthermore, there was a lack of evidence of many features of qualitative research that may improve its validity, such as triangulation, respondent validation, and attention to negative cases (Mays & Pope, 2000). There was also a lack of reflexivity, with studies failing to clearly describe the role of the researcher(s), including the relationship between the researcher(s) and participants (Mays & Pope, 2000). In addition, data did not appear to be ‘rich’, with a lack of evidence of context, detail, and depth in the data. Furthermore, data analysis did not appear to be sufficiently rigorous and there was an overall lack of clear descriptions of qualitative data analysis procedures, involving an ‘audit trail’ of coding or interpretation of the data, such as the development of themes, concepts or categories (Mays & Pope, 2000).

Overall, in terms of considering outcome measures used for the interventions provided, there was a notable lack of focus upon dyadic relationship constructs, suggesting that variables relating to the couple dyad were not taken into consideration as important outcomes of the interventions. Few studies reported relationship variables such as the length of couple dyads relationships, which may have influenced findings. Furthermore, only two qualitative studies gathered data in a way which allowed interventions to be evaluated using a dyadic perspective.

Positive impacts of interventions upon individual outcomes. Six quantitative studies reported some positive individual benefits of their interventions. Positive individual benefits for people with dementia included improvements in mood~~,~~ (Brodaty & Low, 2004), improved quality of life, associated with improvements in mood and self-efficacy (Logsdon et al., 2010), and improved cognitive function (Laakkonen et al., 2016; Quayhagen et al., 2000). Positive individual benefits for partners included reduced anxiety and depression~~,~~ (Brodaty & Gresham, 1989), improved physical health related quality of life, increased perceived effectiveness and preparedness for caring (Gaugler et al., 2011), and significant decreases in hostility and the use of negative emotion-focused coping strategies (Quayhagen et al., 2000). It was notable that one of the conditions of the intervention of Brodaty and Gresham (1989) only resulted in lowered partner anxiety and depression when both members of the couple dyad received an intervention, compared to when only people with dementia received an intervention, suggesting the benefit of interventions provided to couple dyads.

One qualitative study suggested positive benefits of their group intervention for each individual in the couple dyad, including increased knowledge, having a sense of comfort and support, and kinship with others through shared experiences (Alm et al., 2014).

Neutral or negative impacts of interventions upon individual outcomes. Despite a number of positive benefits of interventions reported, six quantitative studies reported no differences, or potentially negative individual outcomes, resulting from their interventions.

Berger et al. (2004) reported no significant differences between treatment and control groups pre or post intervention, with trends towards poorer cognitive, functional and mood outcomes over time in participants with dementia. Prick et al. (2015) and Prick et al. (2016) also overall found no benefits of their intervention. Moreover, findings suggested trends towards worse outcomes, with those participants in the intervention group having significantly higher scores for depression and participants with dementia also having higher scores for behavioural difficulties from pre to post intervention, compared to the control/comparison group. However, the authors stated that after analyses were adjusted so that characteristics of participants with dementia were controlled for (described as including age, gender, dementia type, level of care required, education level, dementia severity and depression score) these differences were no longer significant (Prick et al., 2016). It is unclear why Prick et al. (2016) controlled for participants with dementia's depression scores when assessing differences in depression between participants in the intervention and control/comparison groups, as treating them as confounding variables is likely to have masked any effects of the intervention on participants' depression symptoms.

Quayhagen et al. (2000) found no beneficial outcomes for participants with dementia in their 'dyadic counselling', 'dual supportive seminar group' or 'early-stage day-care' interventions. There also appeared to be some negative consequences of their interventions, with partners in the 'early-stage day-care' intervention reporting a decrease in the use of potentially helpful cognitive restructuring coping strategies post-intervention, and partner participants in the 'dual supportive seminar group' reporting a decrease in morale.

Roberts and Silverio (2009) also reported a lack of positive outcomes of their intervention, finding no significant differences from pre to post intervention in terms of participants' knowledge about dementia or adjustment and coping, including coping self-efficacy, psychosocial adjustment to illness, or caregiver strain. However, participants did report finding the intervention helpful, as well as feeling more supported, more in control~~,~~ and more accepting. Participants also reported a positive impact of the intervention upon participants with dementia's behaviour.

Woods et al. (2012) also found no overall benefits of their intervention, with no significant differences between intervention and control groups. In line with the findings of Prick et al. (2015), Prick et al. (2016) and Quayhagen et al. (2000), results apparently suggested potentially negative consequences of the intervention, with partners in the intervention group reporting significantly higher anxiety than those in the control group 10 months post-intervention. However, compliance analysis did suggest some positive aspects of the intervention, with attending an increased number of sessions associated with improved scores on measures of autobiographical memory, relationship quality, quality of life, and carer stress.

Positive impacts of interventions upon dyadic relationship outcomes. One quantitative study reported a positive benefit of their intervention in terms of couple dyads' communication and interpersonal relationships. Logsdon et al. (2010) found that people with dementia who had significantly improved quality of life post-intervention~~,~~ also demonstrated improvements in communication and interpersonal relationships with their partners, compared to those people with dementia whose quality of life did not improve over time. This suggested that interventions which improve quality of life may also enhance couple dyads' communication and relationships.

Six qualitative studies suggested positive benefits of their intervention in terms of couple dyads' relationships, including adjustment and coping. Epstein et al. (2006) and Auclair et al. (2009) found their intervention to reiterate couple dyads' sense of togetherness, highlighting their reasons for being together and long-term positive patterns of relating, increased optimism, collaboration, assertiveness and confidence in both members of the couple. The intervention reportedly allowed couple dyads to focus upon their strengths and abilities, express their feelings about role changes, and to take positions of equality and acceptance in their relationship.

Ingersoll-Dayton et al. (2013) reported couple dyads found their intervention helpful in terms of communicating with each other, which helped to prompt people with dementia's memory, and sharing their stories with others. Themes identified by Ingersoll-Dayton et al. (2016) also highlighted positive benefits of their intervention on couple dyads' relationships, including partner affirmation (couples encouraged each other to participate and highlighted each other’s strengths), improved engagement (couples related to each other in more significant and meaningful ways), handling losses (couples discussing how they had coped with losses), and fullness of life as a couple (couples discussed their heightened awareness of the continued positive aspects of their relationship).

The qualitative findings of Quayhagen et al. (2000) suggested couple dyads experienced a number of benefits of their intervention, including enhanced communication and interaction, mental stimulation, acquiring insight and information, building relationships, and enhanced emotional involvement. The intervention provided by Sørensen et al. (2008) was also experienced by couple dyads as having a positive impact upon their lives, including in terms of communication, role patterns and relationships, and increased openness and awareness.

Neutral or negative impacts of interventions upon dyadic relationship outcomes. One qualitative study reported some negative effects of their intervention upon dyadic relationship outcomes. Ingersoll-Dayton et al. (2013) described some negative aspects of their intervention, including highlighting gaps in participants with dementias’ memory, and couples identifying losses and changes.

Overall, there was an apparent difference in outcomes between quantitative and qualitative studies. Whilst many quantitative studies suggested a lack of benefits or even potentially negative consequences of interventions, many qualitative studies reported couple dyads’ positive experiences and positive influences of the interventions upon their lives and relationships. This suggests that outcome measures used were perhaps not sufficient or appropriate to capture clinically important benefits of interventions. Despite interventions being provided for couple dyads, most studies only focused upon individual outcomes for participants, such as mood, quality of life and coping. Only a few studies used outcome measures specifically focused on dyadic relationship outcomes for couple dyads, such as communication and interpersonal relationships, marital satisfaction and relationship quality.

Of the 11 mixed methods and quantitative studies which assessed interventions using outcome measures, when assessed using published criteria, their quality was generally poor. Few studies reported the reliability and validity of outcome measures, either generally or for the specific population. Only six mixed methods and quantitative studies were randomised controlled trials, and these were generally of poor quality with evidence of bias, indicating a lack of validity. There was evidence of performance bias as, due to the nature of the interventions provided, it was not possible for participants, facilitators, or assessors to be blinded to randomisation, increasing the risk of bias. There was also evidence of potential detection bias, as in many studies the identity of the assessors collecting study data and their relationship to participants was not clear, for example if they were in a dual role and were also facilitators or researchers, and therefore not blinded, which may have affected findings. In some quantitative studies there was evidence of selection bias, with participants not randomised to groups. Instead, interested potential participants self-selected themselves for allocation to the intervention group, which may have resulted in systematic differences between the groups and may have influenced findings.

Few quantitative studies conducted power calculations; therefore, it was unclear if, with many having relatively small sample sizes, they were sufficiently powered to detect any intervention effects if they existed. Also, in most studies confidence intervals and effect sizes were not reported, limiting objective measurement of the importance of the effects and assessment of the size of the effects in the population. In those studies with no control group, it was therefore unclear if changes in participants who received the intervention could be attributed to the intervention. However, even in those studies which did have a control group, there was significant variation in the type of control group, with some described as ‘waiting list’ (therefore presumably receiving no intervention), some described as ‘treatment as usual’ (with many studies suggesting this was likely to include other standard supportive interventions, however, the amount and type utilised by control participants was not measured), and others described as receiving alternative but often minimal supportive interventions. This therefore makes comparison between intervention and control groups problematic, due to the increased likelihood of confounding variables.

Studies varied in being conducted in different countries, however, these were all European countries or the USA, except Ingersoll-Dayton et al. (2016) who included a Japanese sample with cultural differences such as arranged marriages. However, not all studies reported participant characteristics such as ethnicity or socio-economic status and, in those that did, most participants were white and well educated. There was also a lack of diversity in different types of partner relationship, with only one study containing one couple in a same-sex relationship (Ingersoll-Dayton et al., 2013). Participants may therefore not be representative of the population, and findings on the acceptability and effectiveness of interventions may not be applicable to people of all cultures and backgrounds.

Discussion

Summary of review findings

This review aimed to explore psychological interventions for couple dyads living with dementia, by considering to what extent interventions are dyadic (in terms of intervening with couples as a dyad and considering dyadic relationship factors), and how interventions have been found to impact both individual outcomes (for each person in the dyad) and relationship outcomes (for couple dyads), such as adjustment and coping.

In terms of the types of intervention provided, there was a notable lack of focus upon the couple dyad, with only nine studies involving couple-based psychological interventions for couple dyads together. Intervention aims also varied, with only six studies stating aims involving the dyadic couple relationship, such as promoting coping together, and dyadic interaction and communication. Many group interventions were structured and manualised, rather than being tailored to couple dyads' specific needs or goals. Overall, there was a notable lack of any theoretical or empirical basis for the length or content of interventions provided, either from psychological theory or from the research literature. Exceptions to this were the couple-based interventions provided by Auclair et al. (2009), Epstein et al. (2006), Ingersoll-Dayton et al. (2013), and Ingersoll-Dayton et al. (2016), who described basing their interventions upon specific psychological theories or the literature on the impact of dementia upon couple relationships.

In terms of considering outcomes of the interventions, there was a notable lack of focus upon dyadic relationship constructs, suggesting that variables relating to the couple dyad were not considered important outcomes. Furthermore, only two qualitative studies gathered data in a way which allowed interventions to be evaluated using a dyadic perspective. In terms of individual outcomes, positive impacts of interventions included improvements in people with dementia and partners' mood and quality of life. However, some studies reported no differences, or potentially negative individual outcomes, resulting from their interventions. Findings of some quantitative studies suggested trends towards poorer cognitive, functional and mood outcomes over time in people with dementia, and increases in anxiety and depression in participants who were in intervention groups compared to control groups. In terms of dyadic relationship outcomes, positive impacts of interventions included enhancing couple dyads' communication, interpersonal relationships, adjustment, and coping. However, one qualitative study reported some negative effects of their intervention upon dyadic relationship outcomes, including highlighting gaps in participants with dementia’s memory and couples identifying losses and changes.

Findings highlighted differences in outcomes between quantitative and qualitative studies, suggesting that quantitative outcome measures may not be sufficient or appropriate to capture clinically important benefits of interventions. In contrast, qualitative studies generally reported positive influences of interventions upon couples’ lives and relationships. However, in most studies it was unclear which aspects of the intervention were most effective, or which participants found most helpful. Few quantitative studies reported the reliability and validity of outcome measures, and some measures may not have been appropriate or valid, particularly due to the varying and progressive nature of dementia. Furthermore, studies were generally of poor quality. Many quantitative studies demonstrated increased risk of bias, limited reporting of effects, and confounding variables, preventing objective measurement of intervention effects, or effects being clearly attributed to the intervention. Qualitative studies demonstrated a lack of clearly described qualitative methodology, including the absence of features suggesting validity and sufficiently robust data analysis.

Clinical implications

When considering psychological interventions for couple dyads living with dementia, this review has highlighted potential benefits upon couples’ lives and experiences, in terms of mood, quality of life and relationships. Studies highlighted positive influences of interventions upon dyadic couple relationships, such as strengthening couples’ sense of togetherness, communication and collaboration, allowing expression of feelings about role changes, and the taking on of positions of equality, acceptance and encouragement in their relationships.

It may be important for clinicians to consider that qualitative studies which reported benefits of interventions in terms of dyadic couple relationships provided couple-based interventions to individual couples together, with a psychological theoretical basis for the intervention, and tailored interventions to couple dyads' specific needs or goals. Whereas many services currently only offer separate individual or group therapies, findings suggest it may be important for clinicians to focus upon couples as a dyadic unit and the impact of dementia upon their relationship, and to provide couple-based psychological therapeutic interventions to support couples' adjustment and coping. It may also be tentatively useful for services, when planning interventions and allocating resources, to consider that many structured manualised group interventions, despite a significant investment in time and resources, did not produce beneficial outcomes.

This review focused specifically upon psychological and counselling interventions, however, it may be important for practitioners to consider that therapeutic interventions may be defined in much broader terms, with recent evidence of positive benefits for participants with dementia and their carers for interventions involving art (Camic, Tischler, & Pearman, 2014), music (Osman, Tischler, & Schneider, 2016), and equine therapy (Gallagher-Thompson, Schier Anzelmo, & Hertel, 2016). In terms of some studies reporting potentially negative outcomes, interventions may have provoked increased awareness of current and future potential losses and changes, which may have increased stress and anxiety. Participants' potential longer-term gains from interventions may therefore not be apparent immediately following intervention, the time when interventions in the included studies were mainly evaluated. This suggests that it may also be important for clinicians to evaluate therapeutic outcomes at a post-treatment follow-up stage. For clinicians and services providing and evaluating interventions it may be important to select outcomes that are valid and appropriate for couple dyads' experiences, needs, values and goals, as well as being clinically relevant, and sensitive and specific to the kinds of changes that may occur in this population.

Research recommendations

The findings of this review suggest potential benefits of psychological interventions for couple dyads living with dementia. However, to further understand their effectiveness, there is a need for future research involving high quality studies where participants are representative of the population and interventions are clearly described, tailored to couple dyads' needs and goals, evaluated using appropriate outcomes, and with robust methods of data analysis.

For many interventions, there was an overall lack of a theoretical basis or grounding in the literature. Future intervention studies could draw upon models and concepts from the psychosocial dementia literature, such as relationship and strengths based approaches, the construct of 'personhood', emphasising the importance of a relational context and social interconnectedness, and the construct of 'couplehood', with couples adopting strategies to maintain their relationship and lives together (Hellström et al., 2007; Kitwood, 1997; McGovern, 2011; Merrick, et al., 2016; Molyneaux et al., 2012; Wadham et al., 2016).

Furthermore, the evidence of interventions having benefits in terms of dyadic relationship outcomes supports the use of social contextual models which emphasise the influence of a dyadic perspective, considering relations between partners in social roles (Berg et al., 1998; Braun et al., 2009). This suggests it may be important for future research to explore how couple dyads cope together living with dementia, to further understanding of how interventions could be developed to meet their needs.

The concept of dyadic coping, a reciprocal stress communication process in which couples make shared appraisals of stress and coping has recently been explored in couples coping with physical illness (Berg & Upchurch, 2007; Bodenmann, 2005; Foxwell & Scott, 2011; Regan et al., 2014). It has been suggested that the strain that living with dementia places on a relationship may have an impact on the use of dyadic coping strategies (Berg & Upchurch, 2007). Thus, some have suggested that dyadic coping theory may not be applicable to couple dyads living with dementia, due to its progressive nature and associated cognitive impairment (Martin et al., 2009). However, dyadic coping has not yet been qualitatively explored in couples living with dementia, within the context of theoretical models of dyadic coping, and this has been suggested an important task for future research (Braun et al., 2009).

References

Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. Aging & Mental Health, 13(4), 497-511. doi:10.1080/13607860902774436

Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. Biological Psychiatry, 23(3), 271-284. doi:10.1016/0006-3223(88)90038-8

Alm, A. K., Hellzen, O., & Norbergh, K. (2014). Experiences of long term ongoing structured support in early stage of dementia – a case study. International Journal of Older People Nursing, 9(4), 289-297. doi:10.1111/opn.12034

Almberg, B., Grafström, M., & Winblad, B. (1997). Major strain and coping strategies as reported by family members who care for aged demented relatives. Journal of Advanced Nursing, 26(4), 683-691. doi:10.1046/j.1365-2648.1997.00392.x

Alzheimer's Society (2013). Dementia: The hidden voice of loneliness. Retrieved from https://www.alzheimers.org.uk/downloads/download/1056/dementia_2013_the_hidden_voice_of_loneliness

Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. Aging & Mental Health, 11(3), 281-290. doi:10.1080/13607860600963695

Auclair, U., Epstein, C., & Mittelman, M. (2009). Couples counseling in Alzheimer's disease: Additional clinical findings from a novel intervention study. Clinical Gerontologist, 32(2), 130-146. doi:10.1080/07317110802676809

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy, 17*(3), 289-299. doi:10.1080/14681990220149095

Balfour, A. (2014). Developing therapeutic couple work in dementia care – the living together with dementia project. *Psychoanalytic Psychotherapy, 28*(3), 304-320. doi:10.1080/02668734.2014.934524

Bass, D. M., McClendon, M. J., Deimling, G. T., & Mukherjee, S. (1994). The influence of diagnosed mental impairment on family caregiver strain. *Journals of Gerontology, 49*(3), S146-S155. doi:10.1093/geronj/49.3.S146

Beck, A.T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4*(6), 561-571. doi:10.1001/archpsyc.1961.01710120031004

Bender, M., & Cheston, R. (1997). Inhabitants of a lost kingdom: A model of the subjective experiences of dementia. *Ageing and Society, 17*(5), 513-532. doi:S0144686X97006570

Berg, C. A., Meegan, S. P., & Deviney, F. P. (1998). A social-contextual model of coping with everyday problems across the lifespan. *International Journal of Behavioral Development, 22*(2), 239-261. doi:10.1080/016502598384360

Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin, 133*(6), 920-954. doi:10.1037/0033-2909.133.6.920

Berger, G., Bernhardt, T., Schramm, U., Müller, R., Landsiedel-Anders, S., Peters, J., ... Frolich, L. (2004). No effects of a combination of caregivers support group and memory training/music therapy in dementia patients from a memory clinic population. International Journal of Geriatric Psychiatry, 19(3), 223-231. doi:10.1002/gps.1055

Bergner, M., Bobbitt, R. A., Pollard, W. E., Martin, D. P., & Gilson, B. S. (1976). The sickness impact profile: validation of a health status measure. Medical Care, 14(1), 57-67. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/950811

Blessed, G., Tomlinson, B. E., & Roth M. (1968). The association between quantitative measures of dementia and of senile change in the cerebral grey matter of elderly subjects. British Journal of Psychiatry, 114(512), 797-811. doi:10.1192/bjp.114.512.797

Bodenmann, G. (2005). Dyadic coping and its significance for marital functioning. In T. Revenson, K. Kayser, & G. Bodenmann (Eds.), Couples coping with stress: Emerging perspectives on dyadic coping (pp. 33−50). Washington, D.C.: American Psychological Association.

Bond, J., & Corner, L. (2001). Researching dementia: Are there unique methodological challenges for health services research? Ageing and Society, 21(1), 95-116. doi:10.1017/S0144686X01008091

Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective. Aging and Mental Health, 13(3), 426-436. doi:10.1080/13607860902879441

British Psychological Society (2016). *Psychological dimensions of dementia: Putting the person at the centre of care*. Retrieved from https://beta.bps.org.uk/news-and-policy/psychological-dimensions-dementia-putting-person-centre-care

Brodaty, H., & Gresham, M. (1989). Effect of a training programme to reduce stress in carers of patients with dementia. *British Medical Journal*, 299(6712), 1375-1379. Retrieved from http://www.bmj.com/content/bmj/299/6712/1375.full.pdf

Brodaty, H., & Low, L. (2004). Making memories: Pilot evaluation of a new program for people with dementia and their caregivers. *Australasian Journal on Ageing*, 23(3), 144-146. doi:10.1111/j.1741-6612.2004.00036.x

Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: development of the Bristol activities of daily living scale. *Age and Ageing*, 25(2), 113–20. doi: 10.1093/ageing/25.2.113

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., ... Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Medicine*, 9(10), 1-12. doi:10.1371/journal.pmed.1001331

Camic, P.M., Tischler, V., & Pearman, C.H. (2014). Viewing and making art together: A multi-session art-gallery based intervention for people with dementia and their carers. *Aging & Mental Health*, 18(2), 161-168. doi:10.1080/13607863.2013.818101

Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia*, 9(3), 327-353. doi:10.1177/1471301210375316

CASP (2014). CASP checklists. Oxford: CASP. Retrieved from http://www.casp-uk.net/#!casp-tools-checklists/c18f8

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. Journal of Health and Social Behavior, 24(4), 385-396. Retrieved from http://www.psy.cmu.edu/~scohen/globalmeas83.pdf

Department of Health (2009). Living well with dementia: A national dementia strategy. Retrieved from: https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Derogatis, L. R. (1986). The psychosocial adjustment to illness scale (PAIS). Journal of Psychosomatic Research, 30(1), 77-91. doi:10.1016/0022-3999(86)90069-3

Derogatis, L. R., & Spencer, P. M. (1982). The Brief Symptom lnventory (BSI): Administration and procedures manual-I. Baltimore, MD: Johns Hopkins University School of Medicine, Clinical Psychometric Research Unit.

Epstein, C., Auclair, U., & Mittelman, M. (2006). Couples counseling in Alzheimer's disease: First observations of a novel intervention study. Clinical Gerontologist, 30(2), 21-35. doi:10.1300/J018v30n02_03

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). ‘Mini-mental state’: a practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 12(3), 189-198. doi:10.1016/0022-3956(75)90026-6

Foxwell, K. R., & Scott, S. E. (2011). Coping together and apart: Exploring how patients and their caregivers manage terminal head and neck cancer. Journal of Psychosocial Oncology, 29(3), 308-326. doi:10.1080/07347332.2011.563343

Gallagher-Thompson, E.T., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., & Thompson, L. W. (2000). Impact of psychoeducational interventions on distressed family caregivers. Journal of Clinical Geropsychology, 6(2), 91-110. doi:10.1023/A:1009584427018

Gallagher-Thompson, D., Schier Anzelmo, N., & Hertel, P. (2016). Equine guided workshops for people affected by dementia: Research results. The Gerontologist, 56(3), 325. doi:10.1093/geront/gnw162.1328

Gaugler, J.E., Gallagher-Winker, K., Kehrberg, K., Lunde, A. M., Marsolek, C. M., Ringham, K., ... Barclay, M. (2011). The memory club: Providing support to persons with early-stage dementia and their care partners. *American Journal of Alzheimer's* Disease & Other Dementias, 26(3), 218-226. doi: 10.1177/1533317511399570

Gilleard, C. J., Boyd, W. D., & Watt, G. (1982). Problems in caring for the elderly mentally infirm at home. Archives of Gerontology and Geriatrics, 1(2), 151-158. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/7186322

Goldberg, D. (1972). The detection of psychiatric illness by questionnaire. New York, NY: Oxford University Press.

Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. Age and Ageing, 11, 121–126. doi:10.1093/ageing/11.2.121

Gwyther, L. P. (1997). The perspective of the person with Alzheimer disease: Which outcomes matter in early to middle stages of dementia? Alzheimer Disease and Associated Disorders, 11(6), 18-24. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/9437444

Hamilton, M. (1960). A rating scale for depression. Journal of Neurology, Neurosurgery & Psychiatry, 23(1), 56-62. doi:10.1136/jnnp.23.1.56

Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. Qualitative Health Research, 16(4), 484-502. doi:10.1177/1049732306286851

Hays, R. D., & Morales, L. S. (2001). The RAND-36 measure of health-related quality of life. Annals of Medicine, 33(5), 350-357. doi:10.3109/07853890109002089

Hellström, I., Nolan, M.R., & Lundh, U. (2007). Sustaining couplehood: Spouses' strategies for living positively with dementia. Dementia: The International Journal of Social Research and Practice, 6(3): 383-409. doi:10.1177/1471301207081571

Higgins, J.P.T., & Green, S. (Eds.). (2011). Cochrane handbook for systematic reviews of interventions. The Cochrane Collaboration. Retrieved from http://www.handbook.cochrane.org

Husband, H.J. (1999). The psychological consequences of learning a diagnosis of dementia: Three case examples. Aging & Mental Health, 3(2), 179-183. doi:10.1080/13607869956352

Husband, H. J. (2000). Diagnostic disclosure in dementia: an opportunity for intervention? International Journal of Geriatric Psychiatry, 15(6), 544-547. doi:10.1002/1099-1166(200006)15:6<544::AID-GPS241>3.0.CO;2-8

Ingersoll-Dayton, B., Spencer, B., Campbell, R., Kurokowa, Y., & Ito, M. (2016). Creating a duet: The couples life story approach in the United States and Japan. Dementia: The International Journal of Social Research and Practice, 15(4), 481-493. doi: 10.1177/1471301214526726

Ingersoll-Dayton, B., Spencer, B., Kwak, M., Scherrer, K., Allen, R. S., & Campbell, R. (2013). The couples life story approach: A dyadic intervention for dementia. Journal of Gerontological Social Work, 56(3), 237-254. doi:10.1080/01634372.2012.758214

Judge, K.S., Menne, H.L., & Whitlatch, C.J. (2010). Stress process model for individuals with dementia. Gerontologist, 50, 294-302. doi:10.1093/geronj/gnp162

Katsuno, T. (2005). Dementia from the inside: How people with early-stage dementia evaluate their quality of life. Ageing and Society, 25(2), 197-214. doi:10.1017/S0144686X0400279X

Katz, S., & Akpom, C. A. (1976). A measure of primary sociobiological functions. International Journal of Health Services, 6(3), 493-508. doi:10.2190/uurl-2ryu-wryd-ey3k

Kitwood, T. (1997). The experience of dementia. Aging & Mental Health, 1(1), 13-22. doi:10.1080/13607869757344

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. Ageing & Society, 12(3), 269-287. doi:10.1017/S0144686X0000502X

Kneebone, I. I., & Martin, P. R. (2003). Coping and caregivers of people with dementia. British Journal of Health Psychology, 8(1), 1-17. doi:10.1348/135910703762879174

Kopelman, M. D., Wilson, B. A., & Baddeley, A. (1990). The autobiographical memory interview. Bury St Edmunds: Thames Valley Test Company.

Laakkonen, M.-L., Kautiainen, H., Hölttä, E., Savikko, N., Tilvis, R. S., Strandberg, T. E., & Pitkälä, K. H. (2016). Effects of self-management groups for people with dementia and their spouses - randomized controlled trial. Journal of the American Geriatrics Society, 64(4), 752-760. doi:10.1111/jgs.14055

Lawton, M. P., & Brodie, E. M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist, 9(3), 179-186. Retrieved from http://www.eurohex.eu/bibliography/pdf/Lawton_Gerontol_1969-1502121986/Lawton_Gerontol_1969.pdf

Lawton, M. P., Moss, M., Fulcomer, M., & Kleban, M. H. (1982). A research and service oriented multilevel assessment instrument. Journal of Gerontology, 37(1), 91-99. doi:10.1093/geronj/37.1.91

Lazarus, R. S., & Folkman, S. (1984). The concept of coping. In R.S. Lazarus & S. Folkman (Eds.), Stress, appraisal, and coping (pp. 117-140). New York, NY: Springer.

Leifer, B. P. (2003). Early diagnosis of Alzheimer's disease: Clinical and economic benefits. Journal of the American Geriatrics Society, 51(5), S281-S288. doi:10.1046/j.1532-5415.5153.x

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. Psychosomatic Medicine, 64(3), 510–519. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/12021425

Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. Journal of Gerontology: Psychological Sciences, 65(6), 691-697. doi:10.1093/geronb/gbq054

Maas, M. (1990). Final report. Alzheimer study. (Unpublished doctoral dissertation). University of Iowa, Iowa City.

Martin, M., Peter-Wight, M., Braun, M. Hornung, R., & Scholz, U. (2009). The 3-phase-model of dyadic adaptation to dementia: why it might sometimes be better to be worse. European Journal of Ageing, 6(4), 291-301. doi:10.1007/s10433-009-0129-5

Mattis, S. (1988). Dementia Rating Scale: Professional manual. Odessa, FL: Psychological Assessment Resources.

Mays, N., & Pope, C. (2000). Qualitative research in health care - assessing quality in qualitative research. British Medical Journal, 320(7226), 50-52. doi:10.1136/bmj.320.7226.50

McGovern, J. (2011). Couple meaning-making and dementia: Challenges to the deficit model. Journal of Gerontological Social Work, 54(7), 678-690. doi:10.1080/01634372.2011.593021

Merluzzi, T. V., & Martinez Sanchez, M. (1997). Assessment of self-efficacy and coping with cancer: Development and validation of the Cancer Behavior Inventory. Health Psychology, 16(2), 163-170. doi:10.1037/0278-6133.16.2.163

Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. Dementia, 15(1), 34-50. doi:10.1177/1471301213513029

Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. Dementia, 11(4), 483-502. doi:10.1177/1471301211421070

Moon, H., & Adams, K. B. (2013). The effectiveness of dyadic interventions for people with dementia and their caregivers. Dementia, 12(6), 821-839. doi: 10.1177/1471301212447026

Morris, J.C. (1993). The clinical dementia rating (CDR): Current version and scoring rules. Neurology, 43, 2412-2414. doi:10.1212/WNL.43.11.2412-a

Morris, J. N., Bernabei, R., Ikegami, N., Gilgen, R., Frijters, D., Hirdes, J. P., … & Henrard, J. C. (1999). RAI-Home Care [RAI-HC] Assessment Manual for Version 2.0. Washington, DC: InterRAI Corporation.

Morris, J. C., Heyman, A., Mohs, R.C., Hughes, J. P., van Belle, G., Fillenbaum, G., Mellits, E. D., & Clark, C. (1989). The consortium to establish a registry for Alzheimer's disease (CERAD). Part I. Clinical and neuropsychological assessment of Alzheimer's disease. Neurology, 39(9), 1159-1165. doi:10.1212/WNL.39.9.1159

NICE (2006). Dementia: Supporting people with dementia and their carers in health and social care. NICE clinical guideline 42. London: NICE. Retrieved from https://www.nice.org.uk/guidance/CG42/

NICE (2012). Methods for the development of NICE public health guidance (third edition): Appendix F quality appraisal checklist - quantitative intervention studies. London: NICE. Retrieved from http://www.nice.org.uk/article/pmg4/chapter/appendix-f-quality-appraisal

O’Shaughnessy, M., Lee, K., & Lintern, T. (2010). Changes in the couple relationship in dementia care: Spouse carers’ experiences. Dementia, 9(2), 237-258. doi:10.1177/1471301209354021

Osman, S. E., Tischler, V., & Schneider, J. (2016). ‘Singing for the brain’: A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. Dementia, 15(6), 1326-1339. doi:10.1177/1471301214556291

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. Gerontologist, 30(5), 583-594. doi:10.1093/geront/30.5.583

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior, 19(1), 2-21. Retrieved from http://www.jstor.org/stable/2136319

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? International Psychogeriatrics, 18(4), 577-595. doi:10.1017/S1041610206003462

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. Psychology and Aging, 26(1), 1-14. doi:10.1037/a0021863

Pot, A., Van Dyck, R. & Deeg, D. (1995). Perceived stress caused by informal caregiving. Construction of a scale. Tijdschrift voor Gerontologie en Geriatrie, 26(5), 214-219. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/8750982

Prick, A., de Lange, J., Scherder, E., Twisk, J., & Pot, A.M. (2016). The effects of a multicomponent dyadic intervention on the mood, behavior, and physical health of people with dementia: A randomized controlled trial. Clinical Interventions in Aging, 11, 383-395. doi:org/10.2147/CIA.S95789

Prick, A., de Lange, J., Twisk, J., & Pot, A. M. (2015). The effects of a multi-component dyadic intervention on the psychological distress of family caregivers providing care to people with dementia: A randomized controlled trial. International Psychogeriatrics, 27(12), 2031-2044. doi:10.1017/S104161021500071X

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., ... Salimkumar, D. (2014). Dementia UK: Update. Alzheimer's Society. Retrieved from https://www.alzheimers.org.uk/info/20025/policy_and_influencing/251/dementia_uk

Quayhagen, M. P., & Chiriboga, D. (1976). Geriatric Coping Schedule. In D. J. Mangen & W. A. Peterson (Eds.), Research instruments in social gerontology: Clinical and social psychology, Vol. **I** (pp. 168-169, 182-183). Minneapolis, MN: University of Minnesota Press.

Quayhagen, M. P., & Quayhagen, M. (1988). Alzheimer’s stress: Coping with the caregiving role. The Gerontologist, 28(3), 391-396. doi:10.1093/geront/28.3.391

Quayhagen, M.P., Quayhagen, M., Corbeil, R.R., Hendrix, R.C., Jackson, J.E., Snyder, L., & Bower, D. (2000). Coping with dementia: Evaluation of four nonpharmacologic interventions. International Psychogeriatrics, 12(2), 249-265. doi:10.1017/S1041610200006360

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1(3), 385-401. doi:10.1177/014662167700100306

Rankin, E. D., Haut, M. W., & Keefover, R. W. (2001). Current marital functioning as a mediating factor in depression among spouse caregivers in dementia. Clinical Gerontologist, 23(3-4), 27-44. doi:10.1300/J018v23n03_04

Rausch, A., Caljouw, M. A. A., & van der Ploeg, E. S. (2017). Keeping the person with dementia and the informal caregiver together: A systematic review of psychosocial interventions. International Psychogeriatrics, 29(4), 583-593. doi:10.1017/S1041610216002106

Regan, T. W., Lambert, S. D., Kelly, B., Mcelduff, P., Girgis, A., Kayser, K., & Turner, J. (2014). Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. Patient Education and Counseling, 96(1), 120-127. doi:10.1016/j.pec.2014.04.010

Reisberg, B., Borenstein, J., Salob, S. P., Ferris, S. H., Franssen, E., & Georgotas, A. (1987). Behavioral symptoms in Alzheimer’s disease: phenomenology and treatment. The Journal of Clinical Psychiatry, 48, 9-15. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/3553166

Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry, 139(9), 1136-1139. doi:10.1176/ajp.139.9.1136

Roberts, J. S., & Silverio, E. (2009). Evaluation of an education and support program for early-stage Alzheimer's disease. Journal of Applied Gerontology, 28(4), 419-435. doi:10.1177/0733464809333883

Rosencranz, H. A., & Pihlblad, C. T. (1970). Measuring the health of the elderly. Journal of Gerontology, 25(2), 129-133. doi:10.1093/geronj/25.2.129

Schaefer, C., Coyne, J. C., & Lazarus, R. (1981). The health-related functions of social support. Journal of Behavior Medicine, 4(4), 381-406. doi:10.1007/BF00846149

Seeman, T., McAvay, G., Merrill, S., Albert, M., & Rodin, J. (1996). Self-efficacy beliefs and change in cognitive performance: MacArthur studies on successful aging. Psychology & Aging, 11(3), 538–551. doi:10.1037/0882-7974.11.3.538

Shankar, K. K., Walker, M., Frost, D, & Orrell, M. W. (1999). The development of a valid and reliable scale for rating anxiety in dementia (RAID). Aging & Mental Health, 3(1), 39-49. doi:10.1080/13607869956424

Simmel, G. (1950). The isolated individual and the dyad. In K.H. Wolff (Ed.), The sociology of Georg Simmel (pp.118-144). New York, NY: The Free Press.

Sintonen, H. (2001). The 15D instrument of health related quality of life: Properties and applications. Annals of Medicine, 33(5), 328-336. doi:10.3109/07853890109002086

Skinner, H. A., Steinhauer, P. D., & Santa-Barbara, J. (1983). The family assessment measure. Canadian Journal of Community Mental Health, 2, 91-104. doi: 10.7870/cjcmh-1983-0018

Sørensen, L. V., Waldorff, F. B., & Waldemar, G. (2008). Early counselling and support for patients with mild Alzheimer's disease and their caregivers: A qualitative study on outcome. Aging & Mental Health, 12(4), 444–450. doi:10.1080/13607860802224342

Spruytte, N., Van Audenhove, C., Lammertyn, F., & Storms, G. (2002). The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. Psychology and Psychotherapy: Theory, Research and Practice, 75(3), 295–311. doi:10.1348/147608302320365208

Stinnett, N., Collins, J., & Montgomery, J. E. (1970). Marital need satisfaction of older husbands and wives. Journal of Marriage and Family, 32(3), 428-434. doi:10.2307/350107

Sunderland, T., Hill, J. L., Mellow, A. M., Lawlor, B. A., Gundersheimer, J., Newhouse, P.A., & Grafman, J. H. (1989). Clock drawing in Alzheimer's disease. A novel measure of dementia severity. Journal of the American Geriatrics Society, 37(8), 725-729. doi:10.1111/j.1532-5415.1989.tb02233.x

Svanström, R., & Dahlberg, K. (2004). Living with dementia yields a heteronomous and lost existence. Western Journal of Nursing Research, 26(6), 671. doi:10.1177/0193945904265920

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioural problems in dementia: The revised memory and behaviour problems checklist. Psychology of Aging, 7(4), 622-631. doi:10.1037/0882-7974.7.4.622

Tremont, G. (2011). Family caregiving in dementia. Medicine and Health, Rhode Island, 94(2), 36-38. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3487163/pdf/nihms341863.pdf

Van't Leven, N., Prick, A. J. C., Groenewoud, J. G., Roelofs, P. D. D. M., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. International Psychogeriatrics, 25(10), 1581-1603. doi:10.1017/S1041610213000860.

Vernooij-Dassen, M. J. F. J., Persoon, J. M. G., & Felling, A. J. A. (1996). Predictors of sense of competence in caregivers of demented persons. Social Science & Medicine, 43(1), 41-49. doi:10.1016/0277-9536(95)00332-0

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. Aging & Mental Health, 20, 1-11. doi:10.1080/13607863.2015.1023769

Ware, J. E., Jr., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. Medical Care, 30(6), 473–483. Retrieved from http://www.jstor.org/stable/3765916

Wechsler, D. (1987). WMS-R (Wechsler Memory Scales – Revised). San Antonio, TX: The Psychological Corporation.

Whitehouse, P., Frisoni, G.B., & Post, S. (2004). Breaking the diagnosis of dementia. The Lancet. Neurology, 3(2), 124-128. doi:10.1016/S1474-4422(03)00666-5

Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. The Gerontologist, 46(5), 688-694. doi:10.1093/geront/46.5.688

Williams, A. (1990). EuroQol: A new facility for the measurement of health-related quality of life. Health Policy, 16(3), 199-208. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/10109801

Woods, R., Bruce, E., Edwards, R., Elvish, R., Hoare, Z., Hounsome, B., … Russell, I. (2012). REMCARE: Reminiscence groups for people with dementia and their family caregivers - effectiveness and cost-effectiveness pragmatic multicentre randomised trial. Health Technology Assessment, 16(50), 1-121. doi:10.3310/hta16480

World Health Organisation (2012). Dementia: A public health priority. Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/

Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M. B., & Leirer, V.O. (1982). Development and validation of a geriatric depression screening scale: A preliminary report. Journal of Psychiatric Research, 17(1), 37–49. doi:10.1016/0022-3956(82)90033-4

Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *The hidden victims of Alzheimer's disease.* New York, NY: New York University Press.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*, 20(6), 649–655. doi:10.1093/geront/20.6.649

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–370. doi:10.1111/j.1600-0447.1983.tb09716.x

Zung, W. W. K. (1967). Depression in the normal aged. *Psychosomatics*, 8(5), 287-292. doi:10.1016/S0033-3182(67)71945-3

Section B

An exploration of dyadic coping in couples living with dementia

Word count: 8,146 (plus 184 additional words)

For submission to Dementia: The International Journal of Social Research and Practice

Fay Emily Bolsover

Salomons Centre for Applied Psychology
Canterbury Christ Church University

MAY 2017

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

Abstract

Coping with dementia has generally been conceptualised at an individual rather than relational level. In couples coping with chronic illness, dyadic coping models involving shared appraisals of stress and coping have been explored. This study aimed to explore dyadic coping in couples living with dementia. Qualitative framework analysis methodology was used to analyse data from nine joint interviews with spouse dyads living with dementia. Six main themes were identified: ‘Dementia awareness and ownership’, ‘Emotional closeness’, ‘Responsibility’, ‘Individual needs and difficulties’, ‘Individual coping by people with dementia’, and ‘Wider social context’. Findings suggested couples coping with dementia may utilise dyadic coping strategies, with couples maintaining closeness associated with sustaining joint coping. However, the impact of dementia upon a lack of shared dementia awareness and ownership, and loss of shared responsibility for coping, was associated with a lack of shared appraisals of stress and dyadic coping.

Keywords: coping, couple, dementia, dyadic, spouse.

Introduction

Dementia is a growing public health concern, with the number of people affected predicted to rise with an ageing population (Department of Health [DoH], 2016; World Health Organisation, 2012). In the *Prime Minister's Challenge on Dementia 2020* (DoH, 2016), the UK government outlined plans to improve dementia care and research, prioritising inclusion of people with dementia. This document highlights the relational impact of dementia, focusing upon the families and social networks of people with dementia, pledging to improve awareness and understanding of dementia within society (DoH, 2016).

The relational impact of dementia

Dementia is not experienced in isolation; receiving a diagnosis has a profound effect upon the individual and those around them. Many people with dementia live at home supported by family members, often their spouse (Prince et al., 2014; British Psychological Society [BPS], 2016). It is suggested that the impact of dementia upon spouse couple relationships may be particularly prominent, due to relationship changes (Pinquart & Sörensen, 2011; Rankin, Haut, & Keefover, 2001).

The impact of dementia upon couple relationships

The impact of dementia upon couple relationships may include reductions in reciprocity, mutuality, shared activities, and emotional support. These changes are associated with decline in verbal communication and a negative effect upon couples' experiences, including feelings of hopelessness and loneliness (Baikie, 2002; Balfour, 2014; Svanström & Dahlberg, 2004). However, some relational aspects may be preserved, such as affection and closeness (Ablitt, Jones, & Muers, 2009).

The concept of ‘couplehood’ suggests that couple dyads may work together on their relationship, developing strategies to sustain their lives together. Themes include ‘talking things through’, ‘being affectionate and appreciative’, ‘making the best of things’, and ‘keeping the peace’ (Ablitt et al., 2009; Hellström, Nolan, & Lundh, 2007; Merrick, Camic, & O’Shaughnessy, 2016; Molyneaux, Butchard, Simpson, & Murray, 2012; Wadham, Simpson, Rust, & Murray, 2016).

The literature on psychological interventions for couple dyads suggests these may improve dyadic relational outcomes by strengthening communication and relationships, thereby enhancing couples’ coping and adjustment (Auclair, Epstein, & Mittelman, 2009; Epstein, Auclair, & Mittelman, 2006; Ingersoll-Dayton et al., 2013; Ingersoll-Dayton, Spencer, Campbell, Kurokowa, & Ito, 2016; Quayhagen et al., 2000; Sørensen, Waldorff, & Waldemar, 2008). However, interventions generally lack a theoretical or empirical basis for enhancing coping in couples living with dementia. Therefore, to further understanding of how interventions could be developed to meet couples’ needs, it is important to explore how couple dyads cope with living with dementia (Braun et al., 2009).

Models of coping

The psychological literature mainly focuses upon individual coping, describing it as, “…constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). This is based upon a transactional model of stress and coping, whereby stress arises from the transaction between an individual and their environment. Coping is hypothesised to consist of cognitive processes such as appraisals (assessment and analysis) of stressors, followed by functions to manage this, which may be problem-focused (to directly minimise stressors) or emotion-focused (to regulate emotional responses to stressors) (Folkman, 1997; Lazarus & Folkman, 1984; Tremont, 2011).

However, coping has also been conceptualised at a relational level. The relationship focused model suggests three types of coping: active engagement (joint problem solving, sharing of emotions and communication), protective buffering (denying or hiding worries, concerns or emotions to avoid conflict) and overprotection (individuals underestimating their partner's ability to manage, resulting in undue or undesired help, and reducing self-efficacy) (Coyne & Smith, 1991).

Models of coping with dementia

Coping with dementia has generally been characterised at an individual rather than a relational level, and primarily focused upon caregivers, with the voices of those with dementia often unheard (Braun et al., 2009; Molyneaux et al., 2012). An individual stress process model for caregivers of people with dementia suggests they experience both primary stressors, such as managing features of the person's condition, and secondary stressors, such as social or economic factors (Pearlin, Mullan, Semple, & Skaff, 1990). Coping strategies mediate the relationship between stressors and caregivers' health outcomes (Pearlin et al., 1990).

This model was adapted for individuals with dementia themselves, suggesting that primary stressors such as cognitive status or perceived distress, and secondary strains, such as managing close relationships (including the couple relationship, referred to as 'dyadic strain') impact upon wellbeing (Judge, Menne, & Whitlatch, 2010). This model does consider couple relationships in the context of coping with dementia, but as a strain to be managed individually, rather than as something shared by couple dyads (Judge et al., 2010).

Dyadic coping

In couple dyads coping with physical illnesses, the concept of ‘dyadic coping’ has been explored, defined as a stress communication process in which couples make shared appraisals of stress and coping (Berg & Upchurch, 2007; Bodenmann, 2005; Foxwell & Scott, 2011; Regan et al., 2014; Rottmann et al., 2015). Two models of dyadic coping have been outlined: the systemic-transactional model (Bodenmann, 1995, 2005) and the developmental-contextual model (Berg & Upchurch, 2007).

The systemic-transactional conceptualisation of dyadic coping (Bodenmann, 1995) draws upon the transactional model of individual stress and coping (Lazarus & Folkman, 1984), but also draws upon systemic theory to highlight coping as a shared reciprocal process (Bertalanffy, 1969). Dyadic coping is suggested to occur in interaction between both members of the couple, involving perceiving and appraising their partner’s view and re-evaluating and synthesising one’s own and one’s partner’s appraisal (Bodenmann, 1995). Bodenmann (1995) suggests dyadic coping can be positive or negative and emotion-focused or problem-focused, and distinguishes between different types, including, common dyadic coping (the couple coping together in a joint way), supportive dyadic coping (one partner supporting the other to cope), and delegated dyadic coping (one partner taking over responsibility for coping for the couple).

The developmental-contextual model of dyadic coping with chronic illness (Berg & Upchurch, 2007) (in Figures 2 and 3) suggests couples cope together as dyadic units, highlighting the influence of both developmental and temporal processes (suggesting dyadic coping may differ across time and life span development, including illness stage).

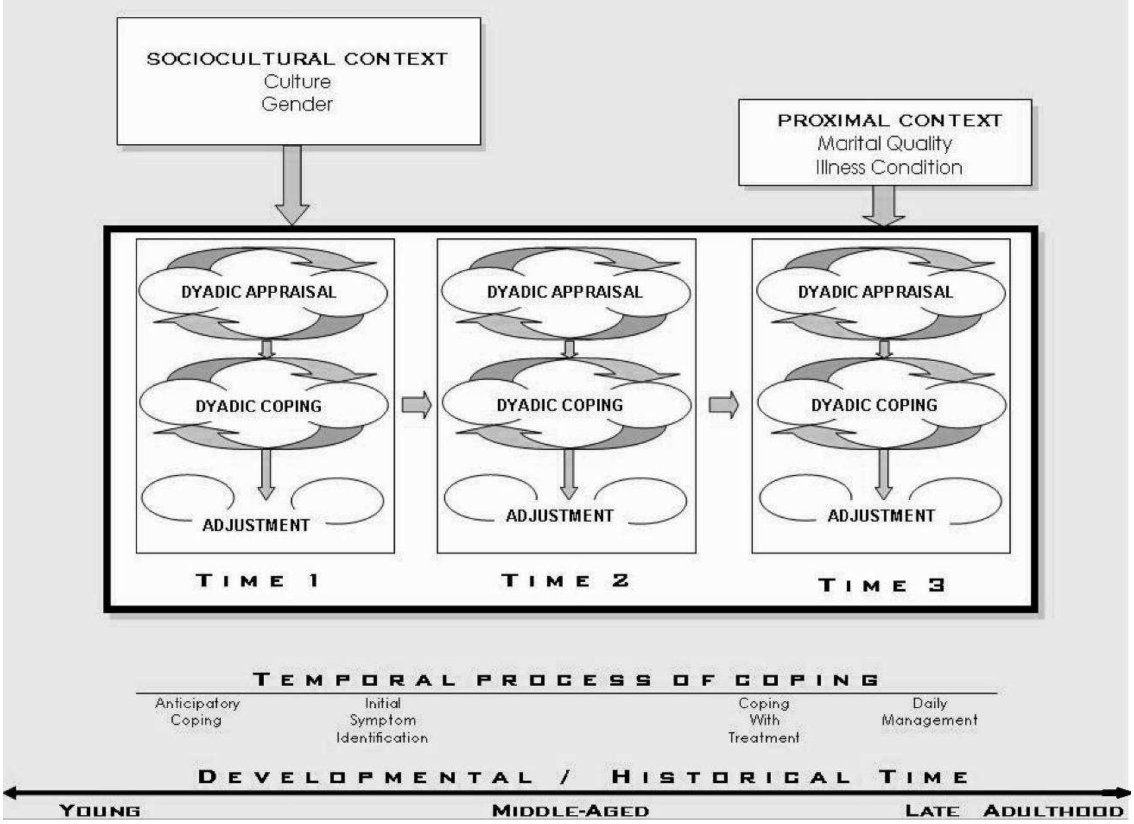


Figure 2. The developmental-contextual model of dyadic coping in couples coping with chronic illness (Berg & Upchurch, 2007).

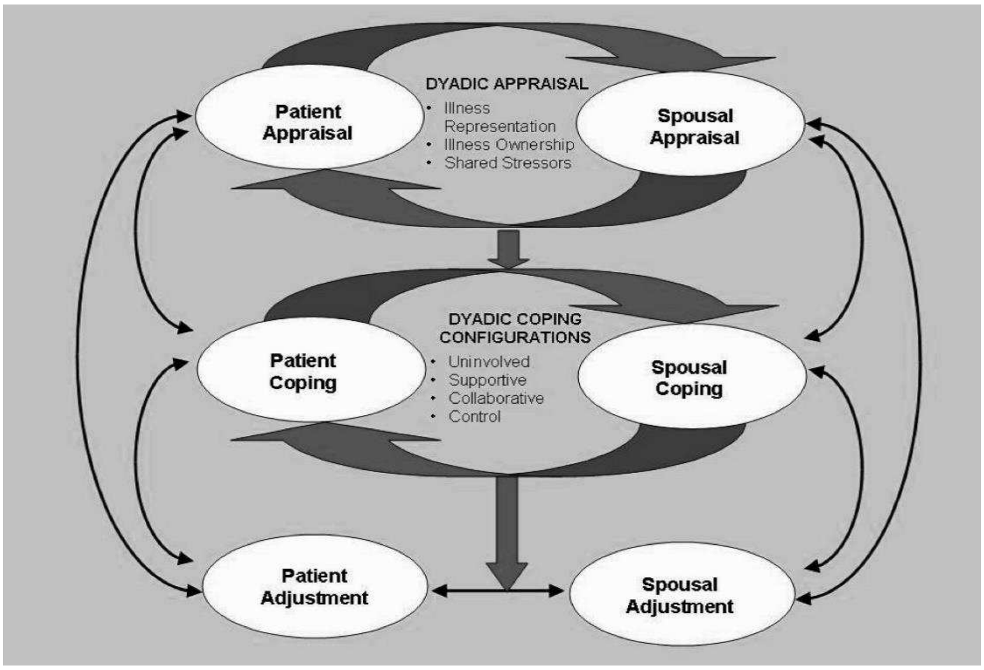


Figure 3. Dyadic coping, appraisal and adjustment within the developmental-contextual model of dyadic coping in couples coping with chronic illness (Berg & Upchurch, 2007).

As outlined above, this model suggests dyadic coping involves shared dyadic appraisals of the illness, its representation and ownership. It also highlights the influence of the specific illness upon dyadic coping, including time course, consequences, and controllability. Berg and Upchurch (2007) also emphasise contextual influences upon coping, distinguished as proximal, such as relationship quality, and sociocultural, such as culture or gender. Rather than discrete categories, dyadic coping is conceptualised on a continuum where the spouse of the person with the illness ranges from uninvolved (the person with the illness perceives themselves as individually coping) to overinvolved (the person with the illness perceives their supporting partner to be unhelpfully dominating) (Berg & Upchurch, 2007).

Dyadic coping in couples living with dementia

To the author's knowledge, only one published study has investigated dyadic coping in couples living with dementia (Hausler et al., 2016), measuring it quantitatively using the Dyadic Coping Inventory [DCI] (Bodenmann, 2008). Findings suggested dyadic coping mediates the relationship between stress and quality of life in spouse partners, but not people with dementia (Hausler et al., 2016). However, as only the DCI total score was used as a mediator, it was unclear which aspects of dyadic coping were involved (Hausler et al., 2016). The strain that living with dementia places on a relationship may impact upon dyadic coping (Braun et al., 2009). It has been suggested that dyadic coping theories may not be applicable to couples living with dementia, due to its often progressive nature and associated cognitive impairment (Martin, Peter-Wight, Braun, Hornung, & Scholz, 2009). Yet, the literature on 'couplehood', with couples sustaining their lives together, suggests that dyadic coping theory may be applicable, particularly in earlier stages when there may be less impact of dementia upon cognition (Hellström et al., 2007; Merrick et al., 2016; Molyneaux et al., 2012).

Applying dyadic coping theories to couples living with dementia has been suggested to be an important task for future research, due to lack of clarity regarding the utility of dyadic coping models (Braun et al., 2009). Some aspects of the Berg and Upchurch (2007) model, such as consideration of both contextual and illness factors, may be helpful in considering coping in couples living with dementia. However, some elements are more uncertain, such as the extent to which appraisal and coping are shared, and which dyadic coping strategies (Bodenmann, 2005) may be utilised by couples living with dementia (Hausler et al., 2016).

This study thus sought to explore coping in couples living with dementia, within the context of theoretical models of dyadic coping. It also aimed to explore couples' experiences of living with dementia, relating to factors that may influence dyadic coping.

Method

Design

The study design evolved following service user consultation with partners of people with dementia, who felt that investigating dyadic coping using quantitative, questionnaire methods was not appropriate for their experiences. Combined with lack of clarity in the literature regarding the utility of dyadic coping models, this supported a qualitative approach exploring couples' experiences of coping. Joint semi-structured interviews were conducted with couple dyads living with dementia. Each couple was interviewed together, as a dyadic perspective has been suggested only possible by including both members of the dyad's perceptions, including observing their interaction (Braun et al., 2009). Interview data were analysed using framework analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie & Spencer, 1994).

Qualitative methodology: Description and rationale. Framework analysis was chosen due to the exploratory nature of the study, as it involves development of themes, focusing upon relationships within data, to make descriptive or explanatory conclusions (Gale et al., 2013; Ritchie & Spencer, 1994). It uses a systematic and transparent framework matrix approach, allowing data analysis by case and by theme (Gale et al., 2013; Ritchie & Spencer, 1994). A combined inductive and deductive analytic approach was used, allowing codes to be generated from both data and pre-existing theory (Gale et al., 2013). Framework analysis was also chosen as the study aim was to explore rather than generate theory, due to its flexibility in being applied across theoretical and epistemological approaches (Gale et al., 2013), and as it has been used to explore dyadic coping in dyads living with cancer (Foxwell & Scott, 2011).

Epistemological position. A ‘critical realist’ epistemological position was taken. This stance makes positivist assumptions, such as a realist ontology that assumes there is an objective reality independent of human consciousness (Maxwell, 2012). However, claims about this reality and our understanding of it are socially constructed through language and social context (Maxwell, 2012).

Participants

Participants were recruited using purposive self-selected sampling, according to set inclusion criteria:

1. Aged over 18 and able to communicate verbally in English.

2. Couples in a romantic relationship and co-habiting (including married/unmarried, heterosexual/homosexual).
3. One partner had a dementia diagnosis of any type.
4. Couples had capacity to give informed consent to participate - assessed by ensuring they met the four elements of the Mental Capacity Act (2005).
5. The partner with dementia had mild to moderate dementia severity, such that they were able to meaningfully participate in the interview - assessed using an inclusion criterion of ≤1 overall score on the Clinical Dementia Rating scale [CDR] (Morris, 1993) (in Appendix B).

Participants were recruited through local older peoples' charitable organisations. The researcher attended groups to introduce the study and distribute information booklets (in Appendix C). Information booklets and recruitment posters (in Appendix D) were also sent to groups, where staff assisted by identifying potentially eligible couples.

Sixteen couples contacted the researcher expressing interest in participating. Two couples dropped out prior to meeting (one person became physically unwell and one person no longer wished to participate), therefore the researcher met with 14 couples. Five were subsequently excluded, due to the person with dementia not meeting study inclusion criteria, for lack of capacity to give informed consent and/or dementia severity. Participants therefore consisted of nine spouse couples (N=18), recruited from six groups, from urban, semi-rural and rural areas (in Table 3). All names are pseudonyms to protect confidentiality.

Table 3

Participants' demographic information

Couple number	Pseudonyms	Age	Gender	Ethnicity[a]	Occupation	Time since dementia diagnosis	Type of dementia diagnosis	Type and length of relationship[b]	Do the couple have children?
1	Oliver	79	Male	White English	Retired Manager			Married, 40 years (second marriage).	Not together. Four children from previous relationships.
	Wendy	86	Female	White English	Retired Administrator	Two years	Dementia with Lewy Bodies with Parkinson's disease.		
2	Brian	67	Male	White English	Retired Engineer			Married, 43 years.	Yes, two.
	Glenys	67	Female	White English	Retired Teacher	Four years	Alzheimer's Disease.		
3	Lucinda	78	Female	White British	Retired Healthcare Worker			Married, 59 years.	Yes, three.
	Vincent	79	Male	White British	Retired Construction Worker	Ten years	Frontotemporal dementia.		
4	Kenneth	74	Male	White British	Retired Driver			Married, 54 years.	Yes, three.
	Amanda	74	Female	White British	Retired Teaching Assistant	Three years	Alzheimer's disease.		
5	Victoria	76	Female	White British	Retired Administrator			Married, 50 years.	No.
	Simon	82	Male	White British	Retired Engineer	Two years	Alzheimer's disease.		

6	Frank	70	Male	White British	Retired Manager			Married, 52 years.	Yes, two.
	Irene	72	Female	White British	Retired Administrator	Three years	Alzheimer's disease.		
7	Nancy	73	Female	White English	Retired Administrator			Married, 32 years (second marriage).	Not together. Three children from previous relationships.
	William	83	Male	White English	Retired Administrator	Three years	Vascular dementia.		
8	George	69	Male	White British	Retired Hospitality Worker			Married, 29 years (second marriage).	Not together. Two children from previous relationships.
	Sylvia	69	Female	White British	Retired Hospitality Worker	One year and 6 months.	Alzheimer's disease.		
9	Yasmin	58	Female	White British	Retired Social Worker			Married, 29 years (second marriage for Alfred).	Yes, one.
	Alfred	74	Male	Black British & Caribbean	Retired Support Worker	One year and 9 months.	Frontotemporal dementia.		

[a] Participants' ethnicities are presented according to how they described them. [b] Some participants described the length of their relationship from the time they met whereas others described the length of their relationship from the time they were married.

Procedure

Ethical approval and guidelines.

Ethical approval and guidelines. Ethical approval was granted by the Salomons Centre for Applied Psychology Ethics Panel at Canterbury Christ Church University (in Appendix E). Throughout the study, the researcher considered the sensitive nature of the research and adhered to the BPS code of ethics (BPS, 2009) and NHS values (NHS Health Research Authority, n.d.).

Study procedures, including measures and ethical considerations. Couples were telephoned to arrange an initial meeting, with all couples choosing to meet at home. During the initial meeting, potential couple participants were firstly seen together for a general study briefing, ensuring they had read the information booklet. Each person was then met individually to assess their eligibility to participate, including assessing the person with dementia's capacity to provide informed consent using the four elements of the Mental Capacity Act (2005) and their dementia severity by administering the CDR (Morris, 1993). At the end of the initial meeting, the researcher sensitively discussed with couples whether they met eligibility criteria and, if so, whether they would like to arrange an interview, or preferred time to consider participating. All couples meeting eligibility criteria chose to be interviewed. During the second meeting, prior to interview, participants were briefed (in Appendix F), providing information regarding the purpose and nature of the study, and the boundaries of confidentiality. Participants' understanding was checked by asking questions guided by the principles of the Mental Capacity Act (2005). All participants completed the study consent form to provide informed written consent (in Appendix G). Participants were informed that, should they find talking upsetting, they could choose not to answer any question or stop the interview at any time. Participant demographic information was collected using a standardised form (in Appendix H). The interview schedule (in Appendix I) included questions about the couple's relationship, their experiences of one partner receiving a dementia diagnosis, their experiences of changes they may have noticed and how that may have affected their relationship, how the couple felt they were coping with living with dementia, and how they felt this may have changed. Following interview participants were debriefed, discussing their feelings, experiences, and whether they felt they needed further support. Participants were provided with written information on sources of support (in Appendix J). All couples were offered and accepted a follow up telephone call by the researcher (in Appendix K). Interviews were audio recorded and transcribed, and ranged from 1 hour 7 minutes to 2 hours 31 minutes, with an average length of 1 hour 28 minutes.

Quality assurance. In line with the critical realist epistemology, the researcher acknowledged their influence upon data collection and analysis (Gale et al., 2013; Maxwell, 2012). This was monitored using quality checks suggested to improve qualitative research validity (Mays & Pope, 2000). The researcher maintained reflexivity by writing a research diary (in Appendix L), bringing into awareness potential sources of bias, including assumptions, feelings, experiences and characteristics, which were discussed in supervision. Research supervisors were consulted throughout data analysis. Three transcripts were indexed by an independent analyst, and all framework matrices were reviewed by another independent analyst, with disagreements discussed and agreed. Due to the systematic and transparent nature of framework analysis, there was a clear data analysis audit trail.

Results

This study aimed to explore coping in couples living with dementia, within the context of theoretical models of dyadic coping. It also aimed to explore couples' experiences of living with dementia, related to factors that may influence dyadic coping.

Data analysis

Framework analysis was conducted following published guidelines (Gale et al., 2013; Ritchie & Spencer, 1994). Following transcription and familiarisation with the data, including initial line by line coding of three transcripts (example in Appendix M), an initial thematic framework was created (in Appendix N). This was refined to create a working analytical framework (in Appendix O), used to index the subsequent six transcripts. Data were charted into framework matrices (spreadsheets) to summarise them by dyad and by theme (example in Appendix P). This allowed further interpretation and refinement of the data and a final thematic framework was created (theme descriptions in Appendix Q), which identified six main themes and 11 subthemes (in Table 4). Themes and subthemes will be described, with supporting quotes from all participants provided with pseudonyms (followed by 'P' indicating partner, or 'PWD' indicating person with dementia, and couple number).

Dementia awareness and ownership

Couples described difficulties due to dementia being either held in the awareness of both partners, owned, accepted and understood as something shared, or, in the awareness of and owned by either partner individually, sometimes denied by people with dementia. This was seen to be associated with either shared or individual appraisals of stressors. Shared or individual awareness and ownership of difficulties were evident, particularly in relation to the dementia diagnostic process and to processes of acceptance versus denial.

Table 4

Final thematic framework

Themes	Subthemes
1. Dementia awareness and ownership	a, Dementia diagnostic process b, Acceptance versus denial
2. Emotional closeness	a, Closeness and coping together b, Distance and coping apart
3. Responsibility	a, Partners supporting their partner with dementia b, Loss of shared responsibility c, Loss of shared concerns
4. Individual needs and difficulties	a, Individual impact of dementia b, Partners of people with dementia's own needs and difficulties
5. Individual coping by people with dementia	
6. Wider social context	a, Relationships and support b, A 'dementia friendly' society

Dementia diagnostic process. Couples either described both being unaware of initial difficulties due to dementia, or difficulties being in the individual awareness of and owned by one person, with their partner initially unaware of or not accepting their concerns:

> Glenys (PWD2): I did think there was something wrong, I did, yes.
>
> Brian (P2): Yeah, I didn't notice that you [Glenys] had a problem apart from the normal sort of things. Being a silly woman… But she didn't tell me, I didn't know about that until later.

> > Sylvia (PWD8): I can’t say that I realised it. I think it was you [George] that said it.
> >
> > George (P8): Yeah.
> >
> > Sylvia (PWD8): I accused you [George] of… lying to me.

Couples’ reactions to receiving the diagnosis were also described as being owned in both shared and individual ways:

> Oliver (P1): Well we both went downhill when you [Wendy] was diagnosed, let’s face it, we were very emotional, we were crying together, and we didn’t know…it was early stages…

> > Nancy (P7): I think William was more upset than me but then I suppose that’s natural because it’s him

Acceptance versus denial. Couples described acceptance of difficulties as a way of feeling more able to manage changes they were experiencing:

> Victoria (P5): Yeah, we know it’s not going to get any better... We just live life, don’t we? It is what it is...You just go with the flow... First it used to get to me but now I just ignore it, put it back where it belongs. That’s the only way you can deal with it… some battles you fight, some you don’t... You just cope with it… I think it’s happened over such a gradual time you just sort of accept it as it goes along.

Couples also described having a shared denial of difficulties, as a way of coping with their feelings:

> Yasmin (P9): …we’re coming up now for two years since Alfred’s diagnosis and Alfred and I have hardly ever had a conversation about it, it just doesn’t really get

> spoken about… I knew that Alfred, well I say I knew, I never discussed it with you, but I kind of guessed that it was something that you felt should never be discussed, nobody should ever be told, it was to be our secret. And so you kind of automatically, out of respect, sort of go quiet about it… out of respect for you.

People with dementia particularly appeared to fluctuate between processes of both acceptance or acknowledgement and denial or avoidance, perhaps due to lack of insight:

> Vincent (PWD3): It doesn't affect our lives at all, dementia, does it?
>
> Lucinda (P3): Yeah, it has to affect it some ways, I mean, doesn't it?
>
> Vincent (PWD3): Doesn't affect me!
>
> Lucinda (P3): (Laughs) Yes, I mean, I can't ... I have to think before I can make arrangements if I'm going to go out, I can't, because Vincent can't be left...

Emotional closeness

Couples' relationships varied in terms of differences in emotional closeness; with closeness associated with coping together and distance associated with coping apart.

Closeness and coping together. Closeness was described in some couples' relationships in terms of them being positive and strong, accepting and celebrating each other's differences. Couples reported staying together through good and bad times, describing continuity and growth in their feelings for each other over time in relation to coping together with dementia:

> Kenneth (P4): …it's a new age of learning how to deal with each other, how to make our life here in this home better, more understanding for each other's problems and yeah, I've developed a stronger love for you [Amanda] I didn't think was possible.

Closeness was associated with couples coping collaboratively and jointly, including talking openly together, using humour together, trusting and relying on each other and making an effort to continue joint activities together:

> Kenneth (P4): We love reading. You'll [Amanda] sometimes tell me where you're at you know… an important part of the story and you'll allow me sometimes to tell you something of mine, so we do love reading so we share that sort of thing. We love to pray together, which is important for us, very important.

Couples also used strengths-based ways of coping together, including seeing the positives and focusing on the present, and emphasising each other's strengths and abilities:

> Amanda (PWD4): I know differently to what you've got in your head. I know that you're a very decent person and a loving person, and one that really thinks he can make a big mess of things, but you don't [Kenneth], you really don't.

> Oliver (P1): I'm lucky really because I've got you [Wendy], a person, my other half, who actually wants to get better, shall we say, or understands that she can't get better, but you're doing everything you can to make life better for us both really.

However, despite current feelings of closeness, couples also hinted at concern about not being together in the future with the progression of dementia:

> Brian (P2): Well, we still feel the same for each other. Yeah, I'm not on the verge of kicking her [Glenys] out or anything like that.
>
> Glenys (PWD2): No, I couldn't… I couldn't do it.
>
> Brian (P2): I know, don't worry.

> Sylvia (PWD8): I think he's [George] trying to put me in a home (Laughs). No, I shouldn't have said that, should I?
>
> George (P8): Well I'll always be there… whatever.
>
> Sylvia (PWD8): Not if you kick the bucket.

Distance and coping apart. Some couples, even those who described coping together, also described distance in their relationships, feeling frustrated, guilty, blamed or misunderstood, and withdrawing from each other:

> Kenneth (P4): I wanted to run away, just to run… just the backing off running away syndrome, I thought, I don't need this.

Distance was associated with couples coping apart in ways that were conflicting or disrespectful, such as arguing with each other:

> Oliver (P1): …because I do shout at her [Wendy] at times, I must admit and regret it afterwards.
>
> Wendy (PWD1): He [Oliver] does come and apologise.

Some partners also highlighted their partner with dementia's difficulties and decline:

> Brian (P2): "There is very little she [Glenys] can actually do now. She's started doing this colouring. Did I show you that last time? So you see what the colouring is like, if you remember?

Responsibility

Couples described changes in responsibility in their relationships, with partners of people with dementia taking over responsibility for coping, including supporting their partner with dementia, loss of shared responsibility, and loss of shared concerns. Although these ways of coping were utilised to support both members of the couple, due to an apparent loss of shared responsibility, it was questionable to what extent they were utilised in a shared way by both members of the couple, or utilised solely by partners of people with dementia in an individual way.

Partners supporting their partner with dementia. Partners helped and supported their partner with dementia to cope in many ways, including focusing on practical ways of support such as home adaptations, gaining knowledge such as learning more about dementia, empathising with their partner, and trying to anticipate or prevent potential difficulties:

> Frank (P6): Yeah, so it has been a question of trying to plan it you know… it's trying to think of things that will make it easier that take away that sort of, well as in you know… she [Irene] has to sometimes check on the time so I make sure there are clocks around and things like that but, because I know without it… it will cause her upset and that won't do her any good at all... so it's certainly made me more aware, and I have to think a lot more about what I'm doing you know.

Partners also discussed finding ways for their partners with dementia to contribute to tasks:

> Brian (P2): But she [Glenys] does a very good job of peeling potatoes. And apples. So it's a case of I've got to find things that she can do and concentrate on that.

Partners also described supporting their partners with dementia by promoting their cognitive function:

> Oliver (P1): I try and make her [Wendy] use her brain, in other words I'm trying to at the same time she's fighting what's happening with her brain. Her brain is saying I'm going to die, not her, but the brain is dying, and I'm just trying to get her to fight against it by doing that.

Loss of shared responsibility. Couples described changes in roles and power in their relationships:

> Nancy (P7): No, it has upset us both really because it's altered all the dynamics in our relationship. I feel that I'm now a carer rather than a wife… Together, yeah. It's our life together that's disappeared.

This was associated with partners taking over roles and responsibilities, which some people with dementia mentioned finding difficult, or their partners acknowledged that this may be difficult for them:

> Victoria (P5): I want him [Simon] to do things but you just go and do it yourself in the end... But I think you find it quite hard, don't you? I have to do everything, I do make all the decisions, eh?
>
> Simon (PWD5): Yeah.

Some couples described coping with changes in roles and responsibilities over the course of their relationship (prior to living with dementia), which seemed to help them adapt to this.

Couples described a loss of shared responsibility, with partners of people with dementia describing feeling alone in discussions and decision making:

> Frank (P6): I guess that it more centres around the depth of our discussions or lack of depth now. Before we'd talk things through and come to an agreement and things, whereas now although we talk about things I generally will deal with them and very often not bother Irene with it… So that's the way it's changed… dealing with dementia is like having a small child but in reverse.

Partners' increased responsibility was also associated with couples spending more time together, with some partners of people with dementia experiencing a loss of their own meaningful activities:

> Brian (P2): It used to be that I'd go fishing but I don't do that anymore because I can't leave Glenys for 12, 14 hours which is what it might be on occasions. I don't get to do any woodturning now. That's only out in my back shed. Because if I went out there and disappeared for most of the day or something I know Glenys is just sitting in here not doing anything. And she can't very well come out and follow me out there, just sitting there getting covered in sawdust.

Loss of shared concerns. Couples described changes in interaction, including doing activities physically together but not engaging with each other, and a loss of empathy and shared understanding. Partners also described hiding their emotions or concerns from their partner with dementia, and feeling they could no longer talk openly together, or finding this uncomfortable:

> Kenneth (P4): …and the memory you know, try not to hurt her [Amanda] by saying the wrong… learning not to banter with her so much, she doesn't like bantering.
>
> Amanda (PWD4): Well it just depends Kenneth on the day.
>
> Kenneth (P4): Okay.

Amanda (PWD4): Go on, if you want… look, would you rather I went out…

Kenneth (P4): No, no.

Amanda (PWD4): …and you can talk…

Kenneth (P4): We're here together.

Amanda (PWD4): I know, I know love, I know.

Couples often had different explanations for or perceptions of difficulties, situations or experiences, with differences of opinion often conceded to by partners of people with dementia to avoid disagreement or conflict:

Irene (PWD6): Well there's always the garden dear that we can do.

Frank (P6): Yes dear, I have tried to get you involved this year, but… (Laughs). That's another thing that Irene used to always take the lead in the garden.

Irene (PWD6): I was the gardener. But he took over you see so I let him get on with it.

Frank (P6): I didn't… I won't argue.

Irene (PWD6): Well it's true.

Individual needs and difficulties

Couples described the influence of each person's needs and difficulties upon how they coped as a couple, including the individual impact of dementia upon the person with dementia, and the influence of partners of people with dementia's own needs and difficulties, such as health conditions or caring responsibilities.

Individual impact of dementia. People with dementia were affected in a number of ways, including changes in mood, personality, behaviour, sleep, perceptual experiences, and cognition. People with dementia also experienced significant losses, including hobbies, working or volunteering, and driving. These changes and losses affected how couples felt able to cope with their daily lives and their relationships with each other:

> Yasmin (P9): It was as if I was looking at Alfred through a camera and somebody had changed the lens. So it was the same person I was looking at, but they were just not quite in focus anymore.

Partners of people with dementia's own needs and difficulties. Partners' own needs and difficulties, including health conditions (three partners disclosed they had cancer), or other caring responsibilities outside of their relationship, interacted with couples' lives together and therefore affected coping. Partners described feeling selfish putting their own needs before their partner with dementia's needs, and how challenging it could be to balance these:

> Yasmin (P9): I have cancer… I think it's important because that is being played out alongside the dementia... So the two keys things in how we plan and how we deal with our life, the backdrop, what underpins both is Yasmin's cancer and Alfred's dementia. So how the two fit together.

Some partners were concerned that deterioration in their own health may affect their partner with dementia if they were no longer able to support them:

> Brian (P2): A big worry, a big, big worry is not if Glenys gets ill, it's if I get ill. Because, come what may, me being ill or otherwise I have to look after Glenys. She cannot look after me apart from doing odd simple jobs…So, really my biggest fear is if I was seriously ill, what could we do about it?

Individual coping by people with dementia

People with dementia used a number of personally meaningful ways of individually coping with dementia, therefore maintaining personal agency and identity. These included religious coping (using their faith to help to manage difficulties), and problem focused coping (using practical ways to try to minimise difficulties), such as using environmental cues to aid memory, seeking information, focusing upon personal strengths and abilities, monitoring themselves and their activities, and using cognitive stimulation to promote cognitive function:

> Alfred (PWD9): Because I'm so mindful now… I will say, "I'm going to put them here. Alfred, you tell yourself you're putting them there"… and I've got to get my things in order... So it's not a game but I am keeping my eye on the ball... And since those days began I have been watching myself, that's the one thing I can do that's 100% correct… I hope that won't give me too bad a dose of it… the things I do, I would call them my form of brain exercises and memory tests. But to explain them to anybody I can't, because I know the tasks that I put myself through on a daily basis.

People with dementia also described trying to prevent decline and promote wellbeing through exercise and healthy eating:

> Vincent (PWD3): I can't do nothing about my brain but I can do about my physical thing, you know, like getting out and eating proper and all things like that...

Partners found these strategies helpful in continuing to recognise and appreciate key aspects of their partner's personality:

> Yasmin (P9): So knowing that Alfred, that key element of what I call my original Alfred, that key characteristic is still there working away, that, "I will monitor

> everything, I will eat the healthiest I can, I will stay as fit as I possibly…" that core element of Alfred's personality, the fact that that is still there and I see it every day… it becomes more manageable because I look and I think, "Okay, that's the bit of my Alfred that's still here", yeah.

Wider social context

Couples described the influence of their wider social context upon coping, including positive and negative experiences of support from family, friends, healthcare services and support services. Couples also discussed the importance of the societal context, including the importance of 'friendliness' from others.

Relationships and support. Many couples described loss and withdrawal from social relationships. They described friends withdrawing from them, and feeling unable to have open discussions about dementia, due to others feeling scared or embarrassed. Couples also described people with dementia no longer being able to engage in social hobbies, or withdrawing from others as a form of self-protection. Couples also discussed a lack of care or understanding from others, including healthcare services, which they felt negatively affected their ability to cope:

> Nancy (P7): Then she came back and she said the diagnosis was vascular dementia, for which nothing can be done. And she left us with some leaflets and that was it.
>
> William (PWD7): Well, I think I was looking towards the _____ Centre and I felt at the time when the diagnosis came through, I felt I didn't get much sense out of them.
>
> Nancy: Yeah, we both felt there wasn't much support given. It was just, well, "This is the diagnosis, nothing can be done, that's it."
>
> William: Tough.

However, couples also described valued social relationships, emotional and practical support, feeling able to be open about dementia with others, and talking to others in similar situations at support services:

> William (PWD7): Some of it you think it's a load of rubbish but it makes me so I can come out of myself a little bit more... when I first went to it, it was a bit, oh, we're playing silly games but you still do it and it makes you realise how you rely on other people.

Couples also described feeling contained within a supportive family:

> *Lucinda (P3): ...*a positive change is that we're much closer as a family because we've had to be, you know... because it's brought us all closer together, hasn't it, really?

A 'dementia friendly' society. Couples felt that an important influence upon coping was how dementia was portrayed in society, including in the media. Couples described a lack of understanding of dementia, but also acknowledged the influence of increased recognition of dementia in society. They expressed the importance of 'friendliness', being treated in a helpful and respectful way by others:

> Yasmin (P9): …from what I've heard about the dementia friendly programme it's supposed to be really good, because… such as shopkeepers and hospitals… they're all receiving some kind of training on people with dementia who are fairly early on in their journey, out there amongst us.

Discussion

In exploring coping in couples living with dementia, within the context of theoretical models of dyadic coping, findings suggested that couples’ individual or shared awareness and ownership of dementia influenced individual or shared appraisals of dementia. Findings also suggested varying emotional closeness in couples’ relationships, with closeness associated with coping jointly together, and distance associated with coping apart, sometimes in conflicting ways. Couples’ relationships involved changes in responsibility, with partners of people with dementia taking increased responsibility for coping, including supporting their partner with dementia, loss of shared responsibility, and loss of shared concerns. Although utilised to support both members of the couple, due to loss of shared responsibility it was questionable to what extent they were utilised in a shared way by both members of the couple, or utilised solely by partners of people with dementia in an individual way.

This study also suggested a number of factors that may influence dyadic coping in couples living with dementia, including the influence of each person’s needs and difficulties (both the individual impact of dementia upon the person with dementia, and the influence of partners of people with dementia’s own needs and difficulties, such as health conditions or caring responsibilities). Individual coping by people with dementia may also influence dyadic coping, maintaining their personal agency and identity, and their partners continuing to recognise key aspects of their personality, therefore strengthening couple relationships. The wider social context may also influence dyadic coping, in terms of positive or negative relationships and support, particularly ‘friendliness’ from others, affecting couples’ ability to cope.

The finding of couples’ individual or shared awareness and ownership of dementia, suggesting both individual and shared appraisals of dementia, is consistent with the dyadic coping model of Berg and Upchurch (2007) highlighting the influence of illness appraisals and ownership. People with dementia particularly seemed to go through processes of denial, associated with a lack of shared dyadic ownership and understanding of difficulties. Denial has been described as a grief reaction, a psychological response to the deteriorating and terrifying nature of dementia (Bender & Cheston, 1997; Kitwood, 1997). People with dementia may also demonstrate lack of insight due to difficulties associated with dementia (Pinner, 2003). It has been suggested that couples living with dementia move between closed communication (with no recognition or discussion of dementia) and open communication (involving full discussion of dementia), with open communication suggested the most adaptive (Marwit, Meuser, & Bryer, 2005). However, the literature on 'couplehood' suggests that closed forms of communication, such as denial, may be a helpful, appropriate way of couples' coping at particular stages in their dementia journey, such as seeking to adaptively normalise and reframe their experiences (Hellstrom et al., 2007).

The study finding of closeness and coping together is consistent with the 'couplehood' literature, suggesting couples develop strategies to sustain their lives together (Ablitt et al., 2009; Hellstrom et al., 2007; Merrick et al., 2016; Molyneaux et al., 2012; Wadham et al., 2016). A number of study findings are similar to types of dyadic coping (Bodenmann, 2005), with coping together akin to common dyadic coping, and distance and coping apart akin to negative supportive dyadic coping. Within the theme responsibility, partners supporting their partner with dementia is similar to supportive dyadic coping (Bodenmann, 2005), and loss of shared responsibility is similar to delegated dyadic coping (Bodenmann, 2005), or consistent with concepts of overprotection (Coyne & Smith, 1991) and overinvolvement (Berg & Upchurch, 2007), potentially difficult for people with dementia. Loss of shared interaction appears similar to the concept of protective buffering (Coyne & Smith, 1991), and is also consistent with 'couplehood' literature themes of ‘keeping the peace’ (Hellstrom et al., 2007), involving ‘knowing the triggers’ (being aware of how to avoid negative reactions) and ‘not responding’ (not engaging in conflict).

Although findings appear consistent with types of dyadic coping, appraisals of dementia were often individual rather than shared. There were examples of both partners coping jointly, however, couples’ accounts were characterised by partners of people with dementia taking responsibility for coping, consistent with literature on the impact of dementia highlighting a lack of reciprocity (Baikie, 2002; Balfour, 2014; Svanstrom & Dahlberg, 2004). In couples living with dementia, there may be a loss of shared responsibility for coping, managing stressors which impact cognitive functioning. Coping for couples living with dementia thus appears different to theoretical models of dyadic coping (Berg & Upchurch, 2007; Bodenmann, 2005), due to a lack of shared dyadic appraisals of stress and dyadic coping occurring in interaction between both members of the couple.

The quantitative findings of Hausler et al. (2016), that dyadic coping mediated the relationship between stress and quality of life in spouse partners but not people with dementia, may also highlight a lack of shared responsibility for coping. The current study therefore adds to the literature on dyadic coping in couples living with dementia, by delineating which aspects of dyadic coping may be involved, as well as suggesting a number of factors which may influence dyadic coping.

The influence of individual needs and difficulties is consistent with the model of Berg and Upchurch (2007) suggesting the influence of life span development upon dyadic coping. Couples in the present study were generally in older adulthood (mean age 74), characterised by numerous stressors including multiple chronic illnesses (Berg & Upchurch, 2007). Couples were also in long-term marriages (mean marriage length 43 years), associated with increased marital satisfaction involving less conflict and more affection, in turn associated with better adjustment to chronic illness (Berg & Upchurch, 2007).

Findings on individual coping by people with dementia add to the scant literature on coping by people with dementia, including utilising their strengths and abilities, which may improve their sense of mastery and quality of life (Bender and Cheston, 1997; Clare, 2002; de Boer et al., 2007; Woods, 2001). The influence of the wider social context upon dyadic coping is consistent with Berg and Upchurch's (2007) model highlighting the influence of the sociocultural context. BPS (2016) and DoH (2016) guidelines also stress the importance of improving awareness and understanding of dementia within society.

Overall, the present study suggested that couples' appraisals and ownership of dementia may often be individual rather than shared, there may be a loss of shared responsibility for coping, with partners of people with dementia taking responsibility for coping, likely due to the impact of dementia upon cognitive functioning. However, findings suggested that, despite experiences of distance and coping apart, couples living with dementia may utilise strengths-based ways of coping collaboratively together, and that couples' ability to maintain closeness in their relationship may be associated with joint coping. It was also found that people with dementia may utilise personally meaningful ways of individual coping, maintaining their personal agency and identity. These novel findings thus highlight the resilience of people with dementia, and the abilities of couples living with dementia to maintain close and nurturing relationships, which may facilitate individual and joint coping, despite difficulties associated with dementia. Findings also suggest the influence of the wider social and societal context upon coping, also highlighting the importance of these strengths being recognised and supported by the systems around couples.

Practice implications

Although NICE (2006) guidelines recommend access to psychological interventions for ‘carers’, they suggest limited involvement of people with dementia. BPS (2016) guidelines suggest psychological interventions should be provided to people with dementia and family members, including systemic family or couple therapy, promoting adjustment and coping. The findings of this study suggest that psychological therapy may be helpful for couples by facilitating dyadic adjustment and coping, helping them to draw upon strengths and abilities, to sustain closeness in their relationship and to process changing factors influencing dyadic coping.

Practitioners also have an important role in facilitating couples living with dementia’s communication when they may experience differing beliefs or realities, involving a person-centred approach, including respect, compassion, flexibility, and exploring and making sense of experiences together (Stokes & Kousoulis, 2017). Psychological therapy may support couples to recognise ways in which people with dementia might cope individually, to support their quality of life and strengthen couples’ relationships. Psychologists also have a role in promoting the support of people with dementia and their families within society (BPS, 2016).

BPS (2016) and DoH (2016) guidelines also highlight the importance of sensitive communication of a dementia diagnosis and high quality post-diagnostic support. However, this was not the experience of some couples in the present study, highlighting a possible need for services to improve understanding and care and to meet policy standards, consistent with the BPS (2016) highlighting an “…urgent need to address the gap in provision” (p. 1).

Limitations

Sample. The study has a relatively small, self-selected sample, and findings may not be transferable to other couples living with dementia. Recruitment was difficult, as some partners stated they did not wish to participate due to being unwilling to discuss their experiences openly with their partner with dementia. This is consistent with study findings of some couples' difficulty with open communication, suggesting that coping with dementia often does not involve shared dyadic appraisals, understanding and interaction. It is also possible that couples who participated had different experiences of coping, which may have influenced findings.

All participants were heterosexual married couples and most participants were white British, therefore findings may not be consistent with the experiences of people who identify with other sexualities, ethnicities or cultures. The sample varied in dementia type, with nine participants with dementia having four different types. This may have been a strength, as broader experiences may have been gained, however, it may also be a limitation as it may have restricted a more focused perspective upon dyadic coping within one dementia type.

Design. The use of an exploratory qualitative methodology allowed for detailed exploration of couples' experiences, but is open to bias. Quality assurance techniques were used to reduce bias and the researcher maintained an awareness of their influence upon data collection and analysis, particularly regards evaluations of coping and the potential to be co-opted into couples' constructions of their experiences, using supervision and reflective practice to explore this.

The cross-sectional nature of the study presents a snapshot in time of couples' experiences of coping with dementia. Due to study inclusion criteria requiring participants' informed consent, participants with dementia were generally in the earlier stages. The study does not therefore capture the impact upon dyadic coping of changes in the disease process over time, which may be particularly important given the often degenerative nature of dementia. Berg and Upchurch (2007) highlight the influence of temporal processes, suggesting that dyadic coping may change over time, across different illness stages. It is hypothesised that as dementia progresses in severity, further changes in the couple relationship, such as further loss of reciprocity, are likely to result in loss of dyadic coping.

The study had a number of strengths, particularly the inclusion of people with dementia, consistent with government policy on research priorities (DoH, 2016), as their voices are often unheard (Molyneaux et al., 2012). Due to the paucity of research investigating dyadic coping in couples living with dementia, the qualitative design suited the exploratory nature of the study, with findings significantly adding to the literature.

Future research

Considering the present study’s limitations, it may be important for future research to explore influences of ethnicity or culture, sexuality, dementia type and severity upon dyadic coping in couples living with dementia. Longitudinal research is needed to identify how dyadic coping may change with disease processes over time. In future studies it may be helpful to interview couples both together and separately, to further explore the theme of open and closed communication and how this may affect dyadic coping. Due to the differences found between dyadic coping models and the experiences of couples living with dementia in the present study, future qualitative studies could seek to develop a grounded theory of dyadic coping in couples living with dementia.

Conclusions

Overall, findings suggested that couples living with dementia may utilise a number of ways of coping consistent with models of dyadic coping (Berg & Upchurch, 2007; Bodenmann, 2005; Coyne & Smith, 1991). Couples’ ability to maintain closeness within their relationship, consistent with the ‘couplehood’ literature (Hellstrom et al., 2007) may be associated with joint coping, despite experiences of distance and coping apart. However, couples’ appraisals of dementia were often individual rather than shared and dyadic, and couples’ accounts were characterised by partners of people with dementia taking responsibility for coping, consistent with the literature highlighting a lack of reciprocity (Baikie, 2002; Balfour, 2014; Svanstrom & Dahlberg, 2004). In couples living with dementia, there may be a loss of shared responsibility for coping, resulting from the impact of dementia upon cognitive functioning. Coping in couples living with dementia thus appears to differ from theoretical models of dyadic coping (Berg & Upchurch, 2007; Bodenmann, 2005), due to a lack of both shared dyadic appraisals of stress, and dyadic coping occurring in interaction between both members of the couple. Due to the paucity of research investigating dyadic coping in couples living with dementia, this exploratory study significantly adds to the literature.

References

Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health*, 13(4), 497-511. doi:10.1080/13607860902774436

Auclair, U., Epstein, C., & Mittelman, M. (2009). Couples counseling in Alzheimer's disease: Additional clinical findings from a novel intervention study. *Clinical Gerontologist*, 32(2), 130-146. doi:10.1080/07317110802676809

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, 17(3), 289-299. doi:10.1080/14681990220149095

Balfour, A. (2014). Developing therapeutic couple work in dementia care – the living together with dementia project. *Psychoanalytic Psychotherapy*, 28(3), 304-320. doi:10.1080/02668734.2014.934524

Bender, M.P., & Cheston, R. (1997). Inhabitants of a lost kingdom: A model of the subjective experiences of dementia. *Aging and Society*, 17(5), 513-532. doi:S0144686X97006570

Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133(6), 920-954. doi:10.1037/0033-2909.133.6.920

Bertalanffy, L. (1969). *General systems theory: Foundations, development, applications*. New York: George Braziller Publishing.

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping in couples. Swiss Journal of Psychology, 54, 34‒49. http://psycnet.apa.org/psycinfo/1996-14234-001

Bodenmann, G. (2005). Dyadic coping and its significance for marital functioning. In T. Revenson, K. Kayser, & G. Bodenmann (Eds.), Couples coping with stress: Emerging perspectives on dyadic coping (pp. 33‒50). Washington, D.C.: American Psychological Association.

Bodenmann, G. (2008). Dyadisches coping inventar: Testmanual [Dyadic coping inventory: Manual]. Bern, Switzerland: Huber.

Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective. Aging and Mental Health, 13(3), 426-436. doi:10.1080/13607860902879441

British Psychological Society. (2009). Code of ethics and conduct: Guidance published by the ethics committee of the British Psychological Society. Retrieved from http://www.bps.org.uk/system/files/documents/code_of_ethics_and_conduct.pdf

British Psychological Society (2016). Psychological dimensions of dementia: Putting the person at the centre of care. Retrieved from https://beta.bps.org.uk/news-and-policy/psychological-dimensions-dementia-putting-person-centre-care

Clare, L. (2002). Developing awareness about awareness in early-stage dementia: The role of psychosocial factors. Dementia, 1(3), 295-312. doi:10.1177/147130120200100303

Coyne, J.C., & Smith, D.A.F. (1991). Couples coping with myocardial-infarction – A contextual perspective on wives' distress. Journal of Personality and Social Psychology, 61(3), 404-412. doi:apa.org/journals/psp/61/3/404

De Boer, M.E., Hertogh, C.M.P.M., Droes, R-M., Riphagen, I.I., Jonker, C., & Eefsting, J.A. (2007). Suffering from dementia - the patient's perspective: A review of the literature. International Psychogeriatrics, 19(6), 1021-1039. doi:10.1017/S1041610207005765

Department of Health (2016). *Prime minister's challenge on dementia 2020: Implementation* plan. Retrieved from https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan

Epstein, C., Auclair, U., & Mittleman, M. (2006). Couples counseling in Alzheimer's disease: First observations of a novel intervention study. Clinical Gerontologist, 30(2), 21-35. doi:10.1300/J018v30n02_03

Folkman, S. (1997). Positive psychological states and coping with severe stress. Social Science & Medicine, 45(8), 1207-1221. doi:10.1016/S0277-9536(97)00040-3

Foxwell, K. R., & Scott, S. E. (2011). Coping together and apart: Exploring how patients and their caregivers manage terminal head and neck cancer. Journal of Psychosocial Oncology, 29(3), 308-326. doi:10.1080/07347332.2011.563343

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Medical Research Methodology, 13, 117. doi:10.1186/1471-2288-13-117

Hausler, A., Sanchez, A., Gellert, P., Deeken, F., Rapp, M.A., & Nordheim, J. (2016). Perceived stress and quality of life in dementia patients and their caregiving spouses: Does dyadic coping matter? International Psychogeriatrics, 28(11), 1857-1866. doi:10.1017/s1041610216001046

Hellström, I., Nolan, M.R., & Lundh, U. (2007). Sustaining couplehood: Spouses' strategies for living positively with dementia. Dementia: The International Journal of Social Research and Practice, 6(3), 383-409. doi:10.1177/1471301207081571

Ingersoll-Dayton, B., Spencer, B., Campbell, R., Kurokowa, Y., & Ito, M. (2016). Creating a duet: The couples life story approach in the United States and Japan. Dementia, 15(4), 481-493. doi:10.1177/1471301214526726

Ingersoll-Dayton, B., Spencer, B., Kwak, M., Scherrer, K., Allen, R. S., & Campbell, R. (2013). The couples life story approach: A dyadic intervention for dementia. Journal of Gerontological Social Work, 56(3), 237-254. doi:10.1080/01634372.2012.758214

Judge, K.S., Menne, H.L., & Whitlatch, C.J. (2010). Stress process model for individuals with dementia. Gerontologist, 50, 294-302. doi:10.1093/geront/gnp162

Kitwood, T. (1997). The experience of dementia. Aging & Mental Health, 1(1), 13-22. doi:10.1080/13607869757344

Lazarus, R. S., & Folkman, S. (1984). The concept of coping. In R.S. Lazarus & S. Folkman (Eds.), Stress, appraisal, and coping (pp. 117-140). New York, NY: Springer.

Martin, M., Peter-Wight, M., Braun, M., Hornung, R., & Scholz, U. (2009). The 3-phase model of dyadic adaptation to dementia: Why it might sometimes be better to be worse. European Journal of Ageing, 6(4), 291-301. doi: 10.1007/s10433-009-0129-5

Marwit, S.J., Meuser, T.M., & Bryer, D.E. (2005). Development of an awareness context theory typology for addressing communication patterns in mild dementia. Clinical Gerontologist, 28(4), 61-80. doi:10.1300/J018v28n04_05

Maxwell, J. A. (2012). A realist approach for qualitative research. London: Sage.

Mays, N., & Pope, C. (2000). Qualitative research in health care - assessing quality in qualitative research. British Medical Journal, 320(7226), 50-52. doi:10.1136/bmj.320.7226.50

Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. Dementia, 15(1), 34-50. doi:10.1177/1471301213513029

Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. Dementia, 11(4), 483-502. doi:10.1177/1471301211421070

Morris, J.C. (1993). The clinical dementia rating (CDR): Current version and scoring rules. Neurology, 43, 2412-2414. doi: 10.1212/WNL.43.11.2412-a

NHS Health Research Authority. (n.d.). Our values. [List of NHS research values] Retrieved from http://www.hra.nhs.uk/about-the-hra/who-we-are/our-values/

NICE (2006). Dementia: Supporting people with dementia and their carers in health and social care. NICE clinical guideline 42. London: NICE. Retrieved from https://www.nice.org.uk/guidance/CG42/

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. Gerontologist, 30(5), 583-594. doi:10.1093/geront/30.5.583

Pinner, G. (2003). Attitudes of people with mild dementia and their carers towards disclosure of the diagnosis. International Psychogeriatrics, 15(3), 279-288. https://www.cambridge.org/core/journals/international-psychogeriatrics/article/attitudes-of-patients-with-mild-dementia-and-their-carers-towards-disclosure-of-the-diagnosis/516130DB8668F43E115797597D6AA21E

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. Psychology and Aging, 26(1), 1-14. doi:10.1037/a0021863

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., ... Salimkumar, D. (2014). Dementia UK: Update. Alzheimer's Society. Retrieved from https://www.alzheimers.org.uk/info/20025/policy_and_influencing/251/dementia_uk

Quayhagen, M.P., Quayhagen, M., Corbeil, R.R., Hendrix, R.C., Jackson, J.E., Snyder, L., & Bower, D. (2000). Coping with dementia: Evaluation of four nonpharmacologic interventions. International Psychogeriatrics, 12(2), 249-265. doi:10.1017/S1041610200006360

Rankin, E.D., Haut, M.W., & Keefover, R.W. (2001). Current marital functioning as a mediating factor in depression among spouse caregivers in dementia. Clinical Gerontologist, 23, 27-44. doi:10.1300/J018v23n03_04

Regan, T. W., Lambert, S. D., Kelly, B., Mcelduff, P., Girgis, A., Kayser, K., & Turner, J. (2014). Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. Patient Education and Counseling, 96(1), 120-127. doi:10.1016/j.pec.2014.04.010

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R.G. Burgess (Eds.), Analysing qualitative data (pp. 173-194). London: Routledge.

Rottmann, N., Hansen, D. G., Larsen, P. V., Nicolaisen, A., Flyger, H., Johansen, C., & Hagedoorn, M. (2015). Dyadic coping within couples dealing with breast cancer: A longitudinal, population-based study. Health Psychology, 34(5), 486-495. doi:10.1037/hea0000218

Sørensen, L.V., Waldorff, F.B., & Waldemar, G. (2008). Coping with mild Alzheimer's disease. Dementia, 7(3), 287-299. doi:10.1177/1471301208093285

Stokes, G., & Kousoulis, A. (2017). What is truth? Dilemmas when two realities meet. Journal of Dementia Care, 25(2), 24-25. http://www.careinfo.org/journal-of-dementia-care/

Svanström, R., & Dahlberg, K. (2004). Living with dementia yields a heteronomous and lost existence. Western Journal of Nursing Research, 26(6), 671. doi:10.1177/0193945904265920

Tremont, G. (2011). Family caregiving in dementia. Medicine and Health Rhode Island, 94(2), 36-38. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3487163/pdf/nihms341863.pdf

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. Aging & Mental Health, 20, 1-11. doi:10.1080/13607863.2015.1023769

Woods, R.T. (2001). Discovering the person with Alzheimer's disease: Cognitive and emotional aspects. Aging and Mental Health, 5, S7-S16. doi:10.1080/713650008

World Health Organisation (2012). Dementia: A public health priority. Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/

Section C

Appendix of supporting material

Appendices

A. Data extraction form

B. Clinical Dementia Rating scale [CDR] (Morris, 1993)

C. Study information booklet

D. Study recruitment poster

E. Ethics panel approval letter

F. Participant briefing prior to interview

G. Study consent form

H. Participant demographic information form

I. Interview schedule

J. Example of written information on sources of support provided to participants

K. Participant follow-up telephone call

L. Abridged research diary

M. Example of a coded transcript

N. Initial thematic framework

O. Working analytical framework (including codebook)

P. Example of a framework matrix

Q. Final thematic framework theme descriptions

R. End of study letter to the ethics panel including summary report for participants

S. Journal for submission’s notes for contributors

Appendix A

Data extraction form

Source (Authors, year and country):	
Methods (Design and methodology):	
Participants (Sample size and characteristics):	
Interventions (Description, number, facilitators):	
Outcomes (Analysis type, outcomes and time points):	
Results **(**Main findings, any missing participants, p values/confidence intervals/effect sizes reported?):	
Miscellaneous (Funding source, key conclusions, and any other comments):	

Based on the checklist for data collection or data extraction in the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Collaboration, 2011).

Appendix B

Clinical Dementia Rating scale [CDR] (Morris, 1993)

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

Appendix C

Study information booklet

(Provided to couples as an A5 booklet)

Couples coping with dementia –

A research study

Information Booklet

I would be grateful if you would consider taking part in a research study looking at coping and relationships in couples where one partner has dementia

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Version 3 17.07.16

Information about the research

Title of research: An exploration of dyadic coping in couples living with dementia

Fay Bolsover,
Trainee Clinical
Psychologist,
Canterbury Christ
Church University.

I am very interested in understanding how couples cope together (known as dyadic coping) after one partner has received a diagnosis of dementia.

I would be very grateful if, after reading this information booklet, you would consider helping me with my research. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it would involve. Please feel free to talk to others, such as family or friends, about the study if you wish.

What is the purpose of the study?

I am interested in exploring how couples cope together after one partner receives a diagnosis of dementia. There are a number of things which might influence this, for example ways of relating to and communicating with each other, or one partner having difficulties with thinking or memory.

By interviewing you and your partner, I hope to gain insight into how you cope together living with dementia, including perhaps helpful ways that you may have found to cope together with difficulties. I hope that this will help healthcare professionals to offer the best possible support to couples.

Why have I been invited?

I am inviting couples to help me with my research, where one partner has received a diagnosis of dementia and both partners are able to meaningfully take part in an interview with me. I am interested in hearing from couples who are living together and where both members of the couple feel that they would like to talk to me about their experiences. I am hoping to recruit up to 15 couples to the study.

Do I have to take part?

It is up to each individual person to decide whether or not to join the study. As I am interested in hearing from couples together, both people must be willing to take part. If you as a couple both agree to take part, you will both be asked to provide informed written consent. Either of you would be free to withdraw from the study at any time, without giving a reason. This would not affect the care that either of you receive.

What will happen if we decide to take part?

If you feel that would like to take part, I would be grateful if you could please contact me – please see the ‘How to contact me’ section at the end of this booklet. I will then contact you by telephone to arrange an initial meeting with you both. At this meeting I will ask you both some questions, simply to be sure that you are eligible to take part. This will include asking about difficulties one partner might be experiencing due to dementia. This will also give you the opportunity to ask me any questions that you may have about my research. If you are eligible to take part, and you would both like to proceed, you will both be invited to meet with me again, as a couple, to take part in a joint interview. Before doing so, I will ask you to sign a consent form, confirming that you have read this information booklet and that you have had any questions answered.

The interview will include questions about whether you feel there have been any changes since one of you received a diagnosis of dementia, how you have both coped with any difficulties and whether you feel there have been any changes in your relationship. I expect the interview to take about an hour, and I will record the interview on my digital data recorder. At the end of the interview there will be time to discuss your experience and how you are both feeling. You will be able to contact me after the interview should you have any questions afterwards. Following the interview, you will not be required to do anything further. You will have a copy of this information booklet and signed consent form to keep.

Expenses and payments

Unfortunately, I am not able to provide payment to participants in the study. If you travel to the interview, I am able to reimburse travel costs up to £10 per person. Interviews can take place at a convenient place of your choosing, either in your home or somewhere in the community, for example a private room in a local community centre or library.

What are the possible benefits of taking part?

I do not anticipate that there will be direct benefit to you from taking part in the study, although some people find it helpful to talk about their experiences. I hope that the information gained from the study will help to inform the support and treatment provided to couples such as yourselves. At the conclusion of the study, you will be sent a written summary of my findings by post.

What are the possible disadvantages and risks of taking part?

I anticipate that the disadvantages and risks of taking part in the study will be minimal. There is a possibility that you may feel upset during or after the interview. If there are questions that you find intrusive or distressing, you are free not to answer them or to withdraw from the study. There will be some time at the end of the interview to discuss how you are feeling. I will also discuss with you if you feel that you might need any further support and if so what kind of support you feel that you might need. I will provide you with written contact details for sources of support and you will also be able to contact me if you would like my help in seeking further support.

What will happen if I don’t want to carry on with the study?

You are free to withdraw from the study at any time – before, during or after the interview. If you decide to withdraw after being interviewed, your interview will be removed from the study and destroyed.

Will the information I provide be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential, meaning that it will only be accessed by the researchers and not shared with anyone else. However, if during the course of the study I become aware of a risk of harm to yourselves or others, I would discuss this with you and would be obliged to take an appropriate course of action. This may be simply providing you with contact details for sources of support, or perhaps contacting an appropriate health professional such as your GP.

Your information will be stored securely in locked cabinets or on password protected computers. Information collected during the interview will be given a number so that it will not be possible to identify you from it, and it will be kept separately from any information that is identifiable, such as your name and contact details. Your information will only be used for the purposes of this research study and it will be kept for 10 years, after which it will be disposed of securely.

What will happen to the results of the research study?
After the end of the study, I will send you a written summary of my findings by post. I intend to publish the findings in an academic journal, including short sections of interviews. All of the information will be assigned a number and/or a different name, so that will not be possible to identify you in any report or publication.

Who is organising and funding the research?
I am conducting this research project for my Doctorate in Clinical Psychology course. It is being organised through and funded by Salomons Centre for Applied Psychology, Canterbury Christ Church University. The study is being supervised by Clinical Psychologists Dr Kate Foxwell and Dr Paula Redmond.

Who has reviewed the study?
The research has been assessed by a group of people called a Research Ethics Committee to make sure that it meets certain standards. This study has been reviewed and approved by Salomons Centre for Applied Psychology, Canterbury Christ Church University Research Ethics Committee.

What if there is a problem?
Any complaint about the way you have been treated during the study will be addressed. If you have any concerns about any aspect of the study, please speak to me in the first instance and I will do my best to answer your questions. Please see 'How to contact me' below. If you would prefer to speak to one of the study supervisors, please say that your message is for Dr Kate Foxwell, who will return your call.
If you remain unhappy and would like to complain formally, you can do this by contacting:
Professor Paul M Camic, Research Director, Salomons Centre for Applied Psychology
Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent TN3 0TF
Telephone: 0333 011 7114 Email: paul.camic@canterbury.ac.uk

How to contact me
If you would like to take part in my research, or would like to speak to me about it, I would be very grateful if you could please **leave a message for me on a 24-hour voicemail phone line on 0333 011 7070. Please say that the message is for me, Fay Bolsover, and leave a name and contact number so that I can get back to you.** Or you can email me on:
f.e.bolsover87@canterbury.ac.uk
Thank you very much for taking the time to read this information.

Appendix D

Study recruitment poster

Couples coping with dementia: A research study

Fay Bolsover,
Trainee Clinical
Psychologist,
Canterbury Christ
Church University.

I am interested in understanding more about how couples cope together after one partner receives a diagnosis of dementia. I hope that this will help healthcare professionals to offer the best possible support to couples.

I would be very grateful if you would consider taking part in my study. I would really like to hear from couples who are living together, where one partner has received a diagnosis of dementia, and where both of you would be interested in taking part in a joint interview with me about your experiences.

If you are interested in taking part or would like further information, **please telephone 0333 011 7070 and leave a message for me on a 24-hour voicemail phone line. Please say that the message is for me, Fay Bolsover, and leave your name and contact number so that I can get back to you.** Or please email: f.e.bolsover87@canterbury.ac.uk

Canterbury
Christ Church
University

Appendix E

Ethics panel approval letter

This has been removed from the electronic copy.

Appendix F

Participant briefing prior to interview

An exploration of dyadic coping in couples living with dementia

Interview briefing

- This interview is about meeting with couples where one partner has received a diagnosis of dementia to find out more from them about their experiences of living together, perhaps unhelpful and helpful ways that they might have found to cope together, and what kinds of things may influence this. This is an opportunity for you to talk about and share your experiences and what it feels important to you to discuss.

- I am a trainee clinical psychologist at Canterbury Christ Church University and this research study is part of my doctorate in clinical psychology qualification. Everything you say to me will remain confidential, meaning that it will not be shared with other people outside the research study. The only exception to this would be if you let me know that you or someone else were at risk of harm from themselves or others, and then it would be my duty to inform someone of this. I would hope to be able to discuss this with you before I did this. You are welcome to talk with anyone else about the interview.

- I hope that you will find talking together helpful in some way, however, sometimes people find talking about things upsetting. You are welcome not to answer any questions that you do not wish to, and can ask to stop the interview at any time. At the end of the interview, we will spend a short time together to talk about your experiences of doing the interview. If anything feels upsetting we will spend some time talking about this, and thinking about what support you might need.

- Do you have any questions?

- Do you give your consent to participate?

(Explain and go over the consent form).

Appendix G

Study consent form

Canterbury Christ Church University
Salomons Centre for Applied Psychology

Consent Form

Version 3 12.07.16

Title of project: An exploration of dyadic coping in couples living with dementia

Name of researcher: Fay Bolsover

Please initial the boxes:

1. I confirm that I have read and understand the information booklet dated 17.07.16 (version 3) for the above study. I have had the chance to consider the information, ask questions and have had my questions answered in a way which I am happy with. ☐

2. I understand that my taking part in the study is of my own free will, and that I am free to withdraw at any time without giving any reason, without my rights being affected. ☐

3. I understand that my interview will be recorded and that my information collected during the study may be looked at by the researcher Fay Bolsover and supervisors Dr Kate Foxwell and Dr Paula Redmond. I give permission for these individuals to look at my information. ☐

4. I understand that the results of my information (which it will not be possible to identify me from) may be written up and published in an academic journal, including short sections of interviews such as quotes. ☐

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

Name of Participant: ____

Date: ________________ Signature: ______________________________________

Appendix H

Participant demographic information form

Demographic questionnaire

Full names:		
Address:		
Telephone number:		
Email address:		
Age:		
Gender:		
Ethnicity:		
Occupation (current): Occupation (former):		
Length of relationship/marriage:		
Children:		
Time since first noticed difficulties:		
Time since dementia diagnosis:		
Type of dementia diagnosis:		

Appendix I

Interview schedule

Interview questions:

1) **(To both members of the couple) I'd like to start by asking you both some questions about your relationship if that's ok?**
   - Can you tell me how long you have been together for as a couple?
   - Are you married/in a civil partnership?
   - Do you have any children together?
   - (To each person in turn) Thinking over the time you've been together, how would you describe your relationship?

2) **(To both members of the couple) I'd like to ask you both about your experience of (name) receiving a diagnosis of dementia.**
   (To each person in turn) Can you please tell me, in your own words, your story of what happened?
   - Can you tell me how long it is since (you/name) first started experiencing difficulties?
   - When did each of you first notice difficulties? Who was more aware of the problem?
   - You've told me that it's X months/years since (name) received a diagnosis - can you tell me what you thought and felt at that time?
   - What happened after that?

3) **(To each person in turn) Since (name/you) received a diagnosis of dementia, have there been any changes that you have been particularly aware of? This could be changes for you, or your partner, or as a couple.**
   - What do you think (name of partner) would say about these changes?
   - Who would you say is more concerned about these changes?
   - Have there been any more positive changes?

4) **(To each person in turn) Do you feel that there are any ways in which (name/you) receiving a diagnosis of dementia may have affected or changed your relationship as a couple?**
   - Have there been any positive changes or new opportunities?
   - Do you feel that your roles have changed in any way?
   - Currently, do you engage in any activities together (e.g. gardening, listening to music, going for a walk)? Has there been any impact upon how you spend time together or how much time you spend together?
   - Could you tell me about anything that has not changed?

5) **(To each person in turn) Currently, how do you feel that you are both coping with these/any changes?**

- What sort of ways have you both used to try to cope? Could you please give me some examples of this from your day to day lives?

- Are there any areas that you are finding it more difficult to cope with? What would you say (name of partner) might be finding more difficult to cope with? Are there any situations in which you are finding coping more difficult?

- Are there any areas that you feel you are coping with well? What would you say (name of partner) might be finding a bit easier to cope with? Are there any situations in which you are finding it easier to cope?

6) **(To each person in turn) Do you think (name of partner) would say that your ways of coping with any difficulties together as a couple have changed since (name) received a diagnosis of dementia?**

If yes – how did you deal with problems or challenges before receiving a diagnosis and how does that compare to now? Could you please give me some day to day examples of this?

- To what extent do you feel that you are currently coping as individuals or as a couple? Has this changed from the time before receiving a diagnosis? Could you please give me some examples of this?

- Do you foresee any further changes in how you might cope –together or individually?

7) **(To both members of the couple) Do you think other people, such as family or friends, might notice any changes in your relationship, or the ways in which you are coping as a couple? What might they say?**

8) **(To both members of the couple) What has it been like for you both to talk together about this here today?**
- Is there anything we haven’t spoken about that you think it is important to say?
- I’m very grateful to you both for talking to me today. Is there anything that you would like to ask me?

Thank you for answering my questions.

Interview debriefing

Thank you both for taking part in the interview. As I said at the beginning of the interview, we now have a short time together to talk about your experiences of doing the interview, how you are both feeling now, and any support you both feel you might need?

Would you like me to check in with you by phone in a few days to see how you are both doing?

(Provide written information on sources of support).

Appendix J

Example of written information on sources of support provided to participants

Support following the research interview

Following the interview, I will ask if you would like me to telephone you in the next week to see how you are both feeling. There is the possibility that you may have found talking about things during the interview upsetting. You may feel that you have someone to talk to about how you are feeling, such as friends, family, charity workers or healthcare workers. Alternatively, you might feel that you would like to receive further support. You may like to talk to your GP. You may also find the following sources of support helpful to you:

Admiral Nursing Dementia Helpline: **0800 888 6678**

Alzheimer's Society National Dementia Helpline: **0300 222 1122**

Age UK Advice Line: **0800 169 65 65**

Carers First: 0300 303 1555

Your local sources of support are:

Alzheimer's Society **[insert name of participants' local branch]**

Telephone: **[insert local branch telephone number]**

Age UK **[insert name of participants' local branch]**

Telephone: **[insert local branch telephone number]**

If you are unsure or have any questions, or if you would like some help with seeking support, please contact me by **telephoning 0333 011 7070 and leaving a message. Please say that the message is for me, Fay Bolsover, and leave a name and contact number so that I can get back to you.** Or you can email me on: f.e.bolsover87@canterbury.ac.uk

Appendix K

Participant follow-up telephone call

Script

Hello, it’s Fay Bolsover here, Trainee Clinical Psychologist at Canterbury Christ Church University. I’m just telephoning as we discussed in our recent interview together - we agreed that I would check in with you both to see how you are both doing following the interview?

How did you find doing the interview?

How have you both been feeling since the interview – do you feel that you would like my help in seeking any further support?

Did you have any thoughts or reflections following the interview?

Do you have any comments or feedback for me about the interview or is there anything that you would like me to know?

Do you have any questions that you would like me to answer?

Thank you ever so much to you both for giving up your time to help me by taking part in the study. I will be in touch again in April/May time by sending you a written summary of the findings in the post. You have my telephone number so please do get in touch if you have any questions or decide that you would like my help in seeking further support.

Appendix L

Abridged research diary

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

Appendix M

Example of a coded transcript

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

Appendix N

Initial thematic framework

(Themes in bold, subthemes listed underneath)

1. Descriptions of the couple relationship
- Factors sustaining the couple relationship

2. Diagnostic journey
- Awareness, ownership and understanding of difficulties
- Experiences of the diagnostic process and services
- Experience of receiving the diagnosis
- Impact of the diagnosis
- Influence of the diagnosis upon the relationship

3. Changes in the couple relationship
- Increased proximity
- Loss of mutuality
- Continuity
- Difference
- Facing the future

4. Coping
- Coping individually and together
- Person with dementia using active problem-focused coping
- Partner using problem-focused coping and seeking information
- Emotion-focused coping
- Acceptance vs denial
- Dyadic supportive coping
- Dyadic joint coping
- Dyadic delegated coping
- Dyadic control coping
- Dyadic negative coping

5. Factors influencing coping with changes

- Awareness of changes
- Differential impact of type of dementia on the individual person
- Cultural differences
- Couples’ previous experiences of coping with changes
- Partner having their own needs and difficulties

6. Social systems

- Continuity in social relationships
- Loss and withdrawal from social relationships
- Positive views and experiences of support
- Negative views and experiences of support
- Family
- Society

7. Other

- Other
- Expectations and experiences of the researcher and the research

Appendix O

Working analytical framework (including codebook)

(Descriptions provided in italics)

Themes	Subthemes	Codes
1. The couple relationship context (Factors relating both to each member of the couple individually, *including each person's own experiences, and couples'* experiences of their relationship)	Relationship qualities *(Couples'* descriptions of their relationship)	Accepting and celebrating differences (Couples acknowledge and appreciate their individual differences e.g. in personality, spirituality, beliefs, or political views)
		Good and bad times (Going through good and bad experiences together)
		Having individual lives as well as lives as a couple (Individual autonomy and agency of both members of the couple perceived as being positive for the relationship)
		Importance of financial stability/living within your means (Appreciation of having had financial stability and having managed the finances as a couple as a shared experience)
		Positive (Perceived strength of relationship)
		Working on the relationship (Couples commenting on their approach to managing relationship difficulties)
		Staying together over time (Idea of still being together)
		Spending more time together as a choice made by partner (Partners describing making a conscious decision that they would like to spend more time with their partner with dementia)
		Continuity and growth in couples' feelings for each other *(Couples' describing having the same or stronger feelings for each* other)

	Influence of previous life experiences (Couples descriptions of times over their relationship of how they have coped with difficulties)	Previous experiences of coping (Couple already coped with changes in roles over time for other reasons)
		Individual differences (Couples feeling that each couple might cope differently based on their previous experiences together)
	Partners of people with dementia's own needs and difficulties (Partners of people with dementia having their own health conditions or other responsibilities outside of their relationship with their partner)	Partner having their own health difficulties to cope with (Partners mentioning their own health difficulties and their concern of the impact these may have on their partner with dementia or their relationship with them)
		Partner feels selfish putting their needs first (Partners*' awareness of having their own needs but feeling unable to prioritise these over their partner with dementia's needs)*
		Partner having other responsibilities (Partners describing the pressure of having caring duties towards other relatives)
		Spend more time together due to partner's health (Partners feeling that they are spending more time at home with their partner with dementia as a result of their own health difficulties and no longer being at work)
	Individual impact of dementia (Descriptions of different ways in which the *person with dementia's functioning such as* mood, behaviour and cognition has been affected by dementia)	Changes in mood (Awareness of the emotional impact of dementia on the person with dementia)
		Changes in personality (Descriptions of the person with dementia behaving in ways which are seen to be out of character)
		Hallucinations and changes in sleep and appetite (Discussions of the impact of these changes)
		Lack of ability to plan and sequence behaviour (Awareness of change and loss of this skill)
		Language difficulties (Awareness of change and loss of this skill)

		Loss of arithmetic skills (Awareness of change and loss of this skill)
		Loss of hobbies (Awareness of limitations and sadness of loss of previously valued, meaningful, enjoyable activities)
		Loss of motivation or interest (Awareness of limitations and sadness of this loss)
		Loss of navigation skills (Awareness of change and loss of this skill)
		Visuospatial difficulties (Awareness of change and sadness at the loss of this skill)
		Experiences of stopping working or volunteering *(Couples' descriptions of the partner with dementia no longer working or* volunteering)
		Experiences of no longer driving *(Couples' descriptions of the* partner with dementia stopping driving)
	Increased proximity (Couples having spending more time together due to a loss of independence of the person with dementia and an associated increased responsibility of their partner)	Loss of independence of person with dementia (Disorientation difficulties impacting on independence)
		Person with dementia more reliant upon partner (Descriptions of people with dementia being dependent on their partner)
		Partner feels able to leave person with dementia for short periods (Partners expressing a lack of fear and a sense of predictability which allows them to feel confident to leave their partner with dementia on their own)
		Partner lost ability to do meaningful activities (Partner awareness of changes to their own activities, attributed to caring for their partner with dementia)
		Person with dementia seeking closeness to partner *(Descriptions of partners with dementia's dislike of being alone or* seeking opportunities to share with their partner)

		Spend more time together – partner feels unable to leave partner with dementia (Partners feeling that they are spending more time with their partner *with dementia as a response to their partner with dementia's limitations,* feeling that they are unable to cope on their own without them also being present)
		Recognising importance of time apart (Couples describing how they feel having time apart is important for them and their relationship)
		Considering options to allow partner's continued social relationships *(Couples' discussions of having to have someone else be with the partner* with dementia to allow their partner to go out with others)
	Loss of shared interaction *(Couples' descriptions of changes in their* joint interaction and communication)	Changes in interaction and communication (Changes in the way couples talk to and interact with each other, including conversations, discussions, problem solving and decision making)
		Loss of shared activities (Changes in joint hobbies or enjoyed activities that were shared in together)
		Doing activities together but apart (When couples are physically together but not engaging together)
		Loss of empathy *(Changes in partners' feelings of concern or understanding towards their partner's difficulties)*
		Couple feeling different emotions (One partner describes feeling an emotion that is not shared with their partner)
		Increased awareness of differences (Each person noticing differences between themselves and their partner)
	Concerns about loss of a shared future *(Couples' references to the future, changes* over time, and the ending of life)	Concern about not being together in the future (Expression of difficult thoughts and feelings about not staying together in the future due to partner with dementia moving to a care home or death)
		Difficulty in planning for the future (Concern that future plans may have to be abandoned)

		Partner worrying about the future (Partner of person with dementia expressing concerns about the future)
		Planning for the end of life (Making reference to having planned for end of life such as advance decisions or funeral arrangements)
2. Couples' constructions of dementia	Awareness, ownership and understanding of difficulties (Whether difficulties are in the awareness, of, owned and understood by both partners as something shared, or by either partner individually)	A shared experience (Having a shared reaction to receiving the dementia diagnosis and seeing it as a shared responsibility)
		Difficulties first noticed by partner *(Partner's being the first to notice changes in their partner before they* were diagnosed with dementia)
		Difficulties first noticed by person experiencing them (People who were subsequently diagnosed with dementia being the first to notice changes in themselves)
		Difficulties initially not shared with partner (One partner not sharing their awareness of initial changes with their partner)
		Difficulties not consistent with previous experiences of dementia (Not being aware of initial changes being due to dementia due to them not fitting with prior understandings of dementia
		Initial lack of awareness of difficulties (Initially not being fully aware of difficulties or considering that they might be due to dementia)
		Person with dementia not aware of difficulties (People with dementia describing having not been aware of their difficulties either at the time of diagnosis or during the interview if they are brought up by their partner)
	Process of receiving the diagnosis *(Couples' descriptions of what i*t was like for them for when one partner received a diagnosis of dementia)	Experience not remembered by person with dementia (People with dementia describing not being able to remember their thoughts or feelings at the time they received the dementia diagnosis)
		Reactions to receiving diagnosis by partner *(Partners of people with dementia's descriptions of their thoughts and feelings immediately after being told of their partner's diagnosis)*

		Reactions to receiving diagnosis by person with dementia *People with dementia's descriptions of their thoughts, feelings and* behaviour immediately after being told of their diagnosis)
3. Coping	Individual coping by people with dementia (People with dementia using individual ways of coping with their difficulties)	Religious coping (People with dementia describing their faith as helping them to cope)
		Individual focusing on strengths and abilities (People with dementia highlighting their strengths and abilities)
		Influenced by early experiences (People with dementia describing their ways of coping with difficulties as being influenced by earlier life experiences)
		Finding out information (People with dementia describing it being helpful to find out information)
		Person with dementia monitoring themselves and their activities (People with dementia describing having an awareness of doing activities to help their mood, or maintaining social contact to stay active, or monitoring themselves whilst doing activities to try to prevent difficulties, for example losing things)
		Person with dementia trying to prevent decline whilst they still feel able (People with dementia describing things that they are actively doing to try to prevent decline in their wellbeing such as exercise and healthy eating)
		Person with dementia using cognitive stimulation (People with dementia doing mental activities to try to help their cognitive function)
		Person with dementia using environmental coping strategies (People with dementia describing using things around them as memory aids and prompts)
		Partner seeing partner with dementia's personality still there *(Partner's descriptions of still recognising key aspects of their partner as* a person)
	Problem focused coping by partners (Partners of people with dementia trying to manage in practical ways to try to minimise *the effect of their partner's difficulties)*	Anticipating and preventing potential difficulties *(Partner's descriptions of having an awareness of potential difficulties* and taking active steps to try to prevent them)

		Focusing on practicalities (Partners focusing on practical ways in which they can cope with difficulties such as making changes in their home)
		Learning process (Partners feeling that they are learning how to cope in the best possible way)
		Promoting cognitive function in person with dementia (Partners describing things that they do or support their partner to do to promote their mental activity)
		Receiving supportive information and guidance (Partners seeking to gain knowledge and understanding)
		Considering moving house *(Partners’ descriptions of having moved house to make life practically* easier for themselves and their partners with dementia, such as being closer to the local community)
	Acceptance versus denial (Couples going through processes of accepting difficulties but then also denying them by rejecting or minimising them or attributing them to other factors, which is played out in interactions between both members of the couple)	Acceptance *(Couples’ descriptions of acce*pting difficulties)
		Accepting responsibility (People with dementia describing accepting and not accepting responsibility for their changes in mood or behaviour)
		Denial (People with dementia rejecting, minimising or normalising any difficulties they might have due to dementia)
		‘I wish there was a cure, a total cure’ (Wishing or hoping for a cure)
		Not as bad compared to others (Couples describing how they did not think their situation was as bad as other peoples, which helped them to feel better about their own situation)
		Difficulty with language used (People with dementia describing not liking the word dementia due to their perceived associations of it)
		Not accepting the diagnosis or diagnostic processes (People with dementia describing that they do not accept the diagnosis or the reliability of the tests used for diagnosis)

		Not discussing the diagnosis (Couples describing not having talked together about the diagnosis)
	Partners supporting their partners with dementia (Ways in which partners provides help or support to their partners with dementia)	Partner empathising with person with dementia (Partners discussing having insight or understanding into their partner *with dementia’s thoughts or feelings)*
		Partner finding ways for the person with dementia to contribute to tasks (Partners of people with dementia describing finding things that their partner can do to and supporting and encouraging their partner to do things, such as contributing to cooking meals, or household chores, or shopping)
		Partners’ knowledge of differences due to dementia type *(Partners’ awareness of the impact of dementia type on specific cognitive* function)
		Partners’ feeling less uncertainty about progression over time *(Partners’ knowledge of dementia types* leading to a sense of knowing more about the prognosis/trajectory of dementia than before)
	Coping together (Ways in which couples cope jointly and collaboratively together)	Making effort to continue activities together *(Couples’ describing planning, shar*ing in and trying to do activities together)
		Having open discussions (Talking openly together perceived as being positive for the relationship)
		Use of humour (Instances of humorous exchanges between couples)
		Trusting and relying on each other (Couples describing having trust in each other to support them)
		‘We talk about it’ *(Couples’ describing discussing things openly together)*
		‘We laugh about it now, don’t we’ (Couples describing how they use humour together as a way of dealing with difficulties)
		Partner recognising person with dementia’s strengths and abilities (Partners of people with dementia recognising and appreciating positive aspects of their partner or things they do which they appreciate)

		Person with dementia emphasising partner’s strengths and abilities (People with dementia highlighting positive aspects of their partner or things they do which they appreciate)
		‘One day at a time’ (Descriptions of focusing on time spent together in the present)
		Externalising problems (Couples using a narrative therapy approach to cope with difficulties by describing them as and attributing them to an external character)
		‘Getting on with it’ *(Descriptions of ‘getting on with it’ or taking life or each day together ‘as it comes’)*
		Seeing the positives (Couples describing positive aspects which they feel they have gained from changes or coping with difficulties)
	Loss of shared responsibility (Ways in which partners take over roles, responsibilities and tasks from their partners with dementia, with a loss of shared responsibility)	Changes in role and power (Couples descriptions of assigning themselves different roles and having different power relations in their relationship)
		‘I’m now a carer rather than a wife’ (Part*ners of people with dementia describing themselves as a ‘carer’)*
		‘You’ve become my carer’ *(People with dementia describing their partners as their ‘carer’)*
		Feeling alone in discussions and decision making (Partners descriptions of how they are now having to problem solve and make decisions on their own)
		Loss of shared responsibility (Couples descriptions of how there was no longer a sharing of responsibility for tasks between them)
		‘Doesn’t affect me’ - Difficulties described by person with dementia as only affecting their partner and not them (People with dementia describing a negative impact of dementia as only causing problems for their partner)
		Partner coping individually for the couple (Descriptions of how the partner had taken on responsibility and was therefore coping on behalf of their partner with dementia)

		Partners describing how they feel their partner with dementia needs their support to be able to cope together (Partners descriptions of how they feel their partner with dementia needs their support to be able to cope together as a couple)
		Partner taking over *(Partners descriptions of how they had 'taken over everything', which* they then acknowledged and questioned with their partner with dementia whether this might be difficult for them)
		Partner taking over responsibility and tasks (Partners descriptions of different responsibilities and tasks which they have taken over doing from their partner with dementia)
		'I never think I'm doing it correctly or properly' *(Partner's descriptions of times when they have found it difficult to cope* with changes in role and responsibility)
		Worries owned by partner *(Couples' descriptions of how partners were more concerned about* difficulties)
	Loss of shared concerns (Ways in which one partner may hide their own concerns or worries from their partner, finding talking openly together uncomfortable, or each member of the couple having different explanations or perceptions, which are often yielded to by their partner to avoid disagreement or conflict)	Each member of the couple having different views or explanations (Couples having different ideas during the interview, particularly regarding reasons for changes or the extent of changes or difficulties)
		Finding talking openly uncomfortable (Couples finding it difficult or upsetting to talk openly in front of each other due to concerns about appearing critical of their partner or not wishing to upset them, or one partner expressing feeling that they ought not to be present)
		Partner not sharing worries with person with dementia (Partners not discussing their concerns with their partner with dementia)
		Partners hiding emotions from their partners with dementia (Partners describing times when they have felt strong emotions in response to their partner with dementia, or difficulties due to dementia, and how they have tried to avoid engaging with these)
	Negative coping (Ways in which one partner relates to the other in a not respectful or hostile way, such as highlighting their *partner's decline or*	'Backing off running away syndrome' (Partners descriptions of withdrawing from their partner as a way of managing during difficult times)

	difficulties, withdrawing from their partner, or arguing or being angry with each other)	‘I did it on purpose because I was getting fed up with you’ (Descriptions of people with dementia expressing negative conflictual thoughts or feelings towards their partner)
		No positive changes (Couples descriptions that there has not been anything that has seemed to be easier to cope with or a more positive change)
		Partner highlighting decline *(Partners emphasising deterioration in their partner with dementia’s* skills or abilities)
		‘Yes we row a lot; we do that together very good’ (Couples descriptions of feeling angry towards and arguing with each other)
		Person with dementia feeling blamed or misunderstood (People with dementia expressing feelings of being blamed for things by their partner which they felt were not the case, or feeling that their partner did not understand why they did activities or coping strategies)
		Person with dementia feels guilty (Person with dementia expresses guilt at their partner not having time to themselves)
		Awareness of and frustration with changes (Pe*ople with dementia or their partners’ being aware of the person with dementia’s difficulties and finding this difficult)*
		Frustration with memory lapses (Frustration/annoyance felt by partner expressed at change/loss of skill for their partner with dementia)
4.Wider social context	Familial context *(Couples’ descriptions of their families and* family members)	Difficulties initially noticed by the family (Descriptions of family members being initially more aware of changes or differences in the person with dementia)
		Difficulties later noticed by the family (Descriptions of family members being initially unaware of changes or differences in the person with dementia, only noticing these later in time)
		Distance from family members (Family members living far away)
		Feeling contained within the family (Feeling supported by, loved, and close as a family unit)

		Lack of care from family members *(Family members not showing care or interest towards couples’* difficulties)
		Lack of time from family members (Family members not spending as much time with couples as they would like them to)
		Lack of understanding from family members *(Couples’ describing that they feel that family members do not* understand their difficulties)
		Looking for guidance from family members *(Partners’ descriptions of gaining advice and feedback from family* members)
		Making family members aware of difficulties *(Couples’ descriptions of telling their family members, particularly* children, about their difficulties)
		Support from family members (Descriptions of receiving help and support from family members)
		Valued family relationships (Descriptions of feelings of love and appreciation towards family members)
		Dementia in the family (People with d*ementia’s descrip*tions of people in their family with dementia)
	Continuity in social relationships (Descriptions of things that have not changed in social relationships such as long friendships)	Continuity in social relationships (Descriptions of a lack of change in friendships and social activities, including having long friendships)
		‘You really do look well… they don’t know the half of it’ *(Couples’ descriptions of friends not seeming to be aware of or to notice* any changes or difficulties, or to comment on an apparent lack of difficulties)
	Loss and withdrawal from social relationships *(Couples’ descriptions of having lost or* withdrawn from friends or social activities, and not feeling able to be open with others)	Difficulty in explaining dementia to others (Descriptions of it not feeling possible for others to able to understand *couples’ experiences of dementia or to be able to explain it to them)*

		Hiding diagnosis from others for protection (People with dementia and subsequently their partners not telling other people, including family and friends, about their diagnosis, with some discussing this as being due to feelings of self-preservation)
		Importance of boundaries to person with dementia (People with dementia discussing how they are careful about what information they share with other people)
		‘It’s a taboo subject, a closed subject’ *(Couples’ discussions of how they have noticed that other people, such as* family or friends, do not say anything to them about dementia)
		Loss in social relationships *(Couples’ descriptions of no longer seeing friends, feeling ignored by* others, friends having noticed changes or differences, not feeling able to engage with friends or in social hobbies and activities due to the changes or difficulties for the person with dementia)
		Person with dementia feeling that they do not need support *(People with dementia’s descriptions of feeling that they do not need help* from other people)
		Person with dementia reducing social relationships *(Couples’ description*s of people with dementia withdrawing from or not engaging in social relationships or social activities)
	Positive views and experiences of support *(Couples’ descriptions of support which is* helpful, valued and appreciated by them)	Being open about diagnosis with others *(Couples’ describing being open with others in telling them about one partner’s diagnosis of dementia)*
		Importance of emotional support *(Couples’ descriptions of finding it helpful to talk to others about their* thoughts and feelings)
		Importance of practical support *(Couples’ descriptions of finding practical support from others helpful)*
		Person with dementia encouraging partner’s social relationships (People with dementia encouraging their partner to engage socially with others)

		Positive experiences of support *(Couples' descriptions of support which they have found helpful, such as* providing people with dementia with activities, friendliness from other people, gaining information and understanding from others, talking to others and help from others)
		Reliance on social network for support *(Partner's descriptions of how they feel reliant on friends and family for* help and support)
		Talking to others in similar situations *(Couples' descriptions of how much they appreciate and* value being able *to talk to other 'carers' and people with dementia who are in similar* situations to them)
		Valued social relationships and support *(Couples' descriptions of how much they appreciate and value social* support from friends, neighbours and support services)
		Importance of communication from healthcare services *(Couples' descriptions of how important and helpful they feel it is that* they are talked to openly by healthcare professionals)
	Negative views and experiences of support *(Couples'* descriptions of support which has felt unhelpful to them)	Negative experiences of support *(Couples' descriptions of experiences of feeling unsupported or let down* by others, a lack of warmth or friendliness from others, a lack of support or explanation of support offered, dislike of being reminded of dementia by support services, support services not feeling suitable for people with dementia)
		Negative views of being with other people with dementia (People with dementia describing finding it difficult to be with other people with dementia)
		Not knowing when or what support might be needed *(Couples' describing not being sure when in the future they might feel* that they needed support or what kind of support they might find helpful)
		Not 'real' friends *(Couples' descriptions of having people who they spend time with but not* seeing them as being friends)

		Perceived lack of support for the caring partner *(Couples’ expressing that they felt the partner of the person with* dementia needed more support)
	Experiences of the diagnostic process and healthcare services *(Couples’ descriptions of their experiences of* the process they went through with appointments with healthcare services)	Difficulties initially dismissed by doctor (Experiences of a doctor initially saying they did not think there was anything wrong with the person who was subsequently diagnosed with dementia)
		Experiences of diagnostic process (Experiences of being referred for and undergoing tests and investigations which led to the dementia diagnosis)
		NHS services (reactive nature/lack of funding or resources) (Descriptions of the NHS having a lack of funding or resources and couples being discharged from services unless they have an acute need leading to a feeling of a lack of ongoing support and some feeling like there is not any help available)
	Societal context (Couples descriptions of how they feel dementia is recognised, understood, responded to or portrayed in society)	Importance of ‘friendliness’ from other people *(Couples’* descriptions of how important it is that people with dementia *are treated in a ‘friendly’ supportive way by other people in society)*
		Influence of increased recognition of dementia in society *(Couples’ descriptions of how they feel there has been an incr*eased awareness and understanding of dementia in society)
		Lack of understanding of dementia in society *(Couples’ feelings that most people in society do not understand* dementia or do not understand that people with dementia are living amongst them in the community)
		Media portrayals of dementia (Descriptions of dementia being discussed in the media)
5. Other	Other	Other (Anything unclear how to code or may not be relevant to the research)
	Expectations and experiences of the researcher and the research (Couples descriptions of how they have found the researcher and the research interview, and hopes or ideas they have about the researcher or the research)	Expectations and experiences of the researcher and the research (Couples descriptions of how they have found the researcher and the research interview, and hopes or ideas they have about the researcher or the research)

Appendix P

Example of a framework matrix

INDIVIDUAL COPING BY PEOPLE WITH DEMENTIA									
	A: Religious coping	B: Individual focusing on strengths and abilities	C: Influenced by early experiences	D : Finding out information	E: Person with dementia monitoring themselves and their activities	F: Person with dementia trying to prevent decline whilst they still feel able	G : Person with dementia using cognitive stimulation	H : Person with dementia using environmental coping strategies	I: Partner seeing partner with dementia's personality still there
1: Oliver & Wendy					WENDY – "It's going to get worse, but I can't see any sign of it at the moment and I try to keep in with all my friends at the club so that I'm sort of active, like they are."			OLIVER – "What year it was, it's difficult…" WENDY – "We'll have to get the book out."	Oliver described aspects of Wendy including her skills and abilities still being present and that he still feels he has his other half, "…you're doing everything you can to make life better for us both really."

2 : Brian & Glenys									
3: Lucinda & Vincent						VINCENT – “I can’t do nothing about my brain but I can do about my physical thing, you know, like getting out and eating proper..."			
4: Kenneth & Amanda	Amanda describes how her relationship with God has helped her and he has given her his grace to cope.				AMANDA – “Well I do have tearful days at times, but I usually read a book or go out for a walk… and I’ve usually got quite a lot of knitting underway”.				
5: Victoria & Simon									Victoria described aspects of Simon's

									personality still being there.
6 : Frank & Irene								IRENE – "I very often turn the television on to find out what the day is, because it's up in the corner, the television. So that's what I've done before now."	
7: Nancy & William		WILLIAM – "I feel quite pleased with myself at times. At the Monday club they have quiz bits and pieces and I manage to outshine one or two of them. (*Laughs*)"		William describes how he finds it helpful to go to clubs and find out information.					
8: George & Sylvia	Sylvia describes how her faith is incredibly important to her and how it		Sylvia describes how her early experiences of her mother		SYLVIA – "I know myself how I work. That I won't take a	SYLVIA – "Well, I eat very well. Not a lot of money, but I			

	has helped her to cope, including after the death of her mother. SYLVIA – “It makes me feel quite strong, and quite sure of myself.”		dying when she was young and being brought up by her grandparents affected her ways of coping in terms of acceptance, ‘getting on with it’ and being secretive and hiding concerns from others.		chance doing anything that I think would harm me or anyone else.”	buy a lot of food, but I eat right things.”			
9: Yasmin & Alfred		Alfred describes how he feels he is still mentally strong, and how he can still beat Yasmin at crosswords. He also describes how he is skilled in physical			Alfred describes how he monitors himself, "I am more circumspect now when I go into the kitchen, when I go out and about.” He also described	Alfred describes how he eats a lot of fruit and vegetables which he feels gives him energy to do activities. ALFRED – “So either whatever I do, I’m	ALFRED – “But I feel that I am actually sufficiently aware now of my sort of activities and I still would say to anyone my mental capabilities are still very, very good		Yasmin describes it being helpful emotionally to recognise that aspects of Alfred's personality are still there in the ways he is trying to cope with difficulties YASMIN - "I do think that’s

		therapy and health, cooking and carpentry. He describes himself as having lots of strengths and being a ‘good protector’.			how he feels Yasmin checks on him but he thinks that is helpful to help him to monitor himself. ALFRED – “So it’s not a game but I am keeping my eye on the ball... And since those days began I have been watching myself, that’s the one thing I can do that’s 100% correct.”	doing, I hope that won’t give me too bad a dose of it. If I get a half dose I would say I contribute that to… as a result of the good work that I do... I can only keep myself in good shape.”	and very strong. Maybe not at sort of a remembering telephone numbers and things like that, but the things I do, I would call them my form of brain exercises and memory tests. But to explain them to anybody I can’t, because I know the tasks that I put myself through on a daily basis.”		your coping mechanism is to monitor yourself. Which is kind of reassuring... from an emotional perspective it’s quite helpful… So knowing that key characteristic is still there working away, that, ‘I will monitor everything, I will eat the healthiest I can, I will stay as fit as I possibly…’ that core element of Alfred’s personality, the fact that that is still there and I see it every day.”

Appendix Q

Final thematic framework theme descriptions

Themes are listed by number and subthemes are listed by letter.

(Descriptions are provided in italics)

(In brackets are descriptions of how the final thematic framework was refined from the working analytical framework)

1. Dementia awareness and ownership

This theme describes couples' awareness and ownership of dementia - either held in the awareness of both partners, owned and understood as something shared, or in the awareness of and owned by either partner individually.

a) Dementia diagnostic process

*This subtheme includes couples' experiences of difficulties due to deme*ntia leading up to and immediately after one partner received a diagnosis of dementia. Couples described initial difficulties mainly being noticed or held in awareness and owned individually by one or other partner. Couples also described their reactions to one partner receiving the diagnosis of dementia, with experiences of both individual and shared ownership of the diagnosis.

(Merged subthemes 'Awareness, ownership and understanding of difficulties' and 'Process of receiving the diagnosis' from theme 'Couples' constructions of dementia').

b) Acceptance versus denial

This subtheme includes processes of awareness and acceptance, or processes of denial, such as minimising or rejecting difficulties, or attributing them to other factors. Couples appeared to go through these processes both individually and in shared interaction with each other.

(From subtheme 'Acceptance versus Denial' from theme 'Coping').

2. Emotional closeness

This theme describes differences in emotional closeness, in terms of closeness and d*istance, evident in couples' relationships. This was associated with couples' ways of* coping, with closeness associated with coping together and distance associated with coping apart.

a) Closeness and coping together

This subtheme includes the idea of closeness in couple relationships. Closeness was associated with ways of couples coping jointly and collaboratively together. Couples also described their concerns about not being together in the future.

(Merged subthemes ‘Relationship qualities’ and ‘Concerns about loss of a shared future’ from theme ‘The couple relationship context’ and subtheme ‘Coping together’ from theme ‘Coping’).

b) Distance and coping apart

This subtheme includes the idea of distance in couple relationships, including experiencing negative emotions and reactions to each other. Distance was associated with ways of couples coping apart in ways that were conflicting or disrespectful.

(From subtheme ‘Negative coping’ in theme ‘Coping’).

3. Responsibility

This theme describes changes in shar*ed responsibility in couples’ relationships. This was associated with couples’ ways of coping, with partners of people with dementia: using* problem focused coping to provide support to their partner, taking over responsibilities from their partner, and hiding concerns from their partner. Although these ways of coping were utilised in a way that supported both members of a couple to cope, due to a loss of shared responsibility it was questionable to what extent they were utilised in a shared dyadic way by both members of the couple, or, whether utilised solely by partners of people with dementia in an individual way.

a) Partners supporting their partner with dementia

This subtheme includes ways in which partners provided support to their partners with dementia.

(Merged subthemes ‘Problem focused coping by partners’ and ‘Partners supporting their partners with dementia’ in theme ‘Coping’).

b) Loss of shared responsibility

This subtheme includes changes in couples' roles and power, ways in which partners took over responsibilities and tasks from their partner with dementia, with a loss of shared responsibility, and partners feeling alone in discussions and decision making. Partners increasing responsibility for their partner with dementia was also associated with couples spending more time together, with some partners experiencing a loss of their own meaningful activities. Couples also described experiences of coping with changes in their roles and responsibilities over time pre-diagnosis.

(Merged subtheme 'Loss of shared responsibility' from theme 'Coping' and subthemes 'Increased proximity' and 'Influence of previous life experiences' from theme 'The couple relationship context').

c) Loss of shared concerns

This subtheme describes ways in which partners may hide their own concerns or worries from their partner with dementia, or people with dementia may feel blamed or misunderstood, due to finding talking openly together uncomfortable, or each member of the couple having different explanations or perceptions, which were often yielded to by their partner to avoid disagreement or conflict.

(Merged subtheme 'Loss of shared interaction' from theme 'The couple relationship context' and subtheme 'Loss of shared concerns' from theme 'Coping').

4. Individual needs and difficulties

This theme describes the influence of each person's needs and difficulties upon how they cope as a couple, including the individual impact of dementia upon the person with *dementia, and the individual impact of partners of people with dementia's own* needs and difficulties, such as health conditions or caring responsibilities.

a) Individual impact of dementia

This subtheme includes ways in which the person with dementia has been affected by dementia, including changes in mood, personality, behaviour and cognition (including individual differences due to differing types of dementia), and how these are in relation to their partner.

(From subtheme 'Individual impact of dementia' in theme 'The couple relationship context').

b) Partners of people with dementia’s own needs and difficulties

This subtheme includes the needs and difficulties of partners of people with dementia, including their own health conditions or other caring responsibilities outside of their relationship with their partner, and how these are in relation to their partner.
(From subtheme ‘Partners of people with dementia’s own needs and difficulties’ in theme ‘The couple relationship context’).

5. Individual coping by people with dementia

This theme describes ways in which people with dementia actively try to manage their difficulties in ways that are personally meaningful to them and promote their personal agency and identity.
(From subtheme ‘Individual coping by people with dementia’ in theme ‘Coping’)

6. Wider social context

This theme includes *couples’ experiences of the influence of their wider social context* upon coping, including both positive and negative views and experiences of support from *friends, family, healthcare services and support services, and couples’ perceptions of the* portrayal of dementia in society.

a) Relationships and support

This subtheme includes couples’ positive and negative experiences of support, from friends, family, healthcare services and support services.
(Merged subthemes ‘Familial context’, ‘Continuity in social relationships’, ‘Loss and withdrawal from social relationships’, ‘Positive views and experiences of support’, ‘Negative views and experiences of support’ and ‘Experiences of the diagnostic process and healthcare services’ in theme ‘Wider social context’).

b) A ‘dementia friendly’ society

Couples’ descriptions and experiences of the influence of the societal context upon coping, including how they feel dementia is recognised, understood, responded to and portrayed in society, including the media. This include*s the importance to couples of ‘friendliness’ from* other people.
(From subtheme ‘Societal context’ in theme ‘Wider social context’).

Appendix R

End of study letter to the ethics panel including summary report for participants

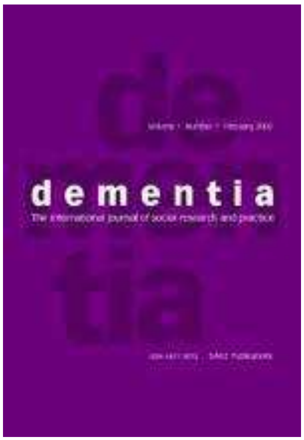
This has been removed from the electronic copy.

This has been removed from the electronic copy.

This has been removed from the electronic copy.

Appendix S

Journal for submission's notes for contributors



dementia

The international journal of social research and practice

Dementia

2015 Impact Factor: 1.083
2015 Ranking: 19/32 in Gerontology
2016 Release of Journal Citation Reports, Source: 2015 Web of Science Data
The International Journal of Social Research and Practice

Editors
John Keady
The University of Manchester, UK and Greater Manchester West Mental Health NHS Foundation Trust, UK
Phyllis Braudy Harris John Carroll University, Cleveland, USA
eISSN: 17412684 | ISSN: 14713012 | Current volume: 16 | Current issue: 1 Frequency: Bi-monthly

Description

Now accepted for inclusion in the Social Sciences Citation Index
Dementia: The International Journal of Social Research and Practice has proved an exciting step forward for the field of dementia care generally, and social research specifically. Dementia acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

The Journal has proved an exciting step forward for the field of dementia care generally, and social research specifically. It acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

"Dementia will be of interest to all clinical disciplines involved in dementia research and the care of individuals with dementia and will be a valuable addition to many libraries and personal collections. It undoubtedly fills a gap among the mass of journals and will make a significant contribution to the effective dissemination of research and the development of high-quality clinical practice." Times Higher Education Supplement

"There is now increasing attention being given to psycho-social aspects of the dementias, with a better balance with biomedical factors being apparent. The journal Dementia has played a key role in developing good quality research in this domain, across a variety of disciplines. It has already contributed to developing and disseminating better practice and quality of care, as we have come to understand better the impact of social and psychological factors on people with dementia and their supporters." Bob Woods, Bangor University

"The field of social research and practice development in dementia care is growing rapidly. There is a compelling need for the key players - people living with dementia, their families and the range of professions supporting them - to work together towards realising the full potential of people living with dementia. The Journal provides just such a forum." Murna Downs, University of Bradford, UK

"Dementia research has come of age and recognizes the value of studying psychosocial aspects related to this disease. Dementia serves an important role in the dissemination of studies on how to improve quality of care and thereby quality of life in people with dementia and their informal carers. It also offers a forum for studies on care staff, which is increasingly important since many countries struggle with a lack of well-educated staff. Dementia helps academics, educators, students, professionals working in dementia care and policy makers in acquiring knowledge and valuation of psychosocial aspects related to dementia. It is a new but well-regarded journal, with an international perspective and a willingness to publish cross-boundary and innovative research which makes it essential reading." Prof. M. Vernooij-Dassen, Radboud University Medical Center Nijmegen, the Netherlands.

Electronic Access
Dementia is available electronically on SAGE Journals Online at http://dem.sagepub.com
This journal is a member of the Committee on Publication Ethics (COPE).
Journal URL: https://uk.sagepub.com/en-gb/eur/journal/dementia

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

Submission guidelines

1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

1.1 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2. Article types

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

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Dementia is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne� Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the **'Online Help'** button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk.

Books for review should be sent to: Book Review Editor Dementia, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

4. Journal contributor's publishing agreement

Before publication SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. For more information please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal.

Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

4.1 SAGE Choice and Open Access

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in SAGE Choice, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE Choice. To check journal eligibility and the publication fee, please visit SAGE Choice. For more information on open access options and compliance at SAGE, including self author archiving deposits (green open access) visit SAGE Publishing Policies on our Journal Author Gateway.

5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'. Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the SAGE Journal Author Gateway.

6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at http://icmje.org. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (http:/www.wma.net) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (http:/www.cioms.ch). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an `Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), Dementia additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit Funding Acknowledgement on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

8. Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC and DOCX. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

9.2 Journal Style

Dementia conforms to the SAGE house style. Click here to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.
Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

9.3 Reference Style

Dementia adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

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 6000 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 and should include the words 'Innovative Practice' after the title of their article when submitting to the journal.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE’s Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online. The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

9.4.4 Guidelines for submitting supplemental files

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's Guidelines for Authors on Supplemental Files.

9.4.5 English Language Editing services

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit English Language Editing Services for further information.

10. After acceptance

10.1 Proofs

We will email a PDF of the proofs to the corresponding author.

10.2 E-Prints

SAGE provides authors with access to a PDF of their final article. For further information please visit http://www.sagepub.co.uk/authors/journal/reprint.sp.

10.3 SAGE Production

At SAGE we work to the highest production standards. We attach great importance to our quality service levels in copy-editing, typesetting, printing, and online publication (http://online.sagepub.com/). We also seek to uphold excellent author relations throughout the publication process.

We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in Dementia with SAGE.

10.4 OnlineFirst Publication

Dementia offers OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our OnlineFirst Fact Sheet.

11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at dem.pra@sagepub.com.