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Relationship continuity/discontinuity - a framework for investigating the role of relationships
in the experience of living with dementia

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Abstract

A recent paper (Riley, Evans and Oyebode, 2018) reported that a sense of discontinuity in carers' experience of their spousal relationship with a person with dementia is associated with a greater sense of burden and fewer rewards from the caregiving role. This commentary sets the paper in context by providing a brief overview of research relating to relationship continuity/discontinuity. Factors that may explain why some carers experience continuity but others discontinuity are reviewed. So, too, is the potential impact of continuity/discontinuity on how the carer copes with the challenges of dementia. Potential future research is discussed.

Keywords: dementia; caregivers; family; relationship quality; continuity

Research on the experience of living with dementia has increasingly focused on the relationship between the person with dementia and the family caregiver (typically the spouse). Studies suggest that dementia has a major impact on the relationship, and that the relationship in turn has a considerable influence on how the couple experience living with dementia¹. Many different aspects of the relationship have been studied in this context¹, but the aim of this commentary is to summarise recent research on one particular aspect known as *relationship continuity/discontinuity*.

Relationship continuity/discontinuity

On the basis of earlier qualitative research, Riley and colleagues² defined *relationship continuity* and *discontinuity* in terms of a cluster of five closely connected experiences associated with being a spousal carer. In *discontinuity*, the relationship no longer feels like a marital one, and may be compared to that between a parent and child; the person with dementia is also experienced as radically changed, and some carers have reported that it feels like living with a stranger; feelings of love and affection are likely to have dwindled and been replaced by other feelings (e.g. protectiveness); the sense of belonging to a couple is likely to have been replaced by a sense of facing the situation alone; and the carer is also likely to feel a sense of grief for what has been lost. In *continuity*, the marital relationship and the person with dementia are both experienced as being essentially the same, despite the inevitable changes that have occurred; feelings of love and affection are retained, as is the sense of couplehood; and the sense of loss is limited or absent. Evidence for the close interconnection between these five dimensions was provided by the high correlations between subscale scores of a questionnaire devised as a measure of the different dimensions (the *Birmingham Relationship Continuity Measure* – BRCM), and by the single-factor solution suggested by factor analysis². However, *continuity* and *discontinuity* are not viewed

as rigid opposites: They are two ends of a spectrum. Individual carers may tend, to a greater or lesser extent, towards one end, and each carer may oscillate within a range on the spectrum³.

Potential influences on the experience of continuity/discontinuity

In line with the broader research on relationships in dementia, research on *continuity/discontinuity* has focused on how it is influenced by the dementia, and how it impacts on the spouse's experience of the dementia. Studies relating to the influence of dementia have focussed specifically on how the symptoms of the dementia may be related to *continuity/discontinuity*. Poveda and colleagues⁴ reported that more discontinuity on the BRCM was associated with higher scores on the Neuropsychiatric Inventory, which assesses symptoms such as irritability and disinhibition. By contrast, the BRCM was uncorrelated with a measure of social cognition that evaluates skills in understanding social cues and theory of mind. Using a broader range of measures that assessed cognition, communication, behavioural disturbance, and the ability to perform activities of daily living, Lewis⁵ reported that, in a multiple regression, the only variables that made a significant unique contribution to the variance in BRCM scores were behavioural disturbances and difficulties in performing activities of daily living.

More work is needed to understand these connections. A recent qualitative study⁶ suggested that aggression may undermine a sense of continuity because of the hostility it creates towards the person with dementia (thereby undermining feelings of love and affection), and because it is so out of character (and therefore discontinuous with the person that went before). However, the study suggested that such responses are not inevitable: Some participants maintained a sense of continuity despite the aggression by separating out the aggression from the person and seeing it as something external and beyond their control.

The connection with the loss of the ability to perform activities of daily living is less clear. Lewis⁵ suggested that the strength of its association with discontinuity in her study may reflect the possibility that, of the measures used, it was the one most sensitive to the severity of dementia. It may be difficult to maintain a sense of continuity in the more severe stages when so many abilities have been lost¹.

Potential impact of continuity/discontinuity

Evidence suggests that continuity/discontinuity may also impact on the spouse's experience of the dementia. In terms of emotional reaction, Riley and colleagues⁷ reported that continuity, as measured by the BRCM, was associated with a reduced sense of burden and deriving greater satisfaction from the caregiving role. Poveda et al.⁴ found that discontinuity was associated with raised levels of anxiety and depression in the carer. These studies are consistent with earlier qualitative studies that have also suggested a link between continuity and emotional well-being^{3,8}. Various suggestions have been offered in the qualitative literature about why continuity and emotional reactions to caregiving may be linked⁷. For example, Boylstein and Hayes⁸ suggested that when a close and loving marital relationship persists (i.e. continuity), the provision of care is one aspect of a multidimensional relationship. By contrast, in the absence of such a relationship, the provision of care may come to define the couple's life together. The all-encompassing nature of the role may then contribute to a sense of being burdened and trapped.

There is also evidence that continuity/discontinuity may have an impact on how spouses cognitively appraise and respond behaviourally to the demands of caregiving. Qualitative research has linked continuity to a more person-centred approach to providing care. For example, Walters et al.³ suggested that continuity was associated with a more empathic approach, whereas discontinuity was associated with greater control and restriction.

In a recent mixed methods study⁹, Riley and colleagues found that, in seeking to make sense of challenging care needs, carers who reported more continuity on the BRCM relied on a broad range of attributions that included person-centred ones such as taking the perspective of the person with dementia and making use of their knowledge of that person as an individual; by contrast, those who reported discontinuity relied more heavily on explanations in terms of the symptoms of dementia. It was suggested that when spouses experiences continuity, they carry on making sense of the person with dementia using many of the same methods that they used before the onset of the dementia, and that, in most cases, these will include some effort to understand challenging care needs using a more person-centred approach, such as taking the perspective of the person with dementia and using their extensive knowledge of the person with dementia as an individual. By contrast, in *discontinuity* the person with dementia no longer feels like the same person and these longstanding ways of understanding them seem less relevant. Because of the prominence of the dementia and its impact on their life, it may be that their efforts to understand are then primarily determined by the fact that their spouse has dementia.

Future research

Further investigation is merited into the factors that might explain individual differences in perceptions of continuity/discontinuity, and into the impact they have on the carer's emotional, cognitive and behavioural response to the situation. Longitudinal and intervention studies would provide more robust evidence of these links. The investigation of the contributors to differences in continuity/discontinuity also needs to be widened: As well as the symptoms of the dementia, characteristics of the spousal carer, the nature of their pre-dementia relationship and changes in their life circumstances should be explored.

Other related issues also merit investigation. The impact of spousal perceptions of continuity/discontinuity on the person with dementia needs to be explored. As suggested earlier, there may be an indirect impact (e.g. mediated through care that is more or less person-centred). Whether there is a more direct impact could also be explored. For example, what awareness does the person with dementia have of the carer's perceptions of continuity/discontinuity, and what impact does that awareness have on the person with dementia?

Another line of enquiry could address the experiences of continuity/discontinuity of the person with dementia, and how these relate to the experiences of their spouse. Some research has already addressed continuity of self identity in dementia. For example, in a qualitative study Daley and colleagues¹⁰ found that participants with dementia saw the maintenance of a continuous sense of self as an important goal in dealing with the condition. This is consistent with Continuity Theory according to which an internal experience of continuity of self makes the world more predictable and controllable, and thus provides a greater sense of security and self-esteem. In line with calls for research to focus more on the relationship¹, this line of enquiry could be expanded into looking at how the person with dementia experiences continuity/discontinuity in the relationship with their partner.

Why does this matter?

The relationship has a strong impact on how couples experience living with the dementia. Relationships of poorer quality have a negative impact on the well-being of both parties, and on how well both parties cope with the challenges. It is important to understand how dementia impacts on the relationship and how these impacts can, in turn, affect the experience of living with dementia. More understanding of these issues should enable the

development of interventions to enable couples to maintain and enhance those aspects of their relationship that have positive benefits.

Declaration of conflicting interests

The Author declares that there is no conflict of interest.

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