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## **Relationship Continuity and Emotional Well-Being in Spouses of People with Dementia**

Running head: Continuity and well-being

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## **Relationship Continuity and Emotional Well-Being in Spouses of People with Dementia**

### **Abstract**

**Objectives:** On the basis of qualitative research on spousal experiences of their relationship with a partner who has dementia, it has been suggested that experiences of discontinuity in the relationship (i.e. the relationship and the person with dementia are experienced as radically changed from what they were before the onset of the dementia) may contribute to heightened feelings of burden, entrapment, isolation, guilt and intolerance of behaviours that challenge. By contrast, experiences of continuity in the relationship (i.e. the relationship and the person are experienced as essentially unchanged) may contribute to a greater sense of achievement and gratification from providing care. The present study served as a quantitative test of these suggestions.

**Method:** A convenience sample of 71 spouses of people with dementia completed three questionnaires – the Zarit Burden Interview, the Positive Aspects of Caregiving measure, and the Birmingham Relationship Continuity Measure.

**Results:** In accordance with the hypotheses, the experience of greater relationship continuity (higher BRCM scores) was highly correlated with fewer negative emotional reactions to caregiving (lower ZBI scores;  $\rho = -.795$ ) and more positive emotional reactions (higher PAC scores;  $\rho = .764$ ).

**Conclusions:** The study provided some quantitative support for suggestions arising from qualitative research about how perceptions of continuity/discontinuity in the relationship may impact on the caregiving spouse's emotional well-being. Helping couples sustain a sense of continuity and couplehood may assist with their emotional adjustment to dementia.

**Key words:** Dementia, spouses, burden, positive aspects of care-giving, well-being, couplehood, relationship continuity

## **Relationship Continuity and Emotional Well-Being in Spouses of People with Dementia**

Caring for a spouse or partner with dementia can often result in high levels of anxiety, depression and distress (Mahoney, Regan, Katona, & Livingston, 2005) and low scores on measures of mental well-being (Orgeta, Lo Sterzo, & Orrell, 2013). It is important to understand what factors influence these outcomes. As well as being a goal of intrinsic value, the emotional well-being of the spouse is likely to have a major impact on the person with dementia (Burgener & Twigg, 2002; Spitznagel, Tremont, Duncan Davis, & Foster, 2006). A wide range of variables have been found to be associated with well-being, including changes in the person with dementia (e.g. behaviours that challenge), characteristics of the spouse (e.g. gender), and social circumstances (e.g. level of social support) (van der Lee, Bakker, Duivenvoorden, & Droes, 2014).

Another likely contributing factor is the relationship between the spouse and the person with dementia. Dementia can have a negative impact on spousal relationships (Ablitt, Jones, & Muers, 2009), and a poorer quality relationship has been reported to be associated with poorer spousal well-being (Ablitt et al., 2009; Mahoney et al., 2005; Rankin, Haut, & Keefover, 2001). Presumably, some of this impact is due to changes in the abilities and behaviours of the person with dementia that undermine the relationship (e.g. losses in cognition that affect the quality of communication and reciprocity in the relationship – Eloniemi-Sulkava et al., 2003). However, it is also likely to reflect how the spouse appraises and responds to those changes in the person with dementia and the consequent changes in their relationship (van der Lee et al., 2014; Wennberg, Dye, Streetman-Loy, & Pham, 2015).

### **Well-being and appraisals of change in the person and the relationship**

One group of appraisals that have been linked in qualitative research to spousal well-being concern the spouse's general reaction to the changes that occur in the person with

dementia and their relationship. For some (but not all) spouses, changes to the person with dementia give rise to the appraisal that the person with dementia is no longer the same person and that the pre-dementia person that the spouse knew and loved has been lost (Boylstein & Hayes, 2012; Evans & Lee, 2014; Hayes, Boylestein, & Zimmerman, 2009; Lindauer & Harvath, 2015; Quinn, Clare, & Woods, 2015). Similarly, for some, the relationship itself is no longer the same. Some perceive that it has changed from a spousal relationship to one that is wholly defined by the giving and receiving of care, or that is equivalent to a parent-child relationship (Boylstein & Hayes, 2012; Evans & Lee, 2014; Hayes et al., 2009; Lindauer & Harvath, 2015; Quinn et al., 2015); and the sense of being part of a couple has been lost (Boylstein & Hayes, 2012; Evans & Lee, 2014; Kaplan, 2001; Lindauer & Harvath, 2015). Whereas for some, the bonds of love are maintained or even strengthened by what is happening (Hayes et al., 2009; Quinn et al., 2015; Merrick, Camic, & O'Shaughnessy, 2016), for others these bonds are weakened and replaced by a sense of protectiveness, emotional detachment or even positive dislike (Boylstein & Hayes, 2012; Forsund, Skovdahl, Kiik, & Ytrehus, 2014; Evans & Lee, 2014; Hayes et al., 2009; Kaplan, 2001; Walters, Oyebode, & Riley, 2010).

Various suggestions have been made in qualitative research about potential links between these general appraisals and the emotional well-being of the spouse. The sense of the person and the relationship having been transformed has been linked to a sense of grief for the person and the relationship that have been lost (Paun, 2003; Boylstein & Hayes, 2012; Evans & Lee, 2014; Lindauer & Harvath, 2015; Quinn et al., 2015). It has also been suggested that, along with the loss of emotional closeness and the sense of being a couple, these appraisals are associated with feelings of isolation, loneliness, burden, entrapment, guilt and intolerance of behaviours that challenge (Boylestein & Hayes, 2012; Murray & Livingston, 1998; Walters et al., 2010).

The continuance of marital closeness has also been linked with more positive appraisals of the caregiving role. The benefits caregivers may derive from their role are wide-ranging and not readily categorised, but include a sense of gratification from completing their caring tasks and an experience of personal growth from taking on the role (Tarlow et al., 2004). It has been suggested that spouses who report continuity in their feelings of love and affection derive a greater sense of satisfaction from the provision of care (Motenko, 1989; Chesla, Martinson, & Muwaswes, 1994; Quinn et al., 2015).

***Relationship continuity as a framework for linking and measuring these appraisals of change***

Qualitative research has suggested that these various appraisals and reactions to change are closely interlinked (Boylstein & Hayes, 2012; Chesla et al., 1994; Hayes et al., 2009; Kaplan, 2001; Lindauer & Harvath, 2015; Walters et al., 2010). For example, perceiving that the person with dementia is no longer the person one married could understandably undermine the feelings of love and intimacy, and both might, in turn, contribute to a sense that the relationship has been transformed into a non-marital relationship between a care-giver and a care-receiver. Perceptions of a transformed relationship and the loss of a sense of couplehood are, in turn, likely to have a mutual impact. Based on these suggested connections, Riley et al. (2013) proposed a framework for understanding and quantitatively measuring these general appraisals of change in the person with dementia and the relationship. The appraisals are viewed as falling on a spectrum between the poles of continuity and discontinuity. 'Relationship continuity' describes a cluster of appraisals focusing on the central experience of the relationship and other person as being continuous with the pre-morbid relationship and person, despite inevitable changes that have occurred. In 'relationship discontinuity', the other person and the relationship are experienced as being radically changed and essentially different from the pre-injury person and relationship. The

cluster of appraisals are, in turn, categorised according to five dimensions: *Relationship redefined* (in continuity, the relationship is viewed as a continuation of the pre-morbid relationship; in discontinuity, the spousal relationship is viewed as finished and replaced with a new type of relationship); *same/different person* (in continuity, the person is seen as essentially the same despite dementia-related changes; in discontinuity, the person is perceived to have changed in a fundamental way); *same/different feelings* (in continuity, the spouse continues to feel the same love and affection for their partner; in discontinuity, these feelings have been replaced with others, such as feelings of resentment or emotional detachment); *couplehood* (in continuity, the sense of being one member of a couple is retained; in discontinuity, the spouse views themselves from an individualist perspective); and *loss* (the sense of loss for the pre-morbid person and relationship felt by those spouses experiencing discontinuity, but not by those experiencing continuity). On the basis of the qualitative research proposing close interlinking between these dimensions, it was hypothesised that a continuous appraisal on one dimension would cluster together with other continuous appraisals, while discontinuous appraisals would cluster with other discontinuous appraisals. Evidence for this interlinking was provided by the high correlations between subscale scores of a questionnaire measuring the different dimensions, and by the single-factor solution suggested by factor analysis (Riley et al., 2013).

### **Present study**

The aim of the present study was to use quantitative methodology to investigate the links that qualitative research has suggested between appraisals of relationship continuity and the negative and positive emotional impact of the caregiving role. Triangulating the evidence from qualitative research with a quantitative study should provide an indication of how confident we can be about these suggested links. In the study, a sample of spousal caregivers



completed questionnaires assessing their appraisals of relationship continuity, their experience of negative emotional reactions to the caregiving role, and their experience of positive emotional reactions. It was hypothesised that higher levels of continuity would be associated with more positive and fewer negative emotional reactions.

### **Method**

The study was given ethical approval via the U.K.'s National Research Ethics Service. A convenience sample was recruited from four sources: three were services providing advice and support for people with dementia and their families (one local, one national and one with a religious affiliation), and one was an agency providing supported housing for older people. The study was advertised in each of these organizations by means of a poster, an oral presentation and flyers that were handed out to potential participants by staff within the organization who were otherwise not involved in the study. Those who might be interested in taking part were invited to contact the researchers and those who responded were provided with further information about the study. Those who subsequently decided to participate were either sent a questionnaire pack through the post or by e-mail, or were given one in person (depending on their preference). All participants were given the option of completing the questionnaires with the assistance of a researcher, or at their own convenience. Those opting for the latter were requested to send back the completed questionnaires in pre-paid envelopes.

To take part in the study, participants needed to be providing care and support on a daily basis to a co-resident spouse or partner with a definite diagnosis of dementia that had been given by a medical practitioner at least 6 months prior to study participation. Their relationship needed to pre-date the diagnosis by at least 5 years. People were excluded if

they were unable to provide meaningful responses to the questionnaire items because of cognitive limitations or because their command of English was insufficient.

A power calculation was conducted using the G\*POWER program (Faul, Erdfelder, Buchner, & Lang, 2009). The main analysis involved tests of the significance of correlations. With alpha set at .05 (two-tailed) and the required power at .80, the calculation indicated that a sample of 82 would be required to detect a moderate correlation ( $r=.3$ ) and a sample of 26 to detect a large correlation ( $r=.5$ ). In anticipation of a return rate of approximately 40% (based on experience of similar recruitment methods in previous studies), it was intended to contact approximately 200 potential participants with the aim of obtaining a sample large enough to detect a moderate correlation. In the event, 193 questionnaire packs were provided to people satisfying the inclusion and exclusion criteria. Although 73 were returned, only 71 provided complete data sets. Only those providing complete data sets were included in the analysis. A sample size of 71 provided power of .74 for detecting a moderate correlation and .99 for detecting a large correlation. Although the study was somewhat underpowered for detecting a moderate correlation, it was more than adequately powered for detecting a large correlation.

Of the 71 participants who provided complete data sets, 6 were recruited through the religiously-affiliated service; 22 through the housing agency; 16 through the local support agency; and 27 from the national support agency. All the participants were of White British ethnicity. Forty-eight were female and 23 male and their mean age was 71 (range 57-90). Participants were asked how long they had been providing substantial care and support to their partner to enable them to complete activities of daily life. The mean length of care was 4 years (range 1-11).

Participants completed three questionnaires; the Birmingham Relationship Continuity Measure (BRCM; Riley et al., 2013), the Zarit Burden Interview (ZBI; Zarit, Reever, &

Bach-Peterson, 1980) and the Positive Aspects of Caregiving measure (PAC; Tarlow et al., 2004). The BRCM provides a measure of relationship continuity and includes items that measure the five dimensions of this construct ('relationship redefined', 'same/different person', 'same/different feelings', 'couplehood' and 'loss'). The measure has been found to have high internal consistency and test-retest reliability, and there is some evidence of construct validity (Riley et al., 2013). Higher scores indicate experience of more continuity in the relationship. Although the ZBI is a measure of general burden rather than a more specific measure of negative emotional reactions to caregiving, it was chosen because it is a widely used measure of caregiver burden with excellent psychometric properties (van Durme, Macq, Jeanmart, & Gobert, 2012) and includes items addressing negative emotional reactions to the role (e.g. stress, resentment, anger and guilt). Higher scores indicate an experience of greater burden. The PAC also has good psychometric properties (Tarlow et al., 2004). It was chosen because it includes items assessing the sense of gratification and achievement from caregiving, which have been specifically reported in qualitative research to be associated with relationship continuity (Motenko, 1989; Chesla et al., 1994; Quinn et al., 2015). Higher scores indicate the experience of more positive aspects.

## **Results**

The means, standard deviations, ranges and internal consistencies of the three questionnaires are contained in Table 1. All three questionnaires showed high internal consistency (Cronbach's alpha) in the study sample. The mean of the BRCM (59) was similar to the means of 64 and 59 reported for two samples in Riley et al. (2013), and the mean of the PAC (30) was similar to the mean of 34 reported in Tarlow et al. (2004). A wide range of means have been reported for the ZBI. The mean for the present sample (46) appeared to be relatively high compared to the means reported for other samples (Braun, Scholz, Hornung, & Martin, 2010).

[Table 1 about here]

Prior to analysis, the data were checked for the suitability of the planned analysis. As noted earlier, only those providing complete data sets were included in the analysis. There were no outliers. On all three questionnaires, inspection suggested that the distribution of scores was bimodal rather than normal. Accordingly, non-parametric correlation coefficients (Spearman's rho) were calculated.

Correlations are reported in Table 2. Both hypotheses were supported. The experience of higher relationship continuity (higher BRCM scores) was significantly associated with fewer negative emotional reactions to caregiving (lower ZBI scores) and more positive emotional reactions (higher PAC scores). The negative correlation between the ZBI and PAC was very high and this precluded a meaningful exploration of whether either one shared a unique proportion of the variance with BRCM scores.

[Table 2 about here]

The demographic variables were analysed to see if they were related to the three questionnaire measures. Spearman's rho was used to evaluate age and length of care; and a Mann-Whitney U-test was used to evaluate gender and each possible pair of recruitment sources. Gender, age and length of care were not significantly related to any of the three questionnaire measures. To explore this further, the sample was divided into younger (71 years of age or younger, n=36) and older participants (72 years of age or older, n=35), and into those who had been providing care for a shorter period of time (3 years or less, n=32) and those who had been providing it for longer (4 years or more, n=39). Mann-Whitney U-

tests were used to compare these groups. The results are shown in Table 3, along with the median score for each group and the corresponding values for gender. Again, there were no significant differences, although the difference between the medians for the BRCM according to the length of care should be noted. The correlations between the three questionnaires were then calculated for each demographic group separately (i.e. males, females, younger, older, shorter length of care and longer length of care). Unsurprisingly, given the non-significant relationships between the demographic variables and the questionnaires, the correlations remained high for all demographic groups. Correlations between the BRCM and the ZBI ranged from  $-.759$  to  $-.875$ ; and those between the BRCM and the PAC ranged from  $.747$  to  $.792$ .

[Table 3 about here]

In terms of source of recruitment, comparison of the medians suggested that those recruited from the religiously-affiliated organization were different from those recruited from the other groups. A Mann-Whitney U-test comparing the former to the rest of the sample indicated that they scored significantly higher on the BRCM and PAC, and significantly lower on the ZBI (Table 3). To check that this subsample recruited through the religious organization had not biased the analysis in relation to the hypotheses, the analysis was re-run excluding the subsample. Although the correlations were reduced, this was not to any meaningful extent (when subsample excluded,  $\rho = -.773$  for BRCM and ZBI;  $\rho = .743$  for BRCM and PAC).

## Discussion

Qualitative research has suggested that the experience of relationship discontinuity may be associated with negative emotional reactions to caregiving, such as feelings of isolation, helplessness, entrapment, guilt, resentment, intolerance and burden (Boylstein & Hayes, 2012; Murray & Livingston, 1998; Walters et al., 2010); and that continuity may be associated with deriving greater satisfaction from caregiving (Chesla et al., 1994; Motenko, 1989; Quinn et al., 2015). The present study provided quantitative support for these suggestions. Experience of higher relationship continuity (BRCM) was strongly associated with fewer negative emotional responses (ZBI) and more positive emotional responses (PAC). Given the limitations of the study (see below), further research is required to confirm these results.

The results are also consistent with evidence from some other quantitative studies. In a sample of spouses caring for someone with dementia, Monin, Schulz and Feeney (2015) investigated 'compassionate love' (i.e. feeling concerned about, and wanting to help, the person with dementia). Higher scores on a measure of compassionate love were negatively correlated with scores on the ZBI, and positively correlated with a measure of the positive aspects of caregiving. Although discontinuity does not preclude compassion (e.g. Walters et al., 2010), the latter may be less evident in the absence of marital closeness and the bonds of intimacy and affection, particularly when these have been replaced by more negative feelings towards the person with dementia. In a study of spouses providing care for a partner with a long-term physical illness, Badr, Acitelli and Carnack-Taylor (2007) found that those who viewed themselves as part of a couple rather than as an individual (i.e. *couplehood*) reported higher levels of burden (overload and role captivity) and lower levels of mental health.

In the present study, scores on the BRCM were not significantly correlated with any demographic variable other than source of recruitment. In one of the two samples reported in Riley et al. (2013), males scored significantly higher than females on the BRCM. Consistent

with this, qualitative studies have suggested that female spouses may be more likely to experience discontinuity in their perceptions of the identity of their partner and relationship (Boylstein & Hayes, 2012; Hayes et al., 2009). Possibly the failure to find this in the present study is due to the relatively modest size of the sample and the likelihood that the effect of gender is also relatively modest and therefore less likely to be less detected in smaller samples. In one of the samples reported by Riley et al. (2013), BRCM scores were also significantly higher the shorter the time since the diagnosis of dementia had been given. In line with this, some qualitative studies have also suggested that appraisals related to continuity may be more difficult to maintain as the person with dementia deteriorates (Forsund et al., 2015; Hyden & Nilsson, 2015; Quinn et al., 2015). Others, however, have suggested that the extent of the deterioration is not a major determinant of perceptions of continuity (Chesla et al., 1993). Perhaps reflecting this uncertainty, the correlation between the BRCM and time since diagnosis reported by Riley et al. was relatively small. Again, the failure to find any correlation between the BRCM and length of care in the present study may arise from the fact that the study was not sufficiently powered to detect smaller effects.

### **Explaining the association between continuity and emotional responses to the caregiving role**

Although links between relationship continuity and emotional well-being have been suggested in the qualitative literature and supported in the present study, the nature of these links are not well understood and require further investigation. The association between continuity and deriving a greater sense of gratification and achievement from caregiving may, in part, be explained by the persistence of the loving relationship that characterizes continuity. Spouses describe a number of reasons why they provide care. For some, it is an expression of love and the continuation of a lifelong supportive relationship; others act out of a sense of duty, fulfilling their marital vows; others provide it to conform to social

expectation; and others because there is no acceptable alternative (Quinn, Clare, & Woods, 2010). Some of these reasons (e.g. expression of love) are associated with a clear goal (e.g. the well-being and happiness of the partner) and delivering care generally ensures achievement of that goal. These reasons may thereby be associated with a sense of satisfaction and achievement from the delivery of care (Murray & Livingston, 1998; Quinn et al., 2015; Tarlow et al., 2004). Other reasons (e.g. because there is no alternative) are not associated with the achievement of a clear goal; the provision of care therefore lacks clear meaning and purpose, and is less associated with satisfaction and a sense of achievement (Quinn et al., 2010; Quinn et al., 2015). In the context of the persistence of a loving relationship that characterizes relationship continuity, the provision of care as an expression of love and the continuation of a lifelong supportive relationship is more likely (Murray & Livingston, 1998; Quinn et al., 2015; Tarlow et al., 2004) and this may partly explain why relationship continuity is associated with a greater sense of the positive aspects of caregiving. In the absence of a persisting loving relationship (discontinuity), other motives and reasons for providing care may become more prominent, and the sense of achievement and satisfaction from caring may be less likely (Quinn et al., 2015).

Another potential explanation of the link between continuity and positive aspects of caregiving was suggested by Chesla et al. (1994) who reported that those who experienced continuity were more likely to appraise the care-recipient's response to the provision of care as an expression of gratitude for the care received, and suggested that this appraisal was likely to render the act of providing care more gratifying. This is consistent with broader research on close relationships which has reported that, when a person loves their partner and is happy within the relationship, they are more likely to make positive attributions about the behaviour of the partner, reflecting their belief in the goodness of their partner's intent and disposition (i.e. in the present case, to interpret the behaviour as expressive of gratitude); but



when they are dissatisfied with the relationship, positive explanations of the behaviour are less likely (Bradbury, Fincham, & Beach, 2000; Regan, 2011).

In terms of explaining the link between discontinuity and negative emotional responses to care-giving, a number of ideas have been put forward in the qualitative literature. It has been suggested that the loss of closeness, intimacy and sense of couplehood associated with discontinuity may result in the spouse feeling isolated and alone in facing the challenges posed by dementia (Boylstein & Hayes, 2012; Wadham, Simpson, Rust, & Murray, 2016). Boylstein and Hayes (2012) also suggest that when a close and loving marital relationship persists, the provision of care becomes one aspect of a multi-dimensional relationship. By contrast, in the absence of such a relationship, the provision of care may come to define their life together and become all-encompassing because there is no other aspect to the relationship. The all-encompassing nature of the role may then contribute to a sense of being overwhelmed, burdened and trapped.

A link has been suggested between discontinuity and an angry and intolerant response to behaviours that challenge (Murray & Livingston, 1998; Walters et al., 2010). General research on close relationships has similarly found that a partner's behaviours with the potential to elicit conflict within the relationship (e.g. unreasonable demands or annoying behaviours) are more likely to elicit a negative emotional reaction (e.g. irritation or anger) when those in the relationship are less satisfied and committed to the relationship; and more likely to be ignored, tolerated or forgiven in stronger relationships (McCullough et al., 1998; Regan, 2011; Ysseldyk & Wohl, 2012). Part of the explanation of this may lie in the evidence mentioned earlier that, when a person loves their partner and is happy within the relationship, they are more likely to make positive attributions about the behaviour of their partner, and positive attributions are associated with understanding, tolerance and forgiveness; but when they are dissatisfied, negative explanations of the behaviour

(associated with intolerance and anger) are more likely (Bradbury et al., 2000; Regan, 2011). This tendency to make positive attributions within stronger relationships may, in turn, arise because partners are more likely within stronger relationships to react with empathy to the negative behaviours of the other person (i.e. to try to understand the behaviour from their perspective) (Fincham, Paleari, & Regalia, 2002; McCullough et al., 1998). This is consistent with the suggestion made by Walters et al. (2010) that continuity in spouses of partners with dementia are more likely to react with empathy, understanding and tolerance to behaviours that challenge.

### **Limitations**

Some limitations of the study should be noted. Firstly, although the ZBI and the PAC contain items addressing the constructs of interest in the present study, both are measures of broader and more complex constructs. Ideally, the hypotheses should have been tested using more focused measures, but such measures do not appear to be available. Secondly, a convenience sample was used and so it is not clear how representative it was of the general population of spouses/partners providing care to someone with dementia. In order to reduce the burden of participation, the amount of demographic data collected about the sample and their spouses was also limited. Care should therefore be taken about generalizing the findings. Thirdly, there was considerable variability in the sample, in terms of both the demographic variables (specifically, ages ranged from 57 to 90 years, and length of care from 1 to 11 years) and the questionnaires (with scores falling on or close to the minimum and maximum possible scores for all three questionnaires). A more accurate picture of the associations amongst the constructs measured by the questionnaires might be obtained by using a more homogenous sample in which any impact of demographic variables was reduced. A larger sample would also allow for a more thorough investigation of the impact

of demographic variables. Fourthly, although the study has been framed as an investigation of the emotional consequences of relationship continuity, the design of the study can only provide evidence of a correlation and causal inferences are not possible. It may be that the emotional status of the caregiver influences whether they experience continuity or discontinuity. Indeed, when considering complex variables of this nature, mutual influence seems more likely than a simple unidirectional causal relationship. Finally, the study has probably oversimplified the relationship between continuity and emotions in other ways, too. For example, it has been suggested in the qualitative literature on this issue that, for some spousal caregivers, the emotional detachment that may feature in discontinuity can serve to protect them from being overwhelmed by the negative emotions generated by seeing someone that they love deteriorate (Chesla et al., 1994; Walters et al., 2010).

### **Clinical implications**

The importance of addressing the impact of dementia from a relational perspective is increasingly advocated (Hyden & Nilsson, 2015; Wadham et al., 2016). Dementia can have a negative impact on the family as well as the person with dementia, and that impact is mediated by the relationship they share (Ablitt et al., 2009). Relationship continuity may be an important aspect of the relationship in this context. If future studies confirm this, then further work would also be required on how best to promote continuity (or, if discontinuity is eventually inevitable as some have argued (Forsund et al., 2015; Hyden & Nilsson, 2015; Quinn et al., 2015) how best to promote continuity for as long as possible, and to assist spouses to manage the transition to discontinuity more effectively).

One avenue worth pursuing would be to build on some existing studies that have investigated how some couples seek to maintain and promote a sense of couplehood in the relationship. Understanding how this is done effectively by some couples may enable clinicians and support services to guide other couples who struggle with it. Examples of

strategies that couples use to maintain a sense of couplehood include continuing to do enjoyable things together or finding new things to do together (Boylestein & Hayes, 2012; Hellstrom, Nolan, & Lundh, 2007; Wadham et al., 2016); continuing with valued roles and activities, such as gendered roles, even though this may require some adjustments (Molyneaux, Butchard, Simpson, & Murray, 2012; Wadham et al., 2016); focusing on retained abilities rather than losses, and using these to ensure successful engagement in valued roles and activities (Merrick et al., 2016; Wadham et al., 2016); the spouse supporting the person with dementia to be involved in joint decisions and to make an active contribution to their life together (Wadham et al., 2016); socializing as a couple (Molyneaux et al., 2012); maintaining physical contact and intimacy (Boylestein & Hayes, 2012); communicating openly about difficulties (Hellstrom et al., 2007); finding alternative ways of communicating and interacting if these are required, with humour often playing an important role in this (Boylestein & Hayes, 2012); reminiscing about their shared past life (Molyneaux et al., 2012; Wadham et al., 2016); resisting the idea of being a care-giver and a care-recipient, and focussing on being first and foremost a husband, wife or partner who supports the other (Molyneaux et al., 2012); and teaming up against dementia, and meeting the challenges and frustrations together (Boylstein & Hayes, 2012; Molyneaux et al., 2012; Wadham et al., 2016). For the most part, these ideas have not yet been translated into workable interventions to support couples in sustaining couplehood. An exception is the 'Couples Life Story Approach' which aims to help couples to develop a narrative of their life together (Scherrer, Ingersoll-Dayton, & Spencer, 2014).

Couplehood is only one aspect of continuity, but these ideas about how to promote couplehood may have wider application to the other dimensions of continuity. For example, promoting the idea of being a spouse first and a care-giver second, could help maintain the sense of an ongoing spousal relationship rather than one that is defined in terms of a care-

giver / care-receiver relationship (which addresses the *relationship redefined* dimension); and maintaining physical contact and intimacy could help maintain the continuity of feelings of love and affection (addressing *same/different feelings*). However, there are other potential strategies for addressing the other dimensions. For example, one option worth exploring would be whether it is possible to help couples to reflect on the fact that, despite all the changes arising from the dementia, there is continuity in many aspects of the identity of the person with dementia (addressing *same/different person*).

In line with a relational perspective, it would be important, when developing these intervention ideas, to work with the couple together, rather than individually (Hyden & Nilsson, 2015; Merrick et al., 2016; Wadham et al., 2016). Both members of the couple can be proactive in maintaining the sense of continuity (Hyden & Nilsson, 2015) and focusing on the two individuals separately could serve to undermine their sense of couplehood (Merrick et al., 2016; Wadham et al., 2016).

## **Conclusion**

In conclusion, the present study provided quantitative support for suggestions arising from qualitative research about how perceptions of continuity/discontinuity in the relationship have an impact on the caregiving partner's emotional well-being. Continuity was associated with fewer negative and more positive emotional responses to caregiving. Further investigations are needed to replicate this finding, and to evaluate the suggestions made in this discussion about the processes whereby continuity/discontinuity and emotional well-being are connected. Confirmation of the connection would provide a rationale for an investigation of whether it is possible to foster a greater sense of continuity and, if so, whether that leads to improved emotional well-being for the spouse. Greater understanding of how relationships mediate the impact of dementia and how to promote strong relationships

are important lines of research because of the intrinsic value of strong relationships and their potential implications for the well-being of both the spouse and the person with dementia.

### **Disclosure Statement**

None of the authors have any financial interest or benefit arising from direct applications of this research.

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Table 1: Descriptive statistics for the BRCM, PAC and ZBI (N=71)

	Mean	Standard deviation	Possible range	Actual range	Cronbach's alpha
BRCM	59.4	28.4	23-115	23-102	.98
PAC	30.5	11.4	9-45	9-45	.95
ZBI	46.1	22.4	0-88	15-88	.96

Table 2. Correlations (Spearman's rho) between the BRCM, ZBI and PAC (N=71)

	ZBI	PAC
BRCM	-.795	.764
p-value (2-tailed)	<.001	<.001
95% CI	-.665 to -.871	.672 to .821
PAC	-.842	
p-value (2-tailed)	<.001	
95% CI	-.731 to -.912	

95%CI = Bias-corrected 95% confidence intervals for the estimate of the correlation

Table 3: Medians and p-values for the Mann-Whitney comparison

	BRCM	ZBI	PAC
<u>Gender</u>			
Male	51	42	33
Female	52	52	37
p-value	.79	.84	.43
<u>Age</u>			
Younger	56	43	35
Older	50	47	33
p-value	.65	.81	.94
<u>Length of care</u>			
Shorter	74	39	36
Longer	43	48	33
p-value	.38	.80	.71
<u>Source of recruitment</u>			
Religious organization	94	21	42
Other sources	50	50	33
p-value	.02	.01	.01

Age: Younger = 71 or younger; older = 72 or older

Length of care: Shorter = 3 years or less; longer = 4 years or more