

THE UNIVERSITY OF HULL

Relationships and dementia: An exploration of partners' experiences

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by

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Overview

This portfolio thesis is made up of three parts; a systematic literature review, an empirical paper and a set of associated appendices. The thesis as a whole considers the experiences of relationships for partners within couple dyads, in which one person is diagnosed with dementia.

The first section is a systematic literature review which explores how couples faced with dementia actively work to sustain their couplehood, as well as the challenges that may arise that pose a threat to couplehood. Ten papers were identified and reviewed, to gain an understanding of the similarities and contradictions in the experiences of couples across the literature. Four super-ordinate themes and nine subthemes were identified across the papers. The findings, which are from both the UK and abroad, are considered within the context of the existing literature in this field, and suggestions for future research are made.

The second section is an empirical paper, which explores how people experience enduring love after their partner has moved into residential care due to dementia. The aim was to understand how couples might sustain love and closeness in their relationship, despite living apart and despite the challenges that dementia brings. A qualitative methodology, using semi-structured interviews was used to investigate participants' lived experiences. Nine participants, six men and three women, who were aged over 65 and married to a person living with dementia who had moved into residential care were interviewed. Interpretative Phenomenological Analysis was used to explore participants' subjective experiences. Three super-ordinate themes and eight subthemes were identified. The findings are considered within the context of existing

literature, and the clinical implications are discussed.

The third section incorporates appendices from both the systematic literature review and empirical paper, in addition to a reflective statement and an epistemological statement, both reflecting the researchers' journey through the research process.

Total word count: 30,669 (including abstracts, tables and appendices, excluding references)

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Part One: Systematic Literature Review

**The shared experience of relationships for couples living with dementia: A
systematic literature review and qualitative synthesis**

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This paper is written in the format ready for submission to the Journal of International
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Abstract

Background

Despite growing awareness of the importance of relationships for people living with dementia (PLwD), there is still very little understanding of couples' shared perspectives on the experiences of relationships when one partner is diagnosed with dementia. This review aimed to synthesize qualitative research that has explored the shared experiences of relationships for PLwD and their partners, in order to understand how marital and/or cohabiting couples sustain couplehood, and the potential challenges that arise which pose a threat to couplehood.

Method

A systematic literature search was conducted using three electronic databases; PsycINFO, MEDLINE, and CINAHL Complete. The findings of included studies were synthesized using a narrative synthesis approach.

Results

The findings of 10 papers included within the review provided knowledge about couples' shared experiences of relationships when living with dementia. The findings were described by four themes: 'Dementia as a threat to couplehood'; 'Love is indestructible'; 'Holding on to what remains' and 'Enhancing a positive relationship'. The findings suggest that couples living with dementia experience potential threats to couplehood with progression of dementia, however they build on the capital of love to

maintain normality, negotiate roles and enhance their relationships in order to sustain couplehood.

Conclusion

The review highlights the importance of considering experiences of relationships from a dyadic perspective, with implications for clinical practice and research recognizing the need for services to support couples' efforts to enhance their relationships in spite of dementia.

Keywords: Dementia, couples, relationships, subjective, experience, qualitative, synthesis, review

Introduction

Dementia has been viewed as a relational condition, with growing awareness of its' impact on the lives of, and the relationships between people living with dementia (PLwD) and the people that care for and care about them (Boss, 2011; Merrick, 2012). Internationally, statistics suggest that PLwD are most likely to be cared for by their spouses (Wimo *et al.*, 2013; Brodaty and Donkin, 2009). This means that married and/or cohabiting couples experience the caring dynamic within the context of their ongoing relationship. It has been suggested that compared to other partnerships, the marital relationship is most vulnerable to strain and risk of breakdown, due to the significant changes required in adapting to the onset of dementia (Evans and Lee, 2014). As such, there has been a move to understanding the experiences of PLwD within their relational context, by focusing on relationship-centered care and couplehood (Nolan *et al.*, 2006; Kaplan, 2001). Couplehood is defined as the extent to which couples feel like a 'we' in their relationship, compared to two individual 'I's' (Kaplan, 2001). Much of the existing literature exploring the experience of relationships for couples where one partner is diagnosed with dementia has focused primarily on the views and experiences of the caregivers - contradicting the idea of relationship-centered care. This suggests that further understanding is required about the experiences of couples in this situation.

The findings of existing literature reviews that have explored caregivers' perspectives on relationship changes in dementia suggest that spousal caregivers report negative changes in their marital relationships as a result of their new caring role (Evans and Lee, 2014). Changes reported include a decline in intimacy, reciprocity and communication, reduced emotional support, fewer shared activities and reduced relationship quality (Quinn *et al.*, 2009; Ablitt *et al.*, 2009; Evans and Lee, 2014; Baikie, 2002). A small

proportion of these reviews also found positive outcomes for caregivers, such as increased closeness, warmth and mutual affection within marital relationships, as well as increased laughter between partners (Quinn *et al.*, 2009; Ablitt *et al.*, 2009).

There is a limited amount of research that has focused on the experiences of relationships from the perspective of the partner diagnosed with dementia. For example, Tranvåg *et al.* (2015) found that PLwD continued to experience reciprocal feelings of love, affection and appreciation for their partners following the onset of dementia. Despite this, the vast majority of findings relating to the experiences of relationships for PLwD have emerged serendipitously, without the studies initially aiming to do so (Moyle *et al.*, 2015; Frazer *et al.*, 2011; Griffin *et al.*, 2015).

These research findings and associated conceptual issues highlight the need to know more about the shared lived experiences amongst PLwD and their partners. An existing review by Braun *et al.* (2009) aimed to explore how dementia can affect both partners within a couple. However, the research they reviewed primarily focused on the separate views of each individual, with only a small proportion of included studies exploring the shared perspectives of the dyad. Furthermore, the research that focused on the shared perspectives of the couple was mainly quantitative and observational, suggesting that the joint perspective of both individuals has so far been neglected in reviews of qualitative research. Due to the suggestion that positive and negative outcomes can result, it is important to explore how couples actively work to sustain their couplehood, as well as the challenges that may arise which pose a threat to the experience of couplehood. Building on previous literature, the current review therefore aimed to synthesize qualitative research that has explored the shared experiences of relationships and couplehood for couples living with dementia (CLwD).

The questions underpinning this review were:

1. How do PLwD and their partners sustain couplehood within their dyad, and what are their shared experiences of this?
2. What challenges arise that pose a threat to couplehood for PLwD and their partners?

Method

Search terms

A systematic search was completed in April 2016, using three electronic databases: PsycINFO, CINAHL Complete and MEDLINE. These databases were chosen in order to find studies from a range of professional disciplines relevant to dementia research. Additional studies were found through manual searches of the reference lists of included papers.

Search terms were developed from previous literature reviews that sought to review peoples' experiences of dementia, or sought to review experiences of relationships in other chronic conditions (Steelman *et al.*, 2006; Wolverson *et al.*, 2015; Traa *et al.* 2015). Additional search terms were gathered from the key words of relevant papers. The search terms were divided into four categories:

- 1) Terms related to dementia: 'dementia' or 'Alzheimer's'.
- 2) Terms which consider lived experience: 'perspective' or 'experience' or 'views' or 'meaning' or "lived experience" or "subjective experience" or 'wellbeing' or 'adjustment'.

- 3) Terms selected to access information about love and relationships: ‘relationship’ or ‘partner’ or ‘love’ or ‘loving’ or ‘marriage’ or ‘marital’ or “romantic love” or ‘romantic’ or ‘romance’ or ‘intimacy’ or ‘sex’ or ‘couple’ or ‘husband’ or ‘wife’ or ‘wives’ or ‘spouse’.
 - 4) Abstracts that explicitly stated that an interview methodology was used: ‘interview’.
- This was to ensure breadth of titles, but to reduce the return of irrelevant studies.

Truncations of the above search terms (e.g. *dement**) were used to allow flexibility in terms and ensure a greater depth of studies could be identified.

Additional filters were applied, to ensure the return of studies that were:

- Written in the English Language only.
- Published from January 1990 - April 2016 only. In the late 1980s, Lyman (1989) called for the subjective perspectives of PLwD to be included within research, which would indicate a rise in this type of research after this time.
- Peer-reviewed only, to evidence scientific rigor.

Inclusion strategy

Papers were chosen for inclusion if they met the following criteria:

- The study aimed to explicitly explore experiences of relationships for couples where one partner is living with dementia. Alternatively, if a study did not aim to directly explore relationships and/or couplehood, it was still included if it had at least one discrete, overarching theme within the findings that related to experiences of CLwD (supported by at least two quotes).
- The quotes within each relevant theme explicitly focused on experiences of

relationships, rather than day-to-day experiences of living with dementia.

- The study employed a qualitative or mixed-methods methodology. Studies had to have incorporated a qualitative interview to ensure that subjective lived experiences could be analyzed.
- The study was empirical (e.g. not a literature review), and used a clear analytic procedure (e.g. narrative analysis).
- The study was written in the English language, to facilitate analysis by the authors.

Exclusion strategy

Papers were excluded if they met the following criteria:

- The combination of aims and results of the study were not relevant to couple dyads' experiences of their relationships.
- Experiences of relationship appeared only as a subtheme within the study, as opposed to an overarching theme.
- The study did not focus on the experiences of PLwD - e.g. different medical problems or co-morbidities.
- The study focused on people with early-onset dementia. Rather than having an age cut-off, the study must have specifically stated that the participants were diagnosed with early-onset dementia for it to be excluded. Based on evidence from Clemerson *et al.* (2013) and Alzheimer's Society (2015), people diagnosed with early-onset dementia are often at a different stage of life, which may include having a career, dependent children or older parents to care for, and as such, they may often feel too young to have developed the condition (Alzheimer's Society, 2015; Clemerson *et al.*, 2013). This therefore means that they are likely to have different experiences of living with dementia.

- The study evaluated prevalence or risk factors for dementia or cognitive impairment.
- The study was a literature review, as opposed to an empirical study.
- The study evaluated interventions, models and treatments to support or enhance life for PLwD.

Quality assessment

To assess methodological quality, an adapted quality assessment tool was used (see Appendix B). Two existing methodological quality checklists suitable to assess qualitative research were adapted to fit with the characteristics of the studies included within the current review. The first measure was the methodology checklist for qualitative studies, developed by the National Institute for Health and Care Excellence (NICE, 2012), and the second quality measure was the Mixed Methods Appraisal tool (version 11) (MMAT) (Pluye *et al.*, 2011). The quality assessment was not used as part of the inclusion/exclusion criteria, but was considered a useful tool to critique and contextualize the findings and to consider the quality of the body of literature overall.

The first author assigned numerical scores (0-1 or 0-2) to each category, to allow an overall quality percentage rating to be provided. More weight (scores of 0 or 2) was given to three questions within the checklist: 5.2. ('Is the analysis reliable?'), 5.4 ('Are the findings convincing?') and 5.5 ('Are the conclusions adequate?'), as these were considered to be the most important and relevant factors to consider in the review, given the questions underpinning it.

The first author assessed the methodological quality of each paper initially, before a subset (5 of the 10 papers) were randomly selected and independently assessed by the

second author. Any discrepancies in scoring were discussed until a final consensus was reached.

Data Synthesis

Data was analyzed using qualitative narrative synthesis, to allow identification of common themes and concepts across the literature. Narrative synthesis encourages the author to narrate the findings, and investigate common patterns and discrepancies within the body of research (Popay *et al.*, 2006; Ryan, 2013).

The process of narrative synthesis involved four key stages, as recommended by Popay *et al.* (2006):

- 1) Development of relevant search terms to ensure the return of suitable research articles, and the use of an inclusion and exclusion criteria to filter out less relevant papers.
- 2) Conduction of a descriptive data extraction, with extraction of information necessary for synthesis.
- 3) Identification of common themes and patterns across the findings, taking into account similarities as well as contradictions.
- 4) Use of quality ratings to assess the robustness of the synthesis in relation to existing literature within this field.

Results

Identification of relevant studies

From the computerized database search, 8 papers met inclusion criteria, and 2 more papers were included following a manual search of included papers' reference lists.

Relevant authors were contacted but no additional papers were identified. This resulted in 10 papers suitable for inclusion. The selection process is outlined in Figure 1.

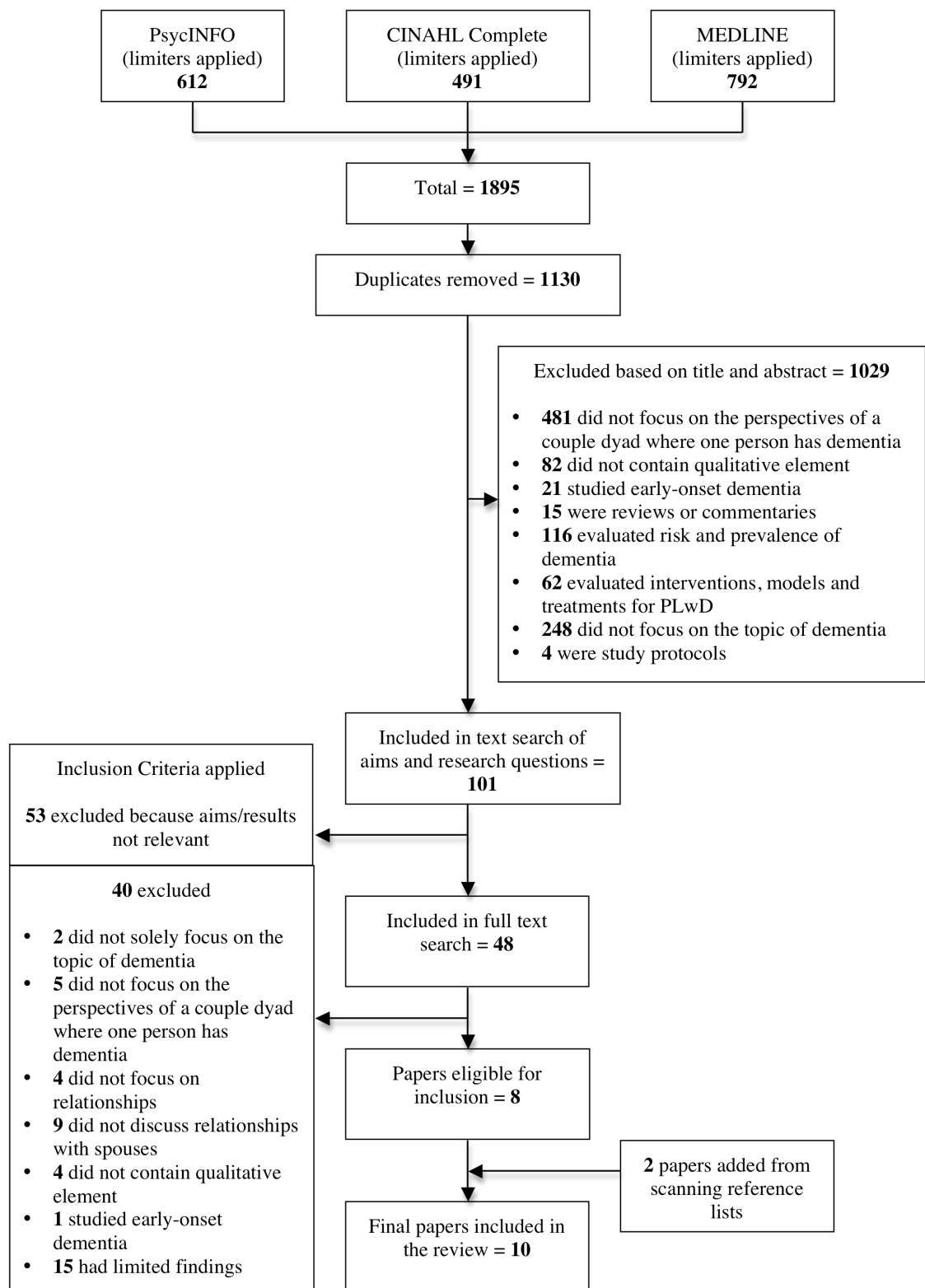


Figure 1. A flowchart to show the paper selection process

Characteristics of included studies

Most of the studies had at least one aim of exploring relationships for PLwD and their partners. Other studies aimed to gain experiences of living with dementia more generally, specifically in terms of receiving a dementia diagnosis (Derksen *et al.*, 2006; Vernooij-Dassen *et al.*, 2006) and engaging in physical activity (Malthouse and Fox, 2014). These studies found that themes of relationships emerged serendipitously. The majority of the studies employed joint semi-structured interviews (N=7), and the remaining studies (N=3) used separate semi-structured interviews but analyzed the findings together. One study employed mixed methodology, utilizing quantitative measures in addition to joint semi-structured interviews (Davies, 2011). Sample sizes varied, with two studies using single case studies of couples (Daniels *et al.*, 2007; Hellström *et al.*, 2005) to samples of 20 couples (Hellström *et al.*, 2007). This gave a total of 92 couples across studies (mean = 9.2 couples per study). Relationship lengths across studies varied between 5 and 63 years. The proportion of participants who were remarried was not reported within any of the studies. A more detailed summary of the characteristics of included studies is displayed in Table 1 (ordered alphabetically).

Table 1. A summary of the main characteristics of included studies

Author(s), date of publication, location	Title of Study	Study aims	Relevant interview topics and themes	Sample characteristics - Sample size (people living with dementia and spouses), dementia subtype (AD = Alzheimer's Disease, VaD = Vascular Dementia, LBD = Lewy Body Dementia, FTD = Fronto-temporal Dementia), age, gender (person living with dementia = PLwD, partner without dementia = partner, male = M, female = F), time since diagnosis prior to interview, length of marriage	Methodological approach
Daniels <i>et al.</i> (2007), USA	An Exploration of the Marital Relationship	To explore how one couple constructed a shared story of their	Meaning of a marriage, experience as husband and wife,	1 couple where one partner had dementia diagnosis (AD) Aged 'mid 80s'	Qualitative single- subject case study, three joint interviews

	and Alzheimer's Disease: One Couple's Story	marriage when Alzheimer's Disease is a component of their relationship	what relationship has been like in the past year, what events or issues have most significantly impacted marriage, 'Experiences with AD'	PLwD: 1 F Partner: 1 M Time since diagnosis: 5 years Married: 63 years	with one couple across two months, analyzed using narrative analysis (holistic content analysis)
Davies (2011), Canada	Preserving the "us identity" through marriage commitment while living with early-	To explore how married couples experienced the meaning of commitment through memory loss represented by transitional process of pre-diagnosis, diagnosis	Impact of marriage commitment over the early, middle and later years of marriage, Relational impact pre-diagnosis, diagnosis and post-	6 couples where one partner had dementia diagnosis (6 early-stage AD) Aged 65-83 (mean not stated) PLwD: 4 F, 2 M Partner: 2 F, 4 M Time since diagnosis: Not stated Married: 44-60 years (mean unknown)	Mixed methods: quantitative measures plus semi-structured interviews with core methodology of narrative analysis, analyzed using

	stage dementia	and post-diagnosis	diagnosis, ‘Partnership for life’, ‘Reciprocity’, ‘Resilience’, ‘Forgiveness’		thematic and content analysis
Derksen <i>et al.</i> (2006), The Netherlands	Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis	To give an in-depth description of the impact of receiving the diagnosis of dementia, both on patients and the patients’ proxies	‘Partnership patients and partners’ - Awareness of the changes in interpersonal relationships with subthemes ‘Reliance on the partner’, ‘Notion of partner’s burden’, ‘Changed	18 couples where one partner had dementia diagnosis (subtype not stated) Age: Range not stated, mean age 71 years PLwD: 4 F, 14 M Partner: Not stated Time since diagnosis: 2-10 weeks (memory problems 1-5 years) Married: Not stated	Separate semi- structured interviews with person diagnosed with dementia and their carer, analyzed using grounded theory methodology

relationship'					
Hellström <i>et al.</i> (2005), Sweden and UK	'We do things together' A case study of 'couplehood' in dementia	To explore the impact of dementia on the couples' understanding of home, their everyday life and relationships, and their dignity and autonomy; to explore how the relationship of a couple with dementia has continued to flourish	'A loving and helping relationship', 'Doing things together'	1 couple where one partner had dementia diagnosis (AD) Aged: 83 and 86 PLwD: 1 F Partner: 1 M Time since diagnosis: 7 years Married: 11 years	Qualitative single-subject case study, eight separate interviews with one couple (16 interviews in total) across 18 months, analyzed using constructivist approach to grounded theory methodology
Hellström <i>et al.</i> (2007), Sweden and	Sustaining 'couplehood' Spouses'	To explore the ways in which people with dementia and their	Quality of everyday life and their relationship,	20 couples where one partner had dementia diagnosis (most common diagnosis was mixed dementia)	152 interviews (3 x 6 monthly) with 20 couples conducted

UK	strategies for living positively with dementia	spouses experience dementia over time, especially the impact it has on their interpersonal relationships and patterns of everyday life	‘Sustaining couplehood’, ‘Talking things through’, ‘Being affectionate and appreciative’, ‘Making the best of things’, ‘Maintaining involvement’, ‘Moving on’	Aged: 65-85 (mean age of PLwD 77 years, mean age of spouse 76 years) PLwD: 8 F, 12 M Partner: Unknown Time since diagnosis: Not stated Married/cohabiting: 8-60 years (mean 49 years)	over 5 years, analyzed using constructivist approach to grounded theory methodology
Hydén and Nilsson (2015), Sweden	Couples with dementia: Positioning the ‘we’	To investigate how spouses in couples with dementia position themselves in relation to one other, by analyzing	When they met and the couple’s everyday life now, ‘Couple as a social unit’, ‘Erosion of the	11 couples where one partner had dementia diagnosis (1 VaD, 1 LBD, 9 AD) Aged 57-86 (mean age 69) PLwD: 5 F, 6 M	Joint interviews conducted with 11 couples, analyzed using positioning theory and

		pronoun use	we'	Partner: 6 F, 5 M Time since diagnosis: <1 year-4 years (mean 2.25 years) Married: 12-60 years (mean 44 years)	conversational analytic approach
Malthouse and Fox (2014), UK	Exploring experiences of physical activity among people with Alzheimer's disease and their spouse carers: a qualitative study	To gain insight into perceptions about the importance of physical activity; to improve understanding about the barriers and facilitators to physical activity for people with Alzheimer's disease and their spouse carers and consider the development of activity	'Couple', with subthemes 'Couple: changing roles', 'Couple: good days, bad days' - routine and mood'	5 couples where one partner had dementia diagnosis (AD) Aged: 64-84 years (mean not stated) Gender: Not stated Time since diagnosis: Not stated Married: Not stated	Separate semi- structured interviews with person diagnosed with dementia and their spouse, analyzed using inductive thematic analysis framework

		interventions that would acceptable, sustainable and feasible for both groups			
Merrick <i>et al.</i> (2013), UK	Couples constructing their experiences of dementia: A relational perspective	To understand the experience of dementia from a relational perspective	Questions related to the couples' history, experience and impact of living with dementia as a couple, how they made sense of and adjusted to dementia, 'Foundations', 'Altered Structures', 'Flexible	7 couples where one partner had dementia diagnosis (4 AD, 1 VaD, 1 Mixed - AD and VaD, 1 FTD) Aged 63-87 (mean age 76) PLwD: 2 F, 5 M Partner: 5 F, 2 M Time since diagnosis: 2-9 years (mean 4.5 years) Married/partners for: 5-61 years (mean 42.6 years)	Joint semi-structured interviews conducted with 7 couples, analyzed using IPA

			scaffolding’, ‘Reviewing the plans’		
Molyneaux <i>et al.</i> (2011), UK	The co- construction of couplehood in dementia	To understand the co- construction of couplehood by couples where one partner has dementia	‘Shifting identities within couplehood’ and ‘Maintaining the relationship despite dementia’, ‘The good old days’, ‘Technically being a ‘carer’’, ‘Sharing the experience of dementia’	5 cohabiting couples where one partner had dementia diagnosis (5 AD) Aged 72-84 (mean age 77.4) PLwD: 2 F, 3 M Partner: 3 F, 2 M Time since diagnosis: 1-4 years (mean 2.5 years) Married/cohabiting: 11-55 years (mean 45.2 years)	Joint interviews conducted with 5 couples, analyzed using constructivist Grounded Theory methodology
Vernooij- Dassen <i>et</i>	Receiving a diagnosis of	To describe and understand the impact	External topics - the person’s	18 couples where one person had dementia diagnosis and the other was a	Separate semi- structured interviews

<i>al.</i> (2006),	dementia The	of receiving a diagnosis	relationships,	family member (subtype not stated)	with person
The	experience	of dementia for	relationship with	Aged: Range not stated, mean age of	diagnosed with
Netherlands	over time	individuals and their	partner, 'Changes in	PLwD 71 years (mean age of spouse not	dementia and their
and UK		family carers over time,	partnership'	stated)	family member,
		in order to suggest best		PLwD: 4 F, 14 M	analyzed using
		practice for services and		Partner: Not stated, 15 were	grounded theory
		practitioners		spouses/cohabiting	methodology
				Time since diagnosis: 2-10 weeks	
				(memory problems <1-4 years)	
				Married/cohabiting: Not stated	

Methodological Quality

Ratings of methodological quality for each paper are displayed in Table 2. As can be seen from the table, none of the papers achieved a quality rating lower than 39%, meaning that they all at least partially filled quality criteria. A more detailed overview of the quality assessment process can be found in Appendix B and C.

Table 2. A summary of the methodological quality ratings of included studies based on NICE (2012) and MMAT (Pluye *et al.*, 2011) guidelines

Study (authors and date of publication)	Quality Rating
Daniels <i>et al.</i> (2007)	100%
Davies (2011)	39%
Derksen <i>et al.</i> (2006)	73%
Hellström <i>et al.</i> (2005)	80%
Hellström <i>et al.</i> (2007)	80%
Hydén and Nilsson (2015)	87%
Malthouse and Fox (2014)	80%
Merrick <i>et al.</i> (2013)	100%
Molyneaux <i>et al.</i> (2011)	73%
Vernooij-Dassen <i>et al.</i> (2006)	73%

To judge methodological quality, the first author weighted scores on the assessment tool more heavily for the reliability of analysis, how convincing the findings were, and the adequacy of the conclusions. These were deemed important aspects of determining the overall reliability and validity of the body of literature. Although the findings and conclusions for all but one study (Davies, 2011) were considered convincing and

adequate, the reliability of analysis was questioned for five of the studies (Hydén and Nilsson, 2015; Hellström *et al.*, 2005; Hellström *et al.*, 2007; Davies, 2011; Molyneaux *et al.*, 2011) due to very little mention of quality assurance. In line with this, half of the studies did not demonstrate any explicit consideration of the impact of researcher bias (Davies, 2011; Derksen *et al.*, 2006; Malthouse and Fox, 2014; Vernooij *et al.*, 2006).

Whilst the role of the researcher was described in detail within the procedure of most studies, their role in analysis for five of the studies was less clear (Vernooij *et al.*, 2006; Davies, 2011; Derksen *et al.*, 2006; Hellström *et al.*, 2005; Hellström *et al.*, 2007).

Of the ten studies, the mixed methods study (Davies, 2011) was the only one considered ‘not defensible’ in justifying its study design. Davies (2011) gave limited reasoning for incorporating quantitative data, and it was unclear what the quantitative element of the results added to the qualitative findings. The quality of data collection for this study was also rating less highly as an interview schedule was not provided, therefore the study could not be easily replicated.

No papers were excluded from the systematic review based on their methodological quality, as it was felt that the findings taken together were important for understanding the body of literature as a whole.

Synthesis of findings

A synthesis of the data identified four themes and nine subthemes. Table 3 shows the papers relating to each theme.

Table 3. A table of themes and subthemes identified through synthesis of the data

Super-ordinate themes	Subthemes	Papers
(1) Dementia as a threat to couplehood	<i>Threat from changing abilities</i>	Davies, 2011; Derksen <i>et al.</i> , 2006; Hellström <i>et al.</i> , 2007; Malthouse and Fox, 2014;
	<i>linked with progression of dementia</i>	Merrick <i>et al.</i> , 2013; Molyneaux <i>et al.</i> , 2011; Vernooij <i>et al.</i> , 2006
	<i>Threat of social isolation and separation</i>	Daniels <i>et al.</i> , 2007; Hellström <i>et al.</i> , 2007; Hydén and Nilsson, 2013; Merrick <i>et al.</i> , 2013; Vernooij <i>et al.</i> , 2006
(2) Love is indestructible	<i>Commitment</i>	Daniels <i>et al.</i> , 2007; Davies, 2011; Hellström <i>et al.</i> , 2005; Merrick <i>et al.</i> , 2013; Molyneaux <i>et al.</i> , 2011
	<i>Closeness and affection</i>	Daniels <i>et al.</i> , 2007; Davies, 2011; Hellström <i>et al.</i> , 2005; Hellström <i>et al.</i> , 2007; Hydén and Nilsson, 2013; Merrick <i>et al.</i> , 2013; Molyneaux <i>et al.</i> , 2011
	<i>Reciprocity</i>	Davies, 2011; Hellström <i>et al.</i> , 2005; Merrick <i>et al.</i> , 2013; Molyneaux <i>et al.</i> , 2011
(3) Holding on to what remains	<i>Negotiating roles</i>	Davies, 2011; Hellström <i>et al.</i> , 2005; Hellström <i>et al.</i> , 2007; Hydén and Nilsson, 2013; Merrick <i>et al.</i> , 2013; Molyneaux <i>et al.</i> , 2011
	<i>Maintaining normality</i>	Davies, 2011; Hellström <i>et al.</i> , 2007; Malthouse and Fox, 2014; Merrick <i>et al.</i> , 2013;

		Molyneaux <i>et al.</i> , 2011; Vernooij <i>et al.</i> , 2006
(4) Enhancing a positive relationship	<i>New appreciation of life and each other</i>	Daniels <i>et al.</i> , 2007; Derksen <i>et al.</i> , 2006; Hellström <i>et al.</i> , 2005; Hellström <i>et al.</i> , 2007; Merrick <i>et al.</i> , 2013; Vernooij <i>et al.</i> , 2006
	<i>Searching for positives</i>	Daniels <i>et al.</i> , 2007; Hellström <i>et al.</i> , 2007; Hydén and Nilsson, 2013; Merrick <i>et al.</i> , 2013; Molyneaux <i>et al.</i> , 2011

The themes reflect a tension between the potential threats to couplehood, and the maintenance and enhancement of couple relationships, in the presence of dementia.

(1) Super-ordinate theme: Dementia as a threat to couplehood

All of the studies recognized how dementia is experienced as a potential threat to couplehood. This threat originates both from cognitive changes experienced by PLwD, and also couples' experiences of social isolation that result following the diagnosis.

Subtheme: Threat from changing abilities linked with progression of dementia

Whilst several studies found that couples strive to maintain their relationships, this did not eliminate ongoing fears that both partners held about the changing dynamics within their relationship as dementia progresses. With acknowledgement of recent changes to their relationships, couples were evidently concerned about the unknown progression of dementia and its impact on their relationships into the future. PLwD described feelings of burden and guilt in response to their changing needs as their cognition deteriorated (Molyneaux *et al.*, 2011; Merrick *et al.*, 2013; Davies, 2011; Derksen *et al.*, 2006; Vernooij *et al.*, 2006; Hellström *et al.*, 2007).

PLwD: "*What a pity for you to get such a difficult husband*" (pp. 403)

Taken from theme: Changes in partnership (Vernooij *et al.*, 2006).

Davies (2011) found that the presence of dementia in a relationship contributed to a move from both individuals having 'an independent, equal standing role in their relationship' (pp. 9) to the PLwD having increased dependency on their partner without

dementia (partner). This dependency meant that partners were required to shift their 'partnership balance' (Vernooij *et al.*, 2006, pp. 404) and restrict their own independence in order to provide necessary support to the PLwD (Molyneaux *et al.*, 2011; Merrick *et al.*, 2013; Derksen *et al.*, 2006; Malthouse and Fox, 2014). As such, this indicates gradual distancing from the independent roles within the relationship with progression of dementia, and may indicate a threat to couplehood:

"It might have been possible for Pauline to go out more on her own, that sort of thing you know, because I mean that can't happen now erm, I mean we may have done things, more things independently" (pp. 6)

Taken from theme: Shifting identities within couplehood (Molyneaux *et al.*, 2011).

Subtheme: *Threat of social isolation and separation*

Several of the studies found that with the progression of dementia, individuals within the couple became more separate and this therefore posed a threat to couplehood.

Hydén and Nilsson (2013) suggested that in conversation, CLwD tend to refer to themselves as 'I' rather than as 'we', especially as the dementia continues. This was suggested to present challenges to the "*couple as a social unit*" (Hydén and Nilsson, 2013; theme, pp. 10). Two studies also found that despite couples wishing to continue their relationship as a 'we', that over time they felt they were "*increasingly becoming an 'I'*" (Hellström *et al.*, 2007; quote, pp. 403), with "*erosion of the we*" (Hydén and Nilsson, 2013; theme, pp. 13).

A number of studies also identified that partners felt increasingly lonely (Merrick *et al.*, 2013; Vernooij *et al.*, 2006; Daniels *et al.*, 2007; Hellström *et al.*, 2007). Merrick *et al.*

(2013) found that loneliness was experienced by both partners, with one PLwD recognizing the loss of communication in his relationship after this was raised by his wife.

Partner: *"We just don't talk much now. I think the best talks we have are when we go to Marks and Spencer's cafe and have a cappuccino and then we sit facing one another and we chat . . . not the same as we used to"* (pp. 41)

PLwD: *"I don't have a solution to that really. I mean I wish there were but. . . It's depressing really"* (pp. 41)

Taken from theme: Altered structures (Merrick *et al.*, 2013).

Partner: *"Sometimes I feel so lonely"* (pp. 403)

Taken from theme: Changes in partnership (Vernooij *et al.*, 2006).

This occurred as a result of loss of companionship; *"We are no longer equal partners . . . there is less to talk about"* (Vernooij *et al.*, 2006; quote, pp. 403), changes to the PLwD's demeanor, loss of communication (Merrick *et al.*, 2013), and loss of shared memories (Daniels *et al.*, 2007). Merrick *et al.* (2013) found that one partner *"used to feel quite secure"* (pp. 40) but with the progression of dementia, felt she had lost the mutual support and security within her relationship and stated *"sometimes I feel when things crop up, difficulties, problems, I just can't cope"* (pp. 40). For another partner, loss of humor was significant:

"The bit that really gets me down is when we've had a bit of a laugh . . . I try and carry on the joke or conversation and he can't remember the conversation" (pp. 41)

Taken from theme: Altered structures (Merrick *et al.*, 2013).

These changes threaten couplehood due to increased social isolation. Hellström *et al.* (2007) framed this as a couple being made up of “*two small worlds*” (pp. 403); in which there is a “*common world*” (pp. 403) but also an “*own world*” (pp. 403).

(2) Super-ordinate theme: Love is indestructible

Despite these threats, the majority of the studies portrayed the desire of the couple unit to avoid defeat and maintain their relationship by using resources already available to them. The studies suggested that an accumulated capital of love underpins the ways in which couples respond to threats associated with dementia in order to preserve their relationship and their sense of couplehood. Across the studies reviewed, love was experienced as indestructible, due to its strong formation through couples’ shared lifetimes together, and as such would not disappear in the presence of dementia. Love forms the foundation on which couples actively work to maintain and enhance their relationships in order to sustain couplehood.

Subtheme: *Commitment*

Within the context of marital love, several studies referred to the vows that couples made on their wedding day, evidencing the commitment that couples had to their marriage regardless of the challenges present in their lives (Merrick *et al.*, 2013; Molyneaux *et al.*, 2011; Davies, 2011).

Partner: “*I married Mark, in sickness and in health and now he’s really sick, but it’s for life*” (pp. 39)

Taken from theme: Foundations (Merrick *et al.*, 2013).

Commitment was referred to as uninterrupted, continuous and lifelong - acting as a foundation for couples facing adversity (Daniels *et al.*, 2007; Merrick *et al.*, 2013).

Three studies indicated that commitment was deeply embedded in relationships, and that dementia was simply a new stage for couples to face in their lives together, therefore meaning that changes were naturally adapted to (Hellström *et al.*, 2005; Daniels *et al.*, 2007; Davies, 2011). A shared sense of commitment buffers against the challenges that dementia brings to a relationship, and motivates couples to persevere and live their lives without any significant disruptions (Davies, 2011; Daniels *et al.*, 2007).

PLwD: “*We don’t segregate, we don’t separate, we’re together*” (pp. 6)

Taken from opening results section (Davies, 2011).

Subtheme: *Closeness and affection*

The majority of the studies reported that closeness and affection, as components of love, were actively maintained within a couple following the onset of dementia (Hellström *et al.*, 2007; Molyneaux *et al.*, 2011; Merrick *et al.*, 2013; Hydén and Nilsson, 2013; Davies, 2011; Daniels *et al.*, 2007; Hellström *et al.*, 2005). Reciprocal closeness and affection were referred to in terms of physical touch and kissing (Hellström *et al.*, 2007; Hydén and Nilsson, 2013), companionship, sexuality (Davies, 2011) laughter and shared pleasures (Hellström *et al.*, 2005). Couples also recognized that they continued to relate to each other in the same way, and continued to appreciate each other regardless of the presence of dementia (Hellström *et al.*, 2007; Molyneaux *et al.*, 2011).

Partner: *“As he is passing me I might get a kiss from him any time, that is no problem, that is nice. Then I thank him very much [laughing]”* (pp. 393)

Taken from theme: Being affectionate and appreciative (Hellström *et al.*, 2007).

Merrick *et al.* (2013) and Hydén and Nilsson (2013) also found that not only was closeness maintained, but dementia also brought a number of couples closer together, with development of a new closeness in the relationship following the onset of dementia.

Partner: *“Well we’ve always been very close, so it’s not a big change . . . I think we’ve become closer”* (pp. 41)

Taken from theme: Altered Structures (Merrick *et al.*, 2013).

Subtheme: *Reciprocity*

Several studies identified that the caring role was not necessarily seen as a separate entity to the relationship. Instead caring was recognized as a way of ‘returning the favor’ of care that they had received earlier in life (Molyneaux *et al.*, 2011; Merrick *et al.*, 2013, Davies, 2011).

Partner: *“It’s just you do that, you know, but she’s taken care of me when, you know, so she, the house was always clean, the food on the table, the kids have always been well dressed so you know, I say it’s a knock for knock you know”* (pp. 14)

Taken from theme: Technically being a ‘carer’ (Molyneaux *et al.*, 2011).

Within the single case study by Hellström *et al.* (2005), the spouse had referred to the couple relationship as ‘genuinely reciprocal’ (pp. 13). This described how throughout a shared life together, both partners had contributed to a reciprocal relationship where they had both loved and helped each other - and this continued despite the presence of dementia:

Partner: “*Certainly I have a mission, I have an important mission to help her, but we are also good company for each other*” (pp. 14)

Taken from theme: A loving and helping relationship (Hellström *et al.*, 2005).

(3) Super-ordinate theme: Holding on to what remains

Where there was a strong foundation of love, couples across the literature engaged in negotiation of roles and routines to avoid changes to their relationship. This was identified as a process in which couples maintained their existing couplehood as much as possible, and found new meaning in their relationship.

Subtheme: *Maintaining normality*

Several studies recognized that following a diagnosis, couples sought to “*move on with life*” (Davies, 2011, pp. 9) and maintain normality within their relationship (Molyneaux *et al.*, 2011; Merrick *et al.*, 2013; Davies, 2011; Vernooij *et al.*, 2006; Hellström *et al.*, 2007). Couples were acknowledged to pursue normality as much as possible through continuing routines and continuing to engage in past times (Malthouse and Fox, 2014; Hellström *et al.*, 2007; Molyneaux *et al.*, 2011; Davies, 2011):

PLwD: *“and we live well, we have a glass of wine with the dinner every day. We think we can afford that and it can’t damage”*

Partner: *“. . . and he [husband with dementia] makes coffee for me every morning . . . and makes a sandwich and then we sit dozing by the telly in the morning”* (pp. 395)

Taken from theme: Making the best of things (Hellström *et al.*, 2007).

Subtheme: *Negotiating roles*

Although the progression of dementia required some roles to be adjusted, couples described negotiating roles in order to maintain PLwD’s involvement as much as possible. Through sharing of roles, and subtly helping the PLwD, couples were able to continue their individual roles within the relationship. Partners offered assistance to PLwD as they were carrying out tasks by ‘keeping them company’ (Hellström *et al.*, 2005, pp. 16), as opposed to taking over (Merrick *et al.*, 2013; Hellström *et al.*, 2007; Hellström *et al.*, 2005). This maintained the PLwD’s sense of identity, and focused on what PLwD could still achieve, rather than focusing on what they could no longer do (Hellström *et al.*, 2005; Hellström *et al.*, 2007; Merrick *et al.*, 2013).

Partner: *“the difficulties come when she is baking, you know. ‘Have I put in the yeast?’, then I ask her ‘tell me out loud what you put in’, because we usually help each other”* (pp. 15)

Taken from theme: A loving and helping relationship (Hellström *et al.*, 2005).

Couples were also found to actively share tasks, chores, organization of finances, and administration of medication (Molyneaux *et al.*, 2011; Hydén and Nilsson, 2013; Davies, 2011; Hellström *et al.*, 2007). Not only did this ensure that the PLwD’s agency

was preserved, it also gave couples an opportunity to spend more time together, and as such was viewed as a positive strategy for maintaining the relationship (Molyneaux *et al.*, 2011).

Partner: “*we had to do a couple of chores in the morning so we did it together*” (pp. 12)

Taken from theme: Reciprocity (Davies, 2011).

(4) Super-ordinate theme: Enhancing a positive relationship

Despite the potential for dementia to pose a threat to couplehood, it was also evidenced across several studies that dementia can contribute to enhancing relationships by encouraging couples to find a new way of being together. A number of studies found that dementia influences how couples relate to each other, and how they change their approach to life together.

Subtheme: New appreciation of life and each other

Across several studies were numerous findings, which recognized both partners’ newfound appreciation of being a couple and spending time together (Merrick *et al.*, 2013; Derksen *et al.*, 2006; Daniels *et al.*, 2007; Hellström *et al.*, 2007; Hellström *et al.*, 2005).

Partner: “*We have a nice time together at home, and that is what we are saying every day. ‘Oh God, such a nice time we have, you and I’; ‘Yes’ says my husband ‘that is thanks to you’; ‘No’, I say, ‘it is thanks to you’*” pp. 394

Taken from theme: Being affectionate and appreciative (Hellström *et al.*, 2007).

This newfound appreciation for simply spending time together was something that couples had previously taken for granted, and now felt lucky to have (Hellström *et al.*, 2007). Within one study, the onset of dementia led couples to begin living for the moment, in order to appreciate their current lives together, rather than thinking about the future (Hellström *et al.*, 2007).

PLwD: “*Take the day as it comes. There is no reason to worry*” (pp. 396)

Taken from theme: Making the best of things (Hellström *et al.*, 2007).

As well as mutual appreciation, PLwD also expressed their gratitude for the care that they were now receiving from their partner (Merrick *et al.*, 2013, Derksen *et al.*, 2006). Vernooij *et al.* (2006) also found that through their appreciation of life together, some couples made spontaneous decisions such as marriage and moving locations to enhance their relationships further following the onset of dementia.

Subtheme: *Searching for positives*

A number of the studies found that couples promote positivity in their relationship by looking on the ‘brighter side’ (Hellström *et al.*, 2007, pp. 395) of the situation (Molyneaux *et al.*, 2011; Merrick *et al.*, 2013; Daniels *et al.*, 2007; Hellström *et al.*, 2007). Although the onset of dementia was recognized as upsetting, this was not viewed as the worst situation possible, and couples sought to find the positives in their situation to maintain each other’s wellbeing (Hellström *et al.*, 2007).

Partner: *“Yes, because we have had a good life before. It’s totally changed. It’s not so funny. Then you have to find the positive things in life. You always search for the positive to be able to feel happy”* (pp. 395)

Taken from theme: Making the best of things (Hellström *et al.*, 2007).

Couples reflected positively on their relationships by reminiscing on the *“good old days”* (theme pp. 11) (Molyneaux *et al.*, 2011) and *“wonderful time(s)”* (Daniels *et al.*, 2007; quote, pp. 167), which was linked to maintaining a sense of shared identity (Merrick *et al.*, 2013, Hydén and Nilsson, 2013). This was also noted to help couples to make sense of their new situation, with reflections on a good life together making the onset of dementia more bearable (Molyneaux *et al.*, 2011).

PLwD: *“We were always happy weren’t we?”*

Partner: *“Yes, we were happy and we didn’t have a lot of money to spend, but nobody did in those days but er, we used to, we used to make our own fun didn’t we?”* (pp. 494)

Taken from theme: The good old days (Molyneaux *et al.*, 2011).

Several studies also found that couples often compared their situation to less fortunate positions, such as living with early-onset dementia, more progressive dementia, or having no support (Molyneaux *et al.*, 2011; Merrick *et al.*, 2013; Hellström *et al.*, 2007). This appeared to help couples to maintain positivity in their situation, and strengthen their views about the importance of their relationship together (Hellström *et al.*, 2007).

Partner: *“I think we have a good time here you mustn’t complain, there are those who have it worse”*(pp. 396)

Taken from theme: Making the best of things (Hellström *et al.*, 2007).

Discussion

Overview of findings

The aim of this review was to synthesize dyadic perspectives on the experiences of relationships for CLwD. The findings of the studies reviewed indicates that couples balance potential threats to their relationship, linked with the impact of dementia progression, with existing strengths in their relationships, in order to maintain normality and live positively with dementia. This builds on Braun *et al.* (2009)'s review, with evidence of the value of studying both partners' perspectives within a dyad, as opposed to only concentrating on the perspectives of one half of the couple.

Although Kitwood (1997) attempted to redefine dementia care within the context of 'personhood', there is still the dominance of a biomedical discourse that places dementia as a problem 'within' a person (Behuniak, 2010). Viewing cognitive changes as internal to the PLwD is likely to create more challenges for couples, as it threatens couplehood, with a transition from being a couple as a 'we' to an individual 'I'. Despite this, the findings principally suggest that couples actively strive to maintain their couplehood when they experience dementia as a threat to the continuity of their relationship. Clare (2002) developed a model that acknowledges that on an individual level, when PLwD are faced with threat in the context of dementia progression, they either endeavor to maintain normality and sense of self by 'holding on' and 'compensating' within their daily lives, or alternatively, by viewing dementia as a challenge to confront. In this case, people balance the difficulties of dealing with the dementia, with acceptance of the situation. This review extends Clare's (2002) findings, by suggesting that not only does this process occur for individuals, but it also occurs on

a dyadic level for CLwD. Similar to Clare (2002), the results of this review found that couples either aim to maintain normality through continuing routines, actively fight the threats by negotiating roles, and find acceptance of dementia through a new appreciation of their lives together. This therefore suggests that existing models on the experiences of PLwD as individuals may in fact transfer to understanding the experiences of CLwD.

A further key finding of this review was that love acts as a capital in relationships, laying a strong foundation to support couples' in their aim to preserve their couplehood in the face of threat. At this time, there is very little understanding of the meaning and experience of love for CLwD. In the existing literature that has focused on the perspectives of partners' separately, there have been serendipitous findings that suggest the importance of love and affection for both PLwD and their partners (Tranvåg *et al.*, 2015; Boylstein and Hayes, 2012) but this has not yet been studied directly. Future research on love and dementia would therefore be beneficial.

Considering the notion of love in the context of caregiving, this review suggests that consistent with findings of a review by Ablitt *et al.* (2009), caregiving was viewed as a natural occurrence born out of reciprocity within the relationship, rather than a simple shift in roles. This reframes the notion of 'caregiving', within the context of relationships that have been and in some ways still are based on reciprocity. This somewhat opposes the idea that relationships are required to adjust to a caregiving role (Robinson *et al.*, 2005), though it is acknowledged that with deterioration in cognitive abilities for the PLwD, there is often an increased dependency on the spouse. This is consistent with findings of the review by Quinn *et al.* (2009).

Many of the papers reviewed identified that couples' will often create new ways of being together following the onset of dementia. This links in with the idea of Socioemotional Selectivity Theory (Carstensen, as cited in Löckenhoff and Carstensen, 2004), which suggests that when people perceive their time as limited, their goals orient towards a focus on the present, and carry more emotional meaning. This can result in changed experiences of relationships as people seek more positive experiences of togetherness. As reflected in the findings of this review, couples discovered a newfound appreciation of spending time together, and were less likely to take their relationship for granted. Dementia alone may not be the only catalyst for the re-evaluation of relationships, as people may also engage in a process of life review through aging. Theoretically, Erikson (1997) acknowledged this life review, and proposed eight psychosocial stages of development, with the final stage referring to wisdom in the psychosocial crises of ego integrity versus despair. This stage proposes that with aging, people go through a process, where they look backwards over their lives as a whole in order to come to terms with their situation in the present. Erikson suggests that those who accept the course of events and the choices made previously within their lives are more likely to develop integrity and look forward to a positive future, whereas people who reflect on their lives with guilt or dissatisfaction instead experience feelings of despair (Erikson, 1997). This aligns with the findings of the review, which identified that couples evaluate their lives together (looking back on strengths, previous successes and challenges faced together), and search for positives in their new situation.

Limitations of the review

It is important to acknowledge that by carrying out a synthesis of qualitative literature, the researcher is in some ways providing a 'triple hermeneutic' (Suri, 2014). This is

because the researcher is to some degree, making their own interpretation of other researchers' interpretations of their own findings. The reliability of the synthesis is therefore somewhat subjective, but this was mitigated by ongoing discussions within the research team, in order to reach a shared consensus on the findings.

Due to the limited number of researchers that have studied the dyadic perspectives of CLwD, the review was only able to synthesize a small sample of papers. However the qualitative nature of these papers gave richness to the data, and as such it was not felt that the depth of the synthesis was necessarily affected by the number of papers (NHS Centre for Reviews and Dissemination, 2001).

With regards to the quality of the papers, several studies did not clearly report their attempts to ensure quality assurance or consider the impact of researcher bias. It is therefore important to be aware that this limited reflexivity, in addition to the lack of detail regarding quality assurance, may influence the reliability of synthesis for the current review.

When taking into account the generalizability of the synthesis, it is important to note that all of the studies that were reviewed were conducted within Western Countries. This means that the results cannot be deemed representative of the experiences of couples across different cultures.

With regards to diagnosis, the majority of partners with dementia were diagnosed with dementia of Alzheimer's type, however there was a small sample of participants diagnosed with other dementia subtypes. Within the results of the studies, the differences between participants diagnosed with different types of dementia were not

discussed, therefore it cannot be clear whether couples' experiences of relationships are affected by the type of dementia.

Across the studies, there was a large variation in the length of time that participants were interviewed following their diagnosis. Future studies could consider longer-term research, in order to explore the potential changing processes involved in relationships for CLwD over a period time. The majority of studies reviewed recruited their participants from memory clinics, health clinics and mental health services, with only two studies recruiting from community services (Merrick *et al.*, 2013; Daniels *et al.*, 2007). This therefore may have altered the overall experiences of the sample, and further investigation may be needed to understand the experiences of couples within community services.

As the current review cannot reliably represent the perspectives of all CLwD, further research is required to explore the experiences of couples across different cultural backgrounds, as well as considering the differences between the experiences of those living with different dementia subtypes and more advanced stages of dementia. Future research may explore the differences between couples of different ages and relationship lengths.

Implications for research and practice

There remains a paucity of research that seeks to understand the shared experiences of CLwD. Within both research and clinical practice, more attention is needed to understand PLwD within the context of their relationships with their partners.

Relationships will ultimately influence the wellbeing of PLwD, therefore more understanding of how relationships can be sustained is essential.

A significant finding within this review was the importance of love as a capital within relationships. Although from a person-centered perspective, love has long been considered a central need for PLwD (Kitwood, 1997), focus on this area in PLwD's close relationships has since been neglected. This review highlights the importance of love in sustaining relationships for CLwD, and suggests that more research is needed to understand love in the context of dementia. Conceptually, studying love as a 'character strength' (Park, Peterson & Seligman, 2004) could build on positive psychology research, and contribute to improving the wellbeing of PLwD and their partners (Wong, 2011).

With regards to implications for services, the findings of the review would indicate that more focus is required on understanding PLwD within the context of their relationships. As such, there may be benefit from offering interventions to both partners within CLwD, therefore seeing them as a couple unit, rather than treating the PLwD individually.

Finally, the findings also provide some indication that the label of 'caregiver' is not necessarily appropriate for all CLwD. For many couples within the papers reviewed, caregiving was seen as a natural progression in the relationship, suggesting that a new label for the caregiving partner is not necessarily required.

Conclusion

CLwD experience potential threats to couplehood due to the cognitive, psychological and social changes associated with dementia. However, this review indicates that couples' shared experiences of resilience and drive to avoid defeat in their relationships buffers against this threat. Couples use love as a resource, as well as actively negotiating changes within their relationships in order to sustain couplehood. The review has highlighted the importance of understanding couples' shared experiences, and it is hoped that more attention will be given to this research area in the future.

Conflict of interest

None.

Description of authors' roles

C. Cowell developed the design of the study, conducted data collection and analysis, and wrote up the paper. C. Clarke and E. Wolverson supervised the process, with assistance in developing the search strategy, design, analysis and preparation of the final paper.

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Part Two: Empirical Paper

**Love and Dementia: A qualitative exploration of spouses' ongoing experiences of
love following a transition into residential care**

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Abstract

Objectives

Dementia care is most commonly provided by spouses, suggesting that caregiving may be an act of love. The experience of love has so far not been explored in dementia research, and very little is known about spouses' experiences of love when their spouse diagnosed with dementia moves into residential care. A qualitative study was therefore conducted to explore the experience and meaning of love in relationships for spouses married to a person living with dementia following a transition into residential care.

Method

Semi-structured interviews were conducted with nine older adults who were married to a person diagnosed with dementia who lives in residential care. Interpretative Phenomenological Analysis was used to understand the subjective lived experiences of love in the participants' relationships.

Results

The analysis identified three super-ordinate themes: 'Love can mean so many things', 'Living with a sense of defeat in caregiving' and 'Making sense of the relationship following a transition', which highlighted the tensions faced within love and relationships for participants' and their spouses, with progression of dementia and the transition into care. The themes are considered within the context of existing research on relationships and dementia.

Conclusions

The findings suggest that a ‘capital’ of love underpins couples’ experiences of relationships, but that tensions exist through progression of dementia and the transition into care. Further understanding is needed about how care homes can support couples to sustain love and couplehood within their relationships.

Keywords: Dementia, love, qualitative, care, transition

Introduction

Love is a universal concept embedded within philosophical, scientific and literary history (Plato, 1989; Catron, 2014; Lopez & Snyder, 2011). Whilst a consensus definition of love as a psychological construct is unlikely, it has been suggested that love is performative (Gratzke, 2015), in that it must be actualized in order to exist, and can be recognized only through acts of love, such as physical touch and declarations of speech. Love, with the exception of self-love, is widely regarded as relational; existing only through connections with other beings or objects. Love is dynamic, and can be experienced differently across relationships - whether this is in the context of family relationships, friendships or professional relationships (Gratzke, 2015).

Love in the context of dementia

Kitwood (1997) recognized love as the central psychological need for people living with dementia (PLwD), and defined it as an '*unconditional acceptance without expectation of direct reward*' (pp. 81). Love is interwoven with a need for comfort, attachment, inclusion, occupation and identity, and is considered a key element in maintaining the personhood of PLwD (Kitwood, 1997). This was the first notable model to recognize the importance of love in the context of dementia, and informed subsequent social health models of dementia (Vernooij-Dassen & Jeon, 2016). With growing recognition that PLwD's sense of self is determined by their interactions with others (Sabat, 2006; as cited in Adams, 2007), there is increasing awareness of the importance of relationships for PLwD's wellbeing, with a move from a person-centered model of dementia care, to a relational perspective (Nolan, Brown, Davies, Nolan & Keady, 2006).

Within the United Kingdom, care for PLwD is most commonly provided by the spouse (Wimo et al., 2013). As it is assumed culturally that the foundation of spousal relationships is mutual love, it is possible that providing care to a spouse may be viewed as an act of love. Whilst little is known about the love experienced between couples living with dementia (CLwD), there is evidence from accounts of lived experiences to suggest its importance (Merrick, Camic & O'Shaughnessy, 2013; Alzheimer's Society, 2005a). Relevant to such findings is the notion of 'couplehood', used to understand the extent to which CLwD feel together in their relationship as a 'we', versus separated as two 'I's' (Kaplan, 2001). It is currently unknown whether love underpins couplehood.

Dementia as a threat to love

It is widely presumed that love changes significantly after the onset of dementia, as couples need to adjust to changes to sustain their relationships (Norman, Redfern, Briggs & Askham, 2004). Robinson, Clare and Evans (2005) proposed a model of adjustment to dementia for couples, central to which is adjustment of relationships. The model highlights that spouses often change their role to 'become' caregiver, a role which has been described to bring feelings of frustration and resentment, alongside commitment, acceptance and desire to maintain the relationship (Boylstein & Hayes, 2012). The 'caregiver' label has been criticized however, as some people feel caring for a spouse represents a new development to a relationship, rather than a new role that suggests lack of love and reciprocity (Molyneaux, Butchard, Simpson & Murray, 2011). The existing literature indicates that love continues to be experienced following the onset of dementia, but perhaps changes with dementia progression (Bauer, Maddox, Kirk, Burns & Kuskowski, 2001).

As dementia progresses, many PLwD will require care from outside of the couple relationship. A significant transition experienced by many PLwD is the move from care within the family to residential care. Within Aneshensel, Pearlin, Mullan, Zarit and Whitlatch's (1995) model, caregiving is viewed as a linear process, in which a transition into residential care signifies an end to the caregiving 'journey'. Post-transition, the model moves on to consider a process of bereavement following the death of the PLwD, before a process of readjustment. The model does not appear to acknowledge the experiences of the original caregiver once the PLwD has moved into residential care, and the support that may be required for them at this time.

Rationale & Aims

Currently, little is known about how love is experienced in relationships following the transition into care, and how love may help couples to maintain their sense of couplehood. The aim of the study is to explore the meaning, experiences and maintenance of love once a PLwD has moved into residential care. A transition into care is a milestone in any relationship and where there is much negative literature surrounding caregiving and this transition, there is only limited positive literature. Crawford, Digby, Bloomer, Tan and Williams (2015) recognised that moving from being a caregiver to a visitor during this transition contributed to a conflict between negative feelings of loss, grief and loneliness, versus positive feelings of relief and reassurance that the PLwD was safe.

The findings of this study have potential clinical relevance. With recent improvements in dementia diagnosis rates (Department of Health, 2016) and longer life expectancy within the population, there are rising numbers of PLwD living in residential care for

longer periods. The findings may help to facilitate relationship-centered care for PLwD, and highlight particular needs and resources for spousal caregivers that services can respond to. Research suggests that the wellbeing of PLwD and their spouses are interlinked (The Relationships Alliance, 2014), indicating that exploration of spouses' perspectives gives an indirect focus on the wellbeing of the relationship, and as such may positively influence PLwD.

In line with positive psychology, the research aimed to highlight where the character strength of love (Park, Peterson & Seligman, 2004) may be used to generate positive experiences and maintain a relationship following a potentially challenging transition. To fully understand spouses' experiences however, it is helpful to consider the dialectics of both positive and negative experiences rather than viewing these separately (Aspinwall & Tedeschi, 2010). As such, the research was approached from a broadly explorative perspective.

Specifically, the study aimed to explore (i) the meaning and experience of love for spouses of PLwD before the person entered residential care, (ii), through the transition into care and (iii) following the transition into care.

Method

Design

The study took an exploratory approach, using photo elicitation (Harper, 2002) and semi-structured interviews to generate qualitative data. Qualitative research was chosen to explore participants' lived experience of love in their relationship with PLwD,

before, during and after their transition into care. Using photo elicitation offered a less interrogative approach, opening opportunities for people less comfortable answering direct questions (Lapenta, 2004). Interviews were transcribed and analyzed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009).

Sample

Purposive sampling was used to target a suitably homogenous sample of participants for in-depth analysis (Smith et al, 2009). Participants were included if they were married or long-term partner to a PLwD who lives in long-term residential care, had lived at home with their spouse until entry into care, were aged over sixty-five and had capacity to give informed consent to participation (see Appendix G and H for information and consent forms). Participants were excluded if they lacked sufficient English language fluency, if they had a new romantic partner, if their spouse had been diagnosed with early-onset dementia and if they were diagnosed with dementia themselves.

Nine people took part in the research and were recruited through advertisements displayed at care homes (N=5) and voluntary services across Yorkshire and the Humber (N=2). Two individuals volunteered after other participants informed them about the study. No participants were excluded. Participant demographics are presented in Table 4 (see Appendix J for further information).

Table 4. A summary of participant demographics

Pseudonym/ Spouse pseudonym	Gender/ Spouse gender	Age/ Spouse age	Dementia type (Alzheimer's Disease = AD, Vascular Dementia = VaD)
Eric	M	82	AD
Florence	F	78	
George	M	77	AD
Pauline	F	76	
Stanley	M	90	AD
Jean	F	82	
Jack	M	69	AD
Thelma	F	72	
Frank	M	78	AD
Barbara	F	76	
Arthur	M	83	VaD
Edith	F	79	
Betty	F	77	AD
Albert	M	79	
Josephine	F	71	Mixed - AD and VaD
Harold	M	78	
Dorothy	F	82	AD
Bernard	M	83	

All nine participants and their spouses were White British. All participants were heterosexual and at the time of interview had been married between 37-60 years (mean

= 51.9 years). There were a larger number of male participants (N=6) than females (N=3). Participants' ages ranged from 69-90 (mean = 78.8 years), and ages of their spouses ranged from 72-83 (mean = 78.1 years). At the point of interview, the time spouses had been in care ranged from 3 months-6 years (mean = 2 years, 2 months). It was recognised that because the spouses had entered residential care, and could no longer be cared for at home, that they were all likely to be in the advanced stages of dementia.

Data Collection

The study was reviewed and given ethical approval by the University of Hull Research Ethics Committee (see Appendix K).

Interviews were carried out using a semi-structured interview schedule, which gave participants opportunity to speak about their individual experiences. The interview schedule began with the participant sharing photographs that represent love in their relationship, before a conversation about the couples' journey, beginning with their early relationship, into the care home transition, and ending with their current relationship.

The interviews were digitally recorded and transcribed, and all but one were conducted at the participants' homes. One participant requested that the interview was conducted at his wife's care home. Interviews lasted between 38 and 86 minutes (mean = 59.5 minutes).

Data Analysis

IPA (Smith et al., 2009) was chosen to analyze the data, allowing exploration of participants' lived experiences of love through their relationship and the transition into care. IPA provided the subjective meanings that experiences held for each participant (Smith & Osborn, 2008).

IPA acknowledges that the analyst's own perspectives influence analysis, and as such state that this should be completed tentatively, with the view that the findings show *'how the analyst thinks the participant is thinking'* (Smith et al., 2009, pp. 80). It is therefore important that the researcher considers what their personal views bring to the process. Through clinical experiences, the researcher held a belief that couples can live well with dementia, and had previously witnessed loving relationships between CLwD. However they had also witnessed more negative experiences, so would not avoid sensitive discussions. On a personal level, the researcher had experience of love in a long-term relationship, but held an outsider perspective on the phenomenon of being married, and being married to a PLwD. This was important to consider, as it may have influenced interactions with participants during interviews, and the analysis of interview data (Dwyer & Buckle, 2009).

The analysis involved three broad stages:

- 1) Transcripts were read multiple times through line-by-line analysis. The first author used exploratory note taking to elicit emergent patterns and themes that encompassed participants' experiences. To ensure no meaningful data went unnoticed, one transcript was coded by the second researcher.
- 2) Descriptive, linguistic and conceptual codes were analyzed to develop an

interpretative understanding of the data. The codes for each transcript were clustered into themes, ensuring each theme reflected a meaningful interpretation of the participants' speech.

- 3) Themes developed from each interview were compared to identify an overall structure of shared themes, incorporating unique experiences of each participant as well as shared qualities between them. The research team then discussed the themes to reach a consensus.

Results

Three super-ordinate themes and eight subthemes emerged from the data, as shown in Table 5.

Table 5. A table of themes and subthemes identified through analysis

Super-ordinate theme	Subtheme
(1) Love can mean so many things	<i>Love as an intangible feeling</i>
	<i>Tension in the continuity of showing love</i>
	<i>Love as caring</i>
(2) Living with a sense of defeat in caregiving	<i>A tension between guilt and acceptance</i>
	<i>Striving for continuity of a caring role</i>
(3) Making sense of the relationship following a transition	<i>Managing losses: A loneliness that you cannot fill</i>
	<i>The importance of quality time</i>
	<i>Evaluating a life spent together</i>

The themes relate to tensions experienced within loving relationships within the context of dementia progression and the transition into care.

(1) Super-ordinate theme: Love can mean so many things

Across participants' accounts, love had no single, clear definition. Although some participants clearly stated what love meant to them, four participants struggled to define love at all. As explained by Eric: *'using the word love, it can mean so many different things'*. Despite this, participants who could not define love were still able to talk about its existence. Love was recognized as a feeling, as well as a performative action that could be shown in the relationship, or through demonstrating practical caregiving. Three subthemes captured the different meanings of love.

Subtheme: *Love as an intangible feeling*

Several participants described love as a feeling, as opposed to a tangible concept, and as such found the meaning of love hard to articulate:

'You can't define love . . . it's a feeling' (Arthur).

For some participants, love was described in positive terms, whereas in contrast, for Arthur, love was viewed as a physical pain:

'To me love is happiness' (Betty).

'I just describe it as a pain' (Arthur).

Love as a 'felt sense' was expressed through participants' deep admiration for their spouses, demonstrated when speaking about them in the past and present. For example, Frank stated, '*she's beautiful isn't she?*' when sharing photographs of his wife earlier in their relationship, and explained '*she's still my lovely wife*' when talking about her in the present. Participants also shared their spouses' past achievements with pride. For most, they stated '*he/she was*' when demonstrating their feelings about who their spouse had been earlier in their relationship:

'She was very talented, erm she was unbelievable in, in erm everything that she did'
(Frank).

'You know he was such a clever, clever man' (Josephine).

Other participants reflected on who their spouses continued to be, highlighting their continuity of feelings:

'She's just shone through the years, she does so many things and has done so many things' (Eric).

When discussing their current relationship, this fondness was still present in all accounts. George reflected on how he still felt the love he had experienced at the beginning of the relationship:

'I certainly get that- this feeling of 'ooh I'm going to see her' which is quite exciting'
(George).

Frank even explained how his feelings of love had grown through the transition into care:

'I don't love her any less now, in fact I love her, love her probably more than ever'
(Frank).

This preservation of fondness for the PLwD demonstrates how feelings of love can continue despite dementia. It would appear love acts as a capital within relationships, and will exist even if it cannot be fully articulated.

Subtheme: *Tension in the continuity of showing love*

Participants also referred to love as a performative action; something that could be shown and seen. The importance of showing love was evident across all participants' accounts, with examples demonstrated through speech and physical actions in the past and present context of their relationships. When describing love, participants expressed feeling a tension between love being preserved and acted upon, whilst at the same time feeling that this was being threatened.

Many participants' accounts demonstrated how expressions of love functioned in providing continuity in their relationship. Frank explained how displays of love and affection continued through communication, despite the absence of reciprocal speech between him and his wife Barbara:

'We both told each other every day that we loved each other and I still tell her now every time I see her' (Frank).

With his wife present, Eric demonstrated affectionate speech during the interview, calling Florence ‘love’ whenever he spoke to her. In describing their visits to see their spouses at their care homes, Eric and Dorothy described how they continue to say ‘*I love you*’ to their spouses as they had always done earlier in their relationships:

‘And like I tell her and she knows that I love her a lot’ (Eric).

‘I usually say ‘I love you’ and hi- his answer is always ‘and me’’ (Dorothy).

Showing love through physical action was also noted within the participants’ current relationships. Physical action included hand holding, kissing and physical closeness:

*‘I mean we kiss each other, I sit on his knee still erm *pause* you know we cuddle each other and we hold hands’* (Josephine).

‘We always hold hands . . . we always sit close together as we can’ (Betty).

Following the care home transition, physical affection was recognized to remain, and even develop for some couples. Eric explained how prior to the transition ‘*there wasn't nearly so much of this er arm round*’. He explained that metaphorically, his relationship with Florence had also transitioned from ‘*a standard, ordinary, everyday life to being a lovebird life.*’

Similarly, Betty highlighted that the reciprocal demonstrations of love between her and Albert had become more important:

‘He picked me right off me feet and told me how much he loved me’ (Betty).

Conversely, when the potential to show love was threatened, it was notable that two participants cast doubt over the reciprocal love in their relationships. George questioned whether he still loved his wife, after the performative love within his relationship was threatened due to the progression of his wife’s dementia:

‘To establish how much love you feel for that person, when they're drifting, distancing themselves from you is very, very difficult’ (George).

George described being unsure if he was continuing to visit his wife through the obligation of their marital commitment, or due to his continued feelings of love. Similarly, with dementia progression, Arthur began to question the reciprocal nature of Edith’s love as she no longer recognized him:

*‘I’ve often said to her ‘how long have you been married?’ *imitates wife* ‘I’ve never been married’ (Arthur).*

This also led Arthur to doubt feelings of love throughout the entirety of their relationship, as he struggled to make sense of the situation:

‘Sometimes I wonder if we had a good marriage . . . 'cause you're always- you're always looking for something’ (Arthur).

The act of performing love appeared significant in participants’ accounts, suggesting that being able to show love gave more certainty about continuity of couplehood.

Subtheme: *Love as caring*

The caregiving role was described to naturally occur through participants' loving commitment to their spouses. Participants instinctively drifted into talking about care whilst discussing their shared lives, suggesting this was not necessarily viewed as a separate role. Several participants explained how love had helped them to adapt and see the positives in caregiving:

*I used to shower her in a morning and erm *pause* er you know, get her up . . . dry her, cream her all over, put her lipstick on, blow dry her hair . . . put nice clothes on her (Jack).*

Although reciprocal caring had always been present, the onset of dementia required participants' to focus on this aspect of their role within the relationship. George acknowledged the care Pauline had provided earlier in their relationship, suggesting his role in caring was a reciprocation of the care he had received earlier in their marriage:

'She looked after me in Athens in the clinic for three days, cause there were no . . . nursing staff as such' (George).

Josephine also acknowledged that '*if the shoe was on the other foot*', Harold would have reciprocated the care.

Caring was therefore viewed as another aspect of love, requiring deep admiration and respect for the person. It was suggested that caring was a way of expressing performative love.

(2) Super-ordinate theme: Living with a sense of defeat in caregiving

For several participants, the decision for their spouse to enter care resulted from the impact of caregiving on their own health: *'I was told that if I didn't do something, I wouldn't have been here in three months . . . because I'd committed myself totally'* (Frank). Participants' accounts highlighted the tensions that arose in making the decision, with feelings of guilt versus acceptance of the situation. This tension could be mediated by care home staff, through facilitation of continuity of participants' caregiving role.

Subtheme: *A tension between guilt and acceptance*

With caring viewed as an act of love, several participants' indicated that the transition signified a failure in their ability to demonstrate love. This led to conflicting emotions of guilt and acceptance, which were influenced by participants' experiences at the care homes. This tension was recognized through contradictions in participants' accounts, where they acknowledged loss but also accepted the transition as the best solution.

Jack and George expressed their guilt about the transition:

'I feel guilty . . . you know, conscience ridden' (Jack).

'Oh I mustn't tell the neighbors, they'll think I've just put her in care and I'm having a jolly good time' (George).

Josephine and Betty feared their spouses' may '*resent*' them following the transition, again reflecting a potential threat to love:

'The only thing is he made me swear on the bible I wouldn't put him in a home'
(Josephine).

'I just get the feeling he resents having somebody looking after him who's not me'
(Betty).

This reflected the remorse participants experienced when their caring role could no longer be fulfilled, and as such, their demonstration of love was threatened. Alongside guilt, fear and resentment, Jack and Betty explained the added tension of wanting their spouse to move back home whilst knowing that the transition was for the best:

'Even now I still think I want to bring him home . . . but I know it's not feasible' (Betty).

In contrast, Dorothy and Eric viewed the move into care more positively:

Interviewer: *'It does sound like it's been a positive experience for you'*

Dorothy: *'Absolutely, I can't believe it'*.

Subtheme: *Striving for continuity of a caring role*

Participants described how they sought to maintain their caring role and continue expressing love through care. In some cases this meant transitioning from a direct caregiver to ensuring the best care was provided by the care home.

For some participants, the transition into care did not take away their caring role.

Especially for Dorothy, staff at her husband's care home encouraged her to keep involved in his care, meaning that she could still continue to participate. In contrast, Arthur had little input in the decision for his wife to enter care, and had made every effort to continue his caring role when he visited his wife, yet he still felt aggrieved that his position as a caregiver had depleted since the transition:

'I want to do everything, I mean when she says 'I want to go to the toilet' . . . should get the carer to do it, but I just think well while I'm there I may as well' (Arthur).

To the other extreme, Josephine felt her carer role had not changed at all, as Harold's care home often contacted her requesting additional support. Josephine referred to herself as a 'carer-wife':

*'Wherever I am I'm always on-call . . . so all I'm having really is *pause* is not having him pounding the house and being incontinent in the bed'* (Josephine).

This highlighted the important influence of care homes in determining participants' experiences. Several participants explained how the transition had strengthened their need to protect their spouse from harm, as care was now out of their direct control. Because some participants could no longer provide loving care themselves, they shifted to ensuring the care home was providing the best care possible. It would seem this was a way of indirectly continuing love in care:

'I haven't lost my caring role, my caring role is still there . . . there to protect her and to look after her and make sure above all else that she's being well looked after' (Frank).

(3) Super-ordinate theme: Making sense of the relationship following the transition

For many participants, love meant being together and sharing activities with their spouses. Many of the photographs shared to represent the love within participants' relationships were examples of them as couples sharing events together. The transition into care was acknowledged to create a tension, with loss of 'being together', versus continuity of loving feelings that remained. Participants were also recognized to re-evaluate their relationships following the transition and the separation that this entailed.

Subtheme: *Managing losses: A loneliness that you cannot fill*

It was notable that for all of the participants, the onset of dementia, and the subsequent transition into care, created feelings of loss, due to the reduced companionship that remained. For George, a physical separation led to '*distancing*' both physically and emotionally:

'They (PLwD) just gradually move away from you' (George).

This separation was referred to on two occasions as being '*like a bereavement*' (Frank, Arthur), suggesting participants were grieving losses from their earlier relationships.

*'It's like a bereavement . . . separation . . . a divorce, a death' . . . 'Every time I see her, I think of what we used to do *cries* where we used to go'* (Arthur).

For five of the participants, loneliness was experienced when they returned to an '*empty house*' (Dorothy, Arthur). Josephine referred to this as a '*loneliness you cannot fill up*':

‘When I come back at night, I put the key in the door, there's no husband and there's no dogs, and this room could be just the way I left it’ (Josephine).

Loss of companionship meant that participants were left feeling confused about the reduced opportunity to demonstrate love and share their lives with their spouses.

Following the initial transition, this sense of loss continued with the progression of dementia, as couples could no longer continue shared activities as they had initially done:

‘At one time we used to sit on her bed and watch television, I’d take in some donuts . . . and sh- we’d s- sit and eat them, that doesn’t happen now, she’s on a pureed diet’ (Arthur).

Subtheme: The importance of quality time

All of the couples continued to spend time together following the care home transition, and several participants referred to the increased shared *‘quality time’* this gave them. Three participants referred to *‘good days’* and *‘bad days’* (George, Dorothy, Arthur), with the types of days they themselves experienced being determined by the time spent with their spouse. Prior to the transition, George acknowledged the lack of quality time spent with his wife:

‘Well I haven’t had quality time. Erm, because there just isn’t time- if you, if you’re sitting next to her watching a TV programme you’ll think “I’ll read a book”’ (George).

The transition into care contributed to more quality time together for several participants as couples now had '*time for each other*' (Dorothy). Josephine explained that when she visited her husband, they continued to engage in activities together:

'He likes to go out in the car and put John Denver on and I sing, I can't sing in tune and he claps and we clap together and he pats my leg and I pat his' (Josephine).

This indicated that participants' actively looked for ways to preserve expressions of love that could be reciprocated by their spouses during their time spent together.

Conversely, Eric explained that reactions of others at the care home had caused detriment to the 'quality time' with his wife, Florence. He gave an example of when he had shown physical affection to Florence in a public area of her care home and was informed of a complaint from a fellow visitor:

'I heard it said that there'd been a complaint, and it- I was guided that I should come to her room for er visits' (Eric).

This indicates that care homes can help or hinder the quality time that couples spend together.

Subtheme: *Evaluating a life spent together*

Following the transition into care, several participants described evaluating their whole relationship in order to make sense of their current situation. Five participants (Stanley, Frank, Betty, Dorothy, Jack) evaluated their relationships and lives together positively:

‘If you have a life like we've had, you'll be alright’ (Stanley).

In contrast, Arthur felt that his relationship with Edith had been cut short:

*‘We were planning on going to Mexico, Canada, South America and there was somewhere else we were gonna go, but we had to squash that because Edith *pause* . . . got dementia’ (Arthur).*

Arthur was the only participant who did not have control over the decision for his wife to enter care, and as such felt aggrieved that his opportunity to demonstrate love had been taken from him.

Several participants began to think about the future of their relationships with their spouses. Frank and Dorothy managed the potential for future loss by living for the moment:

‘I'm taking every opportunity now, to get er as much time with her as I can’ (Frank).

‘One day he won't know me, that's the reason I go’ (Dorothy).

Some participants’ accounts described a future without their spouses at their side.

George explained that his wife had *‘her own life to lead there now’*, and as such was considering ways that he could be more independent. Josephine reported that her *‘life has stopped’* due to dementia, and that she felt she was *‘marking time’* until her husband died. She explained that she felt *‘still married but . . . not married’*.

Discussion

Overview of findings

The current study recognizes love as the ‘capital’ of relationships for CLwD, and consistent with the suggestion of Gratzke (2015), acknowledges the importance of performative love within participants’ relationships. This does not ignore the losses that were also experienced, which were consistent with findings of Crawford et al. (2015), who similarly identified feelings of loss, grief and loneliness in the transition from the role of caregiver to visitor of a PLwD.

Kitwood and Bredin (1992) acknowledged the importance of viewing PLwD within the context of their relationships, with the influence of another person being an essential component within dementia caregiving. Participants’ accounts suggested that the process of caregiving naturally occurred from the loving commitment grounded within an existing relationship, reframing the notion of caregiving as a ‘role’ (Robinson, Clare & Evans, 2005), and instead embedding caregiving within the context of couples’ relationships.

Love as a relational construct helps move beyond an individualistic perspective on ‘personhood’ in dementia (Kitwood, 1997), to understanding PLwD and their spouses in the context of ‘couplehood’ (Kaplan, 2001; Hellström et al., 2007). The findings of this study highlight that over time, a threat to performative acts of love contributed to participants’ feeling alone. This therefore threatens the ‘togetherness’ of the couple, with a move from participants’ considering themselves as a ‘we’, to increasingly feeling like an ‘I’ (Hydén & Nilsson, 2013). Despite this, participants strived to continue the

couplehood within their relationships, and their opportunity to do so was primarily influenced by their experiences at the care home.

When considering the transition into a care home, Aneshensel et al. (1995) proposed a model which views caregiving as a 'career'. This was suggested to begin with the PLwD being cared for at home, with a gradual end to the caregiving role when the PLwD moves into residential care. The findings of the current study however, suggest that this is not necessarily the case. A continued caregiving role can be facilitated by the care home, and where this no longer feels possible, caregivers can focus on ensuring the best care is provided indirectly by the care home. Care homes also played a key role in facilitating the continuity of 'acts of love' for couples. Encouragement of shared activities, and acceptance of physical affection between the couple contributed to participants' experiences when visiting their spouses' in care.

Limitations

The findings are somewhat limited by the small sample size, meaning that the results are not representative of all people married to a PLwD who lives in a care home. It was also acknowledged that there may have been volunteer bias, in that participants' may have been more inclined to volunteer if they had a positive bias towards experiences of love. All of the participants were White British, so the results cannot be generalized to the experiences of individuals across different cultures. With the recommendations of Smith et al. (2009), the sample was fairly homogenous, with six male and three female participants. It was noted however, that there were more male respondents than female, which may have influenced the overall results. Despite this, similar themes arose across participants. By just interviewing spouses, it is acknowledged that the study has not

developed an understanding of the dyadic perspective of the couple in this situation (Braun, Scholz, Bailey, Perren, Hornung & Martin, 2009).

It is recognized that participants' had varying experiences with regards to progression of dementia, with some participants married to spouses in more advanced stages of dementia than others. A PLwD's cognitive deterioration, in terms of their level of communication and ability to recognize their spouse, is likely to have a significant influence on peoples' experiences. The study also found large variation in the time participants' spouses had been in care. This is likely to have had some impact on the participants' stage of adjustment to change without their spouses, and as such may have contributed to different experiences. Within this study, a comparison of these varying experiences was not taken into account.

Implications

The findings offer suggestions for support that care homes may provide in order to continue spouses' caregiving roles, and facilitate continuity of love and couplehood within couples' relationships. For example, care homes may involve couples in a process of life review through life story work and reminiscence, in order to enhance feelings of love in their relationships (Alzheimer's Society, 2005b).

The findings also suggest that more support may be required for caregivers following the transition, with regards to supporting feelings of grief. This may involve work around the grieving process, as well as helping caregivers to adjust and work towards building an independent future.

The study builds on the idea of second wave positive psychology (Wong, 2011), showing the importance of viewing experiences from a dialectic perspective, integrating the richness of both positive and negative experiences. This would suggest that rather than viewing experiences from a purely dichotomous perspective, that integration of experiences is most valuable to increasing the wellbeing of CLwD (Wong, 2011).

Conclusions

Love is a component of dementia care that had been neglected within dementia research. The findings suggest that love as a felt sense is embedded into couples' relationships, and is less vulnerable to threats from transition due to its strong foundation. Despite this, couples experience tensions in their ability to demonstrate love. Further work is needed to understand how care homes can facilitate a continued caring role for spouses of PLwD, and support continuity in sustaining love for CLwD.

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Part Three: Appendices

Appendix A: Instructions for contributors to the journal *International Psychogeriatrics*

Scope and contributions

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

Contributions include original research articles, reviews of the literature, brief reports, “for debate” articles, case reports, letters to the editor, book reviews and guest editorials. Apart from editorials, “for debate” articles and book reviews, which are commissioned, contributions to *International Psychogeriatrics* are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal’s Science Citation Index Impact Factor (2014) is 1.934. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to

submission. International Psychogeriatrics has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

Submission of manuscripts

Note: It is not acceptable to submit to the journal an article that has previously been published or submitted elsewhere. Authors are required to assert that they have not submitted their article elsewhere upon submission to International Psychogeriatrics. Manuscripts should be submitted online via our manuscript submission and tracking site, <http://mc.manuscriptcentral.com/ipg>. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au. To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

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

statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
 2. That the authors have had full control of all the primary data.
 3. That the authors are willing to allow the journal to review their data if requested.
- Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

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

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager. Academic Unit for Psychiatry of Old Age, Department of Psychiatry, The University of Melbourne, RMH Royal Park

Campus, 34-54 Poplar Road, Parkville, Victoria 3052, Australia, Tel: +61 3 8387 2326, Fax: +61 3 8387 2667. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Organization and style of research articles

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

Abstract: Abstracts for original research and reviews should be structured and incorporate 4 sub-headings: background, method(s), results, conclusion(s). Abstracts for protocol only papers should omit the third sub-heading (Results). Abstracts for brief reports and case reports should have no sub-headings. Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length. Abstracts for brief reports should not exceed 200 words.

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

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

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

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

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

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

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

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

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

References: For original research no more than 30 articles that have been published or

are in press should be cited, and for brief reports no more than 15 references. If authors believe that more than 30 references are essential to an original research article this must be justified in the cover letter. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. International Psychogeriatrics uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term “et al.” should be employed, i.e., (Smith et al., 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith et al., 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.

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

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

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

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

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

Figures/Tables: The manuscript should contain no more than five figures or tables (no more than three figures or tables for brief reports). The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some colour to be printed in some issues but authors wishing to publish figures requiring colour to communicate the data may be required to pay some or all the additional cost.

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

Word limits: At present *International Psychogeriatrics* does not have a fixed word limit for articles, other than for brief reports for which the word limit is 1500. Because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue.

Authors intending to submit a literature review should check recent issues of

International Psychogeriatrics to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review

article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

Conflict of Interest

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

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

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

Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects of a drug made by Bigpharma which directly competes with another drug made by Megadrug a declaration might say “Jane Smith has received research support and speaker’s honoraria from Bigpharma and has received financial assistance from Megadrug to enable her attend conferences.”

Appendix B: Adapted Quality Assessment Tool

Adapted Quality Assessment Tool: NICE (2012) methodology checklist for qualitative studies & MMAT (Pluye et al., 2011)

Study identification Include author, title, reference, year of publication	
Guidance topic:	Key research question/aim:
Checklist completed by:	

	<i>Circle or highlight one option for each question</i>	
Section 1: theoretical approach		
<p><u>1.1</u> Is the study clear in what it seeks to do?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> Is the purpose of the study discussed – aims/objectives/research question(s)? Are the values/assumptions/theory underpinning the purpose of the study discussed? 	<p>Clear (1)</p> <p>Unclear (0)</p> <p>Mixed (0)</p>	<p>Comments:</p>

Section 2: study design		
<p>2.1 How defensible/rigorous is the research design/methodology?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? 	<p>Defensible (1)</p> <p>Not defensible (0)</p> <p>Not sure (0)</p>	Comments:
<p>* 2.2 Mixed Methods Studies Only</p> <p>Is the mixed methods research design relevant to address the qualitative and quantitative aspects of the mixed methods question (or objective)?</p>	<p>Appropriate (1)</p> <p>Inappropriate (0)</p> <p>Not sure (0)</p>	Comments:
Section 3: data collection		
<p>3.1 How well was the data collection carried out?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> Are the data 	<p>Appropriate (1)</p> <p>Inappropriate (0)</p>	Comments:

<p>collection methods clearly described?</p> <ul style="list-style-type: none"> • Were the data collected appropriate to address the research question? 	<p>Not sure/ inadequately reported (0)</p>	
Section 4: validity		
<p>4.1 Participants, settings and circumstances</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined? • For the qualitative element of studies, were observations/interviews made in a variety of circumstances and from a range of respondents? 	<p>Clear (1)</p> <p>Unclear (0)</p> <p>Not sure (0)</p>	<p>Comments:</p>

<p>4.2 Is the influence of context considered?</p> <ul style="list-style-type: none"> • Was context bias considered (that is, did the authors consider the influence of the setting where the study took place)? • Was appropriate consideration given to how findings relate to researchers' influence e.g. through their interactions with participants 	<p>Clear (1)</p> <p>Unclear (0)</p> <p>Not sure (0)</p>	<p>Comments:</p>
<p>4.3 Were the methods reliable?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Were data collected by more than one method? • Were other studies considered with discussion about similar/different results? 	<p>Reliable (1)</p> <p>Unreliable (0)</p> <p>Not sure (0)</p>	<p>Comments:</p>

Section 5: analysis		
<p>5.1 Are the data 'rich'?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • Has the detail of the data that were collected been demonstrated? • Are responses compared and contrasted across groups/sites? 	<p>Rich (1)</p> <p>Poor (0)</p> <p>Not sure/not reported (0)</p>	<p>Comments:</p>
<p>5.2 Is the analysis reliable?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • For the qualitative element of studies, did more than one researcher theme and code transcripts/data? If so, how were differences resolved? • Were 	<p>Reliable (2)</p> <p>Unreliable (0)</p> <p>Not sure/not reported (0)</p>	<p>Comments:</p>

<p>negative/discrepant results addressed or ignored?</p> <ul style="list-style-type: none"> For the qualitative element of studies, is it clear how the themes and concepts were derived from the data? 		
<p>* 5.3 Mixed Methods Studies Only</p> <p>Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?</p>	<p>Adequate (1)</p> <p>Inadequate (0)</p> <p>Not sure (1)</p>	<p>Comments:</p>
<p>5.4 Are the findings convincing?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> Are the findings clearly presented? Are the findings internally coherent (that is, are the results credible in relation to the study 	<p>Convincing (2)</p> <p>Not convincing (0)</p> <p>Not sure (0)</p>	<p>Comments:</p>

<p>question)?</p> <ul style="list-style-type: none"> • For the qualitative element of studies, are extracts from the original data included (for example, direct quotes from participants)? • For the qualitative element of studies, are the data appropriately referenced so that the sources of the extracts can be identified? • Is the reporting clear and coherent? 		
<p><u>5.5</u> Are the conclusions adequate?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative 	<p>Adequate (2)</p> <p>Inadequate (0)</p> <p>Not sure (0)</p>	<p>Comments:</p>

<p>explanations been explored and discounted?</p> <ul style="list-style-type: none"> • Are the implications of the research clearly defined? • Is there adequate discussion of any limitations encountered? 		
<p>* <u>5.6</u> Mixed Methods Studies Only</p> <p>Is appropriate consideration given to the limitations associated with this integration?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Is the divergence of qualitative and quantitative data (or results) in a triangulation design? 	<p>Appropriate (1)</p> <p>Inappropriate (0)</p> <p>Not sure (0)</p>	<p>Comments:</p>
Section 6: ethics		
<p><u>6.1</u> Was the study approved by an ethics committee?</p>	<p>Yes (1)</p> <p>No (0)</p>	<p>Comments:</p>

	Not sure/not reported/not applicable (0)	
<p>6.2 Is the role of the researcher clearly described?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately described? • Is how the research was explained and presented to the participants described? 	<p>Clear (1)</p> <p>Not clear (0)</p> <p>Not sure/not reported (0)</p>	Comments:

Appendix C: Summary table of included studies based on adapted quality assessment tool

Study	Theoretical Approach	Study Design	Data Collection	Validity & Reliability	Analysis	Ethics	Overall quality (%)
Daniels, Lamson & Hodgson (2007)	Clear (1/1)	Defensible (1/1)	Appropriate (1/1)	4.1 Not sure (1) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rich (1) 5.2 Reliable (2) 5.4 Convincing (2) 5.5 Adequate (2) (7/7)	6.1 Yes (1) 6.2 Clear (1) (2/2)	100% (15/15)
*Davies (2011)	Clear (1/1)	2.1 Not	Not	4.1 Clear (1)	5.1 Rich (1)	6.1 Yes (1)	39%

		defensible (0)	sure/inadequately	4.2 Unclear (0)	5.2 Not	6.2 Not clear	(7/18)
Preserving the		2.2 Not sure	reported (0/1)	4.3 Reliable	sure/not	(0)	
“us identity”		(0)		(1)	reported (0)	(1/2)	
through		(0/2)		(2/3)	5.3 Inadequate		
marriage					(0)		
commitment					5.4 Not sure		
while living					(0)		
with early-stage					5.5 Adequate		
dementia					(2)		
					5.6 Not sure		
					(0)		
					(3/9)		
Derksen,	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Not sure	5.1 Rich (1)	6.1 Not	73%
Vernooij-		(1/1)		(0)	5.2 Reliable	sure/not	(11/15)

Dassen,				4.2 Unclear (0)	(2)	reported/not	
Gillissen, Olde				4.3 Reliable	5.4	applicable (0)	
Rikkert &				(1)	Convincing (2)	6.2 Not clear	
Scheltens				(1/3)	5.5 Adequate	(0)	
(2006)					(2)	(0/2)	
					(7/7)		
Impact of							
diagnostic							
disclosure in							
dementia on							
patients and							
carers:							
Qualitative case							
series analysis							
Hellström,	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Clear (1)	5.1 Rich (1)	6.1 Yes (1)	80%

Nolan & Lundh		(1/1)		4.2 Clear (1)	5.2 Not	6.2 Not	(12/15)
(2005)				4.3 Reliable	sure/not	sure/not	
				(1)	reported (0)	reported (0)	
‘We do things				(3/3)	5.4	(1/2)	
together’ A case					Convincing (2)		
study of					5.5 Adequate		
‘couplehood’ in					(2)		
dementia					(5/7)		
Hellström,	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Clear (1)	5.1 Rich (1)	6.1 Yes (1)	80%
Nolan & Lundh		(1/1)		4.2 Clear (1)	5.2 Not	6.2 Not clear	(12/15)
(2007)				4.3 Reliable	sure/not	(0)	
				(1)	reported (0)	(1/2)	
Sustaining				(3/3)	5.4		
‘couplehood’					Convincing (2)		
Spouses’					5.5 Adequate		

strategies for					(2)		
living positively					(5/7)		
with dementia							
Hydén &	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Clear (1)	5.1 Rich (1)	6.1 Yes (1)	87%
Nilsson (2015)		(1/1)		4.2 Clear (1)	5.2 Not	6.2 Clear (1)	(13/15)
				4.3 Reliable	sure/not	(2/2)	
Couples with				(1)	reported (0)		
dementia:				(3/3)	5.4		
Positioning the					Convincing (2)		
‘we’					5.5 Adequate		
					(2)		
					(5/7)		
Malthouse &	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Not sure	5.1 Rich (1)	6.1 Yes (1)	80%
Fox (2014)		(1/1)		(0)	5.2 Reliable	6.2 Not	(12/15)
				4.2 Unclear (0)	(2)	sure/not	

Exploring				4.3 Not sure	5.4	reported (0)	
experiences of				(1)	Convincing (2)	(1/2)	
physical activity				(1/3)	5.5 Adequate		
among people					(2)		
with					(7/7)		
Alzheimer's							
disease and							
their spouse							
carers: a							
qualitative							
study							
Merrick, Camic	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Clear (1)	5.1 Rich (1)	6.1 Yes (1)	100%
&		(1/1)		4.2 Clear (1)	5.2 Reliable	6.2 Clear (1)	(15/15)
O'Shaughnessy				4.3 Reliable	(2)	(2/2)	
(2013)				(1)	5.4		

				(3/3)	Convincing (2)		
Couples					5.5 Adequate		
constructing					(2)		
their					(7/7)		
experiences of							
dementia: A							
relational							
perspective							
Molyneaux,	Clear (1/1)	Defensible	Adequate (1/1)	4.1 Clear (1)	5.1 Rich (1)	6.1 Yes (1)	73%
Butchard,		(1/1)		4.2 Not sure	5.2 Not	6.2 Not	(11/15)
Simpson &				(0)	sure/not	sure/not	
Murray (2011)				4.3 Reliable	reported (0)	reported (0)	
				(1)	5.4	(1/2)	
The co-				(2/3)	Convincing (2)		
construction of					5.5 Adequate		

<hr/>							
couplehood in					(2)		
dementia					(5/7)		
<hr/>							
Vernooij-	Clear (1/1)	Defensible	Appropriate (1/1)	4.1 Not sure	5.1 Rich (1)	6.1 Not	73%
Dassen,		(1/1)		(0)	5.2 Reliable	sure/not	(11/15)
Derksen,				4.2 Unclear (0)	(2)	reported/not	
Scheltens &				4.3 Reliable	5.4	applicable (0)	
Moniz-Cook				(1)	Convincing (2)	6.2 Not clear	
(2006)				(1/3)	5.5 Adequate	(0)	
					(2)	(0/2)	
Receiving a					(7/7)		
diagnosis of							
dementia The							
experience over							
time							
<hr/>							

Appendix D: Examples of quotes that contribute to synthesised themes

Themes	Subthemes	Example quotes and extracts from papers
Dementia as a threat to couplehood	Threat from changing abilities	Derksen et al. (2006)
	linked with progression of dementia	Spouse: <i>“He becomes more and more dependent on me, he clings to me”</i> (pp. 528) Taken from theme: Consequences for personal life
		Hellström et al. (2007) Spouse: <i>“I don’t want him to feel like a burden for me”</i> (pp. 394) Taken from theme: Being affectionate and appreciative
		Davies (2011) <i>“The couples experienced a shift in the caring relationship role as a result of the dementia symptoms, from an independent, equal standing role to their relationship to a dependent one”</i> (pp. 9) Taken from theme: Us with a future

Vernooij et al. (2006)

PLwD: *“What a pity for you to get such a difficult husband”* (pp. 403)

Taken from theme: Changes in partnership

Threat of social isolation and
separation

Merrick et al. (2013)

Spouse: *“We just don’t talk much now. I think the best talks we have are when we go to Marks and Spencer’s cafe and have a cappuccino and then we sit facing one another and we chat . . . not the same as we used to”* (pp. 41)

PLwD: *“I don’t have a solution to that really. I mean I wish there were but. It’s depressing really”* (pp. 41)

Spouse: *“I used to feel quite secure. But I don’t any more. And I’m 80 you see, I’m getting on and sometimes I feel when things crop up, difficulties, problems, I just can’t cope”* (pp. 40)

“The bit that really gets me down is when we’ve had a bit of a laugh” . . . “I try and carry on the joke or conversation and he can’t remember the conversation”

		(pp. 41)
		Taken from theme: Altered structures
		Vernooij et al. (2006)
		Spouse: <i>“Sometimes I feel so lonely” “We are no longer equal partners . . . there is less to talk about”</i> (pp. 403)
		Taken from theme: Changes in partnership
		Hellström et al. (2007)
		Spouse: <i>“Yes, despite the fact that we are living together, and we have got a lot in common, nevertheless we are lonely in a way . . . you live in two small worlds. You have a common world and then you have your own world besides too.”</i> (pp. 403)
		Taken from theme: Maintaining involvement
Love is	Commitment	Molyneaux et al. (2011)
indestructible		Spouse: <i>“It’s what a husband does in these circumstances”</i> (pp. 495)

Taken from theme: Technically being a ‘carer’

Davies (2011)

PLwD: “*We don’t segregate, we don’t separate, we’re together*” (pp. 6)

Taken from opening results section

“For Mrs Peters (spouse) the belief in forgiveness came via the wedding vows and promises made at the time of her marriage. The vows were ‘taken to heart’ which meant you don’t give up on your marriage” (pp. 13)

Taken from theme: Forgiveness

Merrick *et al.* (2013)

Spouse: “*I married Mark, in sickness and in health and now he’s really sick, but it’s for life*” (pp. 39)

Taken from theme: Foundations

Closeness and affection

Hellström et al. (2007)

Spouse: “*As he is passing me I might get a kiss from him any time, that is no problem, that is nice. Then I thank him very much [laughing]*” (pp. 393)

Taken from theme: Being affectionate and appreciative

Merrick et al. (2013)

Spouse: “*Well we’ve always been very close, so it’s not a big change . . . I think we’ve become closer*” (pp. 41)

Taken from theme: Altered Structures

Hydén and Nilsson (2013)

“*Both spouses demonstrate their emotional closeness by touching each other*” (pp. 728)

Taken from theme: Couple as a social unit

Spouse: *"We're lucky, love still blossoms for us"* (pp. 724)

Taken from theme: Momentary group constellation

Reciprocity

Molyneaux *et al.* (2011)

Spouse: *"It's just you do that, you know, but she's taken care of me when, you know, so she, the house was always clean, the food on the table, the kids have always been well dressed so you know, I say it's a knock for knock you know"* (pp. 14)

Taken from theme: Technically being a 'carer'

Hellström *et al.* (2005)

Spouse: *"Certainly I have a mission, I have an important mission to help her, but we are also good company for each other"* (pp. 14)

Taken from theme: A loving and helping relationship

Davies (2011)

“Reciprocity, or the ‘give and take’ in each couple’s marital relationship, was present despite one spouse’s dementia” (pp. 11)

Taken from theme: Reciprocity

Merrick et al. (2013)

Spouse: *“She had a rough time with me, I had a serious accident . . . so it’s my turn to look after her” (pp. 40)*

Taken from theme: Foundations

Holding on to what *Maintaining normality*

remains

Hellström et al. (2007)

PLwD: *“and we live well, we have a glass of wine with the dinner every day. We think we can afford that and it can’t damage”*

Spouse: *“. . . and he [husband with dementia] makes coffee for me every morning”*
“. . . and makes a sandwich and then we sit dozing by the telly in the morning”

“We have made a habit to have coffee when we are out. Then we sit looking at people.”

“He [husband with dementia] gives my back a massage as soon as I ask him, and the same way when I shower he helps me to rub in oil.” (pp. 395)

Taken from theme: Making the best of things

Davies (2011)

“Activities were maintained for many of the couples through continuation of daily tasks, engaging in pastimes like gardening, walking, reading and seeing friends” (pp. 10)

Taken from theme: Partnership for life

Molyneaux et al. (2011)

Spouse: *“There’s very few Sundays that we haven’t been out you know for Sunday lunch or something” (pp. 492)*

Taken from theme: Maintaining the relationship despite dementia

Negotiating roles

Davies (2011)

Spouse: *"We had to do a couple of chores in the morning so we did it together"*

(pp. 12)

Taken from theme: Reciprocity

Hellström *et al.* (2005)

Spouse: *"the difficulties come when she is baking, you know. 'Have I put in the yeast?', then I ask her 'tell me out loud what you put in', because we usually help each other."* (pp. 15)

Taken from theme: A loving and helping relationship

Hellström *et al.* (2007)

"He has his things in the garden, and in the house with cleaning we do it together and also with washing up and he reads the recipes, so we do most things together."

(pp. 399)

Taken from theme: Maintaining involvement

Merrick et al. (2013)

“She puts it (laundry) in piles and writes on a bit of paper the number I’ve got to set the washing machine on and I do it. When it’s done I put it in the tumble dryer with the tissues and . . . so long as she gives me a clue . . . I’ll do it” (pp. 43)

Taken from theme: Flexible scaffolding

Enhancing a positive relationship *New appreciation of life and each other*

Hellström et al. (2007)

Spouse: *“We have a nice time together at home, and that is what we are saying every day. ‘Oh God, such a nice time we have, you and I’; ‘Yes’ says my husband ‘that is thanks to you’; ‘No’, I say, ‘it is thanks to you’”* pp. 394

Taken from theme: Being affectionate and appreciative

PLwD: *“Take the day as it comes. There is no reason to worry”* (pp. 396)

Taken from theme: Making the best of things

Merrick et al. (2013)

PLwD: *“He is absolutely fantastic . . . Absolutely. Anything that needs doing, anything . . . We never get upset or anything like that and he’s really, he really is a marvellous person”* (pp. 46)

Taken from theme: Reviewing the plans

Searching for positives

Hellström et al. (2007)

Spouse: *“Yes, because we have had a good life before. It’s totally changed. It’s not so funny. Then you have to find the positive things in life. You always search for the positive to be able to feel happy”* (pp. 395)

Spouse: *“I think we have a good time here you mustn’t complain, there are those who have it worse”*(pp. 396)

Taken from theme: Making the best of things

Molyneaux et al. (2011)

PLwD: *“We were always happy weren’t we?”*

Spouse: *“Yes, we were happy and we didn’t have a lot of money to spend, but nobody did in those days but er, we used to, we used to make our own fun didn’t we?”* (pp. 494)

Taken from theme: The good old days

“To think of something like this coming on 20 years earlier, I mean that would be totally appalling” (pp. 497)

Taken from theme: Sharing the experience of dementia

Daniels *et al.* (2007)

“Wonderful time(s)”

“Good life together”

“No regrets” (quotes, pp. 167)

Spouse: *“Well, I try to think about the things that are a little brighter, on the bright side, than to think about all the bad stuff, you know. You just can’t dwell on it or it*

will run your life” (pp. 168)

Taken from theme: Positive reflections

Appendix E: Manuscript preparation for authors of the journal Aging & Mental Health

Manuscript preparation

1. General guidelines

Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Long quotations of 40 words or more should be indented without quotation marks.

Manuscripts may be in the form of (i) regular articles not usually exceeding 5,000 words (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding 2,000 words. These word limits exclude references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

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

Please supply all details required by any funding and grant-awarding bodies as an

Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:

For single agency grants:

This work was supported by the <Funding Agency> under Grant <number xxxx>.

For multiple agency grants:

This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.

Structured Abstracts of not more than 250 words are required for all manuscripts submitted.

The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

Each manuscript should have 3 to 5 keywords.

Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).

Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.

All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.

All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.

Biographical notes on contributors are not required for this journal.

Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research. For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.

Authors must adhere to SI units. Units are not italicized

When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.

Authors must not embed equations or image files within their manuscript.

2. Style guidelines

Word templates are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk.

References are cited in the text by the author's surname, the publication date of the work cited, and a page number if necessary. Full details are given in the reference list. Place them at the appropriate point in the text. If they appear within parenthetical material, put the year within commas. Within the same parentheses, order alphabetically and then by year for repeated authors, with in-press citations last. Separate references by different authors with a semi-colon. If name and year are in parentheses, include the year in subsequent citations.

With a quotation, citations should be presented as:

- This is the text, and Smith (2012) says "quoted text" (p. 1), which supports my argument.
- This is the text, and this is supported by "quoted text" (Smith, 2012, p. 1).
- This is a displayed quotation. (Smith, 2012, p. 1)

With two authors: Smith and Jones (2012) or (Smith & Jones, 2012)

At first mention: Smith, Jones, Khan, Patel, and Chen (2012) or (Smith, Jones, Khan, Patel, & Chen, 2012)

At subsequent mentions: Smith et al. (2012) or (Smith et al., 2012)

In cases where two or more references would shorten to the same form, retain all three names

For six or more authors: Smith et al. (2012) (Smith et al., 2012)

Authors with two publications in the same year: Put a, b, c after the year
(Chen, 2011a, 2011b, in press-a)

- When citing an entire website, it is sufficient just to give the address of the site in the text: The BBC (<http://www.bbc.co.uk>).

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- Book: Author, A. A., & Author, B. B. (2012). *This is a book title: And subtitle*. Abingdon: Routledge.
- Organisation as author: American Psychological Association. (2003). *Book title: And subtitle*. Abingdon: Routledge.
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- Journal article: Author, A. A. (2011). Title of article. *Title of Journal*, 22, 123–231.
doi:xx.xxxxxxxxxx

Author, A. A., & Author, B. B. (2004). Title of article. *Title of Journal*, 22, 123–231.
doi:xx.xxxxxxxxxx

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- Organisation as author: American Psychological Association. (2003). Title of article: And subtitle. *Title of Journal*, 2, 12–23. doi:xx.xxxxxxxxxx
- Thesis: Author, A. A. (2012). *Title of thesis* (Unpublished doctoral dissertation or master's thesis). Name of Institution, Location.

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Figures must be saved separate to text. Please do not embed figures in the manuscript file.

Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).

All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).

Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly. The captions should include keys to symbols, and should make interpretation possible without reference to the text.

The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

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What is the meaning of love when your spouse lives in care?

**Does your husband, wife, or long-term
partner live in a care home, and live
with dementia?**

**Would you be willing to talk about your
relationship, and what it is like now that
your spouse is in care?**

If you are happy to talk about your experiences,
please contact the researcher by ringing
the telephone number below:

Researcher name: Lottie Cowell

Telephone Number: 07967876237

Email Address: C.F.Cowell@2013.hull.ac.uk

Appendix G: Participant Information Sheet

Information Sheet

Title of the study: An exploration of spouses' ongoing experiences of love in dementia in the post-transitional phase of moving into care

We would like to invite you to take part in our research study, which is looking at the experience of love from the perspective of long-term partners or spouses, in relationships with people living with dementia whom live in care homes. Before you decide if you want to participate we would like you to understand why we are undertaking this research. We would also like you to understand what it will involve for you if you decide to participate. The researcher will be happy to answer any questions you may have.

What is the purpose of the study?

There is a lot of research that explores the stressful or negative effects of dementia on families. The decision for a person to put their spouse into care is often viewed as one of the most difficult choices to ever have to make. This study is interested in the positive aspects of being married or a long-term partner to a person living with dementia whom lives in care, specifically considering the importance of love.

Why have I been invited?

This information is being given to the husbands, wives, or long-term partners, of people living with dementia, who live in a care home, and are above the age of 65.

Do I have to take part?

No, participation is completely voluntary. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. You are free to withdraw from the study up to the point where the study results are analysed and written up and you do not have to give a reason for this. Your decision will not affect your spouses' care.

What will happen if I decide to take part?

If you agree to take part please telephone the researcher on the telephone number provided at the bottom of this information sheet. The researcher will be able to answer any questions you may have and can arrange a meeting with you at a convenient place and time.

The researcher will ask you to select between five and ten photographs that you feel say something about the love between you and your spouse, to bring along to the meeting.

In the meeting, you will have to answer some short questions about you, for example your gender and your age. After this, you will have a conversation with the researcher about your photographs, which will last around 60 minutes. The researcher will ask you questions about your experiences of love throughout your whole relationship, focusing specifically on your experiences of love now that your spouse is in care. The researcher will record the discussion. There are no right or wrong answers and the researcher is only interested in your opinions, your beliefs and your experience of love in your relationship.

Where will the research take place?

It is up to where you wish to take part in this study; it will be at a time and place to suit you. The researcher can meet with you at home, or at another suitable location, or you can come to the University of Hull.

Expenses and Payments

Your participation in this study is voluntary; therefore there will be no payment for taking part.

What are the possible disadvantages and risks of taking part?

The meeting with the researcher will require around an hour of your time, and before this you will need to choose your photographs. The interviews will include discussion of a potentially upsetting and sensitive topic, and some people may become upset when they talk about their experiences because it may bring to mind difficult issues. If this happens,

you can take a break from the interview at any point, or stop the interview completely if you wish.

What are the possible benefits of taking part?

It is possible that discussion of the topic will be enjoyable, as it offers you an opportunity to discuss your life and your relationship with your spouse. It is also hoped that the information you give us will help us to understand more about experiences of love both during and after the care home transition, and where more resources may be required to improve peoples' experiences.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written up without giving a reason. This will not affect your spouses' care at the care home.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

Yes, all the personal information that you provide will be kept strictly confidential. The people who will decide to participate will be given a different name to protect their anonymity. After the research is completed all the audio recordings will be destroyed. If you would like your photographs to be copied by the researcher, to be included in the final research report, you can give consent for this. This will reduce your anonymity, however any other information that could be used to identify you will not be used in the research.

The only time that information given in the meeting cannot be kept confidential is if you say something that suggests that you or someone else is at risk of serious harm, for example, if you talk about bad practice at the care home. If this happens during the

interview the researcher will need to contact appropriate authorities to ensure that you and other people are safe. If this happens, the researcher will discuss this with you first.

What will happen to the results of the study?

After the study is completed, if you wish, you will be given written feedback about the results of the study via letter. Then the results will be written-up for the researcher's thesis, and submitted for publication in an academic journal. Some direct quotes from your interview may be used in the write-up, but your personal details and any identifiable data will not be included in the write-up.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Relevant sections of data collected during the study may be looked at by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed by an independent organisation, which is called a Research Ethics Committee. The Research Ethics Committee protects the interest of people who participate in research. This study has been reviewed by the University of Hull Research Ethics Committee and has received a favourable opinion.

If you have any further questions, comments or queries, please do not hesitate to contact Lottie Cowell. Thank you for taking the time to read this information.

Yours Sincerely,

Lottie Cowell
Trainee Clinical Psychologist

Supervised by,

Dr. Emma Wolverson
Clinical Psychologist

Dr. Chris Clarke

Consultant Clinical Psychologist

Lottie Cowell

The Department of Psychological Health &
Wellbeing

Hertford Building

The University of Hull

Cottingham Road

Hull

HU6 7RX

Tel: 07967876237

E-mail: C.F.Cowell@2013.hull.ac.uk

Dr Emma Wolverson & Dr Chris Clarke

The Department of Psychological Health &
Wellbeing

Hertford Building

The University of Hull

Cottingham Road

Hull

HU6 7RX

Tel: 01482 464170 (Emma)

01482 464106 (Chris)

Email: E.Wolverson@hull.ac.uk (Emma)

C.Clarke@hull.ac.uk (Chris)

Thank you very much for your interest!

Appendix H: Consent Form

CONSENT FORM

Title of Project: An exploration of spouses' ongoing experiences of love in dementia in the post-transitional phase of moving into care

Name of Researcher: Lottie Cowell

Name of Participant:

Please initial boxes

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis.	
3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.	
4. I agree to take part in the interview part of the study and understand that my interview will be audio taped.	
5. I give consent for the researcher to take copies of my original photographs to produce a photograph memento for me at the end of the study.	
6. I give consent for the researcher to use copies of my original photographs to use within the final research report and at research conference presentations. I am aware that this will reduce my anonymity, however no other personal identifiable information will be included in the study.	
7. I wish to receive a summary of the final results once the research is complete.	

Researcher Signature..... Date.....

Participant Signature..... Date.....

Appendix I: Demographic Information Form

Title of Project: An exploration of spouses' ongoing experiences of love in dementia in the post-transitional phase of moving into care

Name of Researcher: Lottie Cowell

Name of Participant:

Care home number:

I would like to start by asking you some questions about you and some questions about your spouse. Please try to answer these questions as accurately as you can, but don't worry if you are not sure about your answer.

1. What is your age in years?

.....

2. What is your spouses' age in years?

.....

3. What is your gender? Please circle the one that applies to you.

Male / Female

4. What is the gender of your spouse? Please circle the one that applies to you.

Male / Female

5. What is your ethnic background? Please circle the one that applies to you.

- White British
- Other White Background (please specify)
- Multiple Ethnic Background (please specify)
- Asian
- Asian British
- African/Caribbean
- African British/Caribbean British
- Other Ethnic Group (please specify)

6. What is the ethnic background of your spouse? Please circle the one that applies to you.

- White British
- Other White Background (please specify)
- Multiple Ethnic Background (please specify)
- Asian
- Asian British
- African/Caribbean
- African British/Caribbean British
- Other Ethnic Group (please specify)

7. How many years have you and your spouse been married?

.....

8. Have either of you been married before?

.....

9. Do you and your spouse have any children? If so, how many?

.....

10. When was your spouse diagnosed with dementia?

.....

11. Do you know what type of dementia your spouse diagnosed with?

.....

12. When did your spouse enter residential care?

.....

**13. On average, how often do you visit your spouse in their care home per
month/week?**

.....

14. Do you receive any support? If yes, what kind of support?

.....

Thank you very much for taking the time to answer these questions!

Appendix J: Table of participant demographics

Pseudonym/	Gender/	Age/	Ethnicity/	Dementia	Length of	Children	Time	Time	Visiting	Support
Spouse	Spouse	Spouse	Spouse	type	marriage		since	since	routine	received
pseudonym	gender	age	ethnicity		(1st or 2nd		diagnosis	entered		
			WB =		marriage)			care		
			White							
			British							
Eric	M	82	WB	AD	54 years	2	Not stated	2 years,	Daily	Cleaner,
Florence	F	78	WB		(1 st)			6		gardener
								months		
George	M	77	WB	AD	55 years	3	8 years	6 years	5 x per	Children, carers
Pauline	F	76	WB		(1 st)				week	group
Stanley	M	90	WB	AD	56 years	0	6 years	5 years	1 x per	Attendance
Jean	F	82	WB		(1 st)				week	allowance
Jack	M	69	WB	AD	37 years	1	5 years,	3	Nearly	No

Thelma	F	72	WB		(2 nd)		6 months	months	every	
									day	
Frank	M	78	WB	AD	54 years	2	5 years,	9	4 x per	Cleaner/Personal
Barbara	F	76	WB		(1 st)		7 months	months	week	Assistant
Arthur	M	83	WB	VaD	60 years	3	7 years	2 years,	6 x per	No
Edith	F	79	WB		(1 st)			8	week	
								months		
Betty	F	77	WB	AD	54 years	3	3 years	5	Daily	Family and
Albert	M	79	WB		(1 st)			months		friends
Josephine	F	71	WB	Mixed -	38 years	1	10 years	3 years	Daily	Limited support
Harold	M	78	WB	AD and	(2 nd)					from son
				VaD						
Dorothy	F	82	WB	AD	59 years	2	3 years	7	Daily	Family,
Bernard	M	83	WB		(1 st)			months		neighbours, care
										home staff

Appendix K: Documentation of Ethical Approval

Removed for hard binding.

Appendix L: Semi-structured Interview Schedule

Interview Schedule

This interview schedule will not be strictly followed in sequence, but will be used to guide questions and the general direction of the interview.

Opening statement:

This interview is interested in finding out more about experiences of love in relationships from people whose spouse is living with dementia and has moved into care. Have you chosen some photographs that represent love in your relationship?

1) Before care home transition - set context:

- So you and *spouse's name* have been together for *number* years. Tell me about how you and *spouse's name* met
- Tell me about when you fell in love.

Look at photographs and for each photograph:

- Tell me a bit about this photograph. Why did you choose to share this one?
- Can you tell me what love means to you when looking at this photograph?
- What does this photograph tell me about your relationship?

2) Care home transition

In light of this, there was decision that *spouse's name* was going to go into care.

- Can you tell me a bit about the process of *name* entering care?

- Can you tell me about your experience of love during that time?

Prompt about barriers and facilitators to love if not mentioned:

- Was there anything that kept your love going during this transition?
- Was there anything that acted as a barrier to love during this transition?

3) Maintenance of relationship following transition

- Tell me about love in your relationship now.
- What are the signs of love in your relationship now?
- Is there anything that keeps the love going in your relationship now?
- How do the photos that you showed me at the start of this interview relate to how you experience love now?

Comments

- If there are no photographs taken in the care home, the researcher will comment on this. E.g. 'I notice that none of these photographs are taken whilst *spouse's name* is in the care home, I wondered whether there was any reason for this?'

Appendix M: Debrief Letters

Information Form - York

Thank you very much for taking part in my research project. I hope you have enjoyed it.

The research aimed to find out more about relationship experiences, from the perspectives of spouses of people living with dementia, whom have moved into care. The researcher was specifically interested in love, with the idea that this may be something that couples draw upon to gain positive experiences once a spouse has moved into care.

If you have any questions for me after we have finished the interview, you can contact me using these details:

Telephone: **07967876237**

Email: C.F.Cowell@2013.hull.ac.uk

If you are upset or worried about anything following our interview, and would like some support, you may benefit from speaking to your GP or accessing support from alternative services, such as:

Alzheimer's Society

Address: Suites G4, G5 and G12, IT Centre, Innovation Way, Heslington, York, YO10 5NP

Telephone Number: 01904 567701

Email: yorkservices@alzheimers.org.uk

Helpline - 0300 222 1122

If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline can provide information and support.

Talking Point – <http://forum.alzheimers.org.uk/forum.php>

This is the Alzheimer's Society's online discussion forum for anyone affected by dementia. It's a place to ask for advice, share information with other people who are affected, join in discussions and feel supported.

York Carers Forum

Address: 15 Priory Street, York, YO1 6ET

Telephone Number: 01904 422 437

Email: yorkcarersforum@tiscali.co.uk

Website: www.yorkcarersforum.org

This is a local service, run by unpaid carers, which provides a safe environment for both carers and former carers to come along to talk to someone if they are feeling isolated.

Admiral Nursing - York

Address: Joseph Rowntree Foundation, Hartrigg Oaks, New Earswick, York YO32 4DY

Telephone Number: 01904 752 211

Dementia UK Helpline: 0845 257 9406 (staffed by Admiral Nurses)

Admiral nurses are committed to improving the lives of all people affected by dementia. Many carers feel under a lot of stress as a result of their caring role, therefore this service provides helpful support and activities.

Age UK York

Address: Norman Collinson House, 70 Walmgate, York, YO1 9TL

Telephone Number: 01904 627995

Email: ageukyork@ageukyork.org.uk

Website: www.ageuk.org.uk/york

This is a charity that provides advice, information and practical help for older people over 60 and their carers, including benefits advice, community befriending and support services.

Age UK - Call in Time Telephone Befriending Service

Telephone Number: 0844 225 0320

Email: callintime@ageuk.org.uk

This is a telephone befriending service provided by Age UK, for people over the age of 60, who may feel lonely or isolated. The service provides friendly phone calls from specialist volunteers.

York Samaritans

York Branch Telephone Number: 01904 655 888

National Telephone Number: 08457 909 090

Email: jo@samaritans.org

Visit the Hull Branch: 88 Nunnery Lane, York, YO23 1AH

If you want some space to talk about your difficulties, Samaritans provide a 24-hour confidential telephone service to talk about general difficulties – not specific to dementia.

York Mind

Website: www.mindhey.co.uk

Address: Highcliffe House, Highcliffe Court, York, YO30 6BP

Telephone Number: 01904 643 364

National Helpline: 0300 123 3393

Email: info@mindhey.co.uk

Mind provide advice and support to help people experiencing mental health problems. There is a local Mind, as well as a national helpline.

Thanks again,

Lottie

Information Form - Hull

Thank you very much for taking part in my research project. I hope you have enjoyed it.

The research aimed to find out more about relationship experiences, from the perspectives of spouses of people living with dementia, whom have moved into care. The researcher was specifically interested in love, with the idea that this may be something that couples draw upon to gain positive experiences once a spouse has moved into care.

If you have any questions for me after we have finished the interview, you can contact me using these details:

Telephone: **07967876237**

Email: C.F.Cowell@2013.hull.ac.uk

If you are upset or worried about anything following our interview, and would like some support, you may benefit from speaking to your GP or accessing support from alternative services, such as:

Alzheimer's Society

Helpline - 0300 222 1122

If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline can provide information and support.

Talking Point – <http://forum.alzheimers.org.uk/forum.php>

This is the Alzheimer's Society's online discussion forum for anyone affected by dementia. It's a place to ask for advice, share information with other people who are affected, join in discussions and feel supported.

Carers Information and Support Service - Hull

Address: 30 King Edward Street, Hull, HU1 3SS

Telephone Number: 01482 222 220

This is a local service which provides a safe environment for carers to come along to talk to someone if they are feeling isolated. The service can also provide advice and information to people after a change in their care situation.

Admiral Nursing - Hull

Email: Irene.walker@humber.nhs.uk

Telephone Number: 01482 336 912

Dementia UK Helpline: 0845 257 9406 (staffed by Admiral Nurses)

Admiral nurses are committed to improving the lives of all people affected by dementia. Many carers feel under a lot of stress as a result of their caring role, therefore this service provides helpful support and activities.

Age UK - Call in Time Telephone Befriending Service

Telephone: 0844 225 0320

Email: callintime@ageuk.org.uk

This is a telephone befriending service provided by Age UK, for people over the age of 60, who may feel lonely or isolated. The service provides friendly phone calls from specialist

volunteers.

Hull Samaritans

Hull Branch Telephone Number: 01482 323 456

National Telephone Number: 08457 909 090

Email: jo@samaritans.org

Visit the Hull Branch: 75 Spring Bank, Hull, HU3 1AG

If you want some space to talk about your difficulties, Samaritans provide a 24-hour confidential telephone service to talk about general difficulties – not specific to dementia.

Hull and East Yorkshire Mind

Website: www.mindhey.co.uk

Address: Wellington House, 108 Beverley Road, Hull, HU3 1XA

Telephone Number: 01482 240 200

Information Line: 01482 336 878

Email: info@mindhey.co.uk

Mind provide advice and support to help people experiencing mental health problems. There is a local Mind, as well as a national helpline.

Thanks again,

Lottie

Appendix N: Worked example of Interpretative Phenomenological Analysis

Emerging Themes	Extract from transcript	Initial notes Descriptive; linguistic; <u>conceptual</u>
	Participant: *long pause* Erm *pause* the *sigh* *pause* yes it, it's, er, I don't know necessarily whether the love's changed but the- the, well, normally, it- in the normal way, before she had her problems and, particularly before she's got to the stage she is now, erm there wasn't	<i>Hesitation and pauses - difficult to explain?</i> 'In the normal way'
Increased physical affection since dementia onset	nearly so much of this er arm round and erm th- that sort of you know- *Wife speaks*	Increased demonstration of love
Difficult to articulate feelings of love	Participant: Erm, we- we were so- *Wife and participant speak over each other*	<u>Hard to articulate</u>

	Participant: A couple that- you know, but now there's now much more wallowing	Wallowing?
	Wife continues to speak over participant	
Demonstration of love	Participant: When I'm here in an afternoon- that arm is-	<i>Wallowing but showing love</i>
		<i>(contradiction?)</i>
	Wife continues to speak	
	Interviewer: Mmm	
	Wife continues to speak	
	Participant: That- that arm round her is a much more involved thing than it was	Arm more involved - physical affection increased

Interviewer: Right, so were you- did you touch much before or was it,
have you beca- become closer kind of physically *pause* now would
you say?

Participant: Well I mean *pause*

Wife speaks

Current relationship is not ordinary	Participant: *Speaks to wife* Can't we? Erm *pause* before she was ill *pause* it was much more of the ordinary day-to-day, erm, you know, she would do this, I would do that, and *pause* there wasn't a lot of the sort of close cuddling and things like that	<i>Pauses when talks about her before 'she was ill' - <u>Loss?</u> Before = ordinary day-to-day - <u>relationship is now more unique?</u></i>
Increased physical closeness	Interviewer: No	More independent roles in the

		relationship
Importance of quality time	Participant: Erm, that we have now, for a good part of two hours	Less physical acts of love
		<u>Time together important?</u>
	Interviewer: Mmm	
Continues to visit regardless of wife's presentation	Participant: If and when it actually happens, which it doesn't always, sometimes we- sometimes she just goes to sleep or dozes most of the	<i>Arm always around her vs. varies (contradiction)</i>
Threat to showing love	time I'm here, so I mean it varies an awful lot	Sleeps but he still continues to visit
	Interviewer: Yeah	<u>Showing love threatened by sleeping?</u>
Shared quality time	Participant: Erm, but we have some lovely times together *smiles*	Lovely times together - <u>quality time?</u>
		<i>Smiles</i>

Appendix O: Epistemological statement

It is important to acknowledge that a researcher's personal perspective and way of viewing the world has a profound impact on the way in which their research is approached, developed and conducted. The purpose of this statement was to explore the underlying ontological and epistemological assumptions, which have contributed to the development and analysis of the current research. Ontology refers to the meaning of reality for a researcher, whereas epistemology refers to the study of that reality (Guba, 1990). This therefore leads to specific choices for methodology based on the way in which the researcher seeks to find out their reality.

The aim of the current study was to understand the experience of love in relationships for couples where one partner is diagnosed with dementia, and has moved into a care home. The research was developed in the absence of literature that considers the strengths and resources that couples draw upon to generate positive experiences and maintain their relationships following a transition into care. In order to understand this very subjective experience, it felt necessary to use a qualitative approach. As such a positivist stance, typically adopted by quantitative methodology, was rejected (Willig, 2001).

A positivist stance suggests that there is always an objective truth, which can be measured quantifiably through hypothesis testing and experiments. This stance emphasises objectivity and assumes that the participant can be studied without the influence of researcher bias (Ponterotto, 2005). As such, the positivist stance was not considered

suitable for exploring the richness of experiences for participants who are married to a person living with dementia, as the analysis may be too reductionist.

In contrast, a constructivist stance assumes that within the world, there is no objective truth and that truths are constructed through social realities. This therefore proposes that realities are entirely subjective and can vary from person to person, depending on the influence of their experiences, social environment and perceptions of the world (Guba & Lincoln, 1994; Ponterotto, 2005). Through a constructivist stance, researchers recognise that knowledge is co-constructed between researchers and participants, and aims to understand participants' experiences through their own realities.

The researcher had initially been introduced to research from a positivist stance during her undergraduate degree at the University of Hull, and had only ever conducted quantitative research prior to beginning her doctoral training. Through development of clinical skills however, the researcher has found benefit from understanding the lived experience of individuals, due to the rich detail that this provides. As such, the researcher's position took a middle ground, acknowledging that a single truth may exist, but that different peoples' experiences influence their perspectives of this.

The current research was therefore approached from a critical realist position, as developed by Bhaskar (1978). This is an ontological position that suggests that there is an existence of truth within the world, but that this exists independently of social constructions, and as such there is no way of gaining a unanimous understanding of true reality (Maxwell, 2012). As Ponterotto (2005) explained, critical realism accepts that there is the existence of a true

reality, but that this ‘can only be reached imperfectly’ (Ponterotto, 2005). Critical realism moves away from the idea of constructivism, which suggests that there can be multiple realities, and instead suggests that people have different perspectives on the one true reality of the world. The approach suggests that any statement of knowledge should be critically examined to allow the best understanding of that reality (Cohen & Crabtree, 2006). In line with the above, a critical realist position was considered most suitable, with regards to the researchers’ perspectives on reality.

Through careful consideration of the different qualitative methods available, it was decided that Interpretative Phenomenological Analysis (IPA) was the most suitable methodology available to address the research questions. Thematic Analysis and Grounded Theory were considered as alternative methods, and are discussed below.

Thematic Analysis

Thematic analysis involves categorising and describing features of qualitative data (Pistrang & Barker, 2010). This approach seeks to identify common themes across participants’ accounts, rather than acknowledging individual experience (Anderson, 2007). Thematic analysis incorporates minimal interpretation, which may limit the researchers’ depth of understanding of participants’ experiences. As this study aimed to gain an understanding, rather than a description, of participants’ experiences, the method of Thematic Analysis was rejected.

Grounded Theory

The aim of grounded theory, as outlined by Strauss and Corbin (1994) is to build on or develop new theories that are grounded within the analysed data. This is an approach that is widely used in health-related studies (Pistrang & Barker, 2010). Within grounded theory, data is systematically analysed until data saturation is reached. This was not considered a suitable methodology for the current research, as the aim was to explore ‘lived experience’ of love, rather than to generate new theory. In addition, as there is very little existing literature that studies the experiences of love in the context of dementia, it would have been difficult to build on existing theoretical frameworks.

IPA

IPA was considered to be the most appropriate methodology for gaining an understanding of the lived experiences of love in relationships for participants’ where their partner is diagnosed with dementia, and has moved into a care home. IPA seeks to understand the subjective meanings that individual experiences hold for each participant (Smith & Osborn, 2008). IPA is underpinned by three areas of ‘philosophical knowledge’, known as; phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009).

Phenomenology refers to the study of individuals’ own subjective experiences. This involves study of the accounts unique to that person, rather than just an objective record of their experiences (Smith et al, 2009).

Hermeneutics refers to the theory and processes of interpretation within phenomenology. IPA acknowledges that individuals interpret their own experiences, in order to understand them, and as such their accounts reflect the ways in which they understand this. IPA also recognises the process of double hermeneutics, in that the analyst's own perspectives will influence analysis, as ultimately the analysis is the researchers' interpretation of what the participant means within their accounts (Smith et al, 2009).

Idiography is interested in the 'particular', with regards to the specifics of individuals' experiences. Idiography aims to understand how a certain person, in a certain context makes sense of their experiences and views the participant as an 'active interpreter' within their subjective world. This acknowledges the importance of unique experiences for individuals (Smith et al, 2009).

IPA is therefore considered as an appropriate and accessible methodology to understand in-depth individual experiences (Pringle, Drummond, McLafferty & Hendry, 2011).

Considering the above, IPA was recognised as the most suitable methodology for the study, in order to explore the experience of love in relationships for a person married to a partner with dementia, who has moved into a care home.

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Appendix P: Reflective statement

The research topic

Choosing a suitable research topic felt incredibly important when I started the course, especially because this was something I wanted to feel entirely committed to and enjoy studying for three years. I began the doctorate with very few preconceived ideas about the research area I would like to study. I had always been interested in working with older people through my voluntary experiences prior to the course, but was unsure which aspect of this broad research area I would like to hone in on and study more closely.

I was drawn to researching positive psychology and dementia following teaching from Dr Emma Wolverson in the first few months of the doctorate. Her enthusiasm and passion for this research area was infectious and my interest was confirmed through subsequent meetings about the potential areas of positive psychology that I could look into.

I instantly felt drawn to the topic of love and relationships, which I suppose, on reflection may have been influenced by my own experiences. I have witnessed long and loving marriages between my parents and grandparents, and I myself have been in a happy relationship for six years. I found myself drawn to understanding the experiences of marital couples, where one person was diagnosed with dementia - as I felt that ultimately this was the relationship most likely to be directly affected. Marital relationships for couples experiencing dementia had been studied very broadly already, but much of the literature looked at burden and coping, rather than solely focusing on the experience and changes that

may have occurred. There was also very little understanding of love in the context of dementia and relationships, therefore focus on this topic felt necessary and important.

Through exploration of the existing literature in the field, the idea was proposed to study the experience of love in relationships for couples living with dementia when they live apart due to residential care. This transition had been given little attention, and it felt important to focus on the unique experience for the individuals involved.

At the time of choosing this topic, my understanding of the separation of couples when one person entered a care home was limited, but I had witnessed the relationships between couples through my voluntary work on an older people's inpatient ward, and was intrigued to find out more about this experience.

I had some understanding of the care home context after my family went through a care home transition after my Grandma was moved into a care home. I witnessed my Mum's ongoing dedication to visiting my Grandma, and the unconditional love that they continued to share until my Grandma died in 2013.

Methodology

During my undergraduate degree, I had only ever gained experience of using quantitative methodology. However I felt that for this topic area, it was really important to understand participants' subjective accounts, and felt the only way to do this was through qualitative

interviews. I initially felt quite daunted by this prospect, and I quickly had to learn that in qualitative research, there are not necessarily right or wrong answers.

Although initially I had wanted to interview couples together, I was aware that quite often, the reasons for a transition to care related to challenges associated with the progression of dementia, and cognitive deterioration. Although I was aware that Braun, Scholz, Bailey, Perren, Hornung and Martin (2009) had suggested dyadic perspectives should be taken in dementia research, I made the decision to interview only the partner without dementia, to avoid complications regarding the person with dementia's capacity to consent or contribute their perspectives within the interviews. Upon reflection, I may have liked to have given couples the choice as to whether they wanted both partners to be present for the interview. I became aware that participants may have liked this alternative option when the first gentleman I met with requested that the interview took place at his wife's care home, so that his wife could listen to the interview - despite not contributing.

As outlined in my epistemological statement (Appendix O), I chose to use Interpretative Phenomenological Analysis (IPA), to allow me to explore the lived experiences of individuals who live apart from their partners with dementia due to a care home transition. This felt appropriate, and with guidance from my supervisors, I built confidence in developing an interview schedule that would allow me to find out about participants' subjective experiences.

In addition to the semi-structured questions, the interview was designed to include a component of photo elicitation. Participants were asked to select photographs that they felt

accurately represented the love between themselves and their spouse, and the interview began with an opportunity for them to share the photographs with the researcher. Using photographs was initially chosen to facilitate conversation between the participants and the researcher, especially for those who were less comfortable talking about their experiences. Upon reflection, I am really pleased that I incorporated the photographs into the interviews, as I felt this gave context to the conversation, and gave a new layer to understanding the participants' views of their relationships with their partners'.

Recruitment

I decided not to recruit through NHS services, as I felt that the participants that I needed were readily accessible through private care homes and local services. I was aware of the sometimes lengthy process involved in gaining ethical approval through the NHS, and opted to take the potentially faster route in order to maximise my time for recruitment of participants.

To begin the process of recruitment, I distributed an eye catching information poster to advertise the study to visitors at care homes and local services in York and Hull. I do remember feeling initially quite disheartened when I started to contact care homes to request their assistance in recruitment, as many of the care home managers were very busy and unable to speak with me. Despite this, I remained determined and with the advice of my supervisor, Dr Chris Clarke, decided to send out letters to explain the study to care home staff and local service managers, which I followed up with phone calls. This was a much more positive approach, and I found that through having an initial understanding of

the study, services were much more enthusiastic about supporting recruitment for the research.

The response to my advertisement was initially very positive, with two participants contacting me very quickly after the posters were displayed. Although this was a very pleasant surprise, my hopes were quickly dampened by the first participant, when he expressed his doubt about further recruitment. I was aware initially that love as a concept may be viewed as being quite 'fluffy', and I was concerned that this may have put some participants off taking part. Following the initial surge of participants, there was a noticeable lull and I did feel like I was 'playing a waiting game' for some time. It wasn't until I began a new placement at an Older People's service that I approached more local care homes and services, and the recruitment again picked up momentum.

I was surprised by the number of male participants who quickly got in touch with me to express their interest in the research study, and the significant lack of females. I had initially thought that it may be the other way round, but this has not been my experience. After interviewing six male participants, I felt it was really important to publicise my need for female participants, to allow both husbands and wives to have the opportunity to share their experiences. I was grateful that my fifth participant passed on my details to a female friend, who was willing to take part in the study. I then contacted all of the care homes and relevant services that had already assisted with recruitment and asked whether they knew of any females who would like to take part. I was pleasantly surprised by the response, and within a week had recruited a total of three ladies.

I found benefit from using advertisement posters, in addition to making direct contact with relevant services that were able to support recruitment. I would definitely choose this approach to recruitment again in future research endeavours.

Interviews

The interviews were without doubt the most enjoyable part of the research process. Before beginning the interviews, I felt quite daunted by the prospect of meeting with participants, but I was pleasantly surprised, and felt privileged to be welcomed into the participants' homes. The home environment felt comfortable and participants were able to readily access photographs, and share their partners' interests and hobbies by showing me paintings and embroidery that they had created, which were displayed around the home.

For the gentleman who was interviewed at the care home in the company of his wife, he provided a relatively positive account of his experiences. I do wonder whether this interview would have been different had it been conducted on a one-to-one basis. The interview felt entirely comfortable and appropriate, however I did note that there were a number of interruptions due to interactions between the participant and his wife, and this may have affected the flow of the answers he gave in response to my questions.

I was really pleased that participants so openly shared stories of their relationships with their partners', backed up by photographs to demonstrate their love. Within many of the interviews, the participants did understandably become emotional whilst speaking about their experiences. At these times, it felt quite unnatural to sit and listen, rather than

intervene in the participants' distress. I feel that these were the only times where I felt conflicted between my role as a researcher, and my role as a clinician.

At the end of the interviews, a number of participants expressed that the interview had been helpful and therapeutic, as it had given them an opportunity to process their feelings in relation to their relationship. This led me to consider whether the semi-structured interview in some ways acted as an indirect intervention, in supporting participants to cope with their situation.

Data Analysis

The process of transcribing and analysing the data was enjoyable, yet lengthy. Listening back to the interview recordings allowed me to re-engage with the participants' experiences, and I found this really helpful when I began to code the transcripts. The sheer amount of detail across the participants' accounts at times left me feeling quite overwhelmed, and I think I did put some unnecessary pressure on myself as I had not used IPA before, and was initially very keen to 'get it right'. Over time I settled with the fact that there is not necessarily a right or wrong way of analysing the data, due to my own influence as a researcher. Upon reflection, I do wonder whether the pressure that I put onto myself during the analysis linked to my need to produce a piece of research that accurately portrayed the participants' deep and meaningful experiences.

Finding themes across the participants' accounts felt exciting, and I spent a great deal of time working with the themes, in order to find those most relevant to the questions set out

within the aims of the study. Once I got to the process of developing a final set of super-ordinate and subthemes, I really felt that the research was coming together, and looked forward to writing it up.

I very much saw the write up as part of the analysis, and I thoroughly enjoyed this part of the process. The write up helped me to understand the themes as a whole, and recognise the links between them. Choosing the most appropriate quotes to illustrate the themes took some time, as I had several in mind that had stood out to me from the interviews. With all of the participants' accounts providing such depth, it was difficult to discard some of their quotes, however I felt that the themes that I eventually settled on embedded each individual participants' experiences, irrespective of whether these included direct quotes.

Systematic Literature Review

I began the systematic literature review with little idea of what I wanted to look into. The literature that had previously been reviewed on relationships for couples living with dementia had primarily focused on the perspectives of the partner without dementia. This led me to initially consider the possibility of reviewing the literature on the experiences from the perspectives of PLwD, however from exploring the literature, I found that there simply wasn't enough literature out there to review. It was only then that I became aware of the very limited understanding of the dyadic perspective of couples living with dementia. I therefore felt it was really important to bring forward an understanding of the shared perspectives of couples in this situation, and looked for papers that incorporated interviews with both PLwD and their partners.

Systematically, finding suitable papers was an extremely time consuming process, which upon reflection, I wish I had begun earlier. When I eventually came to synthesising the data, I became more engaged, and came to recognise the importance of the review in relation to existing literature in the field of dementia and relationships. I also feel that the review links well to the empirical paper, as it highlights the importance of studying the often neglected, experience of love.

Choice of journals

I chose to write my empirical paper for the journal of ‘Aging & Mental Health’, which is a well-respected international peer reviewed journal. This journal welcomes research on the psychological and psychiatric difficulties experienced by the ageing population, and aims to improve mental health for older people and their families. I chose to write for this journal, as it welcomes research on dementia and acknowledges the importance of experiences for both the ageing population, and the people around them.

For my systematic literature review, I chose to write for the journal of ‘International Psychogeriatrics’. This is a leading peer reviewed journal that publishes literature relating to ageing and mental health. This journal also welcomes literature reviews, therefore I felt that a study of relationships in dementia, which ultimately link to psychological wellbeing, would be appropriate.

Final reflections

My view of conducting research has drastically changed whilst being on the course. Having only carried out quantitative research before beginning the doctorate, I now have a newfound appreciation of qualitative research. I now particularly value the opportunity to explore the depth and richness of peoples' subjective accounts, as opposed to potentially reducing this to numbers or statements. Despite finding the process challenging, I have thoroughly enjoyed carrying out this research, and know that I will leave the course with a great sense of achievement in having done so. I feel that my knowledge about relationships for couples experiencing dementia has grown substantially, and I now have a more in depth understanding of the importance of research in the role of a Clinical Psychologist.

Reflective Statement References

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