

The dynamics of continuity and discontinuity for women caring for a spouse with dementia

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The Dynamics of Continuity and Discontinuity

For Women Caring for a Spouse

With Dementia

Abstract

This qualitative study explores spouse caregivers' understanding of and responses to partners with dementia. Six wives who have been providing care to their husbands in the community for at least two years were interviewed. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA) and four interconnected themes were proposed: same person or different; relational change; emotional responses to behaviours; and impact on day-to-day life. Participants' sense of continuity with the past was suggested to influence each theme. The construct of continuity was proposed to be elastic, with both intra-psychic and inter-psychic factors impacting upon its elasticity. Broadly, a sense of continuity seemed to be associated with better adjustment to caregiving.

Key words: caregiver; continuity; dementia; qualitative; spouse.

Introduction

In respect of family caregivers, the responsibility for the community-based care of older adults with dementia is frequently the preserve of a spouse (Lewis 1998). Unlike caring for a partner with a physical health problem, supporting a spouse with dementia has been found to be associated with high rates of depression and a sense of 'burden' (Pearlin, Mullan, Semple & Skaff 1990; Schulz et al 2002; and Murray & Livingston 1998). Researchers have investigated the patient symptoms that engender the greatest distress for carers. Perhaps unsurprisingly, however, carers are not necessarily troubled by the same behaviours (Savorani, Vulcano, Boni, Sarti & Ravaglia, 1998; Paton, Johnston, Katona & Livingston, 2004).

Locating the 'problem' within the patient precludes consideration of the role of the carer in constructing and construing behaviours as problematic. Caregivers' understanding and perception of behaviours in relation to the stress that they experience has also been addressed. Harvath (1994) contended that intrapersonal variables mediate the negative consequences of caregiving and proposed three dimensions of interpretation in respect of dementia behaviours: attribution of the cause of behaviour; perception of care receiver's volition; and assessment of the degree of 'threat' posed by the 'problem'. Harvath observed that whilst caregivers acknowledge that behaviours would not occur if dementia were not present, they often expressed non-dementia explanations.

A study by Tarrier et al (2002), incorporated attribution theory in its

investigation of the responses of family carers to their relative's dementia-related behaviours and suggested a relationship between carers' perceptions and attributions of behaviour and the degree of their distress. They found that 'critical' caregivers were most likely to construe negative behaviours and situations as within the control of care recipients. Tarrier et al (2002) also suggested that caregiver characteristics were as, if not more, important than care receiver characteristics in determining their emotional response to and explanation of behaviours and symptoms.

In contrast with a focus upon caregivers' intrapersonal characteristics, there is also a body of research predicated upon the role of interpersonal processes. Drawing upon social psychology, the person-centred theory of dementia care (Kitwood 1993), with its eloquent elucidation of the centrality of relational and social factors in both the care and understanding of people with dementia, established a discourse very distinct from the prevailing biomedical approach. Given the constriction of social relationships often associated with dementia, Hellstrom, Nolan and Lundh (2005) suggest that the spousal relationship should assume particular salience in research, proposing 'couplehood' rather than 'personhood' as the object of study.

A shift to the study of subjective, emotional and experiential accounts of couples living with dementia has facilitated greater recognition that caregiving is not a wholly negative experience (Hellstrom, Nolan & Lundh 2007). Hellstrom, Nolan and Lundh (2007), for example, contend that many couples look to create a 'nurturative relational context' in

which their relationship can flourish. They carried out interviews over a period of five years and advanced three broad relationship phases following a diagnosis of dementia: sustaining couplehood; maintaining involvement; and moving on. Whilst the dynamic processes described within each phase can occur simultaneously, a deterioration in dementia condition was largely found to be associated with a progression through these phases.

The notion inherent in the theory of Hellstrom, Nolan and Lundh (2007) would seem to be that couples' general motivation to maintain a positive relationship is compromised by the deterioration of the spouse with dementia. Other researchers, however, have proposed a range of relationship contexts. In a study of couplehood involving the spouses of institutionalised 'patients', Kaplan (2001) suggested five forms of relationship along a continuum from a state of remaining firmly entrenched in marriage ('Til death do us part') to caregivers who had considered their marriages to be over ('Unmarried marrieds'). Chesla, Martinson and Muwaswes (1994) explored the continuities and discontinuities in family members' (spouses and adult children) relationships with care receivers suffering from Alzheimer's disease, reporting relational contexts that were perceived as continuous, continuous but transformed or discontinuous. In this study, contrary to the model suggested by Hellstrom, Nolan and Lundh (2007), the severity of dementia did not seem to determine the form of the relationship.

The period when a person finds themselves providing care for a partner may be foreshadowed by a relationship history of many years

and constructions of the past may facilitate the exploration of current relational factors (Forbat 2003). Murray and Livingston (1998) found that adjustment to caring for an older spouse with psychiatric illness (including dementia) was influenced by the intimacy and reciprocity of the pre-morbid relationship and the perception of continuity in the relationship. Lewis (1998) noted that “spouse carers tend to make sense of their partner's behaviour by reference to past behaviour” (page 228) and concluded that the fundamental premise of the life course approach, that people draw upon their whole lives to interpret present experiences, was supported by her findings.

It is recognised that the complex issue of spouse caregiving requires further exploration (Caron & Bowers 2003; Davies & Gregory 2007). This study is a qualitative investigation of spouse caregivers' perceptions of and responses to their partners with dementia. The notion that the past relationship provides a means of understanding caregivers' adjustment to and understanding of dementia (Murray & Livingston, 1998; Lewis, 1998) provides the focus of this paper. It is hoped that by adopting a longitudinal perspective, a more fine grained analysis of the disparate experiences of caregivers will be possible.

Method

Design

This qualitative study employed interpretative phenomenological analysis (IPA). Central to phenomenological inquiry is the concern with how individuals experience and understand their world (Brocki & Wearden, 2006). The goal of IPA is to explore as fully as possible the perceptions of the participant, an interpretative pursuit that necessarily involves the researcher's conceptions and experiences (Hunt & Smith, 2004; Brocki & Wearden, 2006).

Ethical Approval

Ethical approval for the study was provided by the University of Birmingham School of Psychology Human Research Ethics Committee.

Participants

In this study, the six participants were women who reported that they had been providing care to their male partners with dementia for at least two years (see Table 1). All of the participants lived with their husbands in the community. The selection of heterosexual, female carers reflects the influence of gender and sexuality in shaping perceptions of relationship and caring roles. Stipulating that caregivers should consider that they have been caring for their partner for over two years reflected the issue of adjustment to this role. Furthermore, an aspect of the research is the way in which carers adjust within the context of a long term relationship. It was therefore required that caregivers' relationships

with their partners were of duration of greater than fifteen years.

Participants were recruited via a charitable organisation that provides support to caregivers of people with a dementia. An employee of the charity initially approached the six participants. They were then contacted directly by the researcher, who offered to visit to explain about the study. The researcher visited five of the six participants at home; the sixth participant preferred to engage in a telephone conversation. All participants were provided with written information about the study at least one week prior to taking part in the research interview. Participants also signed a consent form before the interview commenced.

Table 1: Background information about participants

	Background Information
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Participant	
Mrs S	Age: 72 years old; Married for: 53 years; Providing care for: 3 years
Mrs B	Age: 78 years old; Married for: 58 years; Providing care for: 2 years
Mrs A	Age: 78 years old; Married for: 56 years; Providing care for: 3 years
Mrs P	Age: 66 years old; Married for: 19 years; Providing care for: 6 years
Mrs K	Age: 64 years old; Married for: 36 years; Providing care for: 3 years
Mrs N	Age: 72 years old; Married for: 51 years; Providing care for; 4 years

Interview

A semi-structured interview schedule was devised. Congruent with the principles of IPA, the schedule did not determine the detailed direction of the interview (Hunt & Smith, 2004) and the researcher endeavoured to enable participants to tell their stories in their own words (Brocki & Wearden, 2006). Thus, the schedule did not prevent participants discussing issues of importance to them but served as an aide memoir for the researcher to ensure that the points contained within were addressed at some point in the interview. Broadly, the schedule addressed aspects of married and daily life, such as leisure activities, managing stressful times and roles within the relationship, both before and after the onset of dementia.

All of the interviews were conducted in person. They were recorded digitally and transcribed for the purpose of analysis. It has been suggested that the location of interviews should be considered, with the

emphasis on selecting a familiar place where the participant feels comfortable, such as their home (Smith & Osborn, 2003). With one exception, due to the need to respect the individual needs of the care receiver, interviews took place in participants' homes. Interview length varied from 36 minutes to 90 minutes, with five of the six participants' interviews lasting for a total greater than 74 minutes.

Data Analysis and Credibility

IPA does not prescribe a specific technique or method for undertaking data analysis (Brocki & Wearden, 2006; Smith & Osborn, 2003). Rather, the aim is to move from the descriptive to the interpretative (Brocki & Wearden, 2006), which requires “a sustained engagement with the text and a process of interpretation” (pp. 64, Smith & Osborn, 2003). When a study involves several participants, Smith and Osborn (2003) advise commencing by analysing in detail one transcript before proceeding to the others on a case by case basis.

The principles outlined in the paragraph above guided the method of data analysis in this study. Having gained familiarity with a transcript, notes were made, initially in the transcript margins, about salient features of the account. The notes were grouped under broad headings, such as 'before dementia', 'view of dementia', 'feelings/emotions' or 'person centred'. Then, the connections between these categories within transcripts were considered, with interpretative accounts produced for the first three analysed transcripts to aid transparency. Finally, themes reflecting issues that were significant for the majority of participants were

derived from communalities across the cases. It was acknowledged that, inevitably, the unitization of data through the search for connections, similarities or divergences across cases obscures personal, sequential accounts (Collins & Nicholson, 2002). However, the method of analysis adopted in this study reflected the goal of conveying a sense of participant's individual experiences within a framework of themes. The transcripts were revisited throughout the process of analysis.

The focus of qualitative research is to provide a credible account of the issue in question (Osborn & Smith, 1998). Several measures were taken to ensure credibility in this study. First, two supervisors oversaw data analysis during meetings throughout the progression from the initial descriptive stage to the development of themes. Supervisors, one male and one female, were supplied with several entire transcripts and three interpretative case accounts. To explore the salience and significance of the issues contained within the themes for spouse caregivers, the themes were then presented to a group of psychologists who work with older adults. The use of direct quotations throughout the results section serves to demonstrate that themes are rooted in the accounts of participants. Quotations that include examples of the researcher's questions or prompts are also supplied. The issue of reflexivity, the interaction between the researcher and the data, was addressed with research supervisors throughout the process of data collection and analysis.

Results

Four interconnected themes are presented in this section. The dynamic of continuity/discontinuity is integral to each theme.

"Same Person or Different"

This theme addresses the degree to which the care recipient is perceived to be the same person. Some caregivers perceived their husbands to be different people as a consequence of their dementia condition, whilst for others the sense of their husbands as the 'same person' was retained.

Mrs A felt that Mr A had become "so different" from the very thoughtful and caring person he had been throughout their marriage. She identified this as a source of distress: "it's because he's so different I think that I get upset." Mrs P reported that she has completed the process of grieving for her husband, explaining that he is now a completely different person: "he is just like a shell of his former self like you know, and they switched someone's, someone else's mind with his kind of thing".

The construction of the spouse as 'different' seemed to be associated with a tendency towards depersonalised, objectifying language and a somewhat negative characterisation.

Mrs S: “But I think *people like that* live in a little world of their own don’t they. I think so.”

Mrs A: “You really can't get away from them because they're there wherever you are.”

Mrs P: (Mr P had changed)... “from being this fabulous man to this wimpering man”.

In contrast, some caregivers seemed to regard their spouses as being fundamentally the same person, although this did not preclude acknowledgement of change. Mrs B referred to Mr B having retained his sense of humour and, when describing what had first attracted her to Mr B, commented: “Errm, the same as he is now. Always got a smile for everybody”. Mrs B recognised some change in Mr B, which, although she seemed to minimise, remained a source of distress for her:

Mrs B: “he's been losing his temper a bit, just very briefly, errm, as he never has before.”

I: “And what do you do then?”

Mrs B: What can I do? He soon forgets it so I do as well.”

I: “Okay.”

Mrs B: “I know that's not him. Errm, sorry, (crying).”

Mrs N, whilst acknowledging Mr N's significant short term memory problems, referred to him as “still a very intelligent man”. Mrs N explained how her sense of Mr N as being essentially the 'same person'

has endured change:

Mrs N: "But he'll wake in the night and he doesn't know where he is. 'Where am I?' And he remembers me, 'Where am I Martha?....Hold me Martha, I'm frightened'. And cuddling him, like you would cuddle and comfort a baby, I find emotionally distressing ..."

I: "Mmm"

Mrs N: "Because I've lost the person he was..."

I: "Right, right"

Mrs N: "Errm, in many ways, you know. But thank goodness he's kept, as I say, his quirky sense of humour. And you know, he, he's there if I look for him, you know, he's there"

It is suggested that 'distancing' perspectives offer protection through providing disconnection from sources of emotional distress, particularly distress engendered by the dissonance between past and present. That is, the disconnection of the person for whom one now provides care from the husband one loved represents a form of defence through the provision of a protective emotional buffer. The interview with Mrs S provides support for this interpretation, as she described a past

comprising of happy memories but found their recall so distressing that she preferred to confine conversation to the present.

It should also be noted that disconnection and discontinuity may translate into two different forms of positioning: a 'different person' or depersonalized perspective. For example, whilst Mrs P regarded Mr P as a different person, continuing to respect his sense of personhood by trying to include him in decisions about financial matters, Mrs S seemed to hold a more depersonalised view of Mr S, as a 'dementia patient' than a person with dementia.

Caregivers for whom the sense of their husband as the same person is retained perhaps also experience distress as a result of change. However, they seek and gain solace from insights of continuity with the past and dispel the distress of change by asserting the enduring essential identity of their husbands. It is also noted that maintaining continuity is, at least in part, a conscious process for some caregivers. Continuity, however, does not necessarily protect against the distress of dementia-related changes. Strategies that promote the maintenance of the spouse as the 'same person', such as minimising distressing behaviour or positioning it as 'not really him', may then be utilised.

'Relational change'

Some caregivers seemed to have re-drawn relational boundaries, positioning dementia at the heart of their definition of relationship. Mrs A advanced a view of inevitable relational transition: "you obviously don't feel about him like you used to feel". Both Mrs A and Mrs P described

their relationships in terms of providing protection and care rather than love and affection. Mrs A's construction of the relationship on a foundation of 'care' rather than 'love', was perhaps evidenced when she responded to Mr A's assertion that she no longer loves him but hates him by stating that she would have left if she didn't care for him. Mrs P referred to caring for Mr P as her job and the re-drawing of the boundaries of their relationship seemed crucial to her ability to cope:

Mrs P: "It's hard because I can't go back down that road again...."

I: "...right...."

Mrs P: "...I've shut off; I've put a barrier up around myself...."

I: "...yeah..."

Mrs P: " (....) but he comes in and he's beaming and he wants to put his arms all around me so I always give him a kiss like you know, and he wouldn't let me go then you know and I, ooh, I just wanted to push him away, and then he said 'are you alright love?', and I thought I hope he is not feeling this tension...."

I: "you were worried that he was...."

Mrs P: "...yeah, and 'yes I feel a lot better now love', and then he comes and he spoils my hair, and I thought no, I am not

putting this barrier down...”

I: “ ...because that is your line...”

Mrs P: “...that's my line, I thought I daren't, I daren't put that barrier down.”

Mrs S did not comment directly on her relationship with Mr S, but substantial relational change may be inferred from the fact that the impact of problem behaviours seemed instrumental in her construction of the relationship dynamic between caregiver and husband. Mrs S discussed reading about a caregiver who feels hate for her husband. Mrs S stated that she did not hate Mr S but understood that hate could arise because of the “absolute stress” of caring for people who “are worse” than Mr S.

Other caregivers did not define their relationships in terms of their husband's dementia. Mrs N described how she tells Mr N that she is able to “read (him) like a book” but observed that, conversely, he couldn't “get past the first page” (of her). Her following comment - “that's the same thing with any husband” - perhaps illustrates her view of her marriage as being like those of other people, rather than constructed in terms of Mr N's dementia. Nonetheless, Mrs N's relationship was also strongly identified by 'protection', which she likened in potency to the feeling of caring for a child. The tension of accommodating these feelings was raised by Mrs N: “And somebody said to me once 'do you find it hard?' and I said 'yes, of course I do.' In many ways, emotionally particularly because he's my husband and he's become like a child.”

Similarly, neither Mrs K nor Mrs B seemed to construe their relationships in respect of their spouse's dementia and reference to relational change was absent from their accounts. Thus, perhaps Mrs N, Mrs B and Mrs K had assimilated the changes wrought by dementia within a continuing relational construction.

A sense of diminished reciprocity was noted in several of the accounts and seemed to be exacerbated by caregivers experiencing a greater need for support, such as difficulties with their own health. Mr K, unaware that Mrs K had been unable to work for several months because of serious health issues, continued to ask how work had been that day and to assume Mrs K was in good health. Mrs K commented that: "I don't get a cuddle or anything because, you know, there shouldn't be anything wrong with me, I've always been healthy old Jan, you know". Although understanding why Mr K did not offer her sympathy. Mrs K acknowledged feeling "a bit hurt". Similarly, Mrs A reported that when she is unwell, Mr A tells her about his ailments and commented: "Well actually it quite upsets me. I think 'oh I wish I had someone who really cared about me'"

It is suggested that the context of relationship history may elucidate why some relationships can assimilate the changes resulting from a spouse developing dementia, whilst others are completely re-defined. The issue of reciprocity and feeling 'cared for' by a spouse can provide an illustration of this point. Perhaps relationships are characterised by different core characteristics and values. For example, Mrs A, Mrs S and Mrs P highlighted that their husbands had been "kind".

Indeed, for Mrs S and Mrs A, kindness was raised in the discussion of initial attraction. In other words, feeling 'cared for' was a vital component of their relationships. Thus, further to the perception that their husbands are 'different' because they are no longer 'kind', the absence of the defining element of the relationship – of reciprocity and feeling 'cared for' - may be instrumental in determining the sense of relational change. For Mrs K, however, who referred on several occasions to her independence throughout their marriage, the absence of care and reciprocity, whilst hurtful, does not serve to compromise a fundamental element of her relationship.

Likewise, Mrs B remembered being attracted in part by Mr B's cleverness and their marriage seemed to revolve around her 'fitting in' with Mr B's work. Even when she doubted business decisions that subsequently resulted in financial loss, Mrs B did not give voice to her concerns. Although Mrs B's experience of providing care is markedly different in many ways from their previous life together, it is contended that the core characteristic of 'fitting in' with Mr B's needs has remained, underpinning a sense of continuity.

The nature of perceived change in partners following the onset of dementia would seem a key consideration in respect of the nature and degree of relational change. Indeed, perhaps the perception of one's partner as a 'different person' inevitably translates into relational discontinuity and re-definition. Conversely, the perception of one's partner as being essentially the 'same person' could be considered a pre-requisite for the assimilation of change within a continuous

relationship.

It is also suggested that relational re-definition is experienced quite differently by caregivers. Mrs A seemed to have fully accepted her new relational positioning, perhaps internalising this transition as an article of fact rather than perspective. The concrete certainty of Mrs A's position seemed to preclude consideration that Mr A may not share this new relational construction. Thus, the fact that Mr A might be seeking reassurance that he is loved and not merely cared for did not seem to occur to Mrs A. Mrs P, however, was concerned that Mr P's perception of their relationship was not congruent with her own. For Mrs P, maintaining the new relational boundaries seemed at times to be a conscious and effortful process. It is noted that fundamental relational change does not seem to extinguish elements such as a sense of 'caring for' the other person. Although referring to caring for Mr P as her job, Mrs P's metaphor of "looking after a brother" perhaps indicates a more complex relationship in which a sense of duty and respect remain influential forces.

'Emotional Responses to Behaviours'

This theme focuses on two forms of emotional response: guilt and empathy. Feelings of guilt were expressed by caregivers in relation to their reaction to dementia behaviours. Mrs S described a cycle involving coping with 'behaviours' and guilt:

Mrs S: "I mean they do things, and you think 'oh you stupid sod', you know? Something like that. But really he can't help it, he doesn't know."

I: "So you think that and it makes you feel guilty for having thought it..."

Mrs S: "Yes it does, so then there's another cycle that keeps going on and on and on"

Removing the sense of personal agency seemed one way to attempt to assuage these distressing feelings of guilt. For example, Mrs S asserted that "a lot of women" would respond in the same way to dementia behaviours. Mrs P commented that "I don't like the part where we have got to learn to lie". However, perhaps this did little to ameliorate Mrs P's distress, as the fact she now conceals some information from Mr P, together with her changed feelings towards him, have compromised her view of herself: "I don't like the woman I'm becoming".

Conversely, Mrs A's view that shouting at Mr A is a source of emotional relief, seemed sufficient to expunge her sense of guilt.

Mrs A: "Well I feel awful shouting at him but then I think 'oh dear, well it relieves me a little bit.' It's like shouting at children if

they're naughty isn't it? You know, you feel a bit better, it doesn't do any good, but you feel a bit better for it."

Another form of emotional response was empathising with the experience of the care recipient. Adopting a person centred approach seemed to underpin empathic responses. Mrs K noted Mr K's dislike of her prompting and questioning him about his actions, recognising how it probably feels for him: "So I suppose he feels he's being watched a lot of the time."

Mrs B's acknowledgement of her beliefs and feelings in respect of Mr B's communication difficulties was balanced by her awareness of Mr B's perspective. Mrs B's account suggests that her ability to view this issue from Mr B's perspective enables her to regard his frustration as both legitimate and proportional.

Mrs B: "...he sometimes doesn't try. I can say 'well, look, tell me. Either say yes or no' and we do get a bit impatient with each other. Errm, because sometimes he's trying so hard to tell me things, errm, and if only he could it would, you know...(...). Errm, but normally, he can't help it, he just forgets what he was going to say anyway.

I: Yeah

Mrs B: So he's just stuck here, you know. It must be very frustrating.

I: Frustrating for..?

Mrs B: For him. Most men would show it more.

Mrs A related an incident which demonstrated how empathy for Mr A's experience of disorientation displaced her more usual feelings of annoyance.

Mrs A: "...he come in that room and he could not think where he was. He had no idea. And I said 'well look through the window' but it didn't work that, it really frightened him because he stopped dead. He said 'do you know what; I can't think where I am.' And I thought god, it must be awful really, his mind must be in such a turmoil to not realise where you are. Now that didn't annoy me that day, I was sorry, really sorry for him that day because he stopped so dead"

Hostile emotional responses seemed at times to be engendered by a belief that behaviour was deliberate or controllable. Mrs S described Mr S's tendency to repeatedly ask if the doors are locked when "he knows" she has settled down to watch television. Holding Mr S responsible for behaviours that have engendered negative emotion seems to enable Mrs S to blame him. However, her conviction in this belief was not consistent. When Mrs S's emotions of anger and irritation are associated with the contrary appraisal that Mr S "can't help it", the blame is turned inwards, resulting in feelings of guilt.

Perhaps a person centred perspective, through engendering an understanding of the legitimacy of a care recipients' sense of frustration or irritation, may influence a caregiver's ability to empathise with, adjust to and accept behaviours. Thus, Mrs K's appreciation of Mr K's feeling

that he is being “watched a lot of the time” seemed to be associated with her “learning” to be more patient and not ask Mr K as many questions. Mrs N advocated a person centred strategy to managing repetitive questions - “just answer as if it's the first time every time” - recognising that this prevented Mr N from becoming upset.

Generally, a person centred view and associated empathic response seemed to be displayed more readily by caregivers who perceived continuity in their spouses and relationships. Caregivers who perceived discontinuity seemed more likely to experience intense negative emotions in response to behaviours, even though they may be able to articulate a person centred or empathic viewpoint. They also seemed more likely to experience guilt. Thus, perhaps one reason for the experience of guilt is that the awareness that behaviour is not deliberate and of the distress experienced by their spouse remains and conflicts with the initial intense negative response. In contrast, caregivers who perceive continuity are less likely to experience guilt because of the dominance of their person centred empathic perspective, a position that would also seem more likely to facilitate practical solutions.

'Impact on day-to-day life'

One element of this theme concerns the loss of previous patterns of daily life. Perhaps the most fundamental example is the loss of conversation, of being able to share information, make future plans or simply pass time conversing with a partner:

Mrs N: "I do miss telling him things, I do miss using him as a sounding board, I do miss telling him, talking to him about things on the news, or in the paper."

Mrs K: "But also, you know, I can't really have a sort of in-depth conversation with him."

The loss of a sense of personal freedom seemed to engender a range of feelings. Mrs B never leaves her husband alone but explained that she has "got used" to the fact that she cannot pursue her previous activities outside of the home. She further minimised the impact by noting that as she now tends to feel more tired, "I don't think I'd want to be going out very much". Mrs N also seemed to have adjusted to the curtailment of personal freedom, but with a greater sense of loss: "I miss the freedom of coming and going. I do get lonely, particularly if the weather is miserable and I haven't really got anything to do in the house"

But it seems that adjustment to the loss of personal freedom and to being largely confined to the home is beset with difficulty if allied to the sense of being hostage to the role of caregiving. Mrs A described how she cannot 'escape':

Mrs A: " Well I do shout at him sometimes but then sometimes I go out of the room (..). But it's not so easy because I go out of the room, (Mr A) follows me out doesn't he? If I go to the lavatory sometimes he's at the bottom of the stairs shouting 'do you want me to do something?'

You really can't get away from them because they're there wherever you are.”

Contextual factors seem important when considering the impact of providing care to a husband with dementia. Constituent to a sense of being 'trapped' could be the difficulties inherent in leaving the home and accessing the community. Mrs A felt acutely the loss of their car, particularly given her increasing mobility problems. Similarly, Mr and Mrs S's recent move to a new home in a hilly area poorly served by public transport, difficult for Mrs S to access by foot and with diminished opportunities for interaction with neighbours, seemed to have exacerbated Mrs S's difficulties. For Mrs S, her day now seemed dominated by the struggle to meet caring and household responsibilities and find meaningful occupation.

Mrs S: “I get up, I sort George out, I wash, I cook, erm, I try and have a conversation with him. We might go for a little walk up the road and back because its very hilly, and that's about it. And I look forward to going to bed. I get up and the only thing I can think of is going to bed again”

It was only Mrs K who had retained a sense of continuity in her daily life. She had been able to maintain her own social networks, employment and activities following Mr K's development of dementia, although her recent health problems had resulted in significant change. Mrs K had

established this pattern when Mr K worked abroad.

Maintaining continuity in the domain of daily life would seem to be readily compromised by the care needs of a spouse with dementia. The historical context of past patterns of daily life seems important to appreciating the impact of caregiving on daily life. Thus, the disparity between past daily life and the present may assist an understanding of the impact of caregiving. Married life for Mrs P, for example, seemed to constitute of considerable joint activities during the day: “we were really happy in the beginning because we did everything together”. Mr P's impaired abilities had therefore wrought significant change in her daily life, whereas Mr K's impairments had not notably impinged on Mrs K's daily occupation.

It is noted that factors which may frequently be associated with later life could serve to exacerbate the impact of dementia. For example, Mr S had developed dementia soon after retiring at 70 years of age, so Mrs S's adjustment to caregiving was conterminous with the adjustment to Mr S being retired and at home during the day. The declining health of caregivers would also seem particularly germane.

Discussion

The themes of ‘positioning of the care recipient’, ‘relational change’, ‘emotional responses to behaviours’ and ‘impact on day-to-day life’, elucidate the similarities and divergences between the participants in respect of their perceptions of and responses to their husbands with dementia. It is suggested that addressing the interconnections between

these themes will aid a discussion of the complex dynamics associated with providing care to a spouse with dementia. The concept of continuity is integral to this discussion.

Broadly, three of the participants – Mrs S, Mrs P and Mrs A – seemed to display a sense of discontinuity with the past. They no longer considered their husbands to be the ‘same people’ and, perhaps somewhat inevitably, this translated into considerable relational change. In contrast, the other three participants – Mrs N, Mrs K and Mrs B – appeared to have maintained continuity by assimilating changes in their spouses and relationships within existing constructs. It is suggested that a sense of continuity increased the tendency for caregivers to empathise with the experience of the carereceiver.

For all bar Mrs K, discontinuity in day-to-life was evident, but Mrs B and Mrs N seemed to have better adapted to this change. Indeed, the sense of being 'captive' to the role of caregiving, a state associated with carer stress (Pearlin et al 1990), resonated with the accounts of Mrs S and Mrs A. Exploring the factors that may explain the continuity/discontinuity dichotomy would seem highly pertinent.

Hunt and Smith (2004), in a study of stroke caregivers, noted the irony that stronger prior relationships appeared to be associated with greater distress. Thus, a possible factor could be that happy pre-morbid relationships predispose towards discontinuity because some caregivers, like Mrs S, disconnect as a defence against the ‘spoiling’ of good memories from the past (Lewis, 1998).

In this study, none of the participants reported poor quality pre-

morbid relationships. But, whilst continuity with the past may have engendered distress for some, others seemed to find it helpful and reassuring. Mrs N's account of seeking and discerning signs that Mr N is 'still there' would seem to echo with the experience of other caregivers. Chesla et al (1994) observed that family relationships perceived to be continuous were characterised by interpretations, for which there may have been little objective evidence, that the person with dementia reciprocates or 'was still there'. Such interpretations were found to be comforting for family members. Furthermore, the ability to perceive continuity was conterminous with the acknowledgement of dementia related impairments. Therefore, perhaps an issue of salience is what enables some caregivers to 'see beyond' dementia.

At an intra psychic level, individual ability to 'hold' competing, contradictory information is subject to variation. In cognitive therapy, for example, the tendency to interpret situations as being either 'black or white' is termed dichotomous thinking (Beck, Rush Shaw and Emery, 1979). Within the psychodynamic model, it is recognised that processing opposing elements of the same 'object' can evoke distress. The defence of 'splitting' describes the unconscious process of protecting against intense emotions by the polarisation of good and bad feelings, of love and hate and of attachment and rejection (Kraft Goin, 1998). Thus, discontinuity in the perceptions of husband and relationship could be viewed as the splitting of past attachment to and love for one's spouse from negative feelings engendered by dementia-related changes. However, the protection offered by splitting is illusory, as the element

that is 'split off' may not be completely excluded from consciousness. The guilt experienced by caregivers could be considered in this context. Negative emotions are 'legitimised' by holding a particular view of the spouse, but when thoughts such as 'he can't help it really' (Mrs S) occur, the legitimacy of negative responses is removed and replaced by guilt.

It is suggested that relational contexts may exacerbate the sense of change, perhaps rendering more likely the defence of splitting. The theme of 'relational change' included the proposition that if core characteristics of a relationship are compromised by dementia, it is more distressing for spouses and increases the likelihood of disconnection and discontinuity. Caregivers who seemed to have maintained continuity had generally led lives involving more significant moves and changes than the caregivers who perceived discontinuity. Both Mrs B and Mrs K, for example, had lived abroad in a number of different countries. Therefore, perhaps exposure to, or the willingness to experience, changes during married life may indicate a capacity to adapt to dementia-related change in later life.

For some caregivers, however, an absolute commitment to the institution of marriage may underpin continuity. Kaplan (2001) reported some spouses' enduring sense of continuity irrespective of their partner's impairments or ability to participate in the marriage. It is noted that such a perspective may explain some caregivers' desire to seek and gain comfort from signs of continuity.

In the field of social gerontology, continuity is construed as a positive force. Atchley (1989) suggests that during the life course,

individuals strive to retain existing internal and external structures of continuity through adaptive choices that draw upon their perceptions of the personal past. He proposed that discontinuity results in life being felt to be too unpredictable whereas optimum continuity is characterised by the individual feeling that they have the coping resources available to meet changes. However, Atchley's theory applied to so-called 'normal aging', a definition that would seem to preclude its application to spouse caregivers. In other words, providing care to a spouse with dementia would be considered to militate against the ability to make adaptive choices to retain and maintain continuity. For example, 'normal aging' may include electing to maintain leisure activities but the onset of dementia could render these activities impossible, thus removing the opportunity for utilising continuity to make adaptive choices.

The results in this study certainly concur with the standpoint that the reality of caring for a spouse with dementia radically impacts on an individual's view of and ability to utilise continuity. As discussed above, signs of continuity, rather than being sought, may be actively repelled and the massive changes associated with a spouse developing dementia clearly pose a significant challenge to a sense of continuity. Indeed, in the domain of day-to-day life, it would seem that the ability to maintain continuity is frequently impossible. However, it is suggested that it is not the degree of change itself but the elasticity of individual concepts of continuity that determine whether a sense of continuity or discontinuity prevails.

The proposed concept of the elasticity of continuity would seem

to fit well with the preceding discussion. Thus, both intrapsychic and relational factors determine the elasticity of individual concepts of continuity. Conceiving of adaptation to spousal dementia in terms of continuity elasticity is suggested to offer a straightforward metaphor for the experience of spouse caregivers. When an individual's sense of continuity is sufficiently elastic to be stretched but not broken by the changes in their spouse, relationship and daily life, they remain able to seek and gain benefit from continuity. If the extent of change ruptures an individual's sense of continuity, a state of dislocation and disconnection ensues.

Thus, it is suggested that the maintaining of continuity for spouse caregivers should be regarded as an adaptive response that contributes to a sense of predictability and control. Further support for this assertion is supplied by the way in which adaptive and maladaptive responses are constructed in a clinical sense. Ward, Opie and O'Connor (2003) regarded displaying respect for emotional well-being, autonomy and safety as adaptive responses, features that in this study were associated with the caregivers who had retained continuity. Conversely, maladaptive responses were identified as being unhelpful, stressful and needlessly restrictive, descriptions redolent of the accounts of caregivers who perceived discontinuity.

The role of continuity in spouse caregivers' perceptions of and responses to their partners with dementia is presented in the spirit of qualitative research, namely to "provide a novel, challenging perspective which opens up new ways of understanding a topic" (pp.223, Yardley

2000). However, several limitations in respect of this study are noted. The participants were initially approached by an employee of a charitable organisation. Thus, the issue of whether these participants are representative of the wider population of caregivers may be raised. For example, perhaps they were approached because they were considered to be the most likely to participate.

The fact that the study did not include an account of the husbands' dementia may also be viewed as a limitation. Perhaps understanding the particular characteristics of the partners' dementia would have enhanced an appreciation of the participants' situation. It may also be argued that it precluded consideration of the potential impact of the degree of dementia upon caregivers.

Retrospective perceptions of the pre-morbid relationship enabled the study of continuity but a more comprehensive exploration of this phase of relationship would have been useful. A longitudinal study design would mean that spousal constructions of their partners and relationships could be monitored over time. Perhaps construing depersonalised perspectives as a response to spousal dementia overlooks the range of relational styles displayed in marriages. After all, some people may regard their spouse in a depersonalised manner throughout a marriage.

The results in this study suggest that the spousal relationship in dementia caregiving is complex and worthy of further investigation. The proposition that couples seek to sustain couplehood (Hellstrom, Nolan & Lundh, 2007) may apply to only some relationships. In addition to

recognising the influence of inter psychic factors, Tarrier et al's (2002) observation of the importance of individual caregiver's perceptions is supported. Indeed, perhaps a strength of exploring spouse caregiving through a lens of continuity is the ability to incorporate the impact of both inter and intra psychic factors. It is proposed that further research, both qualitative and quantitative in design, is required to establish the pertinence of ideas such as continuity elasticity to the wider population of caregivers. It is noted that a longitudinal design may be of particular utility.

In terms of the clinical implications of this research, it is suggested that the notion of continuity may be a useful construct for both understanding the situation of caregivers and intervening therapeutically. Understanding the impact of spousal dementia in the context of continuity directs attention to caregivers' individual psychological characteristics and perception of relationship rather than focussing upon partners' dementia behaviours. The concept of the elasticity of continuity is contended to provide a simple illustration of the variation in the way that people adapt to caring for a spouse with dementia. This concept also emphasises the negative effects of a breakdown in a sense of continuity.

An implication of this research for services to support caregivers experiencing distress would be a concentration upon therapeutic interventions, in contrast with current commonplace interventions such as skills training or stress management. It is envisaged that a variety of

therapeutic approaches may be appropriate. As discussed above, for example, both the cognitive and psychodynamic models may be utilised. Alternatively, approaches based upon social constructionist ideas would also seem germane. Perhaps new interventions during the early stages following diagnosis aimed at promoting continuity could also be considered.

Finally, it was proposed that discontinuity may be associated with a less empathic caring environment. Therefore, an implication of undertaking therapeutic work with caregivers to promote connection and continuity with the past would be that both the caregiver and care receiver would benefit. In other words, promoting caregivers' sense of continuity may also enable them to provide a better quality of person-centred care to their spouses. This would seem an important point. Caregiver interventions are typically evaluated in terms of their benefits to the caregiver or wider society (Schulz et al 2002). It is suggested that alleviating stress or depression may not necessarily impact favourably on the environment of care. That is, caregivers may feel less stressed but continue to view their spouse in a depersonalised way. As promoting continuity is inextricably linked to maintaining the personhood of the spouse, it may be considered a quite different form of intervention.

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