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Title: Family relationships and dementia: A synthesis of qualitative research including the person with dementia.

Publication year: 2013

Journal title: Ageing and Society.

Publisher: Cambridge Journals Online.

Link to final published article: <http://dx.doi.org/10.1017/S0144686X13000056>

Citation: La Fontaine, J. and Oyeboode, J. R. (2013). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. Ageing and Society. Published online: 19 March 2013, pp.1-30
doi:10.1017/S0144686X13000056.

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Family relationships and dementia: A synthesis of qualitative research including the person with dementia

Abstract

Family relationships are important for wellbeing across the life course and are known to be important for people living with dementia, bringing benefits to self-esteem and identity, as well as providing support for people living at home. Recent research has explored the impact of dementia upon relationships. Much of this research is qualitative in nature and rarely included in systematic reviews, however, it has the potential to provide significant contributions to understanding the interplay between family relationships and dementia and to inform interventions.

A systematic synthesis of qualitative research concerning the impact of dementia upon family relationships was undertaken, using thematic synthesis. Eleven articles were reviewed, which address the perspectives of people living with dementia and their spouse and/or adult children. The aims of this review are to illuminate what is currently known about the reciprocal influences between family relationships and dementia from the perspectives of the family (including the person with dementia); and to consider the implications of these findings for research and practice. Four super-ordinate themes were identified: A shared history, negotiating the impact of dementia upon the relationship, openness and awareness, and shifting sands.

This synthesis contributes to an emerging field but also highlights gaps in current understanding of the impact of dementia upon relationships and in providing appropriate interventions. Implications for research and practice are considered.

Keywords

Family relations, Dementia, Alzheimer Disease, Qualitative Research, Synthesis

Family relationships and dementia: A synthesis of qualitative research including the person with dementia

Introduction

Of approximately 800,000 people with dementia in the United Kingdom, it is estimated that around 63.5% live in private households (Luengo-Fernandez, Leal and Gray 2010). Of these, many live with or near other family members who frequently provide the mainstay of support (Knapp and Prince 2007). Such relationships are particularly important, enabling people with dementia to experience well-being, and maintain identity and self-esteem (Livingston *et al.* 2008). Even though the condition is a '*significant driver of demand for health and social care*' (Knapp and Prince 2007: 10) it has been suggested that there has been a widespread failure to support people with dementia and their families (Knapp and Prince 2007).

Additionally, given the 'dynamic nature of family care' (Nolan, *et al.* 2002: 195) and the impact of dementia upon well-being, there is a need to establish a body of knowledge that can inform the development of effective advice or interventions for families providing care, to enhance adaptation and prevent outcomes such as depression (Brodaty, Gresham and Luscombe 2007, Knapp and Prince 2007). Indeed, national and international guidance, and government policy on dementia care highlight the necessity of such action (Department of Health 2009; NICE/SCIE 2006; Prince, Bryce and Ferri 2011; Alzheimer Europe 2006).

In recent years, the emergence of person-centred care and subsequently relationship centred care (Kitwood 1997, Brooker 2008, Nolan *et al.* 2004) have made a significant contribution, including placing the person with dementia and their family caregivers at the centre of the development of policy and research. Consequently, research concerning the impact and

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experience of dementia has increased and [has recently considered](#) the impact of dementia upon relationships (Ablitt, Jones and Muers, 2009, Quinn, Clare and Woods 2009). This relatively recent shift to a relationship focus has found that factors including shared coping strategies and the quality of the current and previous relationship influence the experience of dementia (Ablitt, Jones and Muers 2009, Hellström, Nolan and Lundh, 2007, Keady and Nolan 2003). However, the majority of this research is dyadic in focus; has predominantly considered spousal relationships; has rarely extended to other family members or the potential impact of dementia upon the wider family and has not always included the perspective of the person with dementia. The few studies that have explored the impact upon other and wider family relationships indicate that dementia does affect other family members (Allen, Oyebode and Allen 2009, Garwick, Detzner and Boss 1994). Garwick, Detzner and Boss (1994) suggest that families absorb dementia into their collective identity, where it becomes the whole family's challenge. Furthermore, Spitznagel *et al.* (2006) have found that the wider family has a role in mediating against institutionalisation.

Research into living with other health conditions supports the suggestion that a focus upon family relationships is necessary and beneficial. This is evident in chronic illness (Fisher 2006, Rolland 1987, Walsh 1996, Lyons *et al.* 1998) and in mental health difficulties such as psychosis, where it is recognised that families influence and in turn, are affected by the impact of mental illness (Fadden and Smith 2009). Specifically, family interventions in psychiatry have been found to reduce the relapse rate, aid in recovery and increase wellbeing (Heru 2006). However, it is necessary to recognise that research and interventions from other chronic and long-term conditions cannot necessarily be applied wholesale to the experience of dementia, as the condition includes specific challenges such as changes in cognitive

abilities, relational functioning and roles; and an unpredictable, lengthy and changing course (Sheilds, 1992).

In the absence of a significant body of research which explores the impact of dementia upon the range of family relationships or the family as a whole, it is nevertheless of value to critically consider how current research might inform us further. Much of the research exploring the impact upon relationships involves in-depth, qualitative studies, and has rarely been included in systematic reviews. While not generalisable, such research creates potential for depth of understanding. This article seeks to synthesise current qualitative research exploring the interplay between dementia and family relationships where the research explicitly includes the person with dementia. The goals of this review are to illuminate what is currently known about reciprocal influences between family relationships and dementia from the perspectives of the family (including the person with dementia); and to consider the implications of these findings for research and practice.

Method

Qualitative synthesis is a relatively new approach to bringing together the findings from qualitative studies (Dixon Woods *et al.* 2006). The selection of an appropriate form of synthesis was informed by the wide range of methodologies that have been used in qualitative research concerning the impact of dementia upon relationships. Accordingly, thematic synthesis (Thomas and Harden 2008) was selected, since it is suitable for synthesising studies using a range of epistemologies. Thematic synthesis is described as having “theoretical freedom [and] provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data” (Braun and Clarke 2006: 78).

Systematic Search Strategy

In December 2011, searches were completed through Medline, PsychINFO, PsychArticle, CINAHL, CAB, EMBASE, ASSIA and Web of Science. The search terms included combinations of Dementia OR Alzheimer's Disease AND Caregiv* or Carer AND/ OR Family Relations* or Relations*, Parent Child relations*, Marriage or Marital Relations*, Spouse, Spousal Relations*, Sexual Relations*, Child*, Couplehood, Spousal Caregiv*, Mother Daughter Relations*. This search yielded 875 abstracts from which 20 were retained following review of the title and abstracts. A hand search of these articles, and the journal Dementia, identified 3 further relevant articles. Papers that utilised quantitative methodology were excluded, as these have been reviewed elsewhere (e.g. Ablitt, Jones and Muers 2009, Quinn, Clare and Woods 2009).

Selection Process

The 23 articles were subjected to further scrutiny against the following inclusion criteria. Articles had to be in English; from peer reviewed publications; be qualitative or mixed method; have actively involved the person with dementia and have a central focus upon the relationship between the person with dementia and their family member/s and the impact of dementia. 12 papers were rejected because they did not include direct quotes from participants; they used observational methodologies; they were reviews; or did not address the relationship between the person with dementia and their family members.

Findings

The methodologies, research questions and key findings of the remaining 11 articles are outlined in table 1. Eight had the relationship between the person with dementia and their family member as a central theme. The other three included methods and results which illustrated the participants' reactions to and experiences of dementia and its impact upon their

relationships (Clare and Shakespeare, 2004, Robinson, Clare and Evans, 2005, Svanström and Dahlberg, 2004)

< insert table 1 about here >

Methodologies

A range of methodologies, including constructivist grounded theory, discourse analysis and phenomenological methodologies, explicitly inform ten of the eleven studies. In-depth interviews were the main method utilised for data collection, with seven choosing to interview participants together. Eight used a cross-sectional design, interviewing participants at one point in time.

Participants

In all but three studies the participants were co-habiting couples. The three other studies involved adult-daughter and mother relationships (Forbat 2003, Ward Griffin *et al.* 2007) or a three-generational family (Purves 2010). Participants were generally recruited from service providers including memory clinics. In eight studies, participants with dementia had received a diagnosis of Alzheimer's disease. In the other studies, diagnoses were dementia, mixed dementia or vascular dementia. In over half, the length of time dementia had been experienced is not clear. With the exception of two studies, the type and level of support services received by participants is not described.

Comments on quality

Each article was subjected to an assessment of quality of the research according to the 14 criteria identified by Elliott, Fischer and Rennie (1999, see table 2). The results of the assessment are presented in table 3. Each article was assessed by the first author as: Achieving (y), partially achieving (p) or not (n) achieving the criteria. In order to check the reliability of this process, the second author independently rated a randomly selected sub-set

of 3 of the papers. This process revealed agreement on 13/14 ratings on 2 of the 3 papers. On the third, on 8/14 criteria, one rater viewed the criterion as met where the other viewed it as partially met. Discussion between the authors was used to understand the discrepancies and arrive at agreement. Overall it was felt that the system was good enough to give a general overview of the quality of the papers, although it must be recognised that, to some extent this is a subjective process, and others might make different judgements on some of the criteria.

< insert Table 2 about here >

< insert Table 3 about here >

As illustrated by table 3, the articles were generally of good quality, meeting the criteria either wholly or partially. Limitations include the lack of representation of different relationships, such as parent-child (of both genders), intergenerational families or gay relationships, and different forms of dementia. The age of the person with dementia was rarely reported, and the ethnic and cultural background of participants was not addressed in the majority of articles. A final limitation involves the predominant cross-sectional design. As dementia is a dynamic journey in which progressive changes, loss and adjustment is not a static process, a longitudinal design is perhaps more likely to illustrate the impact of dementia. The account below needs to be read with these limitations in mind.

Analysis

Thematic synthesis was applied to the text in the findings sections of each of the papers (Thomas and Harden 2008). This review is particularly concerned with the participants' perspectives of the impact of dementia upon their relationships, thus it was the participants' data that was given priority. Only segments of text, therefore, that included quotes of participants were subjected to coding.

The analysis involved six stages as described by Braun and Clarke (2006). Stage one involved reading and re-reading the findings sections to achieve familiarity, and taking notes about possible areas of similarity and difference, and possible codes. Seven articles, for example, included quotes that alluded or directly referred to positive experiences of the relationship before diagnosis, which was noted, following which articles were examined for evidence of any contrasting references to prior negative experiences. This led to the tentative codes 'a good life together' and 'disconnectedness'. Stage two involved uploading the articles into NVivo 9 (2010), followed by line-by-line coding. As Thomas and Harden (2008) advise, this involved putting the review questions to one side and staying close to the data. At this stage, 74 codes were identified. Stage three involved the development of descriptive themes. The first author printed the codes with associated quotes. The two authors then reviewed all codes and associated quotes, placing them on post-it notes, so that they could be inductively assembled into hierarchies, with overarching themes identified. From this process, an overarching theme of a shared history emerged, which included the two themes tentatively identified earlier as well as codes which appeared to illustrate other dimensions of this theme.

Stages four and five involved reviewing and refining the themes identified in stage three, including going back to the original data to check for confirmation or contradiction of the emerging hierarchies. Initially, for example, the theme of disconnectedness subsumed codes connected with dissatisfaction, past conflicts and conflict and rejection, all of which seemed to be connected with negative aspects of relationship. Further exploration identified that some quotations in this group referred to the present relationship and some to the past relationship. The theme was therefore split into two, and the elements related to the current relationship were placed in a new overarching theme which closely reflected Keady and Nolan's (2003)

concept of ‘working apart’ in the context of the current experience of dementia and its impact upon relationship.

In this fifth stage, four super-ordinate themes were developed and considered in relation to the goals of this review. For example, under the overarching theme of a shared history, the two subthemes, ‘a good life’ and ‘disconnected’, were consolidated. Each subtheme contained codes which illustrated specific dimensions, ‘A good life together’, for example included affirming current commitment because of past relationship quality, as well as identifying how past difficulties had been overcome, coded as ‘pulling through’.

Comment [J02]: I find it confusing that sometimes you refer to the top level as superordinate and sometimes as overarching. Could you stick with one or the other?

Comment [J03]: Took a sentence out here as it didn't seem to explain any aspect of analysis as far as I could tell.

Analytical Themes

Four, super-ordinate analytical themes were identified: A Shared History, Negotiating the Impact of Dementia upon the Relationship, Openness and Awareness and Shifting Sands.

Table 4 shows the spread of the themes across the 11 papers reviewed. Where possible, the perspectives of both the person with dementia and the spouse or partner are used to illustrate these themes. Contributions arising from the experiences of other family relationships occurred less frequently because of the limited literature addressing these relationships, but to give voice to these relationships, examples from their accounts are also included in the sections below.

< insert Table 4 about here >

A Shared History

In eight articles, reference was made by participants to their relationship history, characterised by positive and/or negative feelings about the relationship and each other. Two subthemes emerged: A Good Life Together and Disconnectedness.

A Good Life Together

This sub-theme primarily reflects the experience of couples. Of the eight articles, seven highlighted positive feelings concerning their shared history, reflecting that they had experienced a good life together with a strong, shared emotional bond.

Although Jane's statements were brief, such as "he's just the best thing I've ever had," they were often paired with grins and glances toward Tom, as she reached for his hand or arm to hold. (Daniels et al. 2007: 167)

Tom made statements such as "she's been a wonderful, wonderful wife," and "I don't think I could have found a better match for me, because uh, we've just, everything's been agreeable and we've always got along. (Daniels et al. 2007: 168)

Couples reflected on the commitment they had made to each other, which involved willingness to compromise in order to maintain togetherness.

Mr Martin: For better and for worse, and on and on. It was the natural, natural thing that we would do and that's what we believed in...

Mrs Martin: Well yeah. I mean we've been together long enough to sort of, at that plateau, we haven't seen things the same. But together, we also come around. We don't segregate. We don't separate. We're together. (Davies 2011: 222)

Such reflections involved recognising the contribution that each person had made to the relationship and to each other, which in the case below provided justification for the caring that a husband was now providing for his wife.

Dawn: Oh, he thinks, thinks of everything for me, don't you love?... Dave: 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. (Molyneaux et al. 2011: 14)

Couples also identified that an aspect of this good life involved resolving or accommodating disagreements and willingness to let go of conflict and bad feelings.

Mrs Martin reports: 'It's a balance and we've, at least I look at it, well if I want to be okay between us, then I just have to make sure that nothing goes between us and he does the same thing, you know. We don't go to bed with a bad attitude, you know.

Mr Martin: I think what my mom said often, she says, in a marriage you make sure by the time the sun sets, if something has happened during the day that maybe you were cross or you did something, you apologize and ask for forgiveness and if the other person, your partner, is

of the same opinion, even so it hurts her, she will forgive you. Then you sleep over it and the next day is a new day. So you wipe out the old day. (Davies 2011: 229)

Only one adult –daughter/ mother study (Ward-Griffin *et al.* 2007) contributed to this sub-theme, with just the daughter’s perspective being quoted in the original article. This illustrated, as with the couples, evidence of a continuing emotional bond and reciprocity in the relationship;

*Oh, my mother [Hazel] and I have always been good friends. (Ward-Griffin *et al.* 2007: 25) I can sit and have a discussion with my mother about anything. She is very wise....It’s a privilege to give back what I got...but I don’t really feel that I’ve given so much than I feel as if I’ve learned. (Ward-Griffin *et al.* 2007: 26)*

Disconnectedness

In contrast to the above sub-theme, although much less frequently, negative perceptions of a shared history were highlighted. This sub-theme was present in only three of the 11 articles, two exploring mother and daughter relationships and one exploring married couple relationships. Although less prominent, this sub-theme involved apparent absence of the emotional connectedness evident in those describing a good life together, along with evidence of past conflict and disagreement.

Barbara tells me: [about Mavis, her mother] ‘Oh yeah! She could be quite violent!... She’d throw knives, forks, saucepans, you name it she threw it.(Forbat 2003: 74)

Mavis: I wouldn’t ill-treat them

Interviewer: Right

Mavis: Er . . . box their ears now and again <chuckle>

Interviewer: You would or you wouldn’t?

Mavis: I would, but I- I didn’t make a habit of it because I didn’t believe in that, you know I think you might do them more damage than, you know (Forbat 2003: 74)

This first theme, A Shared History, reflects the extent to which the participants felt emotionally connected, which seemed to result in open communication, negotiation, sharing of roles and addressing challenges within the relationship. The participants linked their shared positive history with current continuing connection and commitment to the relationship. Where this sense of shared positive history was not present, for example in those mother-daughter relationships where a negative shared history emerges, mothers and daughters reflected on the difficulties evident in their current relationship. Links between past and current relationship quality are thus made in all the articles addressed in this super-ordinate theme. In those articles that did not contribute to ‘a good life’, this appeared to reflect a focus on the current experience of dementia, rather than concern with relational history (Purves, 2010, Hellström, Nolan and Lundh, 2005, Svanström and Dahlberg, 2004) or, in Forbat’s (2003) paper a focus on a single case only, in which there were difficulties within the caregiving relationship.

Negotiating the impact of dementia upon the relationship

All 11 articles contributed to this super-ordinate theme, and two sub-themes emerged, A Problem Shared and Working Apart.

A Problem Shared

Eight of the 10 articles contributing to this sub-theme addressed couple relationships. The diagnosis of dementia and the resulting challenges appeared to be viewed as something to be managed together, with participants continuing to emphasise their continued commitment to each other. Thus couples described continued expression of emotional togetherness in their relationships with each other:

Peter (PWD): You’ve got to, I was just going to say yeah, you’ve got to be, you’ve got to stick together. Denise: Yeah, there’s lots of love in this house. Peter: That’s the main thing to me

anyway. (Molyneaux et al. 2011: 8)

And although less frequently, this was also evident in mother-daughter relationships:

I notice that our relationship is very, very comfortable. Very relaxed, very, you know, mom and I are just totally in sync with one another. (Julie, daughter)" (Ward-Griffin et al. 2007: 24)

I think my relationship with Diane is good. I depend on her quite a bit you know, and she is always there . . . so what more do I need? And she is very thoughtful. (Emily, Mother)(Ward-Griffin et al. 2007: 25)

Furthermore open communication and managing things together was a feature of couple relationships reflected in their discussions about their lives together, in this instance by the person with dementia:

PLWD; Often we consult each other, but there have not been any deeper problems, there might be discussions in what way to go, and then we try to solve it together. (Hellström, Nolan and Lundh. 2007: 393)

Participants also reflected upon the importance of mutual respect, appreciation and reciprocity, thus emphasising the commitment that they continue to express:

I think if every mother had a daughter like I have they'd be very, very happy. ...I, I just worship her. I really do. And you know, I think if, if I call her she'll say, "I'll be right over there mom." If I'm, you know, not well, she'll say, "I'll slip over." (Hazel, mother)(Ward-Griffin et al. 2007: 27)

In the context of their shared lives, in order to manage the impact of dementia, and maintain the relationship, participating dyads described various strategies, such as supporting continuation of valued activities:

Jim: We perhaps do them together now, I mean you have a go and then leave the easy ones for me. Pauline: That's what I tell him anyway. Jim: No, it's surprising actually that erm, I mean I was never terribly good at crosswords but now I mean sometimes we'll, or I've had a look at the one you've done or part completed and you've come up with words that I couldn't think of, you know. I mean it's remarkable really that. Pauline: Well I think it's through reading things, isn't it? (Molyneaux et al. 2011: 8)

In all 10 articles, family members described activities aimed at enabling and maintaining the

identity and functioning of the person with dementia:

When I was in the hospital, she was able to talk to the doctors and the nurses in a way that I couldn't.... Sometimes when I wasn't getting the drift, she would get that across.... She also goes to the doctor's [office] with me. She listens. She keeps it all straightened in my mind. (Margaret, mother) (Ward Griffin et al. 2007: 26)

Such strategies were sometimes carried out without the knowledge of the person with dementia yet were also directed at maintaining their togetherness:

Mr Svensson: She is okay with cooking and so on, but 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. I whip the eggs, and if we make cakes I make sure I am there...

Interviewer: Do you still bake? Mrs Svensson: Oh yes, I enjoy that, I have done it so many years. Interviewer: Is this something that has become more difficult, to bake? Mrs Svensson: No I don't think so, I always keep to the recipe and then there are no difficulties. No I don't think so. (Hellström, Nolan and Lundh 2005: p15)

Additionally, participant accounts illustrated the need for current compromise to sustain the relationship and also to live for today, thereby keeping dementia on a different plane:

PLWD: It is nothing to be happy for, but you have to accept these conditions and do as good as possible. My wife and I don't talk about it either. As we feel that the milieu is shaped by this, but I am pleased and satisfied that it is like it is. The disease is on another plane, it doesn't have to affect others. (Hellström, Nolan and Lundh 2007: 396)

Working Apart

However, although evident in only six of the articles and with less frequency, the impact of dementia upon relationships also resulted in family members experiencing significant difficulties in their relationship. The way in which this manifested corresponded closely to the theme of 'working apart' described by Keady and Nolan, (2003: 30) in which it is highlighted that where previous relationship quality is poor or where it has not been possible to work together in the context of dementia, the experience leads to strained relationships and consequently a feeling of entrapment in the family caregiver. Contributions to this theme arose from articles addressing couple, mother–daughter and family relationships.

This working apart was illustrated by the experience of a loss of connection in one couple relationship, where the partner without dementia described the couple's life as living in two small worlds:

"FM; 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." (Hellström, Nolan and Lundh 2007: 402)

In a few cases this experience led to feelings of powerlessness and an inability to influence their lives.

(pwd) "Well, actually I have no aims anymore. Life is over. (Svanström and Dahlberg 2004: 680)

Additionally, to further breakdown in the relationship:

She is very, very needy. Sometimes I just have to tolerate her but I can't be around her for long. She is so needy! You feel like there is nothing, there is nothing left for you because you give, give, give so much to her.... There are no rewards in this relationship at all and over the couple of years that she's been here, I find myself so stressed and so upset and in tears and I would just say to my husband, "I just wish she was dead.(Tara, daughter)(Ward-Griffin et al. 2007: 24)

In the context of working apart, it appeared that rather than experiencing dementia as a problem to be shared, some family members positioned the problem with the person with the diagnosis:

No, he, he doesn't react. He doesn't care. Surely, that's why it's getting worse so quickly. If you have just a little . . . will to live and just a few interests and little, then, then you cope with things. But therefore it, it's probably because of that it's going down so quickly. The telly is on and he, I think X doesn't, well he sits here and in the evenings until I put him to bed and, and the telly is on but, and he doesn't touch the paper. He quits, he has quit everything. He doesn't care and that's why it goes so quickly. (Svanström and Dahlberg 2004: 679)

Thus blaming the person with dementia for the difficulties and using various strategies to control the person, including deception and confrontation:

My sister gave her [mother] a cigarette and I didn't see it at first. I said, "You are not having a cigarette!" I grabbed it out of her hand. Like I was literally jumping over the table and grabbing the cigarette. It was almost like taking something away from a baby. I said, "You are not having that!" (Linda, daughter) (Ward-Griffin et al. 2007: 43)

I've learned a few things from Maria. She says lie to her [heh-heh] white lies. (Purves, 2011: 23)

When positioned in this way, particularly where confrontation was used, some participants with dementia exercised resistance or denial, perhaps in an attempt to maintain self-esteem and identity:

FM: I don't think you managed to pick up the use of new instruments quite as well as you did, like the ...answer phone....

PLWD: Yeah, well, I was never really the technical type (Clare and Shakespeare 2004: 217)

Openness and Awareness

Nine articles contributed to the third super-ordinate theme, with seven of these concerning couple relationships. Openness and Awareness involved the extent to which it was possible for the participants to negotiate and share their understanding of what was happening (sub-theme of Making Meaning) or, at the other extreme, minimise it and thus deny the impact of it, (sub-theme of Minimising). The capacity for openness and awareness seemed to be central to the coping strategies used by participants, thus being clearly intertwined with the previous super-ordinate theme.

Making Meaning

Although all 9 articles contributed to the sub-theme of Making Meaning, those addressing couple relationships accounted for almost all of the contributions. Open communication appeared to be a central strategy for acknowledging the difficulties being experienced and finding ways of coping. Thus some couples actively engaged in sharing awareness of the challenges, even though these might be difficult conversations:

FM: I mean I'm quite hopeful that whatever deterioration there is, you know, is going to take a long time. I don't, you know . . .

PLWD: You might not enjoy that as much as you think, or not enjoy, you may not be tolerant.

FM: Well, I'm not going to enjoy it, am I? I don't think we're going to enjoy this.

PLWD: No, but you may not be as tolerant as that as time goes on.

FM: That's true.

PLWD: If I go sort of off and off and off, that's fine because I don't even know where I'm going or who I am, er, that's a possibility, er, but I would expect you to be pretty fed up, um, you know, if that happened. (Clare and Shakespeare 2004: 222)

Making meaning also involved developing an understanding of what was happening, including positioning dementia rather than the person as the problem:

But it's Alzheimer's. It's not like she's doing it because she's forgetful and careless. (Purves 2011: 42)

Openness and awareness resulted for some participants in expressions of fear for the future. However participants also responded by a process of gradual adjustment and taking each day as it comes;

In spite of their difficulties, couples described a process of continuing their lives together as they always had, and gradually adjusting and carrying on together as a couple and as individuals: 'You adjust to it, I mean the abnormal has become normal (laughing) as you might say'. [Wife with dementia] (Robinson, Clare and Evans, 2005: 342)

PLWD: I don't look much ahead to be honest. I take more like one day at a time so to speak. (Hellström, Nolan and Lundh 2007: 397)

Minimising

In three articles (one considering the wider family relationship and two considering couple relationships), minimising was also used as a strategy to manage the experience of dementia. Denial appeared to be central to this process. This was used by either the person with dementia or the family member, to deny the emotional experience of the other person and perhaps therefore to shield themselves:

*PLWD: There's no way I want to be gaga with somebody looking after me all the time, not by anybody.
FM: Well, don't worry about it. (Clare and Shakespeare 2004: 222)*

In such circumstances, individual and interpersonal responses occurred, involving resistance to acknowledgement of the possible reasons for changes, the eventual diagnosis and the difficulties it brought. Resistance took the form of normalizing the difficulties or actively choosing not to think about them. However not all parties in the relationship were synchronous in their ways of understanding and coping with the changes. Thus on occasions, the strategies of resistance and confrontation were used and appeared to be challenging for

both parties, particularly where this involved a denial of the difficulties experienced as a consequence of dementia:

Edith: No but, or then he says to me, 'what did you give me? How much did you give me?'
Terry (PWD): Yeah, I'm just thinking what she's said, I'll just say, 'what did you give me?'
Just a normal thing isn't it? Edith: No, you don't you, because you get mixed up with the change. Terry: Nah, nah. (Molyneaux et al. 2011: 11)

Shifting Sands...

This final super-ordinate theme addresses the challenges that dementia brings to relationships. All 11 articles included in the review contributed to this theme.

Shifting Responsibilities

Seven articles (one wider family and seven couple relationships) made reference to the change in roles and responsibilities that dementia brought for the relationship.

Son:... and so she can't cook anymore. I think she feels very very helpless and she looks – if you see her in that situation, she looks very helpless, she's sort of on the outside looking in as the kids are preparing stuff, and she's asking whether she can help – we try to get her to help as much as we can. (Purves, 2011: 45)

Such changes involved a complex process of negotiation involving noticing and managing the risks associated with changes in the person's abilities; negotiating the forms of help that were needed, while maintaining the identity of the person with dementia. For example in the situation described below, the family sought to manage the process of maintaining Rose's identity as a grandmother, while believing that she was no longer able to be responsible for her grandchildren:

Colin: so you're going to come to swimming lessons with us
Rose: oh/is that right?
Colin: yeah
Rose: blast c (one), where, where was it that we had (all that) right by that little_
Colin: ...um:: #name# pool
Rose: yeah
Colin: 'cause dad's not gonna be home...
Colin: Alison/are you excited?
Alison: yay again
Colin: Grandma's coming to swimming lessons with you ... 'member? ... she came swimming

wi- another day too 'member? (Purves 2011: 49-50)

The process of negotiation appeared less challenging where the person with dementia was able to accept that they were no longer able to carry out particular activities or tasks independently:

"PLWD: ... But now we sit together, my wife is helping me when we work with our expenses, so she is becoming familiar with it if something happens. I am happy that my wife gets familiar with all our joint business." (Hellström, Nolan and Lundh 2007: 401)

Nevertheless, some family members found this to be a difficult adjustment to make as it entailed extra responsibility

"You've got to think ahead all the time ... I try and think of everything" Wife, (Robinson, Clare and Evans 2005: 342)

Time Together and Time Apart

Early in the experience of dementia, the continuation of valued activities and independent time was possible and desired:

PWD: Yes, it's good. We get along well actually. We can talk to each other. He is busy with his flying club and I think he should be. He has to have his interests. So we have it well. If there is something that is a problem we can talk to each other straight off. That's nice. (Hellström, Nolan and Lundh 2007: 392)

However, particularly for couples, the consequence of shifting roles and responsibilities tended to result in couples necessarily having to spend more time together as dementia progressed, rather than being able to spend time on their own independent activities. . This was evident in five of the articles addressing couple relationships.

While spending time together was viewed positively, it appeared also to have negative consequences for wellbeing. Participants expressed the need for time apart and for independence and had difficulty engaging in actions that were previously not part of the relationship. This had the potential to be a source of conflict:

"Edith: But I find it very hard to say to him 'well I'm going out' and I leave him in this house by himself. Terry: Well I don't, I don't sit in though do I? Edith: No, you know. Terry: I just go out

myself and have a walk about myself, yeah. Edith: You don't go out yourself. Terry: I do, yeah. Edith: You don't, anymore. Terry: Nah." (Molyneaux et al. 2011: 10)

Such conflict seemed likely, as in this example, where levels of awareness and openness were not synchronous as referred to previously.

Loss

In five articles, reflecting couples, mothers-daughters and wider families, participants' accounts appeared to reflect the loss they experienced as a consequence of the impact of dementia:

"And then, and it also happened ...it also happens today, that he doesn't know who, who I am. Somehow, I can't explain it ...it was, did someone ask or was it what's your wife's name. Yes her name is X...no ...her name is X. Yes, yes that's my wife's name too, he said then, in some odd way."(Svanström and Dahlberg 2004: 681)

These accounts were primarily from the family member involved in caring and included losses such as memories of shared history, remembering who the spouse was, and changes in roles.

Discussion

This synthesis sought to illuminate what is currently known about the interplay between dementia and a range of family relationships, where this research has included the person with dementia as an active participant; and to identify the implications of these findings for research and practice.

Four super-ordinate themes emerged from synthesis of 11 qualitative studies. A Shared History; Negotiating the Impact of Dementia upon the Relationship, Openness and Awareness and Shifting Sands. Taken separately, some of the articles present a largely positive or negative account of the impact of dementia upon relationships. In synthesising the

accounts, a more nuanced view emerges, reflected in the way that the first 3 themes have both positive and negative poles.

The theme of Shifting Sands illustrates the particular psychosocial challenges that dementia brought for all family members in the studies. These included the alterations in roles and relationships and the resulting need for strategies to manage the impact of dementia highlighted in the second and third super-ordinate themes. Such findings have significant parallels with Rolland's (1994) work on the development of a psychosocial typology of chronic and life threatening illnesses, in particular, indicating that it is necessary to focus upon the duration, course, degree of incapacity and outcome of the changes, the life stage at which they occur and their impact upon the relationships rather than solely on the diagnosis.

The nature and quality of the previous and current relationship appear to be important factors influencing the experience of dementia for all family members, thus supporting the value of focusing upon relationships. Dementia appeared to impact differentially upon the well-being of couple and wider family relationships (cf Ablitt, Jones and Muers 2009). Furthermore, it seems that the coping strategies used by family members were important in either providing support to 'scaffold' the identity and self-esteem of the person with dementia or indeed 'positioning' them in such a way as to undermine their personhood (Kitwood 1997). These strategies were used by both partners and adult-children in the articles reviewed.

Furthermore, this synthesis brings together research which has included the person with dementia as an active participant, a voice which has largely been absent from such research (Ablitt, Jones and Muers, 2009). People with early experience of dementia in this synthesis have demonstrated that they continue to actively work with others in their family to maintain their relationships; to make sense of the impact of dementia and to manage the changes that it brings. Consistent with previous research, the accounts of people with dementia demonstrate

continued emotional awareness and awareness of the impact of dementia upon the family member involved in caring for them (Ablitt, Jones and Muers 2010, Burgener and Twigg 2002). Such insight and awareness facilitated opportunities for the relationship to continue to grow and for compromise and adjustment to take place, thus appearing to contribute to well-being and meaningful lives.

People with dementia contributed less to those themes where the experience of the impact of dementia upon the relationship was challenging. Where they contributed, their perspectives appeared to reflect positions of denial and resistance. This seemed to be as a consequence of a previously poor relationship; poor communication; being positioned by the other as a problem; or a lack of synchronicity in awareness and understanding, combined with the use of control by the family member involved in caregiving. Although this is less well developed in the synthesis and as such must be treated with caution, it has parallels with findings from Burgener and Twigg (2002) in highlighting that lower quality of relationship and caregiver stress predicted lower quality of life in the person living with dementia.

This synthesis has largely reflected research considering couple relationships. The contributions from couples have significant parallels with the dynamics of dementia discussed by Keady and Nolan (2003) and the outcomes of recent systematic reviews of quantitative research (Ablitt, Jones and Muers 2009, Quinn, Clare and Woods 2009). In particular, this review supports that, in the context of a previously positive relationship, effective adaptation to the impact of dementia involves emotional connectedness and open communication between the person with dementia and their spouse (Keady and Nolan 2003). Furthermore, 'working together' (Keady and Nolan, 2003) involves positioning dementia as the problem rather than the person. Thus couples appeared to engage in a complex process of 'holding' the dementia apart from the relationship while managing its impact on their day-to-

day lives. One specific contribution of this synthesis is that it demonstrates the active participation of the person with dementia in this process.

The majority of the research studies focused upon the strengths and adaptive characteristics of couple relationships, with minimal material about negative impact, or about how past conflict influences current experiences. This may reflect challenges in recruitment, as couples with a less positive relationship may be reluctant to participate and, in the context of being interviewed together, may be less willing to discuss difficulties. However, it also seems possible that the desire to move away from emphasis on burden and negativity may have resulted in less attention being given to those couples where such outcomes occur. A lesser number of articles within this review address the experience of other family relationships. However the findings suggest that concepts such as commitment, quality of previous relationship and emotional connectedness are relevant across various relationships, as also found in previous qualitative research from the perspective of family caregivers (Piercy 2007).

Implications for research

This synthesis has highlighted possible directions for further research. Firstly, the more negative sub-themes (Disconnectedness, Working Apart and Minimising) occurred significantly less frequently in participants' accounts. Although small in number, the accounts that populated these themes were largely from research in which the person with dementia and their family member were interviewed separately. Additionally, the accounts were predominantly from the perspective of the family member, with significantly fewer quotations coming from a person living with dementia. Previous research has been criticised for its uni-dimensional focus on negative outcomes. However if '*potentially negative and positive outcomes of care for both caregiver and care-receiver*' (Nolan *et al.* 2002: 203), are not recognised by researchers, there is a risk that of shift to a similar uni-dimensional focus

on positive experiences. Future research needs to give consideration to how to recruit and interview families, including the person with dementia, where relationships are less positive and to present a balanced view. To give freedom for expression of both positive and negative experiences it may be necessary to interview participants both together and apart. It is also important for researchers to reflexively consider whether a desire to represent the impact of dementia in a positive light results in a lesser focus on material which contradicts this desire. Methods to achieve this include theoretical sensitivity in grounded theory (Charmaz 2006, Corbin and Strauss 2008).

Secondly, a limitation of current research is that the focus has been on couple relationships. Evidence from this synthesis suggests that intergenerational relationships including adult child-parent relationships are also affected by dementia. Furthermore, this synthesis has highlighted that family members across generations are actively engaged in a process of negotiation and renegotiation of roles and relationships. However, research has rarely considered how intergenerational family relationships manage and mediate the impact of dementia, in spite of evidence demonstrating that multiple generations are affected (Allen, Oyebode and Allen 2009, Garwick, Detzner and Boss 1994, Tolkacheva *et al.* 2010). Further research is therefore required to provide an in-depth insight into the impact and management of dementia in a context of intergenerational family relationships.

Thirdly, existing research has largely focused upon people who have received a diagnosis of Alzheimer's disease, where the potential for maintaining the emotional relationship appeared to contribute to the positive relational experiences highlighted in some of these studies. However this has implications for less common forms of dementia, such as frontotemporal dementia, which involves a loss of empathy (Hodges 2008) and as a consequence, potential loss of an emotional relationship early in the experience of dementia. Further research studies

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are required to address potential differences in adjustment that arise from the psycho-social implications of these forms of dementia for family relationships.

Fourthly, many of the studies utilised a cross sectional design and many of the participants were early in their experience of dementia and able to actively participate in constructing and maintaining the relationship. Relationship quality and strategies to maintain the relationship have been shown to change over time, as the person finds it more difficult to engage in the conventions and strategies used previously to sustain relationships (Hellström, Nolan and Lundh 2007, Nolan, *et al.* 2002). As dementia has a progressive and changing course, more longitudinal studies of its impact on relationships are required.

Finally, it is important to recognise that a significant limitation of current research is its focus on traditional family relationships. Family relationships are influenced by ethnicity, sexual orientation and divorce. Different family constellations and dimensions of difference remain an area for further research.

Implications for Practice

Health and social care practice has tended to use the label of carer or caregiver to describe supportive family members. One implication of this research on relational aspects of living with dementia (Kitwood 1997; Nolan, *et al.*, 2002) is that a move away from a wholesale use of the label carer to define the relationship may be beneficial. This would respect relational roles, with caregiving acknowledged as part of relationships but not wholly defining them.

It is widely acknowledged that multi-component interventions are necessary to address the impact of dementia and support adaptation (Elvish *et al.* 2012). This synthesis suggests that there are a number of significant factors that these interventions will need to consider. These include firstly how the person with dementia can be supported to engage in relational work,

given that they are active in constructing and managing the impact of dementia upon the relationship. While this may be difficult as the illness progresses, with an increasing focus on early diagnosis and intervention, this current research suggests that it is possible for people with dementia to be involved.

Secondly, how family is defined will need to be carefully considered. Families are heterogeneous, and this synthesis has identified that limited evidence exists for understanding the impact of dementia on relationships other than couples. Nevertheless research does point to the involvement of other family members and suggests that they do influence how dementia is experienced and managed (Piercy 2007, Allen, Oyebode and Allen 2009, Garwick, Detzner and Boss 1994). Thus it would be beneficial for practitioners to consider who is defined as family by the person with dementia and their significant others, and to develop an understanding of the nature of the relationship when considering interventions.

Thirdly, the assessment process may benefit from including assessment of previous and current relationship quality (Ablitt, Jones and Muers 2009, Quinn, Clare and Woods 2009). This assessment should incorporate consideration of the way in which the illness is positioned by family members. Consistent with the concept of malignant social psychology described by Kitwood (1997) it seems possible that positioning the problem with the person with dementia may be a factor which engenders less positive outcomes.

Finally, this synthesis lends strength to the need to focus on the psycho-social consequences of dementia for the family. The way in which relationships are negotiated, roles are defined and challenges are managed are likely to be important factors in influencing how family members, including the person with dementia, live with dementia.

Statement of Funding;

The first author has a Florence Nightingale Research Scholarship for the 2nd year of her part time PhD studies. The Florence Nightingale Foundation had no influence over production of this paper.

Author Contribution

The first author planned and designed the process, conducted the literature searches, analysis, and writing of the paper. The second author provided supervision and critical review of the planning, design and implementation of the process, contributed to the analysis and provided critical revision of the paper.

Conflict of Interest

The authors have no conflict of interest to declare

References

Ablitt, A., Jones, G, and Muers, J. 2009. Living with dementia: A systematic review of the influence of relationship factors. *Aging and Mental Health*, **13**,4, 497-511.

Ablitt, A.J. 2008. Relationships between people with dementia and their carers, Unpublished Thesis, The Universities of Coventry and Warwickshire, EThOS uk.bl.ethos.502446, available online at; <http://ethos.bl.uk/Home.do;jsessionid=D073110A7F0CDAEFEF2DCEF888D4CA1E> accessed 27.12.10

Ablitt, A.J., Jones, G. and Muers, J. 2010. Awareness of carer distress in people with dementia, *International Journal of Geriatric Psychiatry*, **25**, 1246-52

Allen, J., Oyebode, J. and Allen, J. 2009. Having a father with young onset dementia, *Dementia*, **8**, 4, 455-480.

Alzheimer Europe, 2006. *Dementia carers' survey*, available online at; <http://www.alzheimer-europe.org/Alzheimer-Europe/Our-work/Completed-AE-projects/2006-Dementia-Carers-Survey#fragment-2> accessed 09.04.2012.

Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology, *Qualitative Research in Psychology*, **3**, 2, 77-101.

Brodaty, H. Gresham, M. and Luscombe, G. 2007. The prince henry hospital dementia caregivers training programme. *Revista Romana de Psihiatrie Seria a III-a*, **9**, 2-3, 140-46.

Brooker, D. 2007. *Person-Centred Dementia Care, Making Services Better*, London, Jessica Kingsley Publishers.

Burgener, S. and Twigg, P. 2002, Relationships among caregiver factors and quality of life in care recipients with irreversible dementia, *Alzheimer Disease and Associated Disorders*, **16**, 2, 88-102

Clare, L. and Shakespeare, P. 2004. Negotiating the impact of forgetting: dimensions of resistance in task-oriented conversations between people with early-stage dementia and their partners. *Dementia*, **3**, 2, 211-32.

Charmaz, K. 2006. *Constructing Grounded Theory, A practical guide through qualitative analysis*, California, Sage Publications.

Corbin, J.M. and Strauss, A.C. 2008. *Basics of qualitative research: techniques and procedures for developing grounded theory*. California, Sage Publications.

Daniels, K. J. Lamson, A. L. and Hodgson, J. 2007. An exploration of the marital relationship and Alzheimer's disease: One couple's story. *Families, Systems, and Health*, **25**, 2, 162-77.

Davies, J. C., 2011. Preserving the "us identity" through marriage commitment while living with early-stage dementia. *Dementia*, **10**, 2, 217-34.

Department of Health, (2009) Living Well with Dementia, A National Dementia Strategy, putting people first, available online at

<http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm> accessed 09.19.2009.

Dixon-Woods, M. Bonas, S. Booth, A. Jones, D.R. Miller, T. Sutton, A.J. Shaw, R.L. Smith, J.A. and Young, B. 2006. How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, **6**,1, 27-44.

Elliott, R. Fischer, C.T. and Rennie, D.L. 1999. Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, **38**, 215-29.

Elvish, R. Lever, S.J. Johnstone, J. Cawley, R. and Keady, J. 2012. Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence, *British Association for Counselling and Psychotherapy*.
http://www.bacp.co.uk/research/Systematic_Reviews_and_Publications/dementia_carers.php
accessed 12.6.2012.

Fadden, G. and Smith, J. 2009. Family work in early psychosis, in Lobban, F. and Barrowclough, C. (eds). *A Casebook of Family Interventions for Psychosis*, Oxford, John Wiley and Sons. 23-46.

Fisher, L. 2006. Research on the family and chronic disease among adults: Major trends and directions, *Families, Systems and Health*, **24**, 4, 373-80.

Forbat, L. 2003. Relationship difficulties in dementia care: A discursive analysis of two women's accounts. *Dementia*, **2**, 1, 67-84.

Garwick, A.W., Detzner, D. and Boss, P., 1994. Family perceptions of living with Alzheimer's disease, *Family Process*, **33**, 327-40.

- Hellström, I. Nolan, M. and Lundh, U. 2005. 'We do things together': A case study of 'couplehood' in dementia. *Dementia*, **4**, 1, 7-22.
- Hellström, I. Nolan, M. and Lundh, U. 2007. Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia*, **6**,3, 383-409.
- Heru, A. M., 2006. Family Psychiatry: From Research to Practice, *American Journal of Psychiatry*, **163**, 6, 962-68.
- Hodges, J.R. 2008. Overview of frontotemporal dementia, in Hodges, J.R. (ed.) *Frontotemporal dementia syndromes*, Cambridge, Cambridge University Press. 1-24.
- Keady, J. and Nolan, M. 2003. The dynamics of dementia: working together, working separately or working alone? Nolan, M. Lundh, U. Grant, G. and Keady, J. (eds) *Partnerships in Family Care: Understanding the caregiving career*. Buckingham: Open University Press. 15-32.
- Kitwood, T. 1997. *Dementia Reconsidered: The Person Comes First*, Buckingham, Open University Press.
- Knapp, M. and Prince, M. 2007. *Dementia UK: The full report*, Kings College London, London School of Economics, Alzheimer's Society, available online at http://www.alzheimers.org.uk/News_and_Campaigns/Campaigning/PDF/Dementia_UK_Full_Report.pdf accessed 30.1.2007.
- Livingston, G. Cooper, C. Woods, J. Milne, A. and Katona, C. 2008. Successful ageing in adversity: The laser AD longitudinal study, *Journal of Neurology, Neurosurgery and Psychiatry*, **79**, 641-45.

Luengo-Fernandez, R. Leal, J. and Gray, A. 2010. *Dementia 2010*, Alzheimer's Research Trust. available online at <http://www.dementia2010.org/> accessed 3.2.2010

Lyons, R. F. Sullivan, M. J. L. Ritvo, P. G. and Coyne, J. C. 1995. *Relationships in chronic illness and disability*, Thousand Oaks, Sage Publications.

Mittleman, M. Brodaty, H. Wallen, A.S. and Burns, A. 2008 A 3 country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer's disease: effects on caregiver depression, *American Journal of Geriatric Psychiatry*, **16**, 11, 893-904

Molyneaux, V.J. Butchard, S. Simpson, J. and Murray, C. 2011. The co-construction of couplehood in dementia, *Dementia*, Published online before print December 2, 2011, doi: 10.1177/1471301211421070.

National Institute of Clinical Excellence and Social Care Institute for Excellence, 2006. *Supporting People with Dementia and their Carers in Health and Social Care*, National Clinical Practice Guideline no 42, National Collaborating Centre for Mental Health. available online at <http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf> accessed 5.12.2006.

Nolan, M.R., Ryan, T., Enderby, P. and Reid, D. (2002) Towards a more inclusive vision of dementia care practice and research, *Dementia*. 1.2.193-211

Nolan, M. R. Davies, S. Brown, J. Keady, J. and Nolan, J. 2004. Beyond 'person-centred' care: a new vision for gerontological nursing, *Journal of Clinical Nursing*, 13, s1, 45-53.

NVivo qualitative data analysis software; QSR International Pty Ltd. Version 9, 2010.

Piercy, K.W. 2007, Characteristics of strong commitments to intergenerational family care of older adults, *Journals of Gerontology, Social Sciences*, **62**, 6, s381-87.

Prince, M. Bryce, R. and Ferri, C. 2011. *Alzheimer's disease international world alzheimer report, the benefits of early diagnosis and intervention, Alzheimer's Disease International* <http://www.alz.co.uk/research/world-report> accessed 16.12.2011.

Purves, B. A. 2011. Exploring positioning in Alzheimer Disease through analyses of family talk. *Dementia*, **10**, 1, 35-58.

Quinn, C. Clare, L. and Woods, B. 2009. The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental Health*, **13**, 2, 143-54.

Robinson, L. Clare, L. and Evans, K. 2005. Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health*, **9**, 4, 337-47.

Rolland, J. 1987. Chronic Illness and the Life Cycle: A Conceptual Framework, *Family Process*, **26**, 203-21.

Sheilds, G. C. 1992. Family interaction and caregivers of Alzheimer's disease patients: Correlates of depression. *Family Process*, **31**, 19-33.

Spitznagel, M.B. Tremont, G. Davis, J.D. and Foster, S.M. 2006. Psychosocial predictors of dementia caregiver desire to institutionalise: Caregiver, care recipient and family relationship factors, *Journal of Geriatric Psychiatry and Neurology*, **19**, 16-20.

Svanström, R. and Dahlberg, K. 2004. Living with dementia yields a heteronomous and lost existence. *Western Journal Of Nursing Research*, **26**, 6, 671-87.

Thomas, J. and Harden, A. 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. , BMC Medical Research Methodology, Open Access Biomed Central, 8. available online at <http://www.biomedcentral.com/1471-2288/8/45> accessed 1.2.2012

Tolkacheva, N. van Groenou, M, B. de Boer, A and van Tilburg, T. 2010. The impact of informal care-giving networks on adult children's care-giver burden, *Ageing and Society*, **31**, 1, 34-51.

Ward-Griffin, C. Oudshoorn, A. Clark, K. and Bol, N. 2007. Mother-adult daughter relationships within dementia care: A critical analysis. *Journal of Family Nursing*, **1**,13, 13-32.

Walsh, F. 1996. The concept of family resilience: Crisis and challenge, *Family Process*, **35**, 261-81.

Table 1: Description of the 11 qualitative research studies on dementia and family relationships

Authors and title	Research Aims or Questions	Sample	Methodology	Key Findings
Clare and Shakespeare 2004 UK	How are the individual voices of PWD and their partners evident in the conversations? What dimensions of resistance can be discerned? What discourses/representations of dominant societal voices are drawn on in constructing an account of their situations?	10 married couples recent attendance at memory clinic One partner had been given a diagnosis of Alzheimer's Disease (AD) in the early stages, MMSE score of 18 or above	Voice relational analysis of tape recorded conversations between spouses, conversation focused around set (rehearsed) task, for 5 minutes, to achieve a statement or sentence describing current situation. Researcher not present during conversation, card describing task left with couple	Political and psychological resistance used by both PWD and partner., Forms of resistance used not congruent and both engaged in not 'hearing' the other's difficulties Difficulty in achieving a joint voice Shift in balance of power to partner, positioning PWD as forgetting Limited range of discourses that could be drawn upon, ageing and memory loss
Daniels, Lamson and Hodgson 2007 USA	How a couple construct a shared story together when AD is a part of their relationship?	1 couple, one of whom diagnosed with AD, Recruited through an agency that serves supports and educates ageing individuals. Diagnosis 5 years prior to study	Case study, narrative methodology and analysis using systemic theory and social constructionism. 3 semi-structured interviews with the couple together over a 6m period.	Positive reflections on life together and lifelong commitment with some evaluation of impact of current changes Exceptions involved experience of losses and anticipated loss The importance of family and social support networks The impact of role changes brought about by the experience of AD
Davies 2011 Canada	To provide a better understanding of what it means for couples to live with early-stage dementia and to explore how couples come to understand commitment as a response	6 couples, recruited from memory clinics after one had received diagnosis of early stage AD. Also involved in drug trial	Mixed methods, scales and interviews, two interviews at home with couple together Narrative inquiry and analysis	Staying together, for richer for poorer Recognition that something is changing looking for answers and maintaining 'us' Relationships matter and involve partnerships for life, reciprocity, resilience and forgiveness
Forbat 2003 UK	To produce a 'discursive analysis' of the accounts of a 'care dyad' exploring constructions and the articulation of longstanding relationship difficulties	1 care dyad, mother and daughter, mother diagnosed with AD. Not clear where recruited from	Case study, separate interviews with mother and daughter using a biographical approach Discourse analysis	Production of "interacting storylines" which illuminate the impact of past relationships on current relational functioning and the impact of caregiving Highlights importance of considering authenticity and positioning in the accounts of dyadic relationships
Hellström, Nolan and Lundh 2007 Sweden	To explore the way in which people with dementia and their spouses experience dementia over time, especially the impact it has on interpersonal relationships and patterns of everyday life	20 couples one of whom diagnosed with dementia (most commonly mixed type), Recruited through a local assessment unit, via a nurse	Longitudinal study, semi-structured interviews, every 6 m over 4 yrs (?). Interviews initially carried out separately but for most couples, ultimately interviewed together. Constructivist grounded theory.	Sustaining couplehood (talking things through, expressing affection, making the best of things and keeping the peace) Maintaining involvement (playing an active part, taking risks, handing over, letting go and taking over) Moving on (remaining a we, becoming an I and a new beginning)
Hellström, Nolan and Lundh 2005 Sweden	To explore the impact of dementia on couples' understanding of home, their everyday life and relationships and their dignity and autonomy	1 couple, one of whom had dementia, recruited through a local assessment unit, via a nurse	Longitudinal study using semi-structured interviews, every 6 m. Interviews carried out separately but ultimately together. Constructivist grounded theory.	A loving and helping relationship Doing things together Beyond personhood towards couplehood

Molyneux et al. 2011 UK	What impact does dementia have upon a couple's relationship or a couple's relationship have on dementia? How do couples co-create their account of couplehood in dementia?	5 co-habiting couples, 1 of whom diagnosed with AD Recruitment through CMHT All PWD were aware of diagnosis, had verbal ability sufficient to participate	In depth interviews, couples interviewed together in their own home . Constructivist grounded theory	Shifting identities within couplehood Maintaining the relationship despite dementia The good old days Technically being a carer Sharing the experience of dementia
Purves 2010 Canada	What impact does dementia have upon a couple's relationship or a couple's relationship have on dementia? To understand how family members negotiate changing roles and relationships associated with a diagnosis of AD in one individual, To understand how meanings of the illness and the changes are constructed	1 family; a couple and their 3 adult children, recruited via a local clinic. The PWD had a diagnosis of AD	In-depth interviews, participant observation, analysis of naturally occurring family conversations Positioning and conversation analysis	The difficulties for the family including the PWD of positioning her as a person with AD, or openly discussing the difficulties she experiences The use of normalising explanations by the family and the competing perspectives of different family members Renegotiation of longstanding roles, maintaining identity while enabling activity to continue Challenging longstanding role, where maintaining the role carries risk
Robinson, Clare and Evans 2005 UK	To explore psychological reactions to a diagnosis of dementia in couples where one has received a diagnosis of dementia within the last two years To explore the extent to which their responses can reasonably be interpreted within a framework of loss	9 couples, one of whom diagnosed with dementia, recruited from 4 memory clinics. PWD had mild or moderate dementia. 7 had a diagnosis of probable AD, 2 of VD	Joint, semi-structured interviews Interpretive phenomenological analysis	Not quite the same person, passing it off/ acceptance Tell me what actually is wrong Everything's changed, We have to go from here Negotiating difficulties while developing resilience and adjusting together and individually
Svanström and Dahlberg 2004, Sweden	To investigate the lived experience of dementia for spouses, where one has a diagnosis of dementia	5 couples, one of whom diagnosed with dementia, all living at home and 4 in receipt of support from community services such as day care and respite. All recruited from primary care	Unstructured interviews using diaries kept by spouses without dementia to explore the lived experience. Partners interviewed separately Phenomenological research	Persons with dementia and their spouses become lost in the experience of dementia and are no longer able to have an independent existence Increasing sense of responsibility for spouse and loss of responsibility for pwd Futility, hopelessness and homelessness of the experience for both parties
Ward-Griffin et al. 2007 Canada	How do mothers and daughter describe their relationships with one another within dementia care? What contextual factors shape these relationships? What are the health experiences of mothers and daughters in dementia care?	10 mothers with AD and their 15 daughters (some mothers had 2 or more daughters). Recruitment from care agencies and primary care	Semi-structured interviews using an in-depth focused approach Participants interviewed twice separately Feminist and life-course theoretical position	Two major "dialectical" dimensions of the relationship Task focused- emotion focused Deficit based- strength based 4 types of mother daughter relationships; Custodial, Combative, Co-operative, Cohesive

Key: PWD= person with dementia, AD = Alzheimer's Disease, VD = Vascular Dementia, CMHT= Community Mental Health Team, m= months

Table 2: Criteria for Evaluation of Qualitative Research Studies in Psychology and Related Fields (Elliott, Fischer, and Rennie, 1999)

A Criteria relevant to all research	1	Explicit scientific context and purpose
	2	Appropriate Methods
	3	Respect for participants
	4	Specification of methods
	5	Appropriate discussion
	6	Clarity of presentation
	7	Contribution to knowledge
B Criteria relevant to Qualitative Research	1	Owning one's perspective
	2	Situating the sample
	3	Grounding in examples
	4	Providing credibility checks
	5	Coherence
	6	Accomplishing general vs. specific research tasks
	7	Resonating with readers

Table 3: Assessment of Quality of Articles

Article/ Criteria	A1	A2	A3	A4	A5	A6	A7	B1	B2	B3	B4	B5	B6	B7
<i>Clare et al.</i>	Y	P	P	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Daniels et al.</i>	Y	Y	P	Y	P	Y	Y	Y	Y	P	Y	Y	Y	Y
<i>Davies</i>	Y	Y	P	Y	P	P	P	P	Y	P	P	P	P	P
<i>Forbat</i>	Y	Y	Y	Y	Y	Y	Y	P	Y	Y	N	Y	Y	Y
<i>Hellström et al.</i>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Hellström et al. (2005)</i>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Molyneaux et al.</i>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Purves</i>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Robinson, L. et al.</i>	Y	Y	Y	Y	Y	Y	Y	Y	P	P	Y	Y	Y	Y
<i>Svanström et al.</i>	Y	Y	P	Y	P	Y	P	P	P	Y	Y	Y	P	P
<i>Ward-Griffin et al.</i>	Y	Y	Y	P	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Key: Y = criterion fulfilled. P = criterion partially fulfilled.

Table 4: Incidence of themes across studies

	Clare <i>et al.</i>	Daniels <i>et al.</i>	Davies	Forbat	Hellström <i>et al.</i>	Hellström <i>et al.</i> 2005	Molyneaux <i>et al.</i>	Purves	Robinson <i>et al.</i>	Svanström <i>et al.</i>	Ward-Griffin <i>et al.</i>
Super-ordinate Theme 1: A Shared History											
<i>A good life</i>	√	√	√		√		√		√		√
<i>Disconnected</i>			√	√							√
Super-ordinate Theme 2: Negotiating the Impact of Dementia upon the Relationship											
<i>A problem shared</i>	√	√	√		√	√	√	√	√	√	√
<i>Working apart</i>	√			√	√			√		√	√
Super-ordinate Theme 3: Openness and Awareness											
<i>Making meaning</i>	√	√	√		√		√	√	√	√	√
<i>Minimising</i>	√						√	√			
Super-ordinate Theme 4: Shifting Sands											
	√	√	√	√	√	√	√	√	√	√	√