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Couples constructing their experiences of dementia: A relational perspective

Kimberley Merrick and Paul M Camic
Salomons Centre for Applied Psychology, Canterbury Christ Church University, UK

Margaret O'Shaughnessy
Psychology Service for Older People, Kent and Medway NHS and Social Care Partnership Trust, UK

Abstract

Many people with dementia are cared for by their spouse or partner, therefore there is a need to understand the ways in which dementia and couple relationships impact upon each other. This study aimed to contribute to our understanding of the experience of dementia from a relational perspective. Seven couples, in which one person had a diagnosis of dementia, were interviewed about their experience of being in a couple where one partner had a diagnosis of dementia. Using interpretative phenomenological analysis, five master themes were identified, which illustrated how couples constructed their experience of dementia in order to make sense of it, and describe the processes that they adopt in order to adjust to dementia. Findings were supported by existing empirical and theoretical literature and suggest that services and interventions could be enhanced if a relational understanding of dementia were more fully considered.

Keywords
couples, dementia, relationships, qualitative research, interpretive phenomenological analysis

Introduction

There are 800,000 people with dementia in the UK alone (Alzheimer's Society, 2012) and as the aging population increases, this figure will rise considerably, presenting a huge challenge to society. The current UK government's plan for improving dementia care (*Challenge on Dementia,* Department of Health, 2012) places emphasis upon the relationship between people with dementia and those who care for them, usually their spouse or partner.

Corresponding author:
Paul M Camic, Salomons Centre for Applied Psychology, Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent TN3 0TF, UK.
Email: paul.camic@canterbury.ac.uk

Interest in this relationship has largely focused upon partners' experiences of stress, burden and wellbeing. However, some studies have considered other aspects of couples' experiences. For instance, a number of questionnaire and interview-based studies have found that partners report that intimacy declines following the onset of their partner's dementia (Baikie, 2002; Duffy, 1995; Eloniemi-Sulkava et al., 2002; Hayes, Boylstein, & Zimmerman, 2009; Wright, 1991; 1998). This is possibly related to how care partners perceive their role and that of the person with dementia.

Care partners have also described experiencing a number of losses including loss of emotional and practical support, shared understanding and a sense of their partner's identity as well as their own (Baikie, 2002; O'Shaughnessy, Lee, & Lintern, 2010). In interviews with care partners and people with dementia, Robinson, Clare, and Evans (2005) found that couples adjusted to losses through a process of looking back and experiencing pain, and looking forward to find ways of coping. They compared this to the dual process model of grief (Stroebe & Schut, 1999).

Daniels, Lamson, and Hodgson (2007) and Davies (2011) found that couples' sense of commitment to one another influenced how they adjusted to dementia, helping them to maintain their couple identity. O'Rouke, Claxton, Kupferschmidt, Smith, and Beattie (2011) found that individuals who idealized their relationship experienced lower levels of distress. Conversely, poor quality pre-morbid relationships have been found to impact negatively upon adaptation (Heru, Ryan, & Iqbal, 2004; Kramer, 1993; Teusink & Mahler, 1984; Williamson & Shafer, 2001). Further research is needed to assess how factors such as commitment and quality of relationship influence couples.

Keady (1999) found that couples worked to promote the 'personhood' (Kitwood, 1997) of the partner with dementia by maintaining their involvement and sustaining their sense of agency. Similar results were described by Hellstrom, Nolan, and Lundh (2005, 2007), who found that in addition to working to maintain the personhood of the partner with dementia, couples also worked to sustain a sense of 'couplehood'. Using grounded theory methodology, Molyneaux, Butchard, Simpson, and Murray (2011) found that couples' identities changed and that couples employed a variety of strategies to try to maintain their relationship including normalising, externalising, sharing the experience and reframing the experience.

Much of this existing research, with some exceptions (e.g. Hellstrom et al., 2005, 2007; Molyneaux et al., 2011; Robinson et al., 2005), focuses upon care partners' perspectives and fails to integrate the views of people with dementia. This is problematic for two reasons: first, it can be difficult to improve understanding of dementia and develop services and interventions without hearing from those directly affected and second, how developing a relational understanding of dementia is diminished if we only hear from one part of the couple dyad. Relationship-focused research needs to incorporate the perspectives of both parts of the couple dyad.

The present study aimed to enrich understanding of the experience of dementia from a relational perspective, which emphasises that a human being is fundamentally a part of a network of relationships. The relational perspective sees the person as continually motivated by the need for relationship and an active participant in shaping the internal consequence of external experience (Mitchell, 1988). Using a relational approach, this study focused on the couple relationship, rather than solely on the experience of the carer or the person with a dementia, in order to explore the impact of dementia upon aspects of couple relationships and the impact of couple relationships upon the experience of dementia; this included how couples adjust to losses, including how couples work to promote the personhood of the partner with dementia, and how a sense of couplehood is sustained. As direct involvement of people with dementia has been minimised or often absent from previous research, an additional aim of this study was to develop an understanding of what it means to be a person with dementia in a couple relationship.

Method

Participants

In studies examining lived experience, it is preferable to explore the accounts of fewer participants at greater depth, than to include more participants but offer a broad, shallow and descriptive analysis (Reid, Flowers, & Larkin, 2005). Smith, Flowers, and Larkin (2009) suggest that a sample of between 4 and 10 is ideal. Therefore, with this as our aim we sought to recruit a purposive sample of couples affected by dementia by approaching branches of the Alzheimer's Society. We made contact with the branch managers, who identified couples they thought might be interested in taking part. With their agreement, couples were then sent written information about the study and asked to contact the researcher if they wished to participate. To be considered eligible for inclusion, one partner had to have a diagnosis of dementia (e.g. Alzheimer's disease, vascular dementia, fronto-temporal lobe dementia) and both partners had to be able and willing to consent. Ten couples volunteered, and of these seven couples (five men and two women with dementia and their heterosexual partners, referred to as 'care partners') met these criteria and completed the study (see Table 1).

Procedure

People with dementia and their partners were interviewed together. A semi-structured interview schedule was developed on the basis of extant literature about couple relationships and dementia. Open-ended questions relating to the couples history, the experience and impact of living with dementia as a couple, their responses to dementia, how they made sense of and adjusted to dementia were included; however, the overall aim was for interviews to take the form of a conversation, lead predominantly by participants. Participants chose to be interviewed within their homes. Each interview lasted between 45 and 75 min and was audio-recorded, transcribed verbatim by the first author and made anonymous. Ethical approval was obtained from a university research ethics committee. To ensure that all participants had the capacity to consent, a consent pathway based upon the process method of consent (Dewing, 2007) was developed and followed.

Data analysis

Interpretative phenomenological analysis (IPA) (Smith, Jarman, & Osborn, 1999) was chosen as the most appropriate method because it allows for participants' views and experiences to be explored in detail and depth, it is considered 'particularly useful where issues relating to identity, the self and sense-making are important' (Smith & Osborn, 2007, p. 520) and it seeks to consider findings within the context of existing theory.

Table 1. Participating couples (all names are pseudonyms)

Couple	Tom and June[a]	Jim[a] and Susan	David[a] and Kath	Betty and Cyril[a]	Lucy[a] and Paul	Bob[a] and Lyn	Mark[a] and Sue
Ages	72 and 74	80 and 69	87 and 80	83 and 84	77 and 77	76 and 77	65 and 63
Diagnosis	AD	AD	Mixed – AD and vascular dementia	Fronto-temporal dementia	AD	Vascular dementia	AD
Approx time since diagnosis	Nine years	Five years	Two years	Four years	Four years	Unknown	Three years
Details about relationship	Married for 53 years	Together for 5 years – not married	Married for 26 years – second marriage	Married for 61 years	Married for 56 years	Married for 52 years	Married for 45 years

[a] Person with dementia.
AD: Alzheimer's Disease.

Interview transcripts were analysed according to the method described by Smith et al. (2009). This involved examining each transcript in detail, reading, re-reading and making initial notes through a process of free association, then looking for emergent themes. Connections between themes were then mapped, and emerging themes were arranged to form clusters of related superordinate themes. Patterns were then sought that occurred across cases, generating master themes.

Quality assurance

The researchers engaged in a number of reflexive practices, in order to help identify and set aside ‘vested interests, personal experience, cultural factors, assumptions, and hunches’ that could influence how the data were viewed (Fischer, 2009, p. 583).

First, during the analysis, the original transcripts were referred to repeatedly to ensure that developing themes were grounded in participants’ experiences.

Second, the first and second transcripts were read and reviewed by the second and third authors to ensure themes were credible and warranted (Lincoln & Guba, 1985). This complies with Smith et al. (2009) suggestion that the first few transcripts be closely read and interrogated by more than one reader.

The research was also assessed by an independent researcher against Yardley’s (2000) quality criteria. Traditional criteria for research quality would be inappropriate and incompatible with this research. Instead, Yardley’s criteria, which have been developed specifically in relation to qualitative methods, provided a useful framework within which this research could be evaluated and validity explicated. Yardley proposes that good quality research should demonstrate sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. The independent researcher concluded that there ‘was a clear, logical sequence leading to the development of themes; that the use of IPA and appreciation of the interactional nature of data collection demonstrated sensitivity to context; and that the care with which interviews and analysis was conducted demonstrated commitment and rigour’.

Initially, we had not sought respondent validation as a check of quality and trustworthiness, because it would have involved asking participants to undertake a triple hermeneutic (e.g. interpreting the researchers’ interpretation of participants’ interpretation of their own experiences), a process that Smith et al. (2009) have not found useful and no longer recommend as adding value to IPA. In the present study, however, a care partner who had expressed interest in the analytic procedure was invited to read and comment on the themes and our interpretative process. She reported that the fives themes, described below, captured her experience well.

Results and discussion

Eighteen superordinate themes emerged from analysis and were subsumed within five master themes: ‘foundations’, ‘altered structures’, ‘self-reconstruction’, ‘flexible scaffolding’ and ‘reviewing the plans’ (Table 2). We drew upon language used within the building and construction industry as it was felt that this metaphorically reflected the way in which couples actively constructed their experience. Each theme is described and illustrated with quotes, and findings are supported and illuminated by existing research and theoretical literature.

Table 2. Superordinate themes relating to each master theme

Master theme	Superordinate themes
Foundations	Commitment Togetherness History and quality of the relationship
Altered structures	Changes to roles Oscillating reciprocity Determination for continuity Bonding over the problem
Self-restoration	Loss of self Holding on to self Acceptance Focus on the present Humour
Flexible scaffolding	Supporting partner's memory Maintaining partner's identity Recognising partner's remaining abilities Loss of partner
Reviewing the plans	Self awareness Awareness for other

Theme 1. Foundations

Central to couples' experiences were the foundations upon which their relationships were built. These quotes from Sue,[1] who had been married to Mark for 45 years, and from Cyril, who had been married to Betty for 61 years, illustrate the commitment that couples felt to one another:

> *I married Mark, in sickness and in health and now he's really sick, but it's for life.* (Sue)
> *The most important thing ...*[2] *is the love between us. I worship Betty and I know she worships me.* (Cyril)

On the basis of their commitment, participants had developed a strong and seemingly unshakeable sense of togetherness, which provided them with a foundation from which they were able to face multiple life experiences, including positive experiences such as having children, but also times of adversity, including dementia, for example, Betty said:

> *It is WE that is going through this. It isn't him-me.*

The importance of commitment and togetherness has previously been highlighted by Daniels et al. (2007) and Davies (2011) and the idea of a foundation links with Keady's (1999) notion of 'building on the past'. Keady developed a six-stage temporal model of care, based upon interviews with 11 caregivers and their partners with dementia. 'Building on the past' is the first stage within this model, upon later stages of the caregiving relationship are built and are heavily influenced by. Many couples talked about the development of their relationship, recalling the story of their first meeting. Despite their memory difficulties, people with dementia were often able to recall this. Reminiscing with warmth and fondness, Cyril shared his memories of his first date with his wife:

> *Our friends were going to the cinema, it was during the war . . . they were all in pairs, so we were in a pair . . . The film we went to see was 'We Dive At Dawn', war time film . . . we went to the cinema and I took her home in the blackout . . . I summoned up all my courage and kissed her on the cheek and ran away.*

Participants' perceptions of the quality of their relationship were positive and appeared to have a positive influence on adjustment, although this seemed to hold more significance for care partners than for people with dementia. When care partners felt that the person with dementia had previously invested in them, for example by being a good carer or provider earlier in their marriage, they wanted to repay them. For example, Paul spoke about repaying his wife Lucy, for the care that she provided in the past:

> *She had a rough time with me, I had a serious accident . . . , so it's my turn to look after her.*
> *Yes you were very poorly weren't you.* (Lucy)
> *Well, you looked after me so this is what it's all about isn't it.* (Paul)

This has previously been linked to models of equity and investment and to the notion of *quid pro quo* (Baikie, 2002; Braun et al. 2009; LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005), but this experience is unlikely to be the case for all couples.

Theme 2. Altered structures

Couples reflected upon how the structure and organisation of their relationship had altered. Participants described how the roles each one of them had taken had changed. Care partners had taken up new roles and responsibilities, whilst people with dementia had given up certain roles. Tom, a male care partner had taken on the role of cooking, which he considered traditionally to be female and had previously belonged to his wife:

> *We've changed complete roles.* (Tom)
> *Yeah. I used to be the one that was in charge. Doing everything.* (June)
> *June used to do all the cooking. Now I do all the cooking.* (Tom)

Lyn and Kath, described how their role shifted from that of wife, to that of carer. Lyn described the impact that this had upon her as a woman:

> *I'm still of the old fashioned type. I still like being a woman. Having doors opened for me and of course I don't get it any more. Where Bob always was very courteous and polite and always did.*

Kath missed the security and support that her relationship with David had provided, leaving her feeling vulnerable:

> *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.*

This links to the work of Molyneaux et al. (2011), who described how couples identities shifted and how crossing traditional gender boundaries caused anxiety and distress.

Another aspect of couples' relationships to alter was the degree of reciprocity. Sue shared how her relationship with Mark no longer consisted of a sense of shared understanding or reciprocal conversation:

> *The bit that really gets me down is when we've had a bit of a laugh, . . . what gets to me is the fact of something will happen and then we have a laugh over it and then like ten minutes later I try and carry on the joke or conversation and he can't remember the conversation.*

Kath also shared this experience:

> *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.*

However, in this moment, Kath's husband, David, was able to reciprocate and the couple connected through their sadness for the loss of this aspect of their relationship:

> *I don't have a solution to that really. I mean I wish there were but.*
> *It's depressing really.* (David)

Despite such experiences, couples were generally reluctant to consider the aspects of their relationships that may have been lost, perhaps because to do so would threaten their sense of couple identity or 'couplehood' (Hellstrom et al., 2005). It seemed instead that couples were determined for things to continue as normal and focused upon what remained the same, or had even strengthened. For example, Tom spoke about how he and June had always been close and had become closer:

> *Well we've always been very close, so it's not a big change . . . I think we've become closer.*

Bob and Lyn also spoke about bonding through the experience of dementia:

> *It's brought us closer together.* (Bob)

This is similar to Molyneaux et al.'s (2011) finding that when faced with changes, couples attempted to maintain their experience of each other and their relationship as they were before.

Theme 3. Self-reconstruction

This theme captures people with dementia's reflections upon their sense of self and how this had changed. All recognised that aspects of themselves had been lost, but also recognised that aspects of themselves still existed and they worked hard to hold on to these remaining aspects and establish a new sense of self, integrating and accounting for their experience of dementia.

People with dementia described what it was like to lose their sense of agency and positions of status and authority that they had once held. David spoke of how the loss of his professional and social status left him feeling directionless:

> *I had all these Air Force connections. They are less and less tenuous these days. They're still there but not to the same strength. So I think the err, I'm more rudderless. I mean I knew which way I was going. Now I don't know where anything is.*

June described what it was like to lose her status, authority and her agency:

> *I want to do the things that I've always done, but he does for me now , . . . I mean you could let yourself go mmm . . . , you know as a person. I always used to be in charge of what we was doing and everything . . . and people used to come and ask me what they had to do. And I found it rather difficult to find that I couldn't do it now . . . it's terrible. You could get yourself quite sad really, just thinking what you used to be and what you can't be.*

Some participants feared that their entire identity would be lost to dementia, as captured by Mark:

> *I always did have this err . . . nightmare, shall we say, umm that I would forgot who I was, where I was and you know, if I went out on my own, I got this paranoia about you know, forgetting. Suddenly, suddenly like you've turned the lights out.*

On the one hand, people with dementia appeared to be quite accepting of their experiences of loss, for example, David talked about coming to accept his losses:

> *I think it's difficult for me to accept the fact that I don't have the err . . . the facilities I had before. I mean I don't find life as easy . . . And that annoys me in one way and I accept it in another . . . The fact is I have to make allowances for it.*

However, on the other hand, it appeared that participants were determined to hold on to what remained of their sense of self and each was eager to demonstrate this to the interviewer, for example, Jim spoke about a time when he was at a multi-agency dementia meeting as a service user, but how he was able to hold on to his sense of self and demonstrate his agency by speaking out:

> *No-one was saying a word, but I was quite prepared to stand up and . . . . I was thinking no-one's doing anything here . . . they're not saying anything. And I stood up and said something which I thought was quite admirable. [laughs].*

It seemed that this active process, which we have called 'self-reconstruction', involved oscillating between reflecting upon what aspects of themselves they had lost and a powerful determination to hold on to what remained. Through this process, they were able to come to terms with, accept and integrate dementia into their sense of self, whilst also maintaining their sense of self-esteem and 'personhood' (Kitwood, 1997). This links with Keady's (1999) finding that as individuals come to realise that things are not going to return to 'normal', they engage in a process he termed 're-grouping', which helps them to maintain their involvement for as long as possible. This also resonates with the work of Robinson et al. (2005), who drew parallels between similar oscillating processes to those described above and dual process models of loss, which describe how people adjust to loss by moving between the position of looking back and experiencing the pain associated with loss, and looking forward and moving on (Stroebe & Schut, 1999). To aid the process of reconstruction, people with dementia found it helpful to focus on the present and use humour. Lucy, who appeared the most cognitively impaired of all the participants, relied heavily on both of these to sustain her sense of self:

> *well I just live for today . . . I just think we can put it right, tomorrow's another day . . . . I only know today at the moment. I haven't a clue about tomorrow . . . I don't get down about it . . . I don't worry about it. I just think, well . . . laugh it off . . . I can laugh at anything and anybody. I think that's my saviour actually . . .*

Theme 4. Flexible scaffolding

Care partners provided a framework within which their partners were supported through the process of self-reconstruction. We have conceptualised this as 'flexible scaffolding', as care partners adapted the level and nature of the support they provided, to reflect the fluctuating abilities and deteriorating functioning of the person with dementia.

Care partners expressed a sense that they were losing the person with dementia and that without their support their partner would be vulnerable:

> *Luckily enough he's got me behind him. I dread to think what some people, who haven't got a me behind him or her, how they get on with all these things, cos it is really difficult.* (Sue)
> *I couldn't bear to think of him on his own.* (Susan)

In a similar way to their partners, care partners seemed to oscillate between two positions: reflecting upon losses (i.e. loss-orientated) and recognising what remained and doing all they could to sustain this (i.e. reconstruction-orientated). This process of oscillating between these positions helped care partners to adjust to losses and also helped to sustain the couples' sense of their relationship.

Betty describes how in a reconstructiong-orientated way, she provides scaffolding to support Cyril's memory:

> *I'm kind of a teacher now , . . . if he forgets a name or forgets something, I go to him remember your vowels, A-E-I-O-U or remember your alphabet. So I'll probably give Cyril a clue. He'll go is it B? And I'll go no, it's the end of the alphabet. Then he'll try that. I'll say no try the middle. So in a way, I'm making him remember . . .*

When supporting Cyril with personal care, Betty aimed to promote his dignity, independence and self-esteem; working in a way that maintained his identity and personhood. This was a primary concern for care partners:

> *he's becoming slightly incontinent now, and I want him to keep his dignity, so I had a bidet put in upstairs . . . What I do with Cyril now, because I don't want him to lose his dignity, because I'm not giving in to it (dementia), I lay his things out on the bed, . . . there's his socks with his underpants on top, then his shirt, then his trousers, then his belt. That's it. I leave him . . . I think that's good for his brain and for his dignity.*

Tom described how he maintained June's self-esteem and identity by attending to her physical appearance:

> *I have to get all her bling out, when she's going anywhere and tell her what day it is. She goes to the hairdressers every Friday. I take her down the hairdressers . . .*

Care partners recognised and promoted their partner's remaining abilities, enabling them to continue to be involved in everyday couple life. For example, with some scaffolding, in the form of written prompts, Mark described how he was able to contribute to the running of the household:

> *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. I couldn't do it without getting the information.*

Susan recognised Jim's remaining abilities and the importance of maintaining his involvement, even if he made a mess in the kitchen:

> *But you still do it (directed to Jim). I think that's the most important thing. He will say "shall I make you a cup of tea?", now I know if I go out there there'll probably be tea spilt . . . in front of the washing machine or wherever. It doesn't matter, because it's just tea . . . I get up early in the morning and I'll just clean it. What does it matter?*

Susan's flexibility meant that she provided Jim with the support that was most helpful for him at the time that he needed it. This theme relates to the work of Keady (1999), who found that the primary aim of both partners within caregiving relationships was to try to maintain the involvement of the person with dementia as an active agent in the world. Similarly, Hellstrom et al. (2005, 2007) and Molyneaux et al. (2011) found that care partners were motivated and invested considerable efforts to promote their partners sense of personhood and sustain their sense of couplehood. In these studies, care partners tended to focus on their partners' remaining abilities rather than on their deficits, for example, Hellstrom et al. (2007) described how care partners did not to dwell on the implications of their partners' diagnosis of dementia, but focused upon sustaining the self-image of their partner and ensuring they maintained an active role in the relationship. Similarly, in this study, care partners tended to think about what their partner could achieve, with their supervision, or in collaboration, rather than dwelling upon their partners' limitations and deficits.

These examples relate closely to some of the ideas proposed by Nolan, Grant and Keady (1996) who built upon the work of Bowers (1987, 1988) to develop a model of family care comprising of six typologies. The concept of 'preservative care', care which is primarily focused upon preserving the dignity, hope, sense of control and abilities that a person has, is directly relevant. Nolan et al. (1996), however, suggest that preservative care is only functional to a point, as in time, as the process of dementia continues, strategies aimed at maintaining abilities and skills will cease to be effective. They found that as this occurred, carers shifted towards what they termed 'reconstructive' type care, which focuses upon rebuilding identity and developing new roles, based upon the foundations and past history of the couples relationship. This also supports the longitudinal aspects of Hellstrom et al.'s (2007) work that examined how couples sustained couplehood over a five-year period by identifying three broad phases, which 'although temporal, were not linear and involved a delicate interactive and iterative relationship' (p. 391).

Theme 5. Reviewing the plans

This theme describes how people with dementia who participated in this study demonstrated a capacity to reflect upon their personal experience and that of their partner, metaphorically akin to reviewing building plans through an on-going renovation project where change is inevitable.

Mark spoke about his experience of short-term memory difficulties, what this meant for him and how he tried to cope with:

> *There's no rule of thumb, what actually happens, with the memory. Sometimes you can, it's all ok, and then other times I can walk from here to there and forgot what's happened. Usually when I go back to the beginning I remember what I went in there for . . . . It's like being like Jekyll and Hyde. There's two of me. The good one and the bad one. But sometimes the bad one don't always come out, you know as good as he should be . . . it is worrying sometimes.*

His description of himself as *like Jekyll and Hyde* illustrates his struggle with his identity; Mark experiences himself as either good (without AD) or bad (with AD). He seems to be grappling with the process of establishing a new identity, which integrates AD.

David also described his grapple with adjusting his identity to integrate the experience of dementia. Throughout his life, David had held positions of authority, status and power, and so when he was diagnosed with dementia and positioned as a patient or sufferer, he found that this did not correspond with his own sense of himself:

> *I find it very difficult, not to . . . I mean, I can sympathise with them, that's fine. But err . . . . I don't want their sympathy. I don't know how to do . . . how to handle that. It's foreign to me that.*

This was substantiated by his wife's description of him as 'a fish out of water'.

The finding that people with dementia were able to reflect upon their personal experience is an important one, as it challenges assumptions and preconceptions. However, the extent to which individuals had this capacity varied and in some instances appeared to fluctuate during the interview. Usually, this related to people with dementia's perceptions of their remaining abilities. For example, Bob claimed to *still do a lot a gardening*, however, his wife, Lyn disagreed: *Oh darling you might think you do, but you don't really*. It was often unclear whether the person with dementia could not remember how their skills had changed or whether they were actively trying to portray a picture of themselves as more able than they knew they were, possibly to preserve self-esteem.

In most cases, individuals with dementia demonstrated an ability to reflect upon and empathise with their partners' experience. June, who had been diagnosed with Alzheimer's disease nine years ago, was able to imagine something of her husband's experience at a psychological and emotional level, and empathise and offer him reassurance:

> *He, he looks after me and I think sometimes it's a bit sad for him . . .*
> *Well, really I think that sometimes he gets a bit worried and if he gets worried about things I'll say "yeah that's fine, fine", just so that he doesn't worry about me so much.*

This captures, how despite nine years with Alzheimer's disease, June has the capacity to think about others' feelings and envisage mental states in others, qualities akin with the concept of 'mentalising' (Allen, Fonagy, & Bateman, 2008). This ability meant that June was able to respond sensitively to Tom's needs, which left him feeling supported and cared for:

> *She looks out for me . . . If I'm feeling a bit funny she'll come and give me a cuddle . . .* (Tom)

David also demonstrated a similar capacity; as he was able to reflect upon his own mental state and envisage the mental state of his wife:

> *This is intensely irritating to Kath, as you can imagine, because she knows that I've done something, but I've forgotten I've done it . . .*

On many occasions throughout the interviews, people with dementia spoke about what a good job their partners were doing:

> *I like him doing my hair . . . You know cos it's something [gestures brushing her hair] and he's holding me* (June)
> *But you (directed to Susan) know my problem and you can talk, it clicks to you quickly, so you can . . . you know.* (Jim)

> *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.* (Lucy)

These findings are supported by Sabat (2001) who found that despite their cognitive difficulties, people with dementia were able to reflect upon and demonstrate concern for the needs of others, a highly valued and highly complex form of cognitive ability. However, these findings have not emerged within previous studies of couples' experiences and can be described as a new in this context. Not only were people with dementia able to reflect upon their own personal experience and provide an account of what it means to be a person with dementia, but in many cases they were also able to reflect upon their partners' experience. Such findings challenge assumptions about people with dementia and as such are worthy of further investigation.

Discussion

This study aimed to explore the experience of dementia in the context of couple relationships and to do so from a relational perspective. The five master themes that emerged from couples' accounts describe the ways in which couples constructed their experiences of dementia and in particular the processes involved in adjusting to this.

All participants, both care partners and people with dementia, seemed to oscillate between the position of acknowledging and letting go of what had been lost and the position of recognising and holding on to what remained for the person with dementia and in terms of the couple relationship. This seems to resonate closely with the work of Robinson et al. (2005) who drew parallels between this oscillating process and the dual process model of loss, in which people are understood to adjust to loss by moving between loss-orientated positions and restoration-orientated positions (Stroebe & Schut, 1999). It therefore seems that this model may be helpful in understanding the experience of dementia from the perspective of affected couples.

Our finding that care partners worked hard to preserve the dignity, skills and abilities of the person with dementia, by providing them with scaffolding to support the process of self-reconstruction, resonates with two of the six typologies of family care proposed by Nolan et al. (1996): preservative and reconstructive care. This suggests that these typologies may be a useful framework for understanding care partners experiences in particular.

In our study, we found that couples were motivated to maintain the person with dementia's sense of personhood and their sense of couplehood, and in turn sustain the existence and quality of their lives together. This resonates with the work of Hellstrom et al. (2007) who found that sustaining couplehood was the primary goal for couples and that couples achieved this through four activities: talking things through; being appreciative and affectionate; making the best of things and keeping the peace. They suggested that these activities were most prevalent early on in the course of the dementia; however, in our study we saw that even in couples where the person with dementia was given a diagnosis over nine years ago, such activities remained vitally important to both the care partner and person with dementia, for example in the case of Tom and June.

A second aim of this study was to give voice to people with dementia in order to readdress the dominance of care partners' perspectives in the literature. A new and important finding in relation to this was the recognition that individuals with dementia were able to reflect upon their personal experience and that of their partner and in some cases attempt to reciprocate care, for example by letting their partners know how grateful they were for their support or in the case of June and Tom, June tuning in to Tom's feelings and offering him a cuddle. Nolan et al. (1996) refer to this as 'reciprocal care' and state that they believe it to be 'the norm' in most caregiving relationships, contributing to caregiver satisfaction. However, they suggest that opportunities for reciprocity are likely to be limited in the later stages of dementia. In this research, the finding that individuals with dementia could reflect on the experience of their partner appeared to play a role in sustaining their couple relationship. This idea and the concept of reciprocity within couple relationships when one person has dementia are therefore worthy of further investigation.

Limitations and future research

Interviewing people with dementia and care partners together allowed for a relational understanding of the experience of dementia, as co-constructed by the couple to be developed. However, a disadvantage of this approach is that the dynamics of couples' interpersonal relationships were likely to have influenced what each partner felt able to talk about in front of the other. The relationship between the couple and the researcher may have also influenced what was talked about. For example, although intimacy, including sexual and physical intimacy, has emerged as a theme in the existing literature, this did not arise in the present study. Another potential limitation is that couples who felt that they were coping well may have been more likely to volunteer to participate than couples who felt they were struggling. Couples who perceived their relationship to be of good quality might also have been more likely to participate than couples who perceived problems in their relationship. Couples may also have felt a pressure to position themselves in a certain way, for example as coping well, and this will have influenced the data.

A further limitation of this research is that as data were collected during a one-off interview, our understanding of the temporal dimension of living with dementia and how or why the processes couples described may unfold over time are limited. Future research could seek to address this limitation by conducting a longitudinal study, comprising of a number of interviews over a period of time.

All of the participants in this study were white British, heterosexual and with the exception of one couple, married. Therefore, the experience of these participants may differ from people from other ethnic and cultural groups and from people in different couple relationships (e.g. same sex or unmarried). These factors could be considered in future research. Further consideration could also be given to diagnosis and stage of dementia.

Conclusions and clinical implications

The findings of this study highlight a number of ways in which health and social care services, including those provided by the charitable sector, could better meet the needs of couples affected by dementia. Firstly, the tendency to 'forget that there is a real living couple behind the disease' (Daniels et al., 2007, p. 162) needs to be addressed. Research has highlighted the importance and influence of the couple relationship and therefore this should be explored during the process of diagnosis and beyond. Risk factors (e.g. negative experience of pre-morbid relationship) could be assessed for and services could consider promoting protective factors, for example by promoting the attachment relationship and feelings of closeness, bonding and reciprocity.

Secondly, research findings suggest that the process of adjustment involves oscillation between loss-orientated and reconstruction-orientated positions. However, many older people's services tend to focus upon the assessment and identification of deficits, limitations and losses and rarely enquire about remaining strengths, abilities or even potential gains. By being entirely loss-orientated, services risk engaging in forms of malignant social psychology, stripping a person with dementia of their personhood and increasing excess disability. The findings of this study suggest that, when appropriate, practices which focus upon reconstruction would be welcomed and conducive to the ongoing process of adjustment. Approaches that are solution-focused and fostering resilience may help couples to maintain the involvement of the person with dementia, and sustain their sense of personhood and sense of couplehood (Camic, Tischler, & Pearman, 2013).

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Notes

1. All names given are pseudonyms.
2. . . . elision in quotation removed for clarity.

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Author Biographies

Kimberley Merrick is a clinical psychologist at Sussex NHS Foundation Trust, East Sussex, UK. She completed this research while at Canterbury Christ Church University.

Paul M Camic is professor of psychology and public health at the Salomons Centre for Applied Psychology, Canterbury Christ Church University, Tunbridge Wells, Kent, UK.

Margaret O'Shaughnessy is a clinical psychologist in the Psychology Service for Older People, Kent and Medway NHS and Social Care Partnership Trust, Kent, UK.