

# Maintaining Relationship Quality in Couples Living with Dementia

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## Acknowledgements

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I would firstly like to thank the couples who kindly volunteered to participate, their willingness to be involved and talk candidly about such a personal experience was very moving, and without which this research would not have been possible.

My gratitude to my supervisors, Jenny and Rosslyn, whose guidance and encouragement helped this project go from a small idea to a fully fledged thesis, in particular your assistance in the write up has been essential.

I want to thank Chris, who has been understanding, motivating and distracting in all the measures I have needed. Thanks also to my friends and family who do not really know what I have been doing these last three years, but nonetheless told me how well I have done and cheered me up when the going has been tough.

Finally, I want to dedicate this thesis to my dad, who would have been so proud of this achievement.

# Abstract

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Mr Thompson (living with dementia):

‘At the end of the day, there is no light at the end of the tunnel, but there can be things we work on together and that is something good about the time we have together, to be working on, it sounds a bit stupid to say it is under control, but, I believe that simply by having the relationship we have, it resolves a lot of issues’

This thesis investigated couples’ relationship quality where one partner has a diagnosis of dementia.

Paper one reports a systematic review of qualitative literature involving both the caring partner and the person living with dementia. This yielded ten studies which were reviewed and rated using a quality appraisal tool. The data extracted from these studies were analysed based on the Double ABCX model of family adaptation and adjustment (McCubbin & Patterson, 1983) to identify how relationship quality is maintained. The utility of this model in understanding the relational experiences of couples was also considered. The findings suggest this model was a useful tool and the results identified couple stressors, resources, coping strategies and appraisals relevant to couple relationship quality maintenance.

Paper two describes a qualitative empirical study investigating how couples respond to relational losses to maintain their relationship quality during the early stages of dementia. Ten married, heterosexual couples, where one partner has a diagnosis of a dementia, were interviewed in dyads. The transcripts were analysed according to a constructivist grounded theory methodology, resulting in an overarching theme of ‘turning to and away’, and three master themes: consolidating us; contextual positioning; and living well together. These elucidate some of the processes engaged in by couples to maintain their relationship quality following relational changes and losses.

Paper three provides a critical evaluation of the strengths and limitations of the systematic review and empirical paper. This paper includes theoretical considerations, along with the clinical and research implications of the work undertaken. The competencies developed from engaging in the research process are discussed in relation to the skill set of a clinical psychologist.

*A note on terminology:* The terms used throughout this thesis to refer to the couples have been selected based on feedback from the Dementia Engagement and Empowerment Project. With an acknowledgment that there may be preferences for different terms within the groups they refer to, the person with the diagnosis of dementia will be referred to as the person living with dementia (PLWD), and their partner who takes on aspects of a caring role will be termed the care partner.

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# 1 Spousal relationship quality in dementia: A metasynthesis of qualitative research using the Double ABCX model

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Prepared in accordance with the author guidelines for the Journal of Aging and Mental Health (Appendix A)

Word count: 7776 excluding references

## 1.1 Abstract

**Objectives:** The experience of dementia is increasingly being considered within a relational perspective, and research has begun to include the perspective of both the person living with dementia and their spousal care partner. This review aimed to identify factors contributing to the maintenance of couples' relationship quality based on the Double ABCX model of family adaptation and adjustment, and to evaluate if this model might offer a framework to understand couples' relational experience of dementia.

**Method:** Four databases (Embase, Cinahl, PsychInfo and Medline) were systematically searched in September 2016 for qualitative research incorporating the views of both the person living with dementia and their care partner.

**Results:** Ten papers met criteria for the final review, their quality was examined and data was extracted and meta-synthesised using the Double ABCX model to frame the results. The findings identified the relational stressors couples face, and how different resources, coping strategies and appraisals interact to maintain relationship quality.

**Conclusion:** The findings furthered understanding of the processes implicated in relationship quality in this area, and highlighted ways couples experiencing discord might be supported. It also evidenced the application of the Double ABCX model to the area of couples' relational experiences in dementia.

**Keywords:** couples; dementia; relationship; systematic review.

## 1.2 Introduction

The experience of dementia affects the person living with the condition as well as their family and wider social network. Following the diagnosis there can be minimisation of the diagnosis, feelings of uncertainty and frustration as families try to make sense of the implications for the future (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). For people living with dementia (PLWD) who are married or have partners, there may be concerns about how their relationship will be affected. Couples can experience changes in responsibilities and increases in anxiety and depression (Robinson, Clare, & Evans, 2005). The relationship may be challenged by perceived relational losses (B. Noyes et al., 2010; Robinson et al., 2005) and a decline in factors such as intimacy, communication and overall happiness in the marriage (Ablitt, Jones, & Muers, 2009). As the dementia advances the relationship may change further with some family carers reporting a shift to an adult-child dynamic (Alzheimer's Research UK, 2015). However despite threats to the relationship, some partners feel increased closeness, warmth and a strengthening of the relational bond (Carbonneau, Caron, & Desrosiers, 2010). These variations may reflect a different profile of changes in the facets which make up relationship quality (RQ). Psychometric measures of RQ such as the Dyadic Adjustment Scale (Spanier, 1976) and the Relationship Assessment Scale (Hendrick, 1988) suggest perceived satisfaction, agreement between partners, emotional expression and quality of time spent together contribute towards overall RQ. There may also be additional processes which influence how couples' RQ changes as a result of living with dementia.

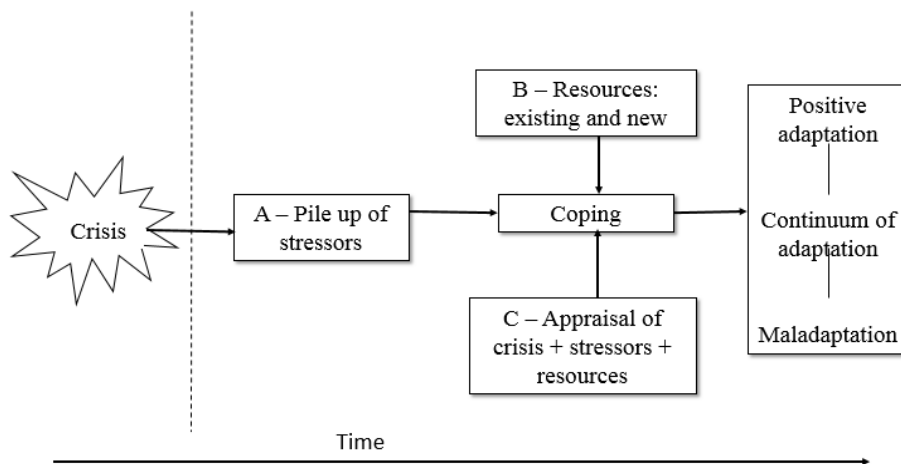
RQ between couples affected by dementia may be an important indicator of outcomes. A systematic review by Ablitt et al. (2009) identified an association between a maintained sense of RQ and higher emotional wellbeing in both the carer and PLWD. However, this review relied predominantly on carer self-report and was constrained to papers which utilised a

quantitative methodology. More recently, the views of the PLWD have increasingly been sought, particularly when exploring the relationship between the care partner and PLWD, or husband and wife as they may identify. A recent systematic review by Wadham, Simpson, Rust and Murray (2016) examined the impact of dementia on couplehood using qualitative studies where both the PLWD and their partner participated. Their review corroborated previous findings that bi-directional links exist between the couple relationship and the experience of dementia, and highlighted the motivation of couples to maintain their sense of couplehood, which may relate to RQ. Factors predictive of RQ in dementia include the relationship form; commitment to continuity of the prior relationship and reciprocation of previous care received (Ablitt et al., 2009). Moreover, marriage commitment may encourage partners to undertake continued activities together and thereby increase marital satisfaction (H. Davies et al., 2010). However, how RQ is maintained has not been systematically studied within a relational perspective and could have significant clinical and therapeutic implications.

To examine maintenance of RQ in dementia it may be useful to draw on existing frameworks (Braun et al., 2009). Whilst other models such as the transactional model of stress and coping (Lazarus & Folkman, 1984) were considered, the Double ABCX model of family adjustment and adaptation by McCubbin and Patterson (1983) was identified as a framework to consider how couples adapt to a stressor over time. This model has been recently applied in intellectual disability and physical health settings (Hesamzadeh, Dalvandi, Maddah, Khoshknab, & Mahmadi, 2015; Paynter, Riley, Beamish, Davies, & Milford, 2013) to explore how families adapt to stressors such as receiving a diagnosis of autism or adapting to life after a stroke. The model has been applied in a dementia context less frequently (Cohler, Groves, Borden, & Lazarus, 1989; Quinn, Clare, & Woods, 2009) but it potentially offers a way of exploring how families, rather than individuals, adapt to challenging experiences. The

Double ABCX model postulates that following a crisis (an event which disrupts the family system), the family encounter additional stressors which can increase demands on the family and precipitate change. Families make use of existing resources as well as acquiring new resources to manage these demands. Families also hold multiple appraisals in relation to the crisis, stressors and resources. Coping is conceptualised as an interaction between the stressor, resource engagement and family appraisals, with the result being family mal/adaptation, as represented in Figure 1.1. In the context of this review the crisis is the couple experience post-diagnosis of living with dementia, and the outcome of interest is couples' ability to maintain their RQ.

Figure 1.1. Double ABCX model of family adaptation and adjustment.



Adapted from McCubbin and Patterson (1983)

### 1.2.1 Aims

The aims of this review are: firstly, to consider what factors influence RQ in couples affected by dementia, and secondly, to evaluate if the Double ABCX model of family adaptation and adjustment might offer a framework to understand couples' relational experience of dementia.

## **1.3 Method**

### ***1.3.1 Design***

A qualitative meta-synthesis approach was used, and the Double ABCX model of family adaptation and adjustment (McCubbin & Patterson, 1983) was tested as a framework for synthesising the data. Use of a theoretically driven approach has been recommended for reviewing qualitative studies (J. Noyes & Lewis, 2011).

### ***1.3.2 Search strategy and article selection***

Four databases (Psychinfo, Medline, Cinahl and Embase) were searched in September 2016. The search terms focused on identifying those with dementia (dementia OR alzheimer), and their spousal carers (family care\* OR marital OR spous\* OR dyad\* OR partner).

Articles were included if they: (1) were available in English; (2) utilised a qualitative methodology; (3) comprised a community dwelling sample, (4) included the views of both the partner and PLWD; and (5) considered the dyad relationship.

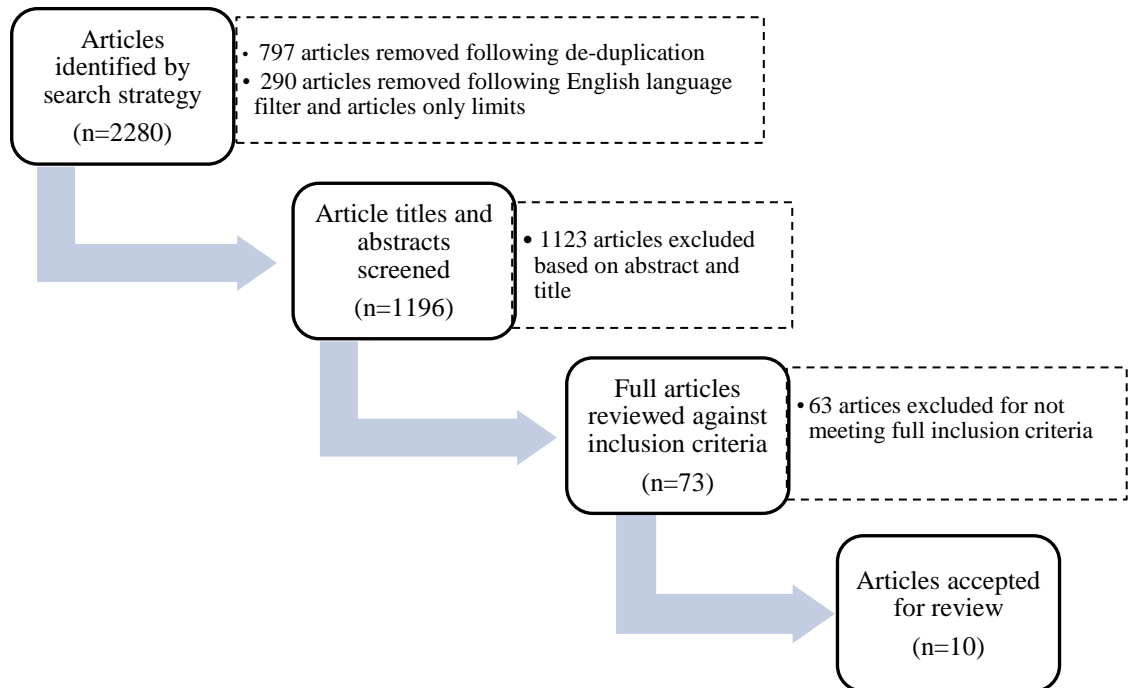
Articles were excluded if: (1) the sample included those with a diagnosis of dementia alongside participants with other neurodegenerative conditions or mild cognitive impairment; (2) participants included partners and/or other family members. Both the above exclusions were applied if the results could not be differentiated by group. Articles employing a mixed methodology were excluded if the qualitative component was not the main focus, and a substantive analytic approach was not employed.

The process for identifying the ten papers included in the review can be seen in Figure 1.2.

The reference list of included articles and relevant reviews were searched, but no further

articles were identified. Further details of the articles read in full and excluded for not meeting the review criteria are available in Appendix B.

Figure 1.2. Pathway explicating the search process.



### 1.3.3 Study characteristics

The articles included in the review were published between 2004 and 2016, reflecting the more recent shift to involve both dyad members in research. Studies mostly utilised grounded theory or interpretative phenomenological methodologies to analyse samples ranging from single case studies (Daniels, Lamson, & Hodgson, 2007) to 26 dyads (Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard, 2008). Eight studies generated data from joint interviews and all studies were cross-sectional in design except Atta-Konadu, Keller and Daly (2011), Daniels, Lamson and Hodgson (2007) and Hellstrom, Nolan and Lundh (2007) who gathered material from couples longitudinally. Participants with dementia most typically had a diagnosis of Alzheimers, vascular or mixed dementia. Further study details can be seen in Table 1.1.

Table 1.1. Summary of the included papers' characteristics.

Authors	Study aims	Sample size	Study location	Participant details (Male=M, Female=F)	Data collection	Analysis method
Atta-Konadu et al. (2011)	To explore couples' experiences of their changing relationship through how they deal with food related changes	N=9	Canada	9F with a diagnosis of dementia. Age 58-88years.	Individual and joint interviews (20-60 minutes) using active interviewing techniques. Completed three times at yearly intervals.	Grounded theory
Daniels et al. (2007)	To explore the dynamics in the couple relationship.	N=1	US	1F with early stage dementia and partner, in their 80s. Diagnosed five years previously.	Three joint interviews conducted over six months. Semi-structured interview comprising nine questions about the relationship, marriage experiences, their life together and significant events in marriage. No direct questions about dementia.	Narrative analysis
J. Davies (2011)	1. To identify couples' commitment to their relationship during early stage dementia and 2, how this affects their experience of dementia	N=6	Canada	4F and 2M with Alzheimer's. Age 65-83years.	Two meetings; first meeting questionnaire completion, interview conducted in second meeting.	Narrative analysis
Hellstrom et al. (2007)	To understand the impact of dementia on their relationships and daily life over time.	N=20	Sweden	12M and 8F with dementia. Age 65-85 years.	Separate and joint interviews over a five year period (max six interviews, 30-45 minutes). Questions covered four themes of home life, memory disturbance, RQ and daily life, dignity and autonomy.	Grounded theory



Merrick, Camic and O'Shaughnessy (2016)	1. To explore the reciprocal impact between dementia and the couple relationship; 2. To consider what it means to be a PLWD in a couple relationship	N=7	UK	5M and 2F with dementia. Age 63-87 years. 2-9 years since diagnosis.	Joint interviews conducted in a conversational style (60-90 minutes). Questions covered couples' relationship history, impact and adjustment to dementia.	Interpretive Phenomenological Analysis
Molyneaux, Butchard, Simpson and Murray (2011)	1. To consider the reciprocal interaction between dementia and couple relationship; 2. To explore how couples co-create couplehood in dementia	N=5	UK	3M and 2F diagnosed with Alzheimers. Age 72-84 years.	Single joint interview about their experiences, actions and views (70-110 minutes).	Grounded theory
Robinson, Clare and Evans (2005)	1. To explore psychological reactions to dementia diagnosis in couples; 2. to elaborate their constructions of and responses to diagnosis; 3, explore responses in relation to loss frameworks	N=9	UK	5F and 4M with dementia. Age 65-85 years. 2-24 months since diagnosis.	Single joint interview (20-90 minutes). Questions about first signs, experience of receiving diagnosis and the impact of diagnosis on relationship.	Interpretive Phenomenological Analysis
Svanstrom and Dahlberg (2004)	1. To investigate the lived experiences for spouses when partner is affected by dementia	N=5	Sweden	2F and 3M with dementia. Age 72-80 years.	Single joint interview (40-80 minutes). Care partners completed a daily diary for a week which was used to inform questions during the interview.	Phenomenological approach

Vikstrom, Josephsson, Stigsdotter-Neely and Nygard (2008)	1. To identify and describe how PLWD and spouses perceive their own, their partners' and their mutual engagements in everyday activities	N=26	Sweden	14M and 12F with dementia, diagnosed with the previous 8 months. Age 59-86 years.	Single interview conducted separately (10-50 minutes). Questions explored views on everyday activities completed separately and together, and the value of different activities.	Grounded theory
Wawrziczny, Antoine, Ducharme, Kergoat and Pasquier (2016)	1. To identify couples' needs; 2, the impact of young onset dementia on their relationship and 3, their individual and dyadic coping.	N=16	France	7M and 9F with dementia. Mean age 57.	Single joint interview (45-160 minutes). Questions covered disease onset, difficulties encountered, current needs, coping strategies and evolution of the relationship.	Interpretive Phenomenological Analysis

#### ***1.3.4 Quality appraisal***

The articles meeting the review criteria were appraised using the Critical Appraisal Skills programme (CASP), which was developed specifically for qualitative research (Critical Appraisal Skills Programme, 2017), with the scores outlined in Table 1.2. Quality appraisal was conducted after data extraction to reduce potential author bias in analysis of the research (Boland, Cherry, & Dickson, 2013). The CASP has two initial screening questions regarding clarity of aims and appropriate use of qualitative methodology, which all ten papers met. Following this, eight further criteria were considered and a numerical scoring system was applied: zero meaning ‘item not present or poorly described’; one meaning ‘partially met’; and three meaning ‘fully present’. The included papers total scores ranged from ten to 15. No cut offs for inclusion were set because the appraisal tool authors do not recommended scores are used for this purpose (Critical Appraisal Skills Programme, 2017), rather the scores set a context for interpreting the findings.

#### ***1.3.5 Data extraction and analysis***

Data extraction was guided by the Double ABCX model (McCubbin & Patterson, 1983). Grounding data extraction in an existing model can focus the process on findings relevant to the review topic, in this case the maintenance of RQ (J. Noyes & Lewis, 2011). Moreover, use of an existing model offered the potential for model refinement and development when applied to a specific population, in this case couples affected by dementia. The key categories from the Double ABCX model were used to create a table which was populated through immersive reading of each paper. Attention was paid to findings relevant to the research question around couple experience and RQ. Findings which were ambiguous in the context of the Double ABCX model or did not seem to align with the model’s factors were noted. Data

extraction was primarily performed by the lead author with support from the second authors, for instance discussing how to table factors relevant to multiple areas.

## 1.4 Results

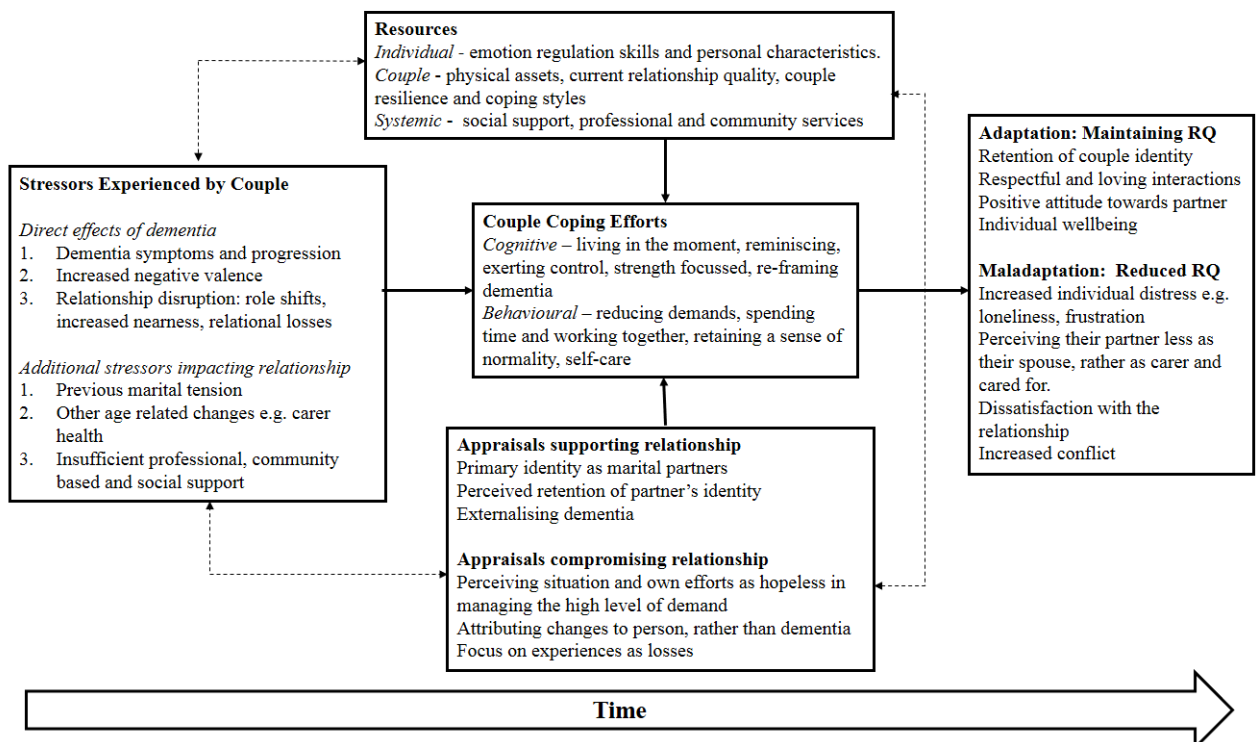
The quality appraisal scores of the reviewed articles are reported in Table 1.2. and the implications of these ratings are raised in the results and discussion.

Table 1.2. Quality appraisal scores based on the CASP quality measure.

Article	Design	Sampling	Data Collection	Reflexivity	Ethical Issues	Analysis	Findings	Value	Total score /16
Atta-Konadu et al. (2011)	2	2	1	0	1	1	2	2	11
Daniels et al. (2007)	2	2	2	2	2	2	2	1	15
J. Davies (2011)	1	1	1	0	2	1	2	2	10
Hellstrom et al. (2007)	2	2	2	2	2	1	2	2	15
Merrick et al. (2016)	2	2	2	1	2	2	2	2	15
Molyeaux et al. (2011)	2	1	2	2	2	2	2	2	15
Robinson et al. (2005)	2	2	1	1	0	2	2	2	12
Svanstrom and Dahlberg (2004)	1	2	2	0	1	1	2	1	11
Vikstrom et al. (2008)	1	2	1	1	0	2	2	1	10
Wawrziczny et al. (2016)	2	2	1	0	2	1	1	1	10

The main results are structured around the Double ABCX model (McCubbin & Patterson, 1983), and discussed in relation to factors promoting or reducing RQ maintenance. The emergent model is depicted in Figure 1.3.

Figure 1.3. Couples' relational experience of dementia and RQ maintenance.



### 1.4.1 Stressors

Stressors are demands faced by the family which represent a challenge to be managed, the response to stressors determines whether adaptation or maladaptation is experienced.

According to the original Double ABCX Model (McCubbin & Patterson, 1983) stressors may arise from the initial stressor, normative family transitions, prior strains and consequences of family efforts to cope. The results suggested two stressor groups; those arising directly due to the dementia, and additional factors impacting the relationship.

#### 1.4.1.1 Direct dementia stressors

The impact of the cognitive, affective and behavioural profile of dementia and unpredictable nature of the disease progression was highlighted in all the reviewed papers. As Wawrziczny et al. (2016) mused: 'an action that is possible one day will be impossible the next, but will become possible again the day after that' (p. 1088) and this could impede couples' ability to make longer term plans and generate uncertainty about the future.

The included articles also described how each partner may experience increases in negative affect which could adversely affect the relationship. One caregiver stated: 'I am so mentally filled with sorrow....my frustration increases and my husband is victimised by it' (Vikstrom et al, 2008, p. 259). Feelings of loss, sadness, frustration and anxiety were frequently reported. Descriptions given by participants were reinforced by researchers' observations that: 'those interviewed perceive their existence as characterised by hopelessness' and 'a feeling of discomfort aggravates their (couple) existence' (Svanstrom & Dahlberg, 2004, p. 679).

Disruption to the relationship was also highlighted as a stressor. Relational losses were reported in all papers, examples included a loss of the couples' planned future together and a loss of physical intimacy. Role shifts were also highlighted which often resulted in one partner taking more responsibilities in a caring role. Role shifts could be catalysed by skill losses, and this could be stressful for instance for husbands who struggled to take on cooking responsibilities previously held by their wives (Atta-Konadu et al., 2011). As one participant described: 'back in our time, the men never did anything at home or very little at home....it's been a real change for me and because you've got an old dog, and you can't teach an old dog new tricks' (Atta-Konadu et al., 2010, p. 308). Shifting roles were associated with increased interdependence or 'enforced togetherness, in which both couples felt trapped and unable to spend time apart' (Molyneaux et al., 2015, p.492). Some partners, in taking on a more caring role, could struggle to retain time for themselves, or express their own needs. This could place additional stress on the couple relationship. For instance Vikstrom et al. (2008) reported: 'one female caregiver mentioned she had ceased going swimming, since the husband with dementia could not manage alone in the changing room'. In general, caregivers told of their partners' strong need for nearness as burdensome' (p. 259). However, for many

couples this was not the experience reported; they perceived increased nearness positively (e.g. Daniels et al., 2007; Hellstrom et al., 2007; & Molyneaux et al., 2011).

#### *1.4.1.2 Additional stressors impacting the couple*

Previous marital tension contributed to challenges in the relationship and was observed by some researchers, for instance in critical ways of talking about their partner. As Molyneaux et al. (2011) observed: ‘argumentative couples were therefore not surprised to be arguing again’ (p. 491), although none of the included papers measured previous marital quality and it was not a sampling criteria.

The stressful impact of inadequate community resources and support from family, friends, and professionals was evident in four papers (J. Davies, 2011; Robinson et al., 2005; Svanstrom & Dahlberg, 2004; Wawrziczny et al., 2016). Inadequate community resources included limited public transport for couples who could no longer drive. Social networks were reported to diminish over time which could increase loneliness: ‘I do not have that many acquaintances anymore... somehow I sit here like a crow in her nest’ (Vikstrom et al., 2008, p.258). Professional input, when difficult to access or poorly matched to couples’ perceived needs, placed additional demands on couples. Robinson et al.(2005) reported dissatisfaction with services such that: ‘all couples felt they should have been told more by health professionals, either about the diagnosis or prognosis of dementia or about what could be done to help them’ (p. 342).

To a lesser extent, additional age-related changes such as identifying suitable accommodation, stopping driving and a decline in the care partner’s health were identified as stressors although the value of these factors is supported by the high quality ratings of both papers (Daniels et al., 2007; Hellstrom et al., 2007). Accordingly, care partners indicated this

could compromise their ability to care for and support their partner: ‘Tom was just as concerned about the decline of his own health as he was Jane’s’ (Daniels et al., 2007, p. 172)

#### ***1.4.2 Existing and new resources***

The Double ABCX model predicts families respond to stressors by using existing resources and acquiring further resources (McCubbin & Patterson, 1983). The review revealed a range of resources accessed at an individual, couple and systemic level but the reporting of results did not allow for differentiation between existing and acquired resources.

Individual resources reported included effective emotion regulation skills. These seemed important for wellbeing in the context of increased emotional distress where: ‘fluctuations directly affect their (the care partners) own emotional state and mood. If the PLWD is doing well, the caregiving spouse will be too’ (Wawrziczny et al., 2016, p. 1088). Several articles highlighted individual qualities displayed by the PLWD (e.g. resilience and acceptance) and care partners (e.g. flexibility, patience, and resourcefulness), although overall more were reported for care partners.

The review identified three main couple resources: physical assets such as financial security and a suitable home environment; coping skills and resilience, and an existing high level of RQ. Elaborating on coping skills and resilience, several papers reported that couples, during their marriage, had often overcome other stressors which gave them: ‘resilience and optimism that this too could be managed’ (J. Davies, 2011, p. 228). Such previous experience could influence factors such as communication style, Hellstrom et al. (2007) stated couplehood was sustained by ‘maintaining open channels of communication and discussing issues, large or small, in order to reach a shared understanding and agreement’ (p.392) which was supported by this quote from a PLWD:



‘I regard our marriage to be very happy; we respect each other. You do not necessarily need to be of the same opinion. It often happens that we discuss something and find that we look differently upon it and I don’t think that is wrong. Of course we have had some harsh words, but it has resulted in full respect for each other’ (p. 392).

A higher existing RQ was another couple resource, which the articles suggested was grounded in a shared pleasurable history and reflected in the ‘foundations’ master theme identified by Merrick et al. (2015). The articles reviewed suggested many couples affirmed their relationship through their shared commitment to the social framework of marriage and their vows. For example, J. Davies (2011) identified a theme of ‘partnership for life’ evidenced by the comments of a participating husband: ‘when you talk about commitment, that’s staying true to what you’ve said, eh, the vows, and you’re gonna follow the wedding vows’ (p. 222). However, adhering to the marital commitment was also reported to function as a stressor and some ‘caregivers seemed to struggle with how to live up to their marital promise of staying together and being supportive, yet to endure the isolated and sometimes tough life they now experienced with their spouse’ (Vikstrom et al., 2008, p. 261).

The third set of resources identified by the review were systemic, including couples’ social networks, and community and professional services. Examples of these resources were evident in all articles except three (Hellstrom et al., 2007; Merrick et al., 2016; Vikstrom et al., 2008) which reinforces the idea couples exist in a social context. Support provided could be practical, such as family facilitating attendance at appointments, as well as emotional. A reported caveat seemed to be the willingness of couples to use this support to assuage their own difficulties as ‘caregivers generally did not think they had the right to burden their children, neighbours and friends with the sometimes intimate and burdensome care their

spouse with dementia needed' (Vikstrom et al., 2008, p. 261), although this was reported in a paper rated as lower quality so the findings may not be as reliable.

Overall if couples were able to use these resources to mitigate the stressors experienced this could create a milieu in which the relationship could continue, termed by Hellstrom et al. (2007) the 'nurturing relational context', whereas a deficit in resources might contribute to maladaptation through having less capacity to adjust to the stressors.

### ***1.4.3 Spousal appraisals***

Appraisals are the meaning given to a situation (McCubbin & Patterson, 1983), the data extraction for appraisals yielded less data than for the other factors such as stressors and resources. The emergent indicators which might maintain RQ include the extent couples appraised themselves as retaining a shared identity as marital partners, and perceived the other as retaining aspects of their personality. Robinson et al. (2005) noticed couples 'described carrying on as a couple by focusing on what remained for each person and for the couple, for example minimising the impact of memory problems on daily life' (p. 344).

Externalising dementia was identified as part of the appraisal process by three studies, two of which were rated as higher quality, and one as low quality (Daniels et al., 2007; Hellstrom et al., 2007; Svanstrom & Dahlberg, 2004). Representing dementia as a separate entity might benefit the relationship as couples might be able to share the distress associated with the condition and ally against the dementia, working together against it. For instance, one partner was quoted as saying 'the Alzheimer's is pretty bad' which was interpreted as meaning the caring partner had 'recognised the influence the illness had on their marriage, and was holding the Alzheimer's disease accountable for the memory loss, instead of (his wife)' (Daniels et al. 2007, p. 171).

Appraisals which might contribute to maladaptation were detailed in only two articles (Svanstrom & Dahlberg, 2004; Wawrziczny et al., 2016). These appraisals included couples who focused on their experiences as losses for instance their future and shared relationship. It was reported some couples perceived the essence of their relationship and the core identity of their partner was lost: ‘I wasn’t seeing my husband as my husband any more, this is not the same person anymore’ with the idea the relationship becomes ‘a wobbly building that frightened those who live in it’ (Wawrziczny et al., 2016, p. 1092). Moreover, couples could appraise the chronic nature of dementia as producing unyielding demands, for instance managing risks and novel situations, which exceeded their ability to manage, as illustrated by this care partner describing their daily life: ‘it’s always the same, there’s never any positive, so to speak, but just worrying stuff’ (Svanstrom & Dahlberg, 2004, p. 680). Importantly the two papers which yielded most information relevant to maladaptation appraisals received the lowest quality ratings of 10 and 11/16 on the CASP. As a result the findings which arise from these studies might need interpreting with caution.

#### ***1.4.4 Coping***

The Double ABCX model conceptualises coping as a cognitive and behavioural bridge between the stressor, resources and appraisals, with a direct link to mal/adaptation (McCubbin & Patterson, 1983). The articles included in the review reflected both these strategies and suggested they contributed to family adjustment by mitigating the distress experienced and reinforcing positives in the RQ.

##### ***1.4.4.1 Behavioural strategies***

There was evidence to suggest couples employed behavioural strategies such as strategically avoiding and manipulating situations which could spotlight symptoms and therefore cause distress. For instance, given the difficulty predicting ‘whether the partner with dementia

would have the interest or strength to join pre-scheduled social arrangements, several caregivers told of compensating by engaging in something on their (the couples) own' (Vikstrom et al., 2008, p. 263).

Couples were also reported to make efforts to share in things together, from routine house chores to going out socially. This approach was described in all papers, which ranged in quality ratings from 10-15/16, as such sharing in things seemed a ubiquitous way of maintaining quality in the relationship. In this example, a husband considers how he involves his wife, who has dementia, in cooking which was previously one of her responsibilities: 'I tell her what we are having. I bring it from the deep freezer, peel the potatoes and those sorts of things and then she prepares and it has worked well so far' (Hellstrom et al., 2007, p. 400).

Couples also attempted to maintain a sense of normality within their relationship, and more broadly their lives through their routines and habits. For instance, physical demonstrations of affection reinforced the marital identity, as a wife whose husband has dementia describes: 'I am sitting downstairs and as he is passing me I might get a kiss from him any time, this is no problem, that is nice' (Hellstrom et al., 2007, p. 393). However, some articles suggested 'carrying on as usual' resulted in partners becoming responsible for findings ways to maintain the involvement of the other person while masking their increased support. For example, one care partner said to enable her husband to continue dressing himself she will 'lay his things out on the bed... his socks with his underpants on top, then his shirt, then his trousers, then his belt. That's it. I leave him' (Merrick et al., 2016, p. 43). This approach could inadvertently place greater demands on the care partner, which could increase their risk of distress.

Finally, five studies suggested it was important for couples to engage in self-care, that is activities which would elicit positive feelings. The nature of activities undertaken depended on couples' tastes and resources, such as the finances for holidays, or a close social network.

#### *1.4.4.2 Cognitive strategies*

Evidence emerged that couples employed several cognitive strategies to reinforce their appraisals and modify the impact of stressors. Firstly, couples were found to maintain a present focus, which was construed as a deliberate effort to make the most of their shared experienced. This was interspersed with reminiscing, encapsulated by the theme of 'the good old days' by Molyneaux et al. (2015, p.493).

The articles also highlighted that couples sought to balance exerting control over their situation with recognising limits to their influence. By accepting these limits, couples may focus on finding ways to cope with this reality, or identifying areas they can control. As this wife who supports her husband explains: 'Can't do anything about it can we? We've just got to... face facts and get on with this' (Molyneaux et al. 2011, p. 492). An exception to this came from Svanstrom and Dahlberg (2004) who found some couples reported feeling completely powerless and were struggling to cope.

An additional cognitive strategy identified was focusing on abilities and successes, for instance one caring partner stated: 'of course, instead of pointing out his mistakes, I tell him "this was very well done", or "how nice of you to do this for me"' (Hellstrom et al., 2007, p. 400). By contrast, the following quote highlights a different relational tone when the focus is on limitations and restrictions, which might be associated with maladaptation:

Partner with dementia: 'I told you there are things I can do, and I don't want anyone else to take over.'

Spouse (talking to the interviewer): You have to follow behind her and do everything!  
It's useless, totally useless. I'd rather she did nothing' (Wawrziczny et al., 2016, p. 1089).

Finally, the data extraction revealed some further strategies used by couples to minimise the influence of dementia which included making favourable comparisons, highlighting unaffected areas and normalising their experience within the aging process. Setting dementia within the aging process is illustrated by this person: 'I mean it's er one of those things about age isn't it. I mean, well I couldn't remember (the doctor's) name but I mean that is just, you know?' (Molyneaux et al., 2011, p. 497).

Collectively these reported cognitive and behavioural strategies seemed to maintain RQ through helping couples attenuate emotional distress caused by the stressors and enabling couples to anchor themselves in core identity concepts and reinforce this through concordant behaviours. The robustness of these conclusions are influenced by the quality of the included studies, a majority of which scored highly for the reporting of their analysis and findings.

#### ***1.4.5 Adaptation***

Adaptation reflects how well the family function along a continuum from maladaptation to successful adaptation (McCubbin & Patterson, 1983). In this review adaptation reflected couple maintenance of RQ. Many couples in the included articles seemed to have successfully adapted hallmarked by a shared couple identity and a loving and respectful attitude toward their partner. This was apparent in themes such as 'being affectionate and appreciative' (Hellstrom et al., 2007) and 'sharing the experience of dementia' (Molyneaux et

al., 2011). Researchers also observed quality in participants' interactions through their actions and comments as Daniels et al. (2007) reflected:

'What cannot be easily captured on paper were the warm interactions the couple engaged in, despite the changes that may have occurred with the onset of Alzheimer's dementia. Another significant component of the interviews was that although Jane's responses did not always fit the questions, Tom let her talk and acknowledged her input' (p. 167).

The review findings suggest couples who maintained a level of RQ seemed to experience a higher level of wellbeing. This might reflect a reinforcing cycle whereby couples who experience a sense of wellness are able to work together and direct this positivity into their relationship, which in turn benefits each individual member.

By contrast maladaptation represented impoverished RQ, included studies suggested this was characterised by couples who no longer shared in their experiences together as husband and wife, who experienced higher levels of individual distress such as loneliness, and dissatisfaction within the relationship, as illustrated by Wawrziczny et al. (2016):

'The dyad is no longer seen as a husband/wife entity..... It is not so much that the partners had committed to each other 'for better or for worse' and that they now seem to be overwhelmed by the 'worse'; it is more that they do not recognize each other and no longer invest themselves in the person that their spouse has become' (p. 1092).

One paper suggested that maladaptation might include more conflict between the couple (Molyneaux et al., 2011). Some of these factors such as increased distress and marital tension also are present in the model as stressors.

The results will be discussed in terms of clinical significance as well as theoretical implications for the application of the Double ABCX Model.

## 1.5 Discussion

The purpose of this systematic review was to critically appraise findings from qualitative research into couples' experience of dementia and devise a model which specifies factors influencing RQ in couples affected by dementia. A second aim was to evaluate the extent to which the Double ABCX Model of family adaptation and adjustment (McCubbin & Patterson, 1983) is useful as an explanatory framework. The results offer support for the application of this model within this subject area and provide helpful directions for clinical services working with couples affected by dementia.

The emergent model identified two main stressor clusters; direct effects of the dementia and additional challenges affecting the couple. The number of stressors identified is important for recognising the demands placed on couples, which they may experience over several years. Whilst couples may encounter these demands to different degrees at different times, overall this is consistent with previous research which indicates living with dementia can be challenging for both partners (La Fontaine & Oyebode, 2013). A strength of the model therefore is its potential to make predictions about how couples, experiencing a plethora of stressors, may differ in their experience of RQ based on the interactions between the dyads resources, coping strategies and appraisals.

One area for focus identified by the review concerns emotion regulation as increased negative valence was reported as a stressor (J. Davies, 2011; Hellstrom et al., 2007; Molyneaux et al., 2011; Wawrziczny et al., 2016). This may be in response to challenges including relational losses and the progressive deterioration of the PLWD. The resources component of the model highlighted specific skills including use of humour, openness between partners, engaging in



distraction and making downward comparisons to re-frame the incident. These skills were reported to have developed through encountering previous challenges, for instance some couples made reference to extra-marital affairs and bereavement (J. Davies, 2011). Couples who have a strong sense of unity in meeting adversity together and well-developed emotion regulation skills might be better able to manage the emotional distress arising from the uncertainty and changes, which could have a positive impact on the relationship. The Double ABCX model makes a distinction between new and acquired resources and this is potentially a resource couples could be supported to develop if required.

Couples were reported to engage in a diverse mix of cognitive and behavioural coping strategies. This review highlights how both partners can be active in enacting these coping strategies, in line with the 'working together' stage identified by Keady and Nolan (2003), where both partners work together to make the best of their situation. For instance when reminiscing remote episodic memory may be better preserved in the early stages of dementia allowing both partners to engage in conversations about shared events from earlier in their lives (Gold & Budson, 2008). Finding meaning in doing things together was another strategy, for instance, jointly engaging in activities such as meal preparation (Atta-Konadu et al., 2011).

Some ways of maintaining RQ identified in this model mirror those reported by couples living with neuropsychological conditions such as stroke, Parkinson's and Huntington's Disease. For instance, couples living with these conditions, who felt they had a continued level of quality in their relationship, attributed this to factors such as the previous quality of their relationship and increased nearness (Downing, Williams, Leserman, & Paulsen, 2012; Hesamzadeh et al., 2015; Summer, 2016). This suggests couples facing a chronic health

stressor may engage in common approaches, and couples who make use of these approaches may experience a higher level of RQ.

Another finding concerns the shared marital identity, which seemed pivotal to maintaining RQ. This can be understood by considering a couple's history; partners in the reviewed studies had usually been married for several decades and navigated several life stages together such as having a family and retirement. Over time, their identity as husband and wife had become a core part of how they thought about themselves, and the qualitative method employed by the appraised articles enabled couples to share how they made efforts to share this identity. There was evidence that their shared life experience had also given them opportunities to develop resources and skills to cope with threats to this identity, which was reflected in the emergent model. McCubbin and Patterson (1983) suggest appraisals are successful in achieving positive outcomes where they reduce the intensity of emotional burdens associated with the crisis, in this instance living with dementia which may disrupt their shared identity.

### ***1.5.1 Critical appraisal of the included studies***

The ten articles meeting the inclusion criteria scored  $\geq 10/16$  on the CASP quality analysis. No minimum score was required for inclusion however the scores suggest the studies were generally well conducted. In particular, a clear statement of findings was consistently reported which facilitated the review analysis. However, a rationale for the sample size, in relation to the methodology and other factors, was often not provided. The sample sizes ranged from single case studies to 26 dyads but the experiences of people with young onset dementia were often neglected with the exception of Wawrziczny et al. (2016) who focused specifically on this topic but whose paper was rated as low quality. As a result, the emergent factors relating to couple RQ may be most reliably applied to couples over 65.

Three methodological approaches were deployed; grounded theory and phenomenological approaches in four studies and narrative approaches in two. Methodological choice was well justified in seven studies but only partially provided for three (J. Davies, 2011; Svanstrom & Dahlberg, 2004; Vikstrom et al., 2008). Reporting of the relationship and positioning between the research, researcher's perspective and participants (reflexivity) was judged as not present or poorly described in four studies (see Table 1.2. of quality appraisal scores) , which is important given the subjective nature of qualitative research (Alvesson & Skoldberg, 2009) and the impact this may have had on the interpretation and reporting of results.

Seven studies (exceptions: Atta-Konadu et al., 2011; Daniels et al., 2007; Hellstrom et al., 2007) conducted their interviews at a single time point which may limit generalisation of the emergent model to couple adaptation over time. However, synthesising the results using the Double ABCX model facilitated the identification of key predictive factors from the literature. For instance, over time couples may re-appraise their couple identity as marital partners and if couples consider themselves more separate this may result in reduced RQ. Future research could use longitudinal methods to explore the presence of these different factors over time.

All the articles used traditional interview formats which arguably require a level of language proficiency for meaningful contribution. Five articles assessed cognitive ability and of these three (Robinson et al., 2005; Vikstrom et al., 2008; Wawrziczny et al., 2016) used the scores to determine whether the participant had the required linguistic skills to participate. In the remaining studies language skills were assessed observationally through the consent process. Some authors reported individuals struggled to articulate their experiences or gave answers which could appear tangential to the question. This may limit the extent to which the derived factors reflect the experiences of the PLWD. Recommendations have been made about how to support the involvement of people with dementia in research and there may be scope to

integrate these in future research (Hubbard, Downs, & Tester, 2003; McKeown, Clarke, Ingleton, & Repper, 2010).

A final consideration is the integration of theory within the studies. A theoretical grounding can facilitate the development of a research question, guide data selection and interpretation of findings (Kelly, 2010; Reeves, Albert, Kuper, & Hodges, 2008). While many studies located their research within the findings of related studies, only five studies in this review made clear reference to relevant theories. A positive example comes from Atta-Konadu et al. (2011) who examined couple relationship changes using food related changes as an exemplar. Their paper referenced guiding theoretical frameworks, and made clear links between theories including role theory and gender role ideology (Fry, 1992) and predictions for the study outcomes. Theoretical ideas referenced by more than one study included a symbolic interactionist framework (Charon, 2004) and the Dual Process model (Stroebe & Schut, 1999). Reporting and critical appraisal may have been informed by theoretical perspectives but not explicitly acknowledged. However, a function of qualitative research is to consider theories in making sense of lived experiences and to synthesise findings into a structure which can inform further research (Reeves et al., 2008).

### ***1.5.2 Critical appraisal of the Double ABCX model***

The Double ABCX model has been more recently applied within intellectual disability and health research and despite early references to the model in a dementia context it has not been systematically tested (Rankin, Haut, & Keefover, 1992). One reason for this may be the recent paradigm shift to incorporate the perspectives of both family carers and the PLWD. In non-dementia contexts the Double ABCX model has been applied to explore relationships between variables, predicting outcomes in families and modelling the causal links between variables (Minnes, Woodford, & Passey, 2007). This review suggests the Double ABCX model has some value in understanding the relational experiences of couples affected by

dementia. However the model has received criticism, for instance that it seems to place equal weighting on each variable (McCubbin & Patterson, 1983) whereas certain variables may have stronger predictive value regarding adaptation. One way to research this would be to operationalise the identified variables using quantitative measures such as psychometric questionnaires, and apply statistical analysis to identify the relative contribution of each factor. This might be useful for identifying specific areas to focus on clinically in supporting couples and for understanding further the associations between variables.

The construction of the Double ABCX model is limited in its capacity to explain processes such as how family functioning may be influenced by the level of convergence between individual members of the family system. Each partner may utilise different resources, appraisals and coping styles at different times, and these may be convergent or in conflict. In this review for example a helpful coping strategy employed by couples was to ‘live in the present’ and direct their attention to mindful living. In a scenario where one dyad member uses this approach, and another ruminates on future problems, it is unclear how this may impact overall relational quality.

### ***1.5.3 Critical appraisal of the review process***

A strength of this review is the inclusion of a quality rating measure which helped to contextualise the articles’ rigour. This process allowed systematic scrutiny of research methodology and identified weaknesses, for instance in reporting of ethical integrity and the reflexive stance of the researcher.

This review excluded mixed samples, for instance studies which reported undifferentiated the views of people with dementia in combination with the perspectives of spouses and adult children (e.g. Phinney, 2006; Phinney, Dahlke, & Purves, 2013). It has been suggested these caring groups have different experiences (Meuser & Marwit, 2001) but including these might

have revealed useful insights. Similarly, some papers were excluded because the samples included participants with mild cognitive impairment and dementia (e.g. Adams, 2006; Beard, Sakhtah, Imse, & Galvin, 2012). Homogeneity of the sample is a marker of quality in qualitative research and given mild cognitive impairment has an estimated annual conversion rate to dementia of between seven and 16.5% based on a systematic review of clinic based samples (Ward, Tardiff, Dye, & Arrighi, 2013) it was not judged appropriate to include these papers because of possible differences in the couples' experiences.

This review used a theoretically driven method to identify factors influencing RQ. The data was extracted into a table structured around the Double ABCX model headings. The broad scope of the model enabled the data to be accommodated and no additional factors were identified. Inter-rater checks indicated convergence in the ratings, however there were discussions about where to integrate some findings. One example is social support, in the original model social support appears as a resource, however, when this was absent for couples, this was also viewed as a stressor in terms of a consequence of their efforts to cope. Through discussion and returning to the papers, it was agreed that social support could function as both a stressor and a resource, and couples may experience social support in either or both of these ways at different times.

A second issue was that some subpoints outlined in the model were not evidenced by reading the papers, which might be taken to suggest these areas are less relevant to understanding differences in RQ. To illustrate, appraisal in the model is defined as the meaning the family gives to a situation, and McCubbin and Patterson (1983) suggest resources are grouped by individual, family and social, and may be acquired or existing. The findings did not enable the authors to differentiate sufficiently between acquired or existing resources in couples, however the headings of individual, family (in this context the couple) and social were supported. In understanding this some of the included articles had quite a specific focus as

with Atta-Konadu et al. (2011) who looked at food related changes and Vikstrom et al. (2008) who looked at activities undertaken separately and together, potentially these contexts may highlight specific aspects of the model more than others.

#### ***1.5.4 Clinical implications***

The review findings reinforce recommendations that memory services take a more holistic approach, with an emphasis on service users relational needs alongside other areas such as pharmacology and assistive technology (Wadham et al., 2016). Services could routinely meet with the couple together and consider their shared perspective on areas of need and strength. Couples may benefit from being supported to discuss factors highlighted by the model as contributing to RQ such as experiences of distress, ways of coping and the presence of support systems. This may be important given the links between RQ and outcomes such as the quality of care provided by the caregiver and wellbeing (Ablitt et al., 2009; Fauth et al., 2012; Quinn et al., 2009).

Moreover, the emergent model highlights areas which could inform a psychoeducational programme on ways for couples to maintain RQ. This fits with guidance from the National Institute of Health and Clinical Excellence (2016) which suggests care partners should be offered tailored interventions and consideration should be given to involving people with dementia in psychoeducational and support meetings for care partners. Psychoeducation content could derive from the findings on resources, coping and appraisal components of the model. Group psychoeducation may benefit couples struggling in their relationship.

Another target identified by the model is external support (social networks and professional services) as this presented in both stressors and resources. Many articles referenced the thinning of couples' social networks, and while some couples were able to maintain their RQ, within this they could feel more isolated. The review highlighted shortcomings in professional services, for instance some couples 'perceived individual clinicians as caring and

supportive but unable to really offer them practical help or advice' (Robinson et al., 2005, p. 342). Consequently this may put additional pressure on couples and result in loneliness which has been linked with impoverished physical and mental health outcomes (Hawkley & Cacioppo, 2010). Couples could be supported by services to access support groups to form new networks and given practical guidance, alongside emotional support. Services may also consider what opportunities exist for service users to feed back about areas for service development, in order to meet the complex needs of this group.

## **1.6 Conclusion**

This review synthesised the findings of ten qualitative papers exploring the experience of couples living with dementia. The results were represented in a refinement of the Double ABCX model, providing support for this model in conceptualising the factors contributing to RQ in couples living with dementia. The emergent model incorporates stressors, resources, appraisals and coping strategies. It highlights the importance of amplifying the resources and coping techniques available to couples and indicates ways professionals could support couples struggling to maintain their RQ. The intention would be that supporting the RQ of couples will have positive ramifications for the wellbeing of both the PLWD and their caring partner. The model acts as a starting point for further analysis of associations between the identified variables and makes predictions about how RQ may be affected.



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## 2 Couples' views on maintaining relationship quality during the early stages of dementia

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Prepared in accordance with the author guidelines for Dementia (Appendix A)

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## 2.1 Abstract

Couples living with dementia face multiple losses in their relationship, and may experience changes in their overall sense of relationship quality with their partner. These topics have predominantly been researched from the caring partner's perspective therefore this study aimed to explore how couples adapt to relational losses to maintain quality in their relationship, from the perspective of both partners. Using a constructivist grounded theory approach ten spousal dyads, where one partner has a diagnosis of dementia, engaged in a joint interview. The results revealed three master themes: consolidating us; contextual positioning; and living well together; as well as an overarching theme of 'turning to and away'. The findings are discussed in relation to theories of loss and family adaptation, and implications for clinical practice and future research are proposed.

**Keywords:** coping; couple; dementia; loss; relationship.

## 2.2 Introduction

Living with dementia can significantly impact the person diagnosed and their family system. The person living with dementia (PLWD) may experience, alongside medical and psychiatric symptoms, destabilisation in their sense of identity (Caddell & Clare, 2011) and multiple losses; for the future, participation in meaningful activity and for their relationships (Steeman, De Casterle, Godderis, & Grypdonck, 2006). PLWD identify meaningful relationships, especially with family, are key for them to feel they are living well (Austin,

O'Neill, & Skevington, 2016), but they may be concerned about stigma and being perceived as a burden by others (Milne, 2010). For many people their spouse chooses to take on a caregiving role (Prince et al., 2014). It has been widely reported spousal care partners can experience psychological difficulties such as caregiver burden, anxiety and depression which has been associated with reduced relationship quality with the cared for person, and a lack of support (Sorenson, Duberstein, Gill, & Pinqart, 2006). However some positive aspects such as feeling useful and proud as well as a deepening in the relationship have also been reported (Cheng, Lam, Kwok, Ng, & Fung, 2013). Together this suggests changes in relationships are a key part of the experience for couples living with dementia, and this may be associated with a range of psychological outcomes (Fauth et al., 2012; Rattinger et al., 2016). The importance of relationships in dementia care fits the argument advanced by Kitwood (1993) that a relational frame is essential in conceptualising good dementia care.

Relationship quality (RQ), has been conceptualised to comprise behaviours (communication and physical intimacy) and emotional factors (felt trust and love) which may change due to dementia (Fincham & Rogge, 2010). Clare et al. (2012) reported care partners rated marital RQ significantly lower than healthy controls, with a trend for partners with dementia to report lower scores. However, it is unclear which aspects of RQ may be contributing to these overall changes. Abdo (2013) focused on physical intimacy and reported couples may face specific difficulties such as hypersexuality, changing preferences and consent, although many couples do maintain some physical intimacy. Ablitt, Jones and Muers (2009) reported practical aspects of couples' relationships (e.g. roles undertaken in running the home) become imbalanced, but their emotional ties persist, and this bond between partners formed a pathway to RQ and emotional wellbeing. This suggests emotional factors may be a key predictor of perceived RQ. However, the included articles in the review by Ablitt et al. (2009)

mostly reflected the care partner perspective only. To understand more fully how RQ may change and factors influencing this, the perspective of people with dementia, and couple co-constructions are necessary.

One area for consideration is changes in couple identity. A review by Wadham, Simpson, Rust and Murray (2016) drew together qualitative studies including the perspectives of both partners. Their metasynthesis reiterated the importance of the relationship in dementia care and highlighted changes in couple identity, including perceived togetherness and attunement. Couples who identify less as marital partners and become less attuned may experience lower levels of RQ. It has been reported couples work to protect their shared identity through engaging in strategies such as holding on to the familiar aspects of their partner which suggests couple identity may be important for the relationship (Gallogly, 2009; LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005).

Another factor influencing RQ may be the losses experienced by the couple during the stages of dementia. B. Noyes et al. (2010) detailed in their Grief-Stress model of caregiving losses to the couple relationship (e.g. companionship, communication and support) and argued that relational losses, along with losses experienced by the care partner, mediate primary caring stressors and caregiver wellbeing. The model predicts adverse outcomes, but the converse is implied in that differential responses to relational and caregiving losses may be associated with care partner wellbeing. Evans and Lee (2014) reviewed the impact of dementia on marriage and again identified losses to the relationship and for the caring partner. These losses were represented as eroding the marital identity and the included quotes suggested lower RQ. However, as highlighted already, most of the studies only included the care partner perspective. Robinson, Clare and Evans (2005) explored marital couples'

psychological reactions to a diagnosis of dementia and identified ‘making sense and adjusting to loss’ as an overarching theme, which mirrors the findings of B. Noyes et al. (2010) and Evans and Lee (2014). Additionally, the scope of this study allowed for losses experienced by the person with dementia to be captured, for instance loss of cognitive skills and roles within the home (Robinson et al., 2005). This suggests losses are experienced throughout the dementia pathway at an individual level and by the dyad, which may be associated with changes in relationship quality.

Where couples are aware of relational losses they may engage in efforts to protect their shared identity and RQ. Merrick, Camic and O’Shaughnessy (2016) found, from interviewing seven couple dyads where one partner had dementia, couples adapt to losses by switching between focusing on the losses, and areas of the relationship and identity which remain intact. Parallels were drawn with Stroebe and Schut’s (1999) Dual Process model, where individuals adapt to loss by oscillating between loss orientated and restorative approaches. Using the lens of loss adaptation might provide a helpful context in which to make sense of how couples respond to different relational losses. Couples who engage in both types of approaches may adapt better to their experiences of loss and report a relatively higher RQ. Additionally, the Double ABCX model by McCubbin and Peterson (1983) provides a framework for couple adaptation to stressors and might have relevance to this context having been applied to other family events such as children with learning disabilities (Paynter et al., 2013). This model suggests adaptation is influenced by stressor characteristics, the resources and coping methods used to ameliorate these stressors, and the appraisals made. Based on this model, enhanced relationship quality may follow from couples’ ability to access and develop resources and coping methods to adjust to the losses, and to appraise losses in a way which reduces their emotional threat. The literature into couples’ experiences during dementia, as



narrated from both perspectives, is still developing. As such the application of different theoretical models could hold particular value in explaining how couples respond to loss and threats to their shared identity in order to maintain their relationship quality.

### ***2.2.1 Researching relationship factors in dementia***

Previous research into relational aspects of dementia has primarily accessed the views of care partners and generalised this to the PLWD. However, greater participation of people with dementia in research can be facilitated by addressing practical and ethical concerns (Hubbard et al., 2003; McKeown et al., 2010). Hubbard et al. (2003) reflected on challenges from their own research experiences including obtaining informed consent and overcoming language impairment and proposed how to approach such issues, for example combining observational methods with interview to facilitate inclusion of participants with language impairment.

Qualitative approaches often use interview methods and stage and type of dementia can influence the nature and content of information obtained. Molyneaux, Butchard, Simpson and Murray (2011) noted in their sample participants with dementia varied in their ability to articulate their experiences in a traditional interview format. There were some broad correlations with stage of dementia, although the authors emphasised the role of other factors such as the relationship between the couple. Cotrell and Schultz (1993) highlighted how people in the early stages of dementia could be supported through making practical adjustments such as meeting the person at home, and allowing them to determine the time of the interview. Hellstrom, Nolan and Lundh (2007) provide a summary of issues raised by interview methodology emphasising the role of a 'safe context' which they argue is key in enabling the interview experience to be optimally inclusive for someone with dementia.

Together this suggests that with thought and sensitivity, the views of people living with dementia can be meaningfully included in research. Advancing understanding and

interventions in dementia care is likely to mean grounding research in the personal accounts of people living with dementia as much as others involved in providing care. Using a qualitative method to obtain rich data on the ways couples perceive and adapt to the impact of dementia on their relationship may enhance understanding of quality of life for couples living with dementia and indicate how those who experience difficulties in their relationship might be supported.

### ***2.2.2 Study aim and focus***

The aim of this study was to examine couples' joint narratives of how dementia impacts their relationship, with a focus on how they adapt to relational losses to maintain their relationship quality.

## **2.3 Method**

A constructivist grounded theory methodology was employed. This allows for qualitative data to be analysed to identify pertinent themes and patterns which are developed into a theory (Charmaz, 2014). The constructivist position assumes the researcher operates from their own perspective which influences the research process. The emergent theory is therefore a construction between the researcher and participants, who themselves hold their own 'theories'. The grounded theory approach is appropriate for this study because of its emphasis on actions and processes, and capacity to develop a theory with explanatory and predictive power.

### 2.3.1 Participants

A sample of ten cohabiting husband-wife dyads was recruited in the South Wales and Bristol area. To participate a diagnosis of dementia must have been given, partners must be living together in the community and both had to provide consent. The capacity of the person living with dementia to give informed consent was assessed observationally by the researcher before and during the interview by attending to their ability to retain and consider information provided about the study and to their receptive and expressive language skills. Six male and four female participants had a diagnosis of dementia, with Alzheimer’s and mixed dementia being the most common diagnoses. Participants with dementia were all within the early stages, as judged by the couples. The sample age ranged from 45-82 years, and couples had received the diagnosis between four months and five years previously. No criteria were set on age, dementia type or time since the diagnosis to achieve heterogeneity between the couples in the sample. Table 2.1 provides further details of the sample characteristics (pseudonyms have been used).

Table 2.1. Participant characteristics.

<b>Couple surname</b>	<b>PLWD gender</b>	<b>PLWD age</b>	<b>Dementia type</b>	<b>Time since diagnosis</b>	<b>Spouse gender</b>	<b>Spouse age</b>	<b>Time married</b>
Dunbar	M	76	Alzheimers	12 months	F	72	51 years
Nunn	M	57	Young onset, Alzheimers	2 years	F	45	12 years
Hood	F	78	Not known	5 years	M	79	55 years
Kelly	F	80	Alzheimers	2 years	M	79	40 years
Lewis	F	54	Young onset, type not known	2 years	M	57	33 years

Thompson	M	65	Lewy body	7 months	F	63	44 years
Wilman	F	75	Alzheimers	6 months	M	76	51 years
Grant	M	72	Mixed	3 years	M	63	13 years
Bremner	M	80	Vascular	2.5 years	F	82	60 years
Noble	M	70	Mixed	4 months	F	69	46 years

### **2.3.2 Recruitment**

Participants responded to adverts and talks given via three charities; local branches of the Alzheimer’s Society; Nexus (a regional charity for people involved in older people’s mental health services), and Join Dementia Research (an online recruitment network for dementia research). Approximately thirty initially interested couples declined or did not respond to email contact, in almost all cases no reason was given however one couple stated they felt they had too many present demands to take part. Ethical approval for the study was granted by Cardiff University, and additionally by each charity through their internal processes (Appendix D).

### **2.3.3 Data collection**

All participants opted to be met at home, citing pragmatic reasons and improved familiarity and comfort. During the meeting the information sheet (Appendix E) was discussed and consent forms (Appendix F) were completed by each participant. Demographic data was collected about each dyad (Appendix G), and interviews were conducted with the partners together to capture their shared narrative. A debrief was completed with participants after the interview (Appendix H).

The interview schedule was semi-structured and comprised seven stem questions drawn from the relational losses conceptualised in B. Noyes et al. (2010) Stress Process model of caregiving. The seven areas cover relational changes since the diagnosis, perceptions of the

relationship's strengths, ways of supporting and connecting with each other, communication and expectations for their future relationship. In line with grounded theory methodology the prompts following each stem question were refined over the course of the interviews (Appendix I) in response to transcript analysis (Charmaz, 2014). Proposed changes were agreed with the research team. Both partners actively participated in the interviews which ranged between 30–75 minutes. The perspectives of both partners were encouraged, although in some interviews the voice of one partner, care partner or PLWD, could be more dominant.

#### **2.3.4 Analysis**

Following each interview the audio recording was transcribed and analysed using line by line coding. This generates initial codes which are grounded in the described experience, for example: 'Before we'd have gone to the evening performance, but now we go to the matinee' was given the initial code 'adapting plans to continue interests', extended coded excerpts are available in Appendix J. Next focused coding was applied, which moves from the first, more descriptive, level to more conceptual categories. The generation of focused codes was influenced by the relevance of the line by line codes to the research topic, their analytic significance and the reflective memos written by the researcher (Charmaz, 2014). Emerging codes and themes shaped the prompts used in subsequent interviews. Data sampling terminated when the interviews were not felt to yield any additional insights indicating data saturation. Potential bias in data collection and analysis was mitigated by 'bracketing' of researcher beliefs and assumptions, researcher triangulation through discussion in the research team, and negative case analysis, where anomalies are identified and analysed (Ahern, 1999; Willig, 2008). Respondent validation took place with two dyads and their feedback was incorporated into the final version of the results.

## 2.4 Results

The analysis yielded one overarching theme and three master themes concerning how couples respond to losses in their relationship to maintain their RQ during the early stages of dementia. The overarching theme ‘turning to and away’ encapsulates the dyad alternation between facing and distancing themselves from their experience of dementia. The master theme ‘consolidating us’ reflects couples’ experiences of their changing roles and identities, the refinement of their couple identity in a new context and the nature of the emotional bond between couples. The second master theme ‘contextual positioning’ captures how couples position dementia within their lives and access different support systems. The final master theme ‘living well together’ captures how couples find meaning and positivity in their relationship, and more broadly their lives through prioritising life areas and engaging differently with the past, present and future. The themes are listed in Table 2.2.

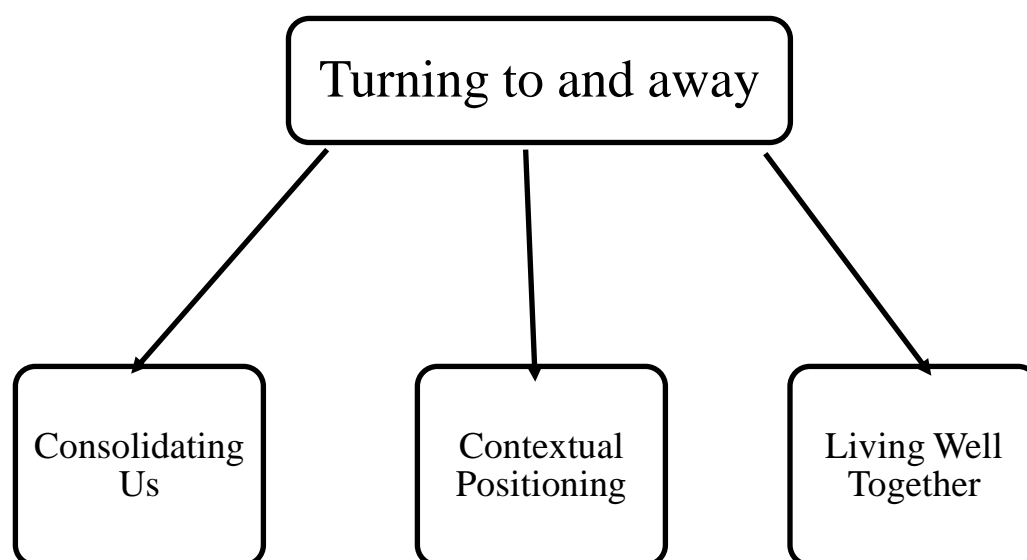
Table 2.2. Summary of themes

<b>Theme Status</b>	<b>Theme Name</b>	<b>Theme Explanation</b>
Overarching Theme	Turning to and away	An oscillating process by which couples engage with, and distance themselves from the experience of dementia
Master Theme 1	Consolidating us	The emergence of an adapted couple identity following multiple changes
Subthemes	Shifting individual identities and roles	The changes at an individual level experienced by each spouse
	Couple identity refinement	Couples’ sense of their new shared identity
	Continuing emotional bond	The experience of the ongoing emotional link between spouses
Master Theme 2	Contextual positioning	How couples relate to wider systems
Subthemes	Dementia within the life stage	How couples locate their experience of dementia within their current stage of life
	Negotiating support systems	How couples access and use personal and professional support networks

Master Theme 3	Living well together	The ways couples find positivity and meaning in their relationship and lives
Subthemes	Prioritising life areas	How couples allocate their finite resources to areas important to them.
	Couple positioning within time	The way couples relate to the past, present and future

The relationship between the themes is displayed in Figure 2.1. The three master themes reflect a cyclical process for couples, with overlaps between each theme. The overarching theme, suspended above, relates to each of the master themes.

Figure 2.1. Representation of couples’ maintenance of relationship quality.



#### 2.4.1 *Turning to and away*

The overarching theme of ‘turning to and away’ reflects a broad process engaged in by couples which relates to the master and sub-themes. ‘Turning to’ refers to times when couples reported to engage with the reality of dementia and the impact this has on their relationship. For instance, one partner explained how they were being taught to manage the household finances in anticipation of when the PLWD could not continue this task (subtheme: shifting individual identities and roles). Within ‘turning to’ some couples also alluded to a degree of acceptance of the changes, as Mrs Nunn stated ‘we have to accept

where we are now and kind of make the most of it, the best of it' (master theme: living well together). 'Turning away' reflects a distancing from the experience and impact of dementia, for instance emphasising the impact of other events such as physical health conditions (subtheme: dementia within the life stage) and other roles (subtheme: shifting individual identities and roles). The process of both turning to and away was apparent in all the accounts given by participating couples, and further examples can be seen in each section.

#### **2.4.2 *Consolidating us***

At an individual level partners described changes to their roles and sense of self, some of which could evoke distress. Participants with dementia described changes such as losing skills, and feeling they were treated differently by others including by their partner. Care partners reported negative changes such as feeling overwhelmed by taking on more caring responsibilities, this could occur as a result of facing the implications of some changes. Couples also reflected developments like becoming more patient and learning new skills. Mr and Mrs Nunn describe some of the difficult changes they each experienced:

Mr Nunn (with dementia): Losing quite a lot of things I could do

Mrs Nunn: So sort of struggling to do practical things yeah? And needing more support, that kind of thing?

Mr Nunn (becoming tearful): Uh huh

Mrs Nunn: I think for me it's almost like the balance of power has shifted, before it was quite evenly balance but now obviously I feel I'm taking the lead more and sometimes that can be frustrating as well

Couples continued to identify themselves strongly as husband and wife and refined their shared identity in light of their individual changes. Couples differed in how much they integrated dementia into their couple identity. Some couples, who seemed to integrate it



more, demonstrated this by openly acknowledging the diagnosis, seeking out support groups and researching the condition. By contrast other couples seemed to direct their attention away from dementia by emphasising other identity roles such as parent or church volunteer. Some couples seemed to externalise dementia and in doing so could attribute behaviours to the dementia, and feel the core character of the partner remained as illustrated by Mrs Dunbar (care partner): ‘Because we’ve been together so long I know how he feels, and I don’t argue back if he says something because he doesn’t mean it, it’s the dementia’. Some couples matched in their approach, either integrating or externalising, whereas those who differed could experience conflict in the relationship as illustrated by the Lewis’ when discussing the impact dementia has had on their relationship:

Mrs Lewis (with dementia): I don’t think about it

Interviewer: You try not to think about it?

Mr Lewis: That’s her coping mechanism which I respect, initially we, I was devastated, well we both, I think we may start arguing a little bit here because we have a different view.

Couples also spoke about their strong emotional bond. This bond reflected a deep attachment cultivated over many years resulting in an ardent commitment as highlighted by the Dunbars:

Mr Dunbar (with dementia): I know it must be difficult for (my wife) to look after me, it must be, I’m not the most patient in the world, far from it, I know my faults and then I say things and after I think “oh you’re a sod, you shouldn’t have said that and so forth”

Mrs Dunbar (taking her husband’s hand): And we are always there for each other whatever happens

Mr Dunbar: Yes you’re always there for me

Mrs Dunbar: And you're always there for me

Mr Dunbar: Yeah but not so good as I used to be is it?

Mrs Dunbar: But you're always there for me

Mr Dunbar: I know love, yes

Mrs Dunbar: There for each other

The above example also illustrates how some couples may hold an awareness of how the symptoms of dementia may pose a threat to the relationship through the potential for increased negative interactions, or upsetting the reciprocity and express their continued commitment in the face of such changes.

### ***2.4.3 Contextual positioning***

This second theme concerns how couples position themselves in relation to aspects of their experience and support systems. Couples tried to make sense of how having dementia fitted with their life course, and at times could be open to exploring this and at others might try to minimise the significance of the dementia. For instance several couples normalised symptoms as part of the ageing process or made comparisons with current physical health conditions with a sense that a changing health status was part of getting older. Couples also made comparisons with others, and themselves at different time points, which could result in reframing their own situation:

Mr Lewis (care partner): It's amazing how it's (giving up work) worked out. But you know in a way it's given us a focus, I'm looking at it as a, forget the diagnosis situation, we both had jobs which were pretty heavy and full on, we've got two children, one at university and one who will be going next year so then you're thinking what does retirement look like... well because of the situation there is a new focus to our retirement which we never ever thought would be there. So it's not all negative, in a way I feel quite positive about it really at this moment.

Couples varied in their engagement with different support networks. Participants' accounts encompassed a broad spectrum from feeling well supported and validated by friends, families and professionals, to feeling dismissed, alone and overlooked. Within this there could be mixed experiences from different groups, or specific individuals within groups. Couples who felt supported described this positively, as seen by the Kellys who benefit from family involvement:

Interviewer: What difference do you think it makes being able to spend time with your family? What impact does that have on your relationship?

Mrs Kelly (with dementia): Well we enjoy it, we both agree on things like that

Mr Kelly: It keeps the relationship strong because we feel involved and we feel loved by them don't we, and that's really nice. It's sort of like a cement which holds everybody together.

Some couples who did not have the same level of support suggested this could bring them closer through feeling they are 'in it together':

Mrs Bremner (care partner): When I rang (my daughter) up and told her (my husband's) diagnosis her first line was, "Come to me. Pack up, come to me. Leave it." And I said, "No, I can't do that. It isn't like that. You can't just walk away from it. You've got to..." But I was given the choice of walking and I refused to take it, so what we've done, we've sort of – we please ourselves basically. And if other people don't like it, they can do the other thing can't they.

Couples, when turning to acknowledge the impact of dementia, described seeking further support to help them manage or considered how this had brought about changes in their network as Mr Lewis (care partner) pondered:

‘We’ve got some friends who have been really good, a small number of people, and others are neutral and some who have distanced themselves. Now we may be perceiving that more than the reality but there are a few, and I think they are probably fearful of it (dementia) really’.

Having a depleted support network could be challenging for couples, and could be upsetting and isolating for the couple, or one partner:

Mrs Thompson (care partner): I see huge, huge changes ahead which is very stressful ...my husband is completely oblivious and that’s where he wants to be so I have no-one to share it with at all apart from my son who doesn’t want to know.’

#### **2.4.4 *Living well together***

This final master theme captures behavioural and cognitive strategies couples use to live well together within new parameters. Each couple described having happy lives together, they enjoyed being in the company of their partner and during the interviews displayed affection and warmth which might indicate a continued quality in the relationship. Living well together included prioritising their time to undertake valued and meaningful action, thereby acknowledging some of the limits they face:

Mrs Wilman (with dementia) We are more determined that we mustn’t put off going to see somebody or a phone, I do loads of phone calls and find that more tiring, it takes more out of me erm but we are determined ... it has made us more aware that you know life is maybe a bit shorter and at (our age), it is going to be, so we have to do things.

Couples differed in what they privileged, for some this meant continuing their individual pursuits, while others undertook more together, depending on what felt most important to them:

Mr Hood (care partner): We've learnt to structure our lives to do the things we want to do so as I said I don't go to watch rugby any longer I used to do that but I don't because it means that I'm spending more and more time out of the house and I've made a conscious decision not to spend more and more time out of the house, and to spend more time with (my wife). That is all you can do.

Living well together also seemed to involve changes in how the couple relate to time.

Couples described endeavouring to make the most of the present for example by sharing moments of pleasure. Care partners additionally described this as important for creating memories with their partner:

Mrs Thompson (care partner) I think we are building memories. I think we've gone through our lives, we've been together for 44 years and yes we've had lots of fantastic things happening but it feels as if now everything is concentrated into this timeslot, however long it may be, to build some special memories and to be as close to each other as we can.

Alongside this couples relinquished their longer-term future, thereby turning away from their expected future, and adjusted this to focus on a more immediate time span of days, weeks or, for some, a few months. When asked about any anticipated changes in the future Mrs Nunn replied:

'I think things inevitably are going to get a bit harder really...so it's quite hard to look into the future and in some ways it's easier not to do that, it's easier not to think about it too much and just focus on what's happening here and now'.

Couples seemed to enjoy identifying something positive to look forward to, but limited this to activities which they felt could be safely achieved. Couples also frequently reminisced about

past achievements and memories which seemed to bolster their connection and provide a source of enjoyment in the present:

Mrs Grant (care partner): When we bought this place after we married, we worked on it together; we wallpapered the walls together, we did the garden together.

Mr Grant: I put a bathroom in.

Mrs Grant (smiling): He put a bathroom in. We did it all together.

However, living well is not a unidimensional experience and couples who made use of these strategies and reported positives in their relationship also conveyed the challenging reality of living with dementia. This extract gives a sense of how couples may struggle with strong negative affect triggered by their experiences:

Mrs Dunbar (care partner): (my husband is) absolutely devastated and more and more depressed and every morning he says he doesn't want to go on because of this (having dementia)... every morning he says that which is very upsetting for me and I still go to my (activities) but lots of mornings I don't want to go and I'm crying all the way.

## **2.5 Discussion**

This study explored couples' experiences of relational losses and RQ from the perspective of both partners. The results provide insights into the process by which couples adapt to relational losses during the early stages of dementia to maintain quality in their relationship. This process may evolve as the PLWD moves into the moderate-severe stages. By engaging in a dialogue framed around adjusting to relational losses, it became apparent couples are

highly motivated to retain a core identity as husband and wife, and seemed to engage in a range of strategies which might help maintain their RQ.

RQ seemed linked to preservation of couples' shared identity, which fits with similar research in this area. For instance, Wadham et al. (2016) conducted a metaethnographic review of papers including both spousal partners and identified a central theme of 'togetherness: continuing as "we" are' which encapsulates the strong commitment between dyads. The present study results make more apparent how maintenance of marital identity involves accommodating individual identity transitions and refining aspects of their shared identity.

While couples experience numerous shifts and experience increased distress, they are able to draw back together and find an adjusted balance. This can be likened to an elastic band which is stretched under tension but remains intact and springs back. The deep emotional bond, formed over the relationship duration, seems to contribute to the shared couple identity and persists in the face of losses to other aspects of the relationship.

Couples reported an extensive range of strategies deployed to sustain their relationship.

Cognitive approaches such as reminiscing and making favourable comparisons were reported by most couples, and might have had the benefit of making couples feel appreciative about aspects of their situation. This has parallels with research into gratitude which suggests helping others and habitually focusing on positives is associated with enhanced wellbeing, strengthened relationships and improved relationship satisfaction (Wood, Froh, & Geraghty, 2010). The combination of cognitive and behavioural approaches supports the findings of Hellstrom et al. (2007) and Merrick et al. (2016) who found both partners use similar strategies, although this study highlights their role in managing the effects of relational loss. Use of such strategies seems to help couples manage the emotional challenges they face, reinforcing their emotional connection and shared identity.

The overarching theme of ‘turning to and away’ reflects the process couples engage in, and this offers support to the Dual Process model (Stroebe & Schut, 1999) which suggests successful adaptation to loss includes engaging with the loss and taking respite through avoidance and developing other areas. This research extends this process from the bereavement literature to within the dementia field, specifically to couple adaptation to relational losses. The Dual Process model (Stroebe & Schut, 1999) concerns individual coping, whereas this research suggests couples responding to loss engage in a similar process, with relationship quality as an outcome, rather than individual wellbeing. Couples in the sample described how they orientate to their losses; through discussing changes and talking about plans they now cannot fulfil. When turning away from their losses, couples minimise the impact of dementia and adjust their lifestyle to maintain quality of life and a sense of normality in the relationship. All couples seemed to describe both approaches, however, it is less clear how much this may still be an individual process, compared to a couple effort.

The findings can also be applied to the Double ABCX model by McCubbin and Patterson (1983), which provides a framework for couple adaptation to stressors. The model suggests adaptation is partly influenced by access to existing resources, and development of new ones. It seemed clear couples used their relationship as a resource, drawing on their mutual trust, love and companionship. Couples also developed new resources including refining personal qualities such as patience and resilience. Social support is identified in the Double ABCX model as a key factor (McCubbin & Patterson, 1983). In this research, several couples accessed existing support networks such as friends, family and faith groups, and developed further social support through professional services and community based dementia networks. However, several couples were reluctant to use their social support and common barriers included fear of burdening others, having experienced invalidating responses or having limited professional services. The Double ABCX model suggests these couples may



struggle in their adaptation and display lower relationship quality. This may hold for some couples but interestingly some couples who reported limited social support felt this resulted in an increased closeness in their relationship. Given couples were in the early stages of dementia, the impact of social support may change over time as the limitations caused by dementia have a greater impact and it may become more difficult to turn away from these.

### ***2.5.1 Study limitations and future research***

For this study no inclusion limit was set on cognitive ability. The consent process acted as a safeguard for ensuring those without capacity and sufficient language capabilities were excluded, however during the interviews some PLWD could struggle to articulate concepts at times. At the points care partners could interject and explain what they felt their partner was trying to communicate, therefore some views of the PLWD may not have been fully articulated. However, efforts were made to support the communication of the person with dementia through using accessible language and pacing the interview (Hubbard et al., 2003).

Within the sample there was a considerable range in participant age (45-82 years) and time since diagnosis (four months to five years). Transcript analysis revealed ways these factors may affect couples' perceptions of how dementia had affected their relationship. For instance, the two couples affected by young onset dementia highlighted some specific concerns such as taking early retirement and child care responsibilities which brought extra stressors on the relationship. However, referencing the themes against transcripts indicated theme relevance across the sample which suggests the findings can be generalised to couples of different ages, who have been in the early stages of dementia for different durations. Future research could seek to explore the model themes with different populations, such as later life remarriages or couples who report impoverished relationship quality.

A key focus of this research was RQ, however this was not objectively measured. This was partly due to challenges identifying a suitable measure of relationship quality which is reliable and validated for administration to both the PLWD and their partner (Fisher, 2010). Participants were informed the research focus was on their relationship, and therefore couples who experienced higher RQ may have been more interested and willing to participate. Certainly, analysis of the interviews and behavioural observations suggested the presence of features implicated in RQ such as physical intimacy, a shared value system, and respectful attitudes towards the partner. However, applying a quantitative measure might have been useful to contextualise the sample, identify couple convergence/discrepancies and corroborate observations of perceived quality. For instance, subjective measures of RQ have reported care partners score RQ lower than their partners with dementia, and this difference is significant when rating communication (Clare et al., 2012). It would be interesting if future research exploring RQ utilised couples' descriptions and psychometric measures.

## **2.6 Conclusion and clinical implications**

The relational losses experienced by couples pose an ongoing threat to their bond, causing emotional distress. In the face of these changes and uncertainty, couples strive to retain their couple identity and to continue sharing in the love, humour, respect and warmth which defines their relationship. Memory services have a responsibility to consider the emotional needs of couples, and can do so by assessing and monitoring relationship quality and emotional wellbeing in couples, and intervening as appropriate. The symbiotic nature of some couple relationships suggested a systemic approach in services may be required.

The national drive to identify and diagnose dementia earlier has resulted in increasing numbers of couples living with a diagnosis (Department of Health, 2015). This sample highlights the resiliencies and coping skills demonstrated by couples, however understandably couples may encounter discord during this time. The experiences of couples might be usefully shared with other couples through a peer support programme, whereby interested couples, or those identified as being at need, could be offered the opportunity to speak with couples willing to share their own experiences.

Finally, in addition to research, use of theories such as the Double ABCX Model (McCubbin & Patterson, 1983) and the Dual Process model (Stroebe & Schut, 1999) might have a value in clinical practice by grounding formulations, and assisting the development of interventions.

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### 3 Critical Evaluation

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Word count: 9994 excluding references

### **3.1 Introduction**

This commentary sets out the context for both the systematic review and empirical paper, then evaluates both papers. This analysis will include reflections on key stages including research decisions taken, and consideration of additional research implications. The clinical and service implications from the two papers along with dissemination are discussed jointly. The final section is a discussion of how broader competencies, in line with the skill set of a clinical psychologist, were developed as a result of the research conducted.

### **3.2 Research context**

This research is timely because of the current national drive, as set out in the Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015) to diagnose two thirds of the estimated number of people living with dementia. Combined with an ageing population, this will result in significant increases in the number of people living with and affected by the condition. Whilst this presents an opportunity to support people affected, it also raises questions about the needs of this group and how services can best enable people to live well.

A key area contributing to this, and the focus of this research, concerns close relationships. Meaningful, quality relationships have long been associated with positive psychological outcomes. The value positive relationships can bring in living well with dementia has been recognised (Kitwood, 1993) but may not be reflected in the pathways offered by memory services (British Psychological Society, 2014b). Moreover, many questions persist around

how to maintain people's relationships during this time of uncertainty and change, which will have implications for clinical practice.

Family carers provide emotional and practical support to their family member which increases over time due to the degenerative nature of the condition. Most commonly this care is taken on by the spouse (Sorenson et al., 2006), so the relationship between spouses seems highly relevant to explore. Both partners can experience losses in the relationship and changes in their social support networks, which can lead to higher levels of emotional distress and the development of mental health difficulties such as anxiety and depression (Sorenson et al., 2006; Steeman et al., 2006). Growing numbers of couples living with dementia may be associated with increases in presentations to mental health services. As a result, it is important to learn more about how couples respond to the protracted challenges of living with dementia.

At present the viewpoint of the spousal care partner and the person living with dementia (PLWD) is not well represented within the literature. A recent systematic review by Wadham, Simpson, Rust and Murray (2016) identified ten qualitative articles comprising both partners. This research highlighted the importance to couples of their relationship, and how they work to maintain their shared identity and cope with the fear, uncertainty and hopelessness triggered by the condition. Further research is needed to explore the processes underpinning couples' adaptation to changes in their relationship, including their relationship quality.



### **3.3 Systematic Review - Spousal relationship quality in dementia: A metanalysis of qualitative research using the Double ABCX model**

#### **3.3.1 Search terms and databases**

The systematic review searched four databases: Embase, PsychInfo, Medline and Cinahl.

These databases were selected as they contain journals which focus on psychological theories and interventions, and were likely to contain research relevant to this topic.

The search terms were selected to identify those living with dementia (dementia OR alzheimer), and their spousal carers (family care\* OR marital OR spous\* OR dyad\* OR partner). A challenge was trying to identify studies which included both the partner and the PLWD through the search terms. Different searches were attempted however a reliable combination of terms to identify studies including both partners could not be reached.

It was discussed in the research team whether inclusion of terms to filter by methodology would be useful. However, test searches using additional parameters resulted in studies being missed as the use of a qualitative methodology was not always apparent in the title or abstract.

#### **3.3.2 Inclusion and exclusion criteria**

Articles were included if they: (1) were available in English; (2) utilised a qualitative methodology; (3) comprised a community dwelling sample; (4) included the views of both the partner and the person living with dementia; and (5) considered the dyad relationship.

Articles were excluded if it was not a published research article i.e. including books, conference abstracts, discussion papers, dissertations, or included a mixed sample of care partners or conditions, that were not separated in the results.

Couples were required to be living together in the community, which could be in their own home or supported accommodation, to construct a sample with shared day to day challenges and opportunities which may affect their relationship.

### **3.3.3 *Quality assessment***

#### *3.3.3.1 Assessment tool*

Use of a checklist approach for appraising research has been recommended as part of a systematic review protocol as it allows for components of the research to be transparently evaluated with a view to gauge bias and integrity (Hannes, 2011). Several measures for qualitative research exist including the CASP (Critical Appraisal Skills Programme, 2017) the Quality Framework (Spencer, Ritchie, Lewis, & Dillon, 2003) and Long and Godfrey's (2004) self-named measure, but there is currently no gold standard (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004).

The CASP quality assessment tool was selected because it has been developed specifically for use in systematic reviews of qualitative research (Critical Appraisal Skills Programme, 2017). A pragmatic advantage of the CASP is its brevity, particularly with the use of the screening questions, compared to other tools like the Quality Framework (Spencer et al., 2003).

The CASP is also a user-friendly measure with additional guidance to facilitate administration. For instance, one question examines whether ethical issues were appropriately considered and gives three prompts to support the ratings. This additional guidance was helpful when discussing differences in team members' ratings. A final consideration was the recent use of the CASP in other qualitative systematic reviews such as Evans and Lee (2014) and Wadham, Simpson, Rust and Murray (2016).

However, the CASP does have some limitations. The use of appraisal tools generally has received criticism due to variability in content between different tools (Katrak et al., 2004). In the CASP for instance the use of theory in developing the research design and interpretation is not assessed, yet this is an important consideration (Hannes, 2011). In addition, ratings of different factors are open to debate, and there is a risk ratings are too stringently applied resulting in oversimplified judgements about the quality of a paper (Murphy, Dingwall, Greatbach, Parker, & Watson, 1998). It was important therefore in the application of the CASP to be mindful of these issues, and a decision was made to use the CASP to consider the relative strengths and weakness of each paper, with an awareness that additional limitations may exist outside of this identified in the CASP, and that papers rated as lower quality by the CASP may still have value.

### *3.3.3.2 Credibility of research findings*

The extracted articles scored between 10-15 from a CASP total of 16. Four papers scored 15/16 suggesting a higher level of quality (Daniels et al., 2007; Hellstrom et al., 2007; Merrick et al., 2016; Molyneaux et al., 2011). The application of the CASP was helpful in appraising the articles individually and identifying themes across papers. Two common issues which became apparent were insufficient discussion of ethical issues and reflexivity.

For ethical issues, no papers were assigned the highest score of three, reflecting a fully present description. Two papers (Robinson et al., 2005; Vikstrom et al., 2008) were given a zero indicating not present or poorly described, and two articles (Atta-Konadu et al., 2011; Svanstrom & Dahlberg, 2004) scored one indicating partially met. Important ethical issues relevant to this study include obtaining informed consent, and attending to the needs of participants during joint interviews. This does not mean the researchers did not consider these issues, rather insufficient information was provided to allow the reader to determine if such ethical issues were considered. This feels important given the potential vulnerability of this

population, plus discussion of these issues might be beneficial for researchers and clinicians working in the area.

A second area yielding lower scores was reflexivity. Four papers (Atta-Konadu et al., 2011; J. Davies, 2011; Svanstrom & Dahlberg, 2004; Wawrziczny et al., 2016) were assigned a score of zero. When interpreting the results of these studies it therefore had to be considered a higher level of bias may be present in the analysis arising from the influence of the researcher(s) values, assumptions and beliefs.

It is unclear why these two areas may be less well reported in published articles, but it was useful to be aware of this when writing the empirical paper to ensure adequate coverage of these issues was given.

#### *3.3.3.3 Timing of quality ratings*

Quality ratings can be applied before, during or after data extraction, with no clear consensus on the most suitable timepoint (J. Noyes & Lewis, 2011). If applied before or during this can familiarise the researcher with the articles. On the other hand, if completed after this enables the researcher to extract the data unbiased and subsequently focus on the task of appraising quality. From discussion in the research team it was agreed to conduct the quality ratings after the data extraction, as papers were not going to be excluded based on their ratings, and the quality of papers could be taken into account in the synthesis stage.

#### *3.3.4 Data extraction*

The approach selected for data extraction was to use a theoretical framework, the Double ABCX model (McCubbin & Patterson, 1983), as a guide. An advantage of this approach is it helps focus data extraction on findings relevant to the review question (J. Noyes & Lewis, 2011). In addition, when developing the review focus it became apparent that application of existing theories in the development and interpretation of studies in this area was limited.

Some studies referenced theories such as the Dual Process model (Stroebe & Schut, 1999) and Role Theory (Biddle, 1979), but this was evident in a minority of the included articles. Underpinning research with theory is crucial in supporting the identification of research questions, analysing the data, and contributing to knowledge about the topic (Kelly, 2010) As a result, it seemed helpful to test the utility of a model in this area to further what is known, and to use this model as a lens through which to make sense of the data on this topic. An alternative approach would be to inclusively extract data in line with the research question, as in the case of meta-ethnography where all relevant data including the interpretations of authors are included. However, the Double ABCX model, with its focus on familial adaptation, seemed relevant to the topic and was felt to confer a benefit in offering a provisional structure within which to explore the results, with a view to refine the model based on the needs of this population. Furthermore, given the lack of theoretical references in the literature, using this approach would enable a model to be tested for suitability for subsequent use.

One potential risk of using a theoretical framework for data extraction is the model may be applied rigidly thereby constraining data extraction, for instance if information which is relevant but does not easily sit within the model is omitted (J. Noyes & Lewis, 2011). Use of predetermined categories might also inhibit a curious approach to the data through a confirmation bias; a cognitive error when someone interprets information in a way which confirms their pre-existing hypotheses. However, steps were taken to minimise these risks, for instance two research team members extracted data from the same paper and compared their results. Furthermore, aware of the risk incongruous information may be overlooked, a section for this was specifically tabled and populated where appropriate.

Overall use of this approach was beneficial as the model identified key factors involved in the process of relationship quality maintenance. Knowledge about the links between factors such

as social support, emotion regulation skills and appraisals acts as a springboard for further research, as predictions can be made about how couples' relationships may be affected as these factors change.

### ***3.3.5 Review of the Double ABCX Model***

In selecting a suitable model to inform the systematic review two main models were considered, the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983), and the Lazarus and Folkman Transactional Model of Stress (1984), which were identified from discussions with supervisors. The Transactional model of stress (1984) emphasises how an individual's level of coping to a stressful event depends on how they appraise the nature of the stressor, and their ability to cope. This model was considered because it seeks to understand differences in coping and the process by which different outcomes may be reached. This fits with the systematic review which sought to identify factors influencing differences in relationship quality, and higher relationship quality might be framed as adaptive coping.

However, the Double ABCX Model was felt to confer several advantages, firstly the model aims to understand family functioning in challenging situations, this was relevant to the research question which sought to identify what factors influence differences in relationships quality for couples living with dementia. Also while both models take a broad perspective on contributing factors including internal and contextual influences, the transactional model (Lazarus & Folkman, 1984) places greater weight on the appraisal process in influencing coping. In this population where one partner is experiencing cognitive impairment, a primary focus on appraisals might be less helpful. By contrast, the Double ABCX model seems to give an equal role to resources, coping and appraisals.

Although relatively dated, the Double ABCX model continues to be used in areas of clinical health including families with a child with autism, learning disability, or physical health condition (Joseph, Goodfellow & Simko, 2014; Paynter et al., 2013; Shahrier, Islam & Debroy, 2016), as well as understanding family functioning following familial events such as remarriage (Greeff & Du Toit, 2009). This suggests that the model has relevance in a modern setting. However, the Double ABCX model has not been as readily applied to neurodegenerative conditions, and it may be less equipped to make sense of an illness where the stressors might increase over time, and where the ability of a family member to make complex appraisals and acquire further resources is likely to become more impaired. This projects goes some way to consider whether this model can be used as a framework for understanding the experience of both partners.

In addition to those discussed in the systematic review (section 1.5) and empirical paper (section 2.5) the model has received some further criticisms which are important to consider. For example, the starting point of the model process is the identification and experience of stressors. In the model these are conceived as events which place demands on the family thereby implying they are inherently negative. While stressors often represent challenges for the couple, they may be exposed to such demands (e.g. lack of professional support, symptoms of dementia) but not experience this as a stressor. It is useful to think about differences in what constitutes a stressor for couples, however the principle of stressors as a negative experience fits with research in this field which posits couples do perceive a number of difficulties throughout the journey of living with dementia.

Another criticism directed at the model is that some concepts are less clearly defined such as 'coping' as a bridging concept (Smith, 1984). The model raises questions such as by what process do families/couples combine their resources and appraisals to cope, how might individual family members enact this differently and what impact may this have on the

overall family level of adjustment that, based on the current definition, it may struggle to adequately answer. Related to this the model is not well annotated developmentally to explain how shifts may occur over time. It was noted that research using this model has frequently employed a cross sectional quantitative paradigm (Greeff & Du Toit, 2009; Hesamzadeh et al., 2015; Paynter et al, 2013; Shahrier et al., 2016) which provide ‘snapshots’ of how participants might be adapting at a specific point in the trajectory of the illness. The model may be less strong in its predictive power to how the accumulation of co-morbidities across time, or the proliferation of stressful events might change the adaptation process. Given dementia is neurodegenerative, it may be this model has more application during the early stages of dementia, which may last for several years, when the level of impairment is least.

### ***3.3.6 Theoretical implications***

The systematic review paper considers the applications of the Double ABCX model in a dementia context and suggests it is a useful model for making sense of couple adaptation and functioning however, the model does have some limitations which are discussed in the systematic review. An additional theoretical consideration is McCubbin and Patterson (1983) conceptualise adaptation as a dynamic process which fluctuates over time. Thus, the model allows for a longitudinal understanding of family functioning and makes predictions about how families may adapt more successfully or struggle as a result of changes in their resources, appraisals and coping (Rankin et al., 1992). However, in the systematic review seven studies interviewed participants once, offering a cross-sectional viewpoint of adaptation. As a result, links between the model components have been tentatively suggested based on the original model and the included study findings.



### ***3.3.7 Avenues for further research***

A key area for future research concerns the use of longitudinal methodologies. As previously discussed most of the included articles in the systematic review met with participants once. Engaging both dyad members over a longer time interval would be challenging because of the degenerative nature of dementia, for instance Hellstrom et al. (2007) met with 20 dyads and completed between one and four interviews in a two year period. Couples were approached four years after the first interview and only eight dyads completed a further interview. Attrition in the remaining couples was due to loss of a partner or participant withdrawal, which may have been due to a deterioration in the person with dementia's functioning. However, the rate of progression can vary significantly and there is scope to obtain significant data sets through utilising different methodologies at regular intervals.

Qualitative research offers an advantage in its scope for obtaining rich data sets and valuable insights into shared and individual aspects of participants' experience. However, a challenge is how to meaningfully facilitate the inclusion of respondents whose language skills may be compromised. Perhaps for this reason, most of the review articles included people in the mild-moderate stages of dementia. Additional techniques have been suggested to support data collection, for instance Hubbard, Downs and Tester (2003) suggest the use of observations to provide further information about the participant's experience. A study by Svanstrom and Dahlberg (2004), included in this review, asked spousal participants to keep a diary for one week which formed the basis of their interview with both dyad members. They felt this facilitated the discussion as it was grounded in personal, concrete examples. Future research could explore other techniques to support data collection in qualitative approaches.

### **3.4 Empirical Study- Couples' views of maintaining relationship quality during the early stages of dementia**

#### ***3.4.1 Selection of methodology***

A grounded theory approach was selected because it places emphasis on actions and social processes, which was deemed relevant to the research question looking at how couples maintain their relationship quality (Charmaz, 2014). In addition, the generation of a theory is useful in an area where there is a paucity of relevant theory, as is the case for couples' construction of relationship quality within a dementia context.

Specifically, a constructivist approach was selected because of its epistemological position which suggests the emergent theory is co-constructed between the participants and the researcher. This aligns with the authors own beliefs about the social nature of interactions between individuals and how understandings of experiences are conceptualised. It has been suggested that within qualitative research it is important that the selected method reflects the orientations of the researcher (Willig, 2008).

Alternative qualitative methodologies such as interpretative phenomenological analysis (IPA) were considered. IPA seeks to explore in detail the meanings individuals ascribe to particular experiences and can be useful for addressing exploratory questions about the individual experience (Smith, 1996). After consideration, a constructivist grounded theory approach seemed more appropriate because of the emphasis placed on exploring processes and generating understandings that can be more broadly applied. This method fits the research question, which aimed to analyse how relationship quality is maintained by couples affected by dementia.

### **3.4.2 Ethical considerations**

In engaging with vulnerable adults several ethical considerations were present in the planning and conductance of the study. Two key issues identified were managing the potential for emotional distress and obtaining informed consent.

The potential for emotional distress was tied to a dilemma about the acceptability of asking PLWD and their care partner questions about changes in their relationship, when it is understood from the literature that couples can experience distress arising from the losses and changes following a dementia diagnosis (Baikie, 2002; Halpin, Dillard, Clevenger, Puentes, & Chicas, 2015; Robinson et al., 2005). However, an alternative was considered in which, with thoughtful management, couples may find it helpful to reflect on their experiences and value having their opinions sought and listened to (Cotrell & Schulz, 1993). The British Psychological Society's Code of Human Research Ethics (2014) states the principle of 'maximising benefits and minimising harm' and within this suggest psychology researchers are sensitive to the potential impact of participation and take steps obviate and manage any risks. Firstly, in developing and framing the interview questions, much thought was given to balance addressing the areas of research interest with supporting participants to have a positive experience of research. Where appropriate this included asking questions in a neutral or positive frame. For instance, regarding communication, the question was phrased 'Dementia can affect how you talk to each other e.g. finding and understanding words. How has it affected you?'. Secondly, the principle investigator utilised their clinical training to notice and respond sensitively to individuals' needs and manage any distress accordingly. Finally, a contingency for additional support was implemented which meant if either or both participants displayed a level of distress beyond which the interview should continue, it would be terminated and further support provided in the moment. After, as soon as

practicable, the clinical supervisors would be informed who could provide additional support options such as liaising with the GP.

The second ethical consideration was obtaining informed consent. This was managed by providing information about the study (Appendix E) and opportunities to ask questions in the initial email contact, and again in the face-to-face meeting. The consent form was adapted to each recipient and the PLWD was given the option for their information to be read aloud. Attention was paid to potential power differentials that may affect informed consent. For instance, participants were given the choice to meet at home or at Cardiff University, with all selecting to be seen at home. Potentially being seen in this setting may make it easier for participants to decline, as it is a more familiar environment. Partners were aware participation in the study required the involvement of both partners, which might have created a sense of obligation in one partner to agree. However, it was made explicit that while this was a requirement, if either partner preferred not to take part this would be accepted without any adverse consequences. This is in line with the first principle, respect for the autonomy and dignity of persons, of the British Psychological Society's Code of Human Research Ethics (2014). Finally, during the interview participants were monitored to assess continued willingness to participate through clarification following high levels of distress and noticing non-verbal feedback.

### ***3.4.3 Recruitment***

#### ***3.4.3.1 Sampling***

The sample inclusion criteria were; a diagnosis of dementia must have been given and known by the person affected; the dementia is judged as being in the early stages; the partner must be a marital or mutual partner; both partners must agree to take part; and they must be living together. No limits were set on participant age, type of dementia, or time since diagnosis. Decisions about criteria were influenced by achieving a balance between sample heterogeneity

and homogeneity. A formal diagnosis of dementia and awareness of this was important for receiving informed consent, and also for ensuring the sample did not include people with mild cognitive impairment, as this is a related but distinct diagnosis (Garand et al., 2007). The requirement for couples to live together pertained to the study focus of relationship quality and the experience of this may differ if couples live separately i.e. one resides in a care home. Marital or mutual partners were specified as they are the most common provider of informal support to people in the early stages of dementia (Prince et al., 2014). Also the nature of the relationship between romantic partners and other groups such as adult children is qualitatively different (Pinquart & Sorensen, 2011) and analysis of both groups was beyond the scope of this research due to the time constraints.

As part of the inclusion criteria use of a brief cognitive assessment tool, for instance the Addenbrookes Cognitive Examination-III (Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013), was considered to operationalise 'early stages' and contextualise the sample. Cognitive screens can be administered in under fifteen minutes and include language components which might have been useful for screening. However, in discussion with supervisors working with this population, there was a concern administering a cognitive assessment might set the wrong tone for the interview because completing these measures can highlight areas of difficulty and be fatiguing, plus the content is not relevant to the relational focus of the study. Moreover, couples may be interested to discuss the results and implications of these, which could place the researcher in a difficult position. Finally, this does not appear to be routine practice within qualitative dementia studies (Atta-Konadu et al., 2011; Hellstrom et al., 2007; Merrick et al., 2016; Molyneaux et al., 2011) and there is some dispute over how predictive cognitive screen scores are of an individuals' ability to meaningfully participate in an interview study (Pratt & Wilkinson, 2001).

### *3.4.3.2 Recruitment challenges*

Recruiting sufficient dyads was a challenging process and the author found it useful to reflect on which approaches seemed most effective. Given the large numbers of people living with early stage dementia, many of whom are supported by their partner, it was anticipated to be viable to recruit through two local charities; the Alzheimer's Society and Nexus. Both charities were interested in the objectives of the research and readily consented to facilitate recruitment. In practice, there were challenges working with the Alzheimer's Society who, due to staff shortages, felt unable to facilitate the author engaging in face-to-face promotion and as a result, the study was solely promoted through their usual communication routes such as a newsletter. With Nexus two internal events were attended to introduce the research and appeal for participants. After approximately eight weeks through these two strands no participants had been procured. In addition to discussing with these charities ways to improve recruitment the author decided to engage the Join Dementia Research (JDR) network, a recruitment website for dementia studies, which proved crucial in achieving the sample. Interestingly, despite targeting an audience who had registered their interest in dementia research, the response rate was relatively low from JDR; only seven of the 30 eligible dyads responded. However, this formed 70% of the final sample, compared to two dyads recruited through speaking at Nexus events and one couple who responded to the research advert in the Alzheimer's Society newsletter. Taken together this suggests it is most effective to target people who have expressed an interest in participating in research, followed by meeting directly with potential participants and engaging in a dialogue where one can answer questions and tailor the information provided. This fits with the recruitment experiences of McHenry et al. (2015) who found it was important to build trusting relationships with participants through face-to-face contacts, alleviate feelings of anxiety about the research experience and express gratitude for participation to affirm the importance of their

contribution. These considerations might be useful for future research projects looking to recruit this sample.

#### *3.4.3.3 Termination of recruitment*

There is no specified sample size for grounded theory studies, or ways of calculating statistically the number of participants required. As a result, sample sizes can vary considerably, in the systematic review for example the number of participant dyads in grounded theory studies ranged from  $n=5$  to  $n=26$  (Molyneaux et al., 2011; Vikstrom et al., 2008). A review paper for National Centre for Research Methods (2012) consulted experts in the field of qualitative research who generated issues for consideration when deciding sample size.

One factor was the concept of data saturation. Data saturation is said to have occurred when no new categories are identified during coding, and no further variants of the existing categories emerge (Henwood & Pidgeon, 2006). Factors such as the duration and content of interviews, and range of questions explored will have a bearing on data saturation. For this study some of the more dominant codes were apparent after the first few interviews, and continued to be identified in further transcripts. However, additional codes continued to emerge through subsequent interviews. When the lead author felt data saturation was reached this was discussed with the research team.

Several experts in the field highlighted a perception among some that a higher number of participants will confer a greater sense of credibility (Baker & Edwards, 2012), this belief is something the lead author could identify with. Baker and Edwards (2012), however, emphasise the importance of quality in the content of each interview and analysis. The author can attest to this based on their experience of conducting and analysing each transcript, which highlighted the richness of this methodology and the volume of themes generate by a single

interview. Efforts were therefore directed at ensuring each interview was conducted to maximise the quality of data, for example through preparing the materials and using the interview schedule to focus the questioning to relevant topics whilst remaining open to new avenues to pursue. In between interviews sufficient time was given to code the data, reflect using memos and discuss with the research team different ideas and observations.

#### ***3.4.4 Development of the interview schedule***

The seven stem questions for the interview were influenced by the areas of relational loss identified by B. Noyes et al. (2010). In line with the grounded theory approach the prompts used were refined over the course of the interviews in response to the analysis (Charmaz, 2014). Appendix I includes the initial and final version of the interview schedule.

Feedback on the phrasing of each question was provided by a supervisor working with this population. Alongside this, Wilkinson (2002) described ways to support people living with dementia to engage in interviews. Advice included keeping questions succinct and direct, and using concrete exemplars. This resulted in a refinement of the questions, for instance when collecting demographic information at the start instead of asking the person's age, they were asked for their date of birth, which is fixed and likely to be better recalled.

#### ***3.4.5 Data collection***

Conducting the interviews was a hugely rewarding part of the research process for the main author, as couples entrusted the author to hear their experiences which they shared with a frankness and honesty. Meeting with couples together provided a rich opportunity to observe them whilst sharing in their construction of their experiences. However, the interview could elicit difficult emotions for couples, and some of their experiences were hard for the researcher to hear. One interview stands out for being particularly challenging due to disclosures from the care partner about the emotional toll of supporting their partner, which



had contributed to the care partner feeling very low. This triggered the activation of a study protocol for managing high levels of distress which included liaising with the participant's GP and offering a follow up session with a senior team member. The author found it was useful to draw on skills from the clinical training to manage these emotional challenges. In supporting participants, techniques such as taking breaks, providing validation, employing active listening and pacing the sessions were effective. For the main author, skills in self-awareness enabled them to notice changes in feelings and make a note of these but, through using the interview crib sheet, stay focused in facilitating the interview.

Meeting with couples together was selected to access a dynamic, observable experience of how the couple interacts and jointly narrates their experience. Certainly, during the interviews there were many physical demonstrations of affection which would otherwise have been missed. Another benefit was comments of one partner could spark an observation or further elaboration from their partner as seen in this extract from Mr and Mrs Noble who were discussing the support they had received from different services:

Mrs Noble: It's almost comforting to know there is some back up there. If I want it's there.

Mr Noble (with dementia): Yes, and for that matter there are dementia support groups available if you, if you want to get involved with them.

Researchers who have chosen to meet individually with couples have argued this allows individual members to express views which they might otherwise censor out of consideration for their partner (Atta-Konadu et al., 2011; Svanstrom & Dahlberg, 2004). Separate interviews may indeed provide a different perspective that the researcher may not otherwise have access to. Interestingly one couple who participated had completed another study in which they were seen separately, and they reported this had caused some friction between

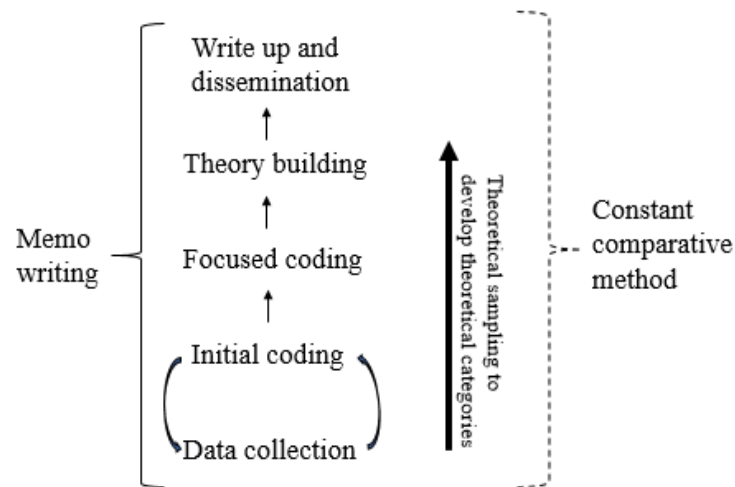
them when sensitive information was disclosed in a feedback slot where both partners were present. Another potential benefit of individual interviews is it might allow the PLWD to be better supported to engage in the interview, as the researcher can adapt the pace, language and demands more closely to their need. Bearing this in mind, couples were given the option to meet separately if they preferred by this was not taken up. At times in the interviews care partner could help elicit information by asking the question in a way more suited to their partner, or providing a personal example to help make sense of the question.

The outcome of interest in this study was relationship quality between couples living with dementia. A consideration was whether to administer a questionnaire measure of relationship quality to couples to support triangulation and contextualise the sample. Studies employing subjective measures of relationship quality have reported care partners score lower than their partners with dementia, and this difference is significant when rating communication (Clare et al., 2012). However, there was insufficient evidence for a validated and reliable measure of relationship quality suitable for administration to both the PLWD and their partner (Fisher, 2010). Participants were informed the research focus was on their relationship, and therefore couples who experienced higher relationship quality may have been more interested and willing to participate. Certainly, analysis of the interviews and behavioural observations suggested couples were close and felt a high degree of love and affection for their partner. Future research may want to consider use of couples' descriptions in conjunction with psychometric or analogue measures.

#### **3.4.6 Analysis**

A constructivist grounded theory approach was utilised in the study, this yields an emergent theory which 'states relationships between abstract concepts and may aim for either explanation or understanding' (Charmaz, 2014, p.228). The development of this theory followed the analytic process outlined by Charmaz (2014) and is depicted in Figure 3.1.

Figure 3.1 Constructivist grounded theory analysis process.



Adapted from Charmaz (2014)

#### 3.4.6.1 Line by line coding

Figure 3.1 represents a feedback loop between initial coding and data collection. Recorded interviews were transcribed and coded in advance of the next interview. Additional prompts, reflecting new ideas identified in the initial codes, were added and discussed in subsequent interviews. The line by line codes were primarily descriptive, brief and stayed close to the accounts given by participants, for instance using their terms where possible. The codes were framed as gerunds to build action into the analysis (Charmaz, 2014). An example of line by line coding in this style is ‘we had two things thrown at us’ was assigned the code ‘having multiple demands’. A transcript excerpt demonstrating line by line coding further is available in Appendix J.

#### 3.4.6.2 Focused coding

In this stage the many potential avenues created by line by line coding are filtered based on the most frequent or significant codes (Charmaz, 2014). Through integration with memos these are tentatively raised to categories, which are more abstract and conceptually encompass a range of codes. Some examples of categories identified were: ‘making active

comparisons' and 'managing difficult emotions'. Through further analysis these were raised to the final master themes and subcategories outlined in the empirical paper.

#### *3.4.6.3 Credibility of analysis*

Given the subjective nature of qualitative research it is important to safeguard against bias in the development, collection and interpretation of the data, and to adhere to the research method. The methods employed in this study were bracketing, triangulation and negative case analysis (Charmaz, 2014; Willig, 2008).

Bracketing is a process of identifying beliefs, hypothesis, preconceptions and assumptions relating to the research topic which might influence the study outcomes (Ahern, 1999). The main author engaged in bracketing prior to data collection through discussion with other researchers and recording the outcomes in a self-reflective log. Below is an excerpt from an early bracketing exercise:

From facilitating a dementia carers group, I think it might be difficult to elicit the views from the carer about more emotional aspects of their experience, as in this group they often focused on practical problems such as medication and activities of daily living. How might this be managed in an interview, and might this be a part of their adjustment?

I think couples may try to minimise the impact of dementia on their relationship as a coping strategy. This might make it hard to find out how they really feel, although if this is the case it might tell me something about what they find helpful or is a common response.

During data collection bracketing took the form of memo writing. The content of memos included reflections, personal emotional responses, behavioural observations, and further

questions. For instance, the following memo was made on 26<sup>th</sup> November 2016 after interviewing six couples.

I am finding it so moving to be privy to couples' experiences at such a challenging time, I am amazed by how willing they are to share with me information about their lives. But it is more upsetting that I expected it to be, despite my clinical training. It might partly be to do with being in a different role and seeing people together in their homes. Thinking about the emotional response it has evoked in me, I wonder how couples are able to deal with this. How do they find a way to manage the frustration, upset etc. that comes from the uncertainty and change? How would they usually cope?

I think it would have been so helpful to be able to come back and meet with couples again to see if the responses they are describing have changed at all. The couple today talked about how they have overcome so many difficulties in their lives, including bankruptcy, that in some ways having dementia does not feel as big a threat. This was so interesting because coming from an outsider position I imagine that receiving the diagnosis would feel enormous and, while it is, in some ways they seem to be downplaying it. This is making me think about how couples over their lives will have overcome other challenges and whether they are responding to dementia using these same skills. I wonder about the role of resilience, and the cognitive and behavioural strategies associated with resilient people.

Another method to reduce bias was triangulation, which occurred through investigator triangulation and member validation. At multiple points the author discussed the codes and themes with the research team and received feedback on drafts of the results. Member validation allows for participants' reactions to the provisional findings to refine the final results (Mays & Pope, 2000). Member validation was completed with two dyads and

involved the author meeting with each couple to share the provisional results and discuss the extent to which these tentative themes reflected their experiences. It has been suggested that this feedback generates further reflection and development of the themes, and be used alongside other methods of error reduction as the constructed interpretation by the researcher will differ from the specific individual account given (Mays & Pope, 2000). An extract of feedback provided during the member validation is provided in Appendix K.

Negative case analysis was applied where anomalous cases or examples are identified and analysed to strengthen the validity of the emergent theory (Willig, 2008). For instance, one set of codes related to increased proximity seeking in couples. This led to a hypothesis that couples wanted to maximise their time together as a way of maintaining their relationship. However, two couples described how they continued their independent hobbies thus spending time apart. Integration with memos and discussion in subsequent interviews elucidated the importance of values in guiding couples' behaviour and contributing to their shared identity; couples who valued pursuing their own interests and viewed this as part of what defined them as a couple carried this on and couples who valued spending free time together continued this approach.

A common grounded theory dictum states the researcher should avoid reading relevant literature to reduce bias (Charmaz, 2014; Ramalho, Adams, Huggard, & Hoare, 2015). In practice this is difficult, as to develop the research questions the author was required to explore the current research base. However, to minimise the potential influence of further knowledge on the empirical data analysis, the systematic review data extraction was delayed until after the analysis was completed.

### ***3.4.7 Evaluating the theory***

Charmaz (2014) outlines four ways of evaluating the theory produced through the research. These have overlaps with the standards set out by Elliott, Fischer and Rennie (1999) as a means of ensuring quality in qualitative research. The four measures are discussed:

**Credibility-** There should be strong links between the data and analysis, with sufficient evidence that an outsider should agree with the claims. Section 3.4.7.3. details the analytic process and quotes have been used throughout to provide examples in support of each theme.

**Resonance –** The grounded theory should make sense to the included participants and others in similar circumstances. The main way this was assessed was through member validation, with the two dyads both corroborating the relevance of the themes. For instance, when discussing the theme of ‘living well together’ Mrs Kelly reflected she is ‘aware that there is probably you know, a limit to the relationship in a way that wasn’t there before, and so you use the time better, and I’m more aware of that now’.

**Originality –** The theory should extend or challenge existing practice, the author argues this research does so by contributing to the emerging research paradigm which includes the perspective of both carers, and highlighting the relational needs of couples in terms of managing relational losses and maintaining their relationship quality which may contribute to positive psychological wellbeing. A fuller description of the contribution this theory makes is available in the empirical paper discussion (Section 2.4).

**Utility –** The results should raise questions about areas for future research and offer ideas with value in everyday practice. As discussed in section 3.4.9. one area for future research concern the examination of the theory in relation to other dyads including same sex couples and BME groups. Key clinical implications such as the practice of memory services and use of peer support groups are discussed in section 3.5.

### **3.4.8 Further research**

In the empirical paper it was suggested future research could explore the relevance of the emergent themes to other groups such as later life re/marriages and young onset dementia cases. Another area for further exploration is couples who identify as black and minority ethnic (BME) and LGBT groups as this study's sample comprised white, British, heterosexual couples. People who identify as BME often present later to services when the dementia is more advanced, which may be due to misunderstandings about the condition and stigma (Mukadam, Cooper, & Livingston, 2010). As a result, people from BME groups are less likely to receive an early diagnosis and support, and are less represented in research generally, perhaps due to the lack of contact with agencies studies recruit through. The National Care Forum (2016) produced a good practice paper on dementia care and LGBT communities which highlighted some concerns relevant to this topic of relationship quality. For instance, people who identify as LGBT may be more likely to be estranged from close family or feel they cannot disclose their sexuality to services due to concerns about prejudice. Researching the relational needs and experiences of these two groups may lead to a better understanding of their beliefs and needs, which may or may not overlap with the themes in this study.

## **3.5 Clinical and service delivery implications**

The implications are discussed in relation to the systematic review and empirical paper which both pertain to spousal relational quality during dementia.

Firstly, the findings highlight behavioural, cognitive and emotional strategies utilised by couples to maintain quality in their relationship. Given that relationship quality has been



associated with improved wellbeing (Ablitt et al., 2009), sharing information about ways to maintain relationship quality may be beneficial. To optimise the integration of information, consideration needs to be given to the timing and format of delivery. The NICE Quality Standard for Dementia (2010) states verbal and written information should be provided on areas such as treatment and support options. However, the results of a survey by Healthwatch Nottinghamshire (2016) indicated less than 25% of respondents had received information in both formats. A first step for services might be to routinely make information on supporting relationships available, for instance through leaflets and at drop in sessions or follow up appointments. In the same survey 65% of respondents felt either too little or too much information was provided post diagnosis (Healthwatch Nottinghamshire, 2016). Although achieving this balance for couples may be an idiosyncratic issue, it may be useful for clinicians to simply ask couples routinely about their relationship and enquire if they would like further information on this area.

Related to this, the provision of post-diagnostic follow up may be helpful for meeting with couples and exploring the relational impact of living with dementia. The current focus on early diagnosis has not been matched by an equal emphasis on providing support after (British Psychological Society, 2014b). The systematic review identified numerous stressors for the couple following diagnosis, as well as ways of coping and resources which might be important to explore. The personal nature of this topic may mean follow up appointments with the couple are an appropriate place to ask in more detail about the relationship.

However, some of the strategies such as reminiscing together and making the most of the present moment may be broached within a peer support group setting under the theme of living well with dementia. Psychologists may be well placed to have these conversations due to their skills working with distress and sensitive topics, biopsychosocial approach and ability to work with multiple family members. Indeed, this is raised in the British Psychological

Society's guidelines (2014a), which highlight how psychology can be effective in the early stages of dementia through offering individual therapy and facilitating groups, as well as helping memory teams recognise the emotional impact on people living with dementia.

Following on from this, the findings from this study emphasise the need for services to understand dementia care in a relational context. Guidelines often differentiate between the needs of people with dementia and their family carers, however this study highlights how in the early stages couples still identify as a romantic couple. It may be appropriate therefore to integrate relational aspects into guidance. For instance the Social Services and Wellbeing Act for Wales (2014) mandates the requirement for carers assessments which includes a needs assessment of whether the person is able and willing to provide care, and what support they need to achieve their desired outcomes. In local practice this could mean asking specifically about their relationship with the person they care for and what assistance might be needed to support this.

Finally a scoping exercise carried out by the Alzheimer's Society (2012) asked carers to rank their priorities for future research which highlighted areas of need in clinical practice. Of the 200 respondents 60% rated 'getting access to appropriate help and support to keep caring at home' as an important research topic. One factor relevant to this highlighted by the systematic review was the impact on couples when professional and community support services were inadequate. Couples described how poor public transport impeded community access which could result in isolation and frustration. Conversely, couples living in areas with community resources such as Dementia Cafes and dementia friendly shops reported benefits for the relationship as well as on an individual level. This suggests regional variation in services as well as the multi-faceted needs of couples affected by dementia. At a service level professionals may have a role in liaising with local services and taking responsibility for signposting couples to local resources. Nationally, the 'Dementia Friendly Communities'

initiative suggests councils coordinate to identify opportunities to disseminate and promote good local projects to help areas become more dementia friendly (Local Government Association, 2015).

### **3.6 Dissemination**

To maximise the reach of the findings dissemination is planned through multiple channels. All the participating couples indicated that they would like to receive information about the results, therefore a summary of the findings will be sent.

Plans have also been made to share the results with people affected by dementia through Nexus and Alzheimer's Society, the two local charities involved in recruitment. A poster will be produced for display at local branches of the Alzheimer's Society and Nexus function rooms about the empirical study. This will be accompanied by a leaflet outlining the strategies and resources identified by couples and in the systematic review as contributing to relationship quality. The author has also been invited to speak at the Nexus group events, which are attended by people living with dementia.

Dissemination to professionals and academics will be targeted by submitting the empirical paper and systematic review for publication with the journals *Dementia* and *Aging and Mental Health* respectively. The abstract has also been submitted to the 12<sup>th</sup> UK dementia congress, which is organised by the Journal of Dementia Care. The remit of the congress is to share ideas and innovations in dementia research and practice, and is open to professionals and people with personal experience. In May 2017, the empirical paper was presented at the Speaking of Science conference for post-graduate researchers from the GW4 universities. Feedback from delegates and the organising committee was positive and the presentation

slides are included in Appendix L. Finally, the author has been invited to present the research and co-facilitate a discussion on supporting relationships in dementia care with the Memory Team and Young Onset Dementia Team in a local Health Board.

### **3.7 Competency development**

Conducting the thesis has been a lengthy process spanning almost two years during the doctorate training programme. Alongside improving specific research skills, this has contributed to the author's personal and professional development. This section considers how engagement with the research project has developed different competencies relevant to being an effective clinical psychologist by drawing on; the Standards for the accreditation of Doctoral programmes in clinical psychology (British Psychological Society, 2016); the Clinical Psychology Leadership Development Framework (British Psychological Society, 2010); and the NHS Knowledge and Skills Framework (Department of Health, 2004).

#### **3.7.1 Leadership**

The process of completing this project allowed the author to develop key skills relevant to leadership in research and clinical settings. One skill is developing and maintaining effective working relationships to bring a task to successful completion (British Psychological Society, 2010). For this project, the author built positive relationships with diverse groups including research supervisors, charity contacts and participants. When approaching individuals, the author found it helped to find an area of common interest, which for this project was often a shared goal of wanting to improve the experience of those living with dementia. Additionally, it was important to consider the benefits conferred on each side. For instance, when approaching charities to support recruitment it was clear how this was useful for the author.

However, the author also needed to consider how the charities may gain from their involvement. Working with others also posed some challenges, for instance negotiating roles and responsibilities. With the research team the author noticed a tendency to want to demonstrate their autonomy and competency through taking the lead. However, it was important to feel comfortable sharing a 'not knowing' position and use the skills and experience of the supervisors, such as on the development of the interview materials.

A range of personal qualities relevant to leadership can be demonstrated through engaging in this research. Self-awareness has been identified as an important quality (British Psychological Society, 2010) and was essential in processes such as bracketing when considering how one's assumptions and values may influence interpretation. Moreover, in conducting the research the author endeavoured to act with integrity in their responses to ethical issues. One ethical dilemma occurred during the initial consent process, when it became apparent that the person with dementia, although willing to take part, did not have the capacity to consent. In this instance it was important to explain sensitively why this study was not appropriate for the couple and express gratitude for their interest in taking part. This also maintained quality in the research by ensuring participants were suitable based on the inclusion criteria.

### **3.7.2 *Communication***

Dissemination of the research findings provided an opportunity to enhance communication skills through adapting the content to different audiences (British Psychological Society, 2016; Department of Health, 2004). This study is being disseminated through different written formats, including a poster at the Alzheimer's Society and journal publication. Presentations at research conferences and at local dementia groups also call for adapting the content and tone to the audience. The terminology used is one key difference, for instance terms such as 'people with dementia', often abbreviated to 'PwD' and 'carer' can be

commonly found in academic writing. However, the Dementia Engagement and Empowerment Project, a national forum for bringing together groups of people with dementia to change services and policies, request these terms are substituted for ‘people living with dementia’ and ‘care partner’. The author was therefore mindful about use of such terms in different settings, and how these may be interpreted.

### ***3.7.3 User involvement and collaboration***

On reflection, this study might have gone further engaging people living with dementia and their care partners in the development and completion of the study. This is in line with the Prime Minister’s Challenge on Dementia (2015), which has an objective of giving people the opportunity to be involved in research, and the British Psychological Society’s (2016) principle that psychologists collaborate with service users and carers to improve services and advance psychological practice. Potential opportunities included meeting with this group to discuss the topic and find out what aspects are most of interest to them. Also, in developing the interview materials (information sheet, consent form and interview questions), the perspective of a care partner or person living with dementia would have been valuable (National Institute for Health Research, 2010). However, practical and time constraints meant initial attempts made by the author to engage with this group did not come to fruition.

Efforts were made where possible to engage the target population in the study, for instance through member validation where participants were invited to comment on the emerging themes. At this meeting feedback was also obtained about their experience of taking part in the research, which both couples described in positive terms. Factors contributing to this included being met at home in a familiar environment and having choice over the appointment time. Each couple also commented on the role the interviewer plays in shaping their experience. Mrs Wilman said ‘you (the interviewer) do it so delicately, erm and you also seemed to get the essence of what we are, without pushing us to say things or without expecting things... certainly

for me it's been easy to be natural' and she went on to comment that she felt by 'allowing a bit of space, listening' she was helped to feel comfortable during the interview. In clinical practice the use of routine outcome monitoring is becoming part of standard practice. It is useful to think about how research using clinical populations might be able to employ some of these methods to obtain feedback about the research experience including methods of recruitment and study materials.

#### **3.7.4 Assessment**

Interviewing couples could be framed as a type of assessment; the researcher needs to form a working relationship with both partners to obtain relevant information. This research helped enhance the author's skills engaging with couples, building on their previous experience of primarily individual interviews. Some of the challenges included maintaining the engagement of both participants, following up contributions and not weighting the discussion unduly to one person's perspective. Moreover, probing differences in participants' perspectives and managing any tensions posed further challenges.

The author found it helpful to draw on the systemic family therapy principles of neutrality and hypothesising (Palazzoli-Selvini, Boscolo, Cecchin, & Prata, 1980). Neutrality concerns the ability of the therapist to be allied with each member of the family, and not privilege any one person (Palazzoli-Selvini et al., 1980). In this research context, this was applied by being open to the perspective of each participant, and finding ways to encourage each person to share their views. Participants could invite the researcher into complicity over an aspect of their partner's behaviour they considered unhelpful or frustrating. At these points holding the principle of neutrality in mind helped the researcher to manage this by remaining curious about their experiences and inviting both participants to comment.

Hypothesising involves using the available information to formulate an understanding of processes and relationships (Palazzoli-Selvini et al., 1980). Within family therapy a hypothesis may be the starting point for investigation, however if disconfirming evidence is identified then it is important to be able to move on from this and form new ideas integrating this information. This was useful in the interviews when subsequent comments challenged an earlier belief formed. Audio recording the interviews enabled the researcher to note observations and questions to elaborate in memos after the session. During the interviews hypothesising meant not being wedded to specific ideas identified by other couples and approaching each interview as an opportunity to find out something new.

Having had this additional experience of engaging with couples, the author feels more confident in working with couples in clinical settings.

### ***3.7.5 Clinical psychologists as reflective scientist practitioners***

The idea for this research project came from the author's experiences working in a memory team where they were involved in post-diagnostic support for families. Partners seemed to describe multiple shifts in the relationship, which often seemed connected to losses. The author wondered how couples made sense of their experiences, particularly in terms of the impact on their relationship quality. The development of the project from a clinical observation is relevant to the status of clinical psychologists as reflective scientist-practitioners. Clinical psychologists are skilled in utilising both evidence based practice and practice based evidence so that one can draw on research to inform clinical work, and reciprocally research can be guided by clinical issues. This is important for developing the literature base and improving clinical practice, and will be integrated into the post-qualification practice of the author.



### 3.8 References

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## 4 Appendices

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### Appendix A

#### *Journal of Aging and Mental Health Author Submission Guidelines*

##### About the journal

*Aging & Mental Health* provides a leading international forum for the rapidly expanding field which investigates the relationship between the aging process and mental health. The journal addresses the mental changes associated with normal and abnormal or pathological aging, as well as the psychological and psychiatric problems of the aging population. The journal also has a strong commitment to interdisciplinary and innovative approaches that explore new topics and methods.

*Aging & Mental Health* covers the biological, psychological and social aspects of aging as they relate to mental health. In particular it encourages an integrated approach for examining various biopsychosocial processes and etiological factors associated with psychological changes in the elderly. It also emphasizes the various strategies, therapies and services which may be directed at improving the mental health of the elderly and their families. In this way the journal promotes a strong alliance among the theoretical, experimental and applied sciences across a range of issues affecting mental health and aging. The emphasis of the journal is on rigorous quantitative, and qualitative, research and, high quality innovative studies on emerging topics.

**Readership:** The journal is directed at an international audience, with editors in London, Hong Kong and North America and an Editorial Board from around the world. The readership of the journal is drawn from many disciplines, with particularly strong representation from psychiatrists and psychologists working with older people. Its strong scientific foundation makes it of considerable interest to basic and applied scientists interested in the biological, psychological and social aspects of aging and mental health. Please note that this journal only publishes manuscripts in English.

##### Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer-reviewed by independent, anonymous expert referees. Find out more about [what to expect during peer review](#) and read our guidance on [publishing ethics](#).

##### Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the [Uniform Requirements for Manuscripts Submitted to](#)

[Biomedical Journals](#), prepared by the International Committee of Medical Journal Editors (ICMJE).

### Structure

Your paper should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

### Word limits

Please include a word count for your paper.

A typical manuscript for this journal should be no more than 5000 words; this limit does not include tables; references; this limit includes figure captions; footnotes; endnotes.

A typical short report for this journal should be no more than 2000 words; this limit does not include tables; references; this limit includes figure captions; footnotes; endnotes.

### Style guidelines

**Font:** Times New Roman, 12 point, double-line spaced. Use margins of at least 2.5 cm (or 1 inch). Guidance on how to insert special characters, accents and diacritics is available [here](#).

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

**Abstract:** Indicate the abstract paragraph with a heading or by reducing the font size. Check whether the journal requires a structured abstract or graphical abstract by reading the Instructions for Authors. The Instructions for Authors may also give word limits for your abstract. Advice on writing abstracts is available [here](#).

**Keywords:** Please provide keywords to help readers find your article. If the Instructions for Authors do not give a number of keywords to provide, please give five or six. Advice on selecting suitable keywords is available [here](#).

**Headings:** Please indicate the level of the section headings in your article:

First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.

Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.

Third-level headings should be in italics, with an initial capital letter for any proper nouns.

Fourth-level headings should be in bold italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

Fifth-level headings should be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

**Tables and figures:** Indicate in the text where the tables and figures should appear, for example by inserting [Table 1 near here]. The actual tables should be supplied either at the



end of the text or in a separate file. The actual figures should be supplied as separate files. The journal Editor's preference will be detailed in the Instructions for Authors or in the guidance on the submission system. Ensure you have permission to use any tables or figures you are reproducing from another source.

Advice on obtaining permission for third party material is available [here](#).

Advice on preparation of artwork is available [here](#).

Advice on tables is available [here](#).

**Running heads and received dates** are not required when submitting a manuscript for review; they will be added during the production process.

**Spelling and punctuation:** Each journal will have a preference for spelling and punctuation, which is detailed in the Instructions for Authors. Please ensure whichever spelling and punctuation style you use is applied consistently.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

#### Formatting and templates

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting templates.

A [LaTeX template](#) is available for this journal.

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact [authortemplate@tandf.co.uk](mailto:authortemplate@tandf.co.uk)

#### References

APA (American Psychological Association) references are widely used in the social sciences, education, engineering and business. For detailed information, please see the *Publication Manual of the American Psychological Association*, 6th edition, <http://www.apastyle.org/> and <http://blog.apastyle.org/>.

Please use this [reference guide](#) when preparing your paper. An [EndNote output style](#) is also available to assist you.

## *Dementia Author Submission Guidelines*

### **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.

### **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.

### **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. dement). 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](#).

## Appendix B: Details of full text articles excluded

73 articles were read in full, 63 were excluded resulting in 10 papers being included in the systematic review.

<b>Reason for exclusion</b>	<b>Number of articles removed</b>
Not available in English	2
Used a quantitative methodology	11
Sample not living in the community	2
Study focus not on relationship quality	4
Sample only included the views of the partner, or other family members were included but could not be differentiated in the results	40
Full text not available e.g. conference abstract	2
Other diagnoses present in sample group, and dementia group could not be differentiated	3

Note: Totals exceed 63 because some papers were excluded for multiple reasons, for example using a quantitative methodology, and only including carers.

## Appendix C: Systematic review data extraction template

Adapted from the McCubbin and Patterson (1983) Double ABCX Model.

<b>Article Title and Author</b>		
<b>Stressor</b>		
life event or transition impacting upon the family unit which produces, or has the potential of producing, change in:		
(a) <b>individual family members,</b>		
(b) <b>the family system, and/or</b>		
(c) <b>the community of which the family and its members are a part.</b>		
<b>There appear to be <i>at least</i> five broad types of stressors contributing to pile-up:</b>		
(a) the initial stressor and its hardships,		
b) normative transitions,		
c) prior strains,		
d) the consequences of family efforts to cope		
(e) ambiguity, both intra-family and social		
<b>Resources: Existing or acquired</b>		
Individual: PwD		
Individual: Carer		
Family resources		
Social support		
<b>Family appraisal = the meaning the family attributes to the crisis, the stress and demands and their resources to deal with them</b>		
<b>Successful re-appraisal usually involves:</b>		

<p>a) clarify the issues, hardships, and tasks so as to render them more manageable and responsive to problem solving efforts;</p> <p>b) decrease the intensity of the emotional burdens associated with the crisis situation;</p> <p>c, encourage the family unit to carry on with the fundamental tasks of social and emotional development</p>	
<p><b>Coping – at family level family uses existing family resources and develops new behaviours and supplies to strengthen the family unit</b></p>	
<p><b>a) eliminating and/or avoiding stressors and strains; (b) managing the hardships of the situation; (c) maintaining the family system's integrity and morale; (d) acquiring and developing resources to meet demands; and (e) implementing structural changes in the family system to accommodate the new demands</b></p>	
Cognitive coping	
Behavioural coping	
Other	
<p style="text-align: center;"><b>Adaptation:</b> Outcome = relationship quality</p> <p>Adjustment includes individual wellbeing and family/couple wellbeing, sense of control, development and maintenance of family relationships</p>	
<b>Other Relevant Information</b>	



## *Nexus*



### dementia and couple relationships study update



Helen Joy <nexus@cavamh.org.uk>

Wed 19/04, 10:39

Anna Colquhoun ✉

  Reply all | 

Anna

I am happy to confirm that Nexus gave consent and indeed advertised this project in order to support recruitment of volunteers, both service users and carers.

We were delighted to introduce you, Anna, to our groups and look forward to reading the report on the findings in due course.

Helen

**Helen Joy**

Carer & Service User Involvement Officer in Older People's Mental Health

Nexus

029 20 222000

[nexus@cavamh.org.uk](mailto:nexus@cavamh.org.uk)

## Alzheimer's Society



de Sainte Croix, Ruth <Ruth.deSainteCroix@alzheimers.org.uk>

Fri 10/06/2016, 17:05

Anna Colquhoun; Murray, Matt <Matt.Murray@alzheimers.org.uk>; Grinbergs-Saull, Anna <A.Grinbergs-Saull@alzheimers.org.uk> ✉



Reply all | ▾

LSRP

You replied on 15/06/2016 09:38.



Action Items

Dear Anna,

Thanks for your enquiry. Firstly apologies for the delay in getting back to you, we are just getting our Research Partnerships process back up and running following a period of review.

We met recently to discuss your application and we are happy to support Relational change and grief in individuals with dementia and their care partner.

- Firstly, have you considered using [Join Dementia Research](#) to help with recruitment?
- I can ask our local staff to promote your research to our service users – before I can do this, please can you add some details of support organisations to your information sheet? For instance for questions about dementia contact Alzheimer's Society's helpline. Then please can you send me the revised information leaflet and any other documents that will be useful for me to send to our local teams who will decide whether they have the capacity to promote your study to our service users.
- We really liked your dissemination plan included in your application form

I hope that all makes sense. I look forward to hearing from you.

Kind regards

Ruth

**Ruth de Sainte Croix**

Innovation and Research Development Manager

Research and Development Directorate

Office phone 020 7423 5110

## Appendix E: Information sheet

### *Information sheet for relational change and grief in individuals with dementia and their carepartner study*



Dear Sir/Madam

My name is Anna Colquhoun and I am undertaking my training to become a Clinical Psychologist. As part of this training I am completing a research study within the School of Psychology, Cardiff University.

You have been given this information sheet because I am looking for people like you to take part in my study. This sheet describes what the study is about, and what happens if you take part to help you decide whether you would like to participate.

This study has been approved by the School of Psychology ethics committee.

#### **What is the study about?**

I am interested in understanding more about what it is like for someone with a diagnosis of dementia and the family member/partner they identify as their carer. In particular I want to know more about your relationship; what you enjoy doing together, what has been different since the diagnosis, and how each of you feel about these things.

#### **Why have we been invited to take part?**

I am asking people with a diagnosis of dementia and their carer to take part. We can only include people in this study who have capacity to consent to taking part. This means each person must be able to give their own consent to be involved. We cannot accept someone giving consent for another person if that person is not able. For this study we require both of you independently to agree to be in the study. If either of you do not want to take part that is fine, it will not affect any of the support or services you use.

#### **What happens if we take part?**

We will arrange to meet once together. This can be at Cardiff University or your house, wherever would feel comfortable. I have some questions to ask you both together and expect this will take about an hour, but it may be longer or shorter. With your permission, I will record our conversation so that I can type up your answers afterwards.

#### **What will happen to the information we give you?**

After typing your answers I will delete the audio recording. The written copy of your answers will be kept secure. All information about you will be kept confidential, which means only people involved in the research team will have access to your information. When the study is written up those reading it will not know who you are because your names and personal information will not be included.

Your personal information would only be shared if you told us you had plans to harm yourself or others. We would talk to you about who we need to share this information with,

for example your GP, and the priority is to keep you and others safe. Dr Jennifer Moses works in the research team and is my supervisor, if I have any concerns I will also contact her for advice and support.

### **Could there be any downsides to taking part?**

We do not expect there to be any downsides to taking part. Potentially talking about the impact of dementia on your relationship may make you feel upset. If this is the case then we can stop the interview and talk about what support options might be useful for you. If there are any other problems or concerns then you are welcome to contact me or my supervisors (contact details below). If you would like to make a formal complaint, you can contact the Cardiff School of Psychology Ethics who approved this study- Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk), Tel: 029 2087 0360.

### **What might the benefits be?**

The questions encourage you to think about a variety of aspects of your relationship, including what your strengths as a pair are and how you connect with each other. I hope talking about these things will be interesting for you.

As you may be aware, the UK population is growing meaning in the future more people will be diagnosed with dementia and more families will have an experience caring for someone with dementia. Our aim is to identify more ways to support people affected by dementia and believe that speaking to people currently affected will give us ideas about what may help. Taking part in the research would help us with this.

### **What will happen to the results?**

I will submit a thesis on this study to Cardiff University as part of my training. I may also write a summary to be published in a research journal or a poster for presentation to relevant professionals. Any written documents will be available for the public, including you, to read. For all of these, it will not be possible for the reader to identify you.

### **What next?**

Thank you for taking the time to read this information sheet. If you would *not* like to take part you do not need to do anything. If you are interested please contact Anna Colquhoun, Trainee Clinical Psychologist, on 02920 870582 or email [colquhouna@cardiff.ac.uk](mailto:colquhouna@cardiff.ac.uk) with your name, telephone number, email, and address.

## **Research Team Contacts**

### Chief Investigator:

Anna Colquhoun, Trainee Clinical Psychologist, Email: colquhouna@cardiff.ac.uk.  
Tel: 02920 870582

### Academic Supervisor:

Dr Jennifer Moses, Consultant Clinical Psychologist and Academic Director of the  
South Wales Doctoral Programme in Clinical Psychology.  
Email: jenny.moses@wales.nhs.uk. Tel: 02920 870582

### Clinical Supervisor:

Dr Rosslyn Offord, Highly Specialist Clinical Psychologist in Cardiff and the Vale  
Memory Team. Email: rosslyn.offord@wales.nhs.uk. Tel: 029 2071 6961

**Many thanks again. Anna Colquhoun, Trainee Clinical Psychologist**

## Appendix F: Consent forms



### *Caring Partner*

### CONSENT FORM - C Version 1.0. January 2016

Study Title                      *Relational change and grief in individuals with dementia and their carepartner.*

Chief Investigator              Anna Colquhoun, Trainee Clinical Psychologist

Supervisors                      Dr Jennifer Moses, Consultant Clinical Psychologist

Dr Rosslyn Offord, Highly Specialist Clinical Psychologist

Please read the statements below carefully and if you agree mark 'X' in the box.

1. I understand that by taking part in this study I will be asked questions about my experiences in a relationship with someone affected by dementia and that this interview will take about an hour.
  
2. I have read and understand the information sheet, and have asked any questions I have.
  
3. I understand that my participation is voluntary and I can withdraw at any time without giving a reason. Withdrawing will not affect my access to services.

4. I understand I can ask questions at any time and discuss my concerns with the research team or the university ethics committee.
5. I understand information given by myself will be kept securely and confidentially and it will not be held longer than the research requires.
6. I understand the interview will be audio recorded and once typed up, this will be deleted. The written version will be stored anonymously so it cannot be traced back to me.
7. I understand that quotes may be used but will not be linked to me personally.
8. I understand the researcher will share information with their clinical supervisor if they are worried about myself or others safety.
9. I understand that at the end of the study I will receive extra information about the study.
10. I agree to take part in the study.

I, \_\_\_\_\_ (NAME) consent to participate in the study conducted by Anna Colquhoun, School of Psychology, Cardiff University with the supervision of Dr Jennifer Moses and Dr Rosslyn Offord.

Signed:

Date:

*Person living with dementia*

CONSENT FORM – PLWD

Version 1.0. January 2016



Study Title                      *Relational change and grief in individuals with dementia and their carepartner.*

Chief Investigator              Anna Colquhoun, Trainee Clinical Psychologist

Supervisors                      Dr Jennifer Moses, Consultant Clinical Psychologist  
Dr Rosslyn Offord, Highly Specialist Clinical Psychologist

Please read each section. If you agree please put a 'X' in the box e.g.

If you don't agree leave the box empty.

**1. What will happen**

I will be asked questions about myself and my family member. This will take about an hour.

**2. Information sheet**

I have read and understand the information sheet. I have asked any questions.



**3. Choice to take part**   
I know I can choose to take part. I don't have to take part if I don't want to.

**4. Asking questions**   
I can ask questions when I want. I can ask the research team or ethics team.

**5. Keeping my information safe.**   
My information will only be seen by the research team. My information will be deleted at the end of the study.

**6. Recording the interview.**   
I know the interview will be recorded and written up. This recording will be deleted at the end of the study. The written part will not have details like my name on it.

**7. Using what I have said**   
Quotes of what I said may be used when the research is written about but people will not know I said it.

**8. Sharing my information**   
I know the researcher will talk to their supervisor if they are worried about my safety or others safety.

**9. Extra information**

I know at the end of the study I will get more information about the study.

**10. Taking part**

I agree to take part in the study.

I, \_\_\_\_\_ (NAME) agree to take part in the study run by Anna Colquhoun, School of Psychology, Cardiff University with the supervision of Dr Jennifer Moses and Dr Rosslyn Offord.

Signed:

Date:

## Appendix G: Participant demographic form

Participant Number

.....

Age and gender of person with dementia .....Age & gender of carer.....

Type of dementia

.....

Dyad relationship (marital partners) ..... Years married.....

Length of time since diagnosis

.....

## Appendix H: Participant debrief form

Study Title: *Relational change and grief in individuals with dementia and their carer/partner.*



Firstly thank you for taking part in this study, your involvement is much appreciated.

### What happens next in the research study

The information you gave during the interview will be put together with other interviews collected for this research. We hope that by looking at what different people said we will be able to better understand relationships between someone with a diagnosis of dementia and the person identified as their carer. For this study that usually means their partner or child.

### What is the study trying to find out

We hope to learn more about how each person views the relationship, what feels similar and what feels different since receiving the dementia diagnosis, and what each person thinks about it for example what aspects do they focus on and what emotions does it bring up. This information will be helpful in enabling services to better support families in the future.

### What will happen to the information I gave

The information gathered will be used in several ways. Firstly the Chief Investigator (Anna Colquhoun) will use the data as part of a thesis submitted to Cardiff University for her training. She may also write a summary for a scientific paper or a poster for presentation to relevant professionals. Any written documents will be available for the public, including you, to read. For all of these, it will not be possible for the reader to identify you.

As a reminder your information will be kept securely; the audio recording will be deleted once it has been typed up and the written form will be anonymised.

If you wish to receive information about the study results please let Anna know (contact details below) and she will send you a summary of the results when they are available (likely to be around summer 2017).

If you have any questions please contact one of the research team:

Chief Investigator:

Anna Colquhoun, Trainee Clinical Psychologist, Email:  
[colquhouna@cardiff.ac.uk](mailto:colquhouna@cardiff.ac.uk). Tel: 02920 870582

Academic Supervisor:

Dr Jennifer Moses, Consultant Clinical Psychologist and Academic Director of the South Wales Doctoral Programme in Clinical Psychology. Email:  
[Jenny.moses@wales.nhs.uk](mailto:Jenny.moses@wales.nhs.uk). Tel: 02920 870582

Clinical Supervisor:

Dr Rosilyn Offord, Highly Specialist Clinical Psychologist in Cardiff and the Vale Memory Team. Email: [rosslyn.offord@wales.nhs.uk](mailto:rosslyn.offord@wales.nhs.uk). Tel: 029 2071 6961

Alternatively if you have any concerns or complaints about the research you can contact the School of Psychology Research Ethics Committee in writing at:  
Secretary to the Research Ethics Committee, School of Psychology, Tower Building,  
70 Park Place, Cardiff, CF10 3AT  
Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

## **Appendix I: Semi structured interview schedule**

### *Original Interview Schedule*

Today I want to speak with you both about your experiences since receiving the diagnosis of dementia. I will be asking about different aspects of your relationship and am interested in hearing both your views about what it has been like.

I expect the questions will take about an hour, if you feel you need a break please let me know, that is not a problem. At the end I will go over again what happens next.

#### **1. Orientation/setting question**

Can you tell me a bit about how having dementia has affected your relationship?

- impact on different aspects eg. roles, routines
- beliefs about the relationship
- differences in ways affected

#### **2. Relationship qualities**

What are your strengths as a couple?

- How accessed during this time
- Effect on wellbeing

#### **3. Dynamic change**

What has been the most difficult change in the relationship for each of you?

- What made this so difficult
- Impact on each partner
- Ways of coping

#### **4. Companionship**

What do you do which you might call spending 'quality time' together?

- What is it like for you to be able to have these times together?
- What goes through your mind when you do (use their example) together?
- Have you changed what you do together?

#### **5. Future loss**

How do you think your relationship may change in the future?

- What happens when you think about that?
- How do you think you will manage X change?

## **6. Communication**

Dementia can impact people's communication skills (e.g. their understanding and how well they can express themselves), has this been an issue for you?

- how do you feel you best communicate with each other?
- How do you resolve any difficulties?

## **7. Support**

I can hear that things have been difficult at times (use their examples), how are you able to support each other?

- impact of this support on relationship
- impact on wellbeing

## **End**

Ok that was the last question I had for both of you. Thank you so much for taking the time to talk with me, how are you both feeling now?

Is there anything we haven't covered that feels important to share?

is there anything you would like to ask me about the study?

*Adapted interview schedule – used after interview 5 (changes highlighted in italics)*

Today I want to speak with you both about your experiences since receiving the diagnosis of dementia. I will be asking about different aspects of your relationship and am interested in hearing both your views about what it has been like.

I expect the questions will take about an hour, if you feel you need a break please let me know, that is not a problem. At the end I will go over again what happens next.

### **1. Orientation/setting question**

Can you tell me a bit about how having dementia has affected your relationship?

- impact on different aspects eg. roles, routines, *responsibilities, in/dependence*
- beliefs about the relationship
- differences in ways affected
- *changes in feelings – can the couple relate to increases in negative emotion*

### **2. Relationship qualities**

What are your strengths as a couple?

- How accessed during this time
- *Have these strengths benefited you in any way?*
- Effect on wellbeing

### **3. Dynamic change**

What, if anything, has changed in your relationship?

- *Experience of positive changes e.g. spending more time together, appreciating life*
- *What has been the most difficult change? What made this so difficult*
- Impact on each partner
- Ways of coping

### **4. Companionship**

What do you do which you might call spending 'quality time' together?

- What is it like for you to be able to have these times together?
- What goes through your mind when you do (use their example) together?
- *Feelings elicited when together*
- Have you changed what you do together?



## 8. Future loss

How do you think your relationship may change in the future?

- What happens when you think about that?
- *Have you got a plan for how you might cope?*
- *How do you think you will maintain your relationship as partners?*

## 9. Communication

Dementia can impact people's communication skills (e.g. their understanding and how well they can express themselves), has this been an issue for you?

- *have you found any ways to overcome this?*
- how do you feel you best communicate with each other?
- *What are the non-verbal ways (e.g. cwtching) you might show how you feel?*
- How do you resolve any difficulties?

## 10. Support

I can hear that things have been difficult at times (use their examples), how are you able to support each other?

- *Physical intimacy, talking about problems*
- impact of this support on relationship
- impact on wellbeing
- *how have you tried to overcome difficulties in the past? Are your ways of supporting each other now similar?*
- *Support received from social networks (friends and family)*
- *Access to professional services for support*

## End

Ok that was the last question I had for both of you. Thank you so much for taking the time to talk with me, how are you both feeling now?

Is there anything we haven't covered that feels important to share?

is there anything you would like to ask me about the study?

## Appendix J: Excerpts of transcripts after line by line coding

Excerpt from interview with Mr and Mrs Hood (PLWD)

Interview Text	Initial Coding
<p>I: And what's it like doing more things together now? What's that like?</p> <p>H: Fine</p> <p>W: We're always together aren't we?</p> <p>H: Yeah I mean we're very happy. Your life changes and you learn to change with it</p> <p>I: Hmm</p> <p>H: It works fine I said we try to do as much, not as many things as we used to, we just do things together ermm I think I'd like her to be more interested in sports so she'd watch rugby with me that would be nice but she doesn't</p> <p>When she was younger she used to watch rugby with me</p> <p>W: I do it from time to time (laughing) big men</p> <p>I: And you said you've been married for over 55 years. So what would you say is your strengths as a couple?</p> <p>H: Our strengths as a couple that's an interesting one</p> <p>W: We just get on. We just do get on pretty well, we try and pretend sometimes (humourously)</p> <p>H: We like each others company</p> <p>W: Yes</p> <p>H: I think its that</p> <p>W: Yes very much so</p> <p>H: Were very comfortable with each other and</p> <p>W: And the dogs</p> <p>H: Yes the dogs no doubt they are a godsend we've had them for 8 years they're 12 but we've had them since they were 4 and and you know well I do go out occasionally they're a great comfort for my wife they are a comfort when she on her own</p>	<p>Being together a lot</p> <p>Feeling happy in relationship</p> <p>Life changing</p> <p>Adapting to life changes</p> <p>Doing as much as can</p> <p>Doing less than before</p> <p>Wanting partner to share same interest</p> <p>Recalling younger days</p> <p>Getting on well</p> <p>Liking others company</p> <p>Feeling comfortable together</p> <p>Caring for pets together</p>

<p>I: So you were saying one of the things that is really good is that you feel like you get on, you really enjoy each others company?</p> <p>H: Absolutely</p> <p>W: And we like doing the same things generally, my husband with the men's things, obviously I'm not there then</p> <p>H: Because I'm more sport orientated than my wife</p> <p>I: Right that's interesting. Has that changed since, over the last 5 years?</p> <p>H: Changed to the extent that obviously I do less of it I don't go to watch rugby any more I watch it on tv erm but put that down to age if you like</p> <p>I: Mm</p> <p>H: It's just that we as we've grown older we've learnt to adapt our life to do the things we could do and it works fine</p> <p>I: So do you feel like some of the things that have changed, like doing more things together and not doing so much would have happened anyways just as a part of getting older rather than it being-</p> <p>H: I'd have said yes but not as quickly</p>	<p>Pets providing comfort</p> <p>Sharing same interests</p> <p>Having time apart</p> <p>Adapting to continue interests</p> <p>Aging causing some changes</p> <p>Adapting life as age</p> <p>New balance working fine</p>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Excerpt from interview with Mrs and Mr Bremner (PLWD)

Interview text	Initial coding
<p>I: The first question that I want to ask then is if you could just tell me a bit about how you feel having dementia has affected your relationship?</p> <p>W: Do you want to go first love?</p> <p>H: Yes, I could do. I think that... it's brought us closer together... Hmm, I'm stuck.</p> <p>I: Can you tell me a bit about the first thing you said about feeling like it's brought you closer together?</p> <p>H: About my right-hand partner... I mean I would say at the moment that without her now I'd be lost. The simple reason being that I've got a short-term memory, right, and that stumps me. I can't personally see how... how I can get</p>	<p>Speaking affectionately</p> <p>Feeling closer after diagnosis</p> <p>Being a team</p> <p>Depending on partner</p> <p>Describing memory problems</p>

<p>out of the scenario that I'm in, unless it's something that we... I don't know whether that's... they say that it's like a short-lived, a short... short-term whereas in another month's time I will be unable to remember what I said a year ago. Does that make sense?</p> <p>I: Yeah, and what is it that makes you feel like you are closer?</p> <p>H: ((pause)) Well I think it's just the... we've... we've always had like a very happy life but this has brought in something that makes you appreciate what you've got and I've got her and at the moment that's all that counts. Does that make sense?</p> <p>I: It does – so for you this diagnosis and the extra help that you needs with some things has made you appreciate your wife even more? So although you feel like you've always had a happy life together there's something now that means you are really appreciating what it is you have together?</p> <p>H: Yeah, and I would say this applies to... outside the family; friends that are very good but I mean they were good before but since I've been in this scenario, right, there's been a more together link than what there was. We've always had good friends but it seems that they're closer.</p> <p>I: What effect has that had on you – feeling like good friends have become even better, that your wife if there for you?</p> <p>H: Well I think to a certain extent my wife gets... gets help through our friends, even if it's only in comfort. I think we've all got a good relationship love, have we? I can't – I can't pinpoint anything that would be detrimental.</p> <p>W: You get very upset because you say you should be looking after me, not me looking after you and that... when you are trying to do something you are getting yourself in a state because this ain't right and that ain't right, you can't remember this and then you get upset and say, "You shouldn't be having to do this for me. I should be able to do it." But... he washes up, don't you love? ((laughing))</p> <p>H: Yeah. I do what I can.</p>	<p>Feeling stumped by problems Not seeing a way out of situation</p> <p>Symptoms getting worse</p> <p>Remembering happy life Appreciating partner Valuing relationship now</p> <p>Strong existing social support Family supporting more Friends becoming closer</p> <p>Recognising carer need for support Friends comforting Seeking reassurance about relationship quality</p> <p>Finding role changes upsetting Couple roles changing Feeling upset by limitations Resisting help Wishing for own independence Recognising partners input and role</p> <p>Doing what one still can</p>
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## Appendix K: Excerpt of member validation

Mr and Mrs Kelly (PLWD)

Theme discussed	Feedback Excerpt
<p>Consolidating us</p> <p>Subtheme: Couple identity refinement</p>	<p>Husband: we've never thought about being separate individuals, I think largely because of the fact we had six children so we always stuck very close together, we never thought he's my carer, we just are..</p> <p>Wife: yeah that's true</p> <p>Husband: two people are stronger than one</p> <p>Wife: we are husband and wife, and we enjoy it, and we are good at working together</p> <p>Husband: it's an old fashioned word but it's that thing of loyalty and it's a very important part of marriage, you have to have this loyalty between you and when you feel that and practice it so long it's a very strong piece of glue, you're not going to say 'to hell with them'. You know, we haven't come back together because we have never split, you know, and the glue of marriage, when you've been married a long time is very strong and because of all the things we've done together and our experiences in life, so we are a unit, you don't think of yourselves as separate.</p>
<p>Living well together</p> <p>Subtheme: prioritising life areas</p>	<p>Researcher: One thing couples seemed to do was to think about what is the most important thing for us as a couple and find a way to keep doing it, so if it was about travelling they might try to adapt, so maybe accept they can't do long haul flights any more but find a way to do short journeys. Can you identify with that?</p> <p>Husband: I think so, because we just did it, we did a cruise from X because we don't want to go through the blasted airports any more and hanging about, it takes so long, so we did that exactly as you said.</p>

Mr and Mrs Wilman (PLWD)

Theme discussed	Feedback Excerpt
<p>Consolidating us</p> <p>Subtheme: Couple identity refinement</p>	<p>Researcher: One of the things couples seemed to talk about, and I'd be interested to know your views on this, was the strength of their bond..</p> <p>Wife: I'd agree with that yeah</p> <p>Researcher: lots of couples we met seemed to have had happy lives together and they talked about special memories, their children, and how this had resulted in a strong emotional link which helped them now. Does that fit with your experience?</p> <p>Husband: Yeah I think, I mean let's face it in a week today we will have our anniversary, and er we can't say these years have been unalloyed bliss, like any relationship we've had our ups and downs, but I would say if anything at the moment..</p> <p>Wife: It's better</p> <p>Husband: Yeah in many ways we are closer now</p> <p>Wife: It's a deeper love</p>
<p>Living well together</p> <p>Subtheme: Prioritising life areas</p>	<p>Researcher: Couples were very motivated to make the most of the time they had together, and some of the ways they did that was by prioritising areas of their lives, so that might be committing to certain areas of importance like their faith or family. Can you relate to that?</p> <p>Wife: I guess perhaps there is an element of it being you know there isn't, okay life can stop like that always, but that you are aware that there is probably you know, a limit to the relationship in a way that wasn't there before, and so you use the time better, and I'm more aware of that now. We have kept our priorities but we have been too tired and are realising we have to cut back now more.</p>
<p>Contextual positioning</p> <p>Subtheme: Negotiating support systems</p>	<p>Researcher: One thing that seems to make a difference to couples is what is around them, be it the church, friends, family, medical professionals. What exactly varies, but having support can affect how the couple operate. I've heard very mixed experiences with people either having lots or not enough support, but either way it seems to result in the couple coming together. Based on your experiences how have you found that?</p>

	<p>Husband: Initially, we felt very apart from any system that we could link in to, by the nature of things, because we have both been around a bit and are used to tackling systems, and because of various friends we have been able to find a way in which has helped us, now we spend a lot of time in the car on the way to do things and always end up talking. You mentioned faith, and that has been incredibly supportive. As you say one friend, when they heard, was obviously gobsmacked and said 'it is what it is, we are here for you'.</p> <p>Wife: I have used that in loads of talks and that is very much the feeling. As long as you know people are there for you, be it friends or doctors.</p> <p>Husband: I think it is a very important thing.</p>
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## Appendix L: Speaking of Science conference presentation slides

# MAINTAINING COUPLES' RELATIONSHIP QUALITY IN EARLY STAGE DEMENTIA




Findings from a DClinPsych research project

Anna Colquhoun

## Introduction

### Dementia and the importance of relationship quality

- Dementia is a neurodegenerative condition affecting 850,000 people in the UK (Alzheimer's Society, 2016)
- People with dementia (PwD) have important social networks comprising spouses, children, friends and neighbours. Usually care is provided by their spouse (Prince et al. 2014)
- Relationship quality is predictive of both carer and PwD wellbeing



Aim: To explore couples' perceptions of how they maintain their relationship quality during the early stages of dementia

## Method: Recruitment

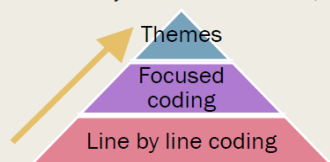
- A qualitative study using constructivist grounded theory methodology (Charmaz, 2016)
- Inclusion criteria – married couples, person with dementia formally diagnosed and aware of the diagnosis, in the early stages of dementia, with sufficient language skills to participate, both partners willing and able to consent
- Recruited through 3 charities; Nexus, Alzheimer's Society and Join Dementia Research
- N=10 husband-wife dyads living in South Wales or Bristol area

Participant characteristics	Details
Gender ratio of people with dementia	6M:4F
Age range of participants	45-82 (4ppts <60 years)
Mean number of years married	40 years
Mode diagnosis	Alzheimers
Time since diagnosis	4months-5 years



## Method: Data Collection and Analysis

- Single interview conducted with the couple together at their home
- Interviews lasted between 31-75 minutes, yielding over 9 hours of recorded data (I)
- Grounded theory approach (Charmaz, 2016)
  - 7 stem questions with follow up
  - Focus on relationship e.g. What has changed in your relationship? What are your strengths as a couple? How have these helped you cope?
  - Analysis after each interview, allows for question refinement



### Analysis

E.g. "Before we'd have gone to the evening performance but now we go to the matinee" was given the line by line code 'adapting plans to continue interests'

## Results

### Master theme 1: Consolidating us

Couples undergo individual changes but ultimately draw back together and reinforce their identity as a couple - having a strong relationship before seems to facilitate this.

Mr Kelly, who cares for his wife, describes how he draws on the couple's shared history and deep connection "...it's been such a long relationship and such amazing adventures that it's really a glue, it's really the glue that binds us"

### Master theme 2: Dyadic contextual positioning

Couples seem to work hard to see 1, where dementia fits into their couple identity, 2, how dementia fits in their life stage, and 3, the role of their personal and professional support systems

*Interviewer: what difference do you think it makes being able to spend time with your family? What impact does that have on your relationship?*

*Mrs Kelly (with dementia): well we enjoy it, we both agree on things like that*

*Mr Kelly: it keeps the relationship strong because we feel involved and we feel loved by them don't we, and that's really nice. It's sort of like a cement which holds everybody together'.*



## Results Continued

### Master theme 3: Living well together

By prioritising how they spend their time...

Mrs Wilman (with dementia) "we are more determined that we mustn't put off going to see somebody or a phone, I do loads of phone calls and find that more tiring, it takes more out of me erm but we are determined ... it has made us more aware that you know life is maybe a bit shorter and at (our age), it is going to be, so we have to do things"

and shifting how they exist in time...

Mrs Thompson (carer) "I think we are building memories. I think we've gone through our lives, we've been together for 44 years and yes we've had lots of fantastic things happening but it feels as if now everything is concentrated into this timeslot, however long it may be, to build some special memories and to be as close to each other as we can."

### Overarching theme - Turning to and away

Couples adjust to losses and changes in their relationship by engaging in this reality, and avoiding it - the process of doing both seems important.



## Discussion: Limitations

- Cross-sectional – cannot make any causal assumptions
- Sample size
- Language impairment – challenges of interviewing someone with cognitive decline
- No formal measure of relationship quality used

## Implications and Future Work

### Clinical

- Services to routinely ask about key relationships
- May lead to improved identification of those who are struggling
- Development of peer support groups and couple support

### Research

- Generalisability to other groups: young onset dementia, later life re-marriage
- Explore the relative role of the different factors
- Longitudinal research – Are the same factors relevant at later stages?

