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investigation of spousal partners' responses to the challenging care needs of those with

acquired brain injury

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Relationship continuity and person-centred care: An exploratory mixed-methods investigation of spousal partners' responses to the challenging care needs of those with acquired brain injury.

Abstract

Some partners of people with an acquired brain injury experience the person with the injury and their relationship as continuous with the pre-injury person and relationship, but others experience the person and relationship as very different to what went before. Previous qualitative research has suggested that the experience of continuity may promote a more person-centred approach to how partners respond to challenging care needs. Given the value of triangulating evidence, this exploratory study used a mixed-methods design to investigate this suggestion. Twenty-six partners of people with an acquired brain injury completed the Birmingham Relationship Continuity Measure and a semi-structured interview about their response to challenging care needs. Interviews were coded and scored to provide a measure of the extent to which the participants' understanding, management and emotional responses showed a person-centred approach. The findings supported the hypothesis. Greater continuity was significantly correlated with a more person-centred approach. Associating relationship continuity and person-centred care is a novel approach to the issue of how family relationships may impact on care quality. Person-centred care can have important benefits for both the giver and receiver of care. Whether it can be promoted through fostering a sense of continuity in the relationship merits further investigation.

Keywords: brain injury, family carer, relationship continuity, person-centred care, challenging behaviour

Relationship continuity and person-centred care: An exploratory mixed-methods investigation of spousal partners' responses to the challenging care needs of those with acquired brain injury.

Partners who provide care to people with acquired brain injury (ABI) find it particularly challenging to deal with changes such as aggression, loss of motivation and reduced emotional warmth (Burridge, Williams, Yates, Harris, & Ward, 2007; Marsh, Kersel, Havill, & Sleigh, 1998; Wood, Liossi, & Wood, 2005). Partners vary in how they cope with such changes. Some experience a more negative emotional impact than others, both internally (e.g. feeling helpless) and externally (e.g. expressing anger) (Bodley-Scott & Riley, 2015; Hammond, Davis, Whitside, Philbrick, & Hirsch, 2011). There are differences in the sense they make of the changes and in the extent to which they feel that they understand them (Bodley-Scott & Riley, 2015; Braine, 2011; Riley, 2007; Villa & Riley, 2017). There are also differences in how they try to manage the changes and in their general behavioural reaction to them (Bodley-Scott & Riley, 2015; Hammond, Davis, Cook, Philbrick, & Hirsch, 2012; Villa & Riley, 2017; Tam, McKay, Sloan, & Ponsford, 2015).

Broader research on intimate relationships suggests that how people respond to negative behaviours of their partner depends, unsurprisingly, on the general characteristics of the relationship (Regan, 2011). When there are problems within the relationship and the couple are dissatisfied with it, negative behaviour is likely to elicit distress and hostility, and disapproving attributions about the behaviour (e.g. that it is motivated by malice). By contrast, in stronger loving relationships, partners are more likely to respond by trying to understand it from the perspective of their partner, giving more positive explanations of why it is occurring, and tolerating and forgiving it (Bradbury, Fincham, & Beach, 2000; Fincham, Paleari, & Regalia, 2002; McCullough et al., 1998).

Relationship continuity

In ABI research, one general characteristic of the relationship that has been linked to how partners respond to challenging care needs is *relationship continuity/discontinuity*. This is a concept that arose in the context of dementia research but has more recently been applied in the field of ABI (Bodley-Scott & Riley, 2015; Riley, Fisher, Hagger, Elliott, Le Serve, & Oyebode, 2013; Villa & Riley, 2017). It refers to the partner's experience of the relationship with the person they care for. When the experience is one of *discontinuity*, the person with the ABI and the relationship are viewed as being radically different from what they were pre-injury, and this is associated with a decline in the sense of togetherness and being a partnership, the replacement of love and affection with other feelings, and a sense of loss and grief for the pre-injury person and relationship. When the experience is one of *continuity*, the other person and the relationship are viewed as being essentially the same, despite the changes that have inevitably occurred, and the feelings of love, togetherness and partnership are retained. Evidence that partners differ in terms of each of these specific components of the concept of continuity/discontinuity has been widely reported in the ABI literature (Villa & Riley, 2017). For example, there have been several reports of some partners experiencing the person with the ABI as being radically changed (a "stranger"), but others experiencing them as essentially the same (Gill, Sander, Robins, Mazzei, & Struchen, 2011; Gosling & Oddy, 1999; Kratz, Sander, Brickell, Lange, & Carlozzi, 2017). The construct of relationship continuity/discontinuity provides a framework for integrating these different components in a way that relates them to one another (Villa & Riley, 2017).

Several qualitative studies in ABI and dementia research have linked relationship continuity/discontinuity to differences in how partners respond to the challenging care needs of the person they are supporting. In an ABI study, Bodley-Scott and Riley (2015) suggested that continuity may be associated with a less distressed and more tolerant response to challenging care needs, a better understanding of the needs, and more effective management

of them. By contrast, discontinuity appeared to be associated with lack of understanding and a consequent difficulty in managing the needs effectively. There was also a sense of bewilderment about why the other person was behaving as they did, and helplessness and hopelessness about the prospect of ever managing the behaviour effectively. Similarly, in another ABI study, Villa and Riley (2017) reported that the participants who experienced continuity appeared to cope more effectively with the challenging needs of their partner. They drew on their pre-injury knowledge and understanding of their partner to develop a richer understanding of the needs and this enabled them to manage them more effectively; whereas those who experienced discontinuity drew almost exclusively on medical explanations for making sense of the needs and relied on external support to assist them in managing them. In qualitative studies in dementia, discontinuity has likewise been linked to a more negative emotional response to challenging care needs (Murray & Livingstone, 1998; Walters, Oyebode, & Riley, 2010). Lewis (1998) and Walters et al. (2010) also suggested that discontinuity was associated with a more controlling and restrictive managerial response, and with a more objectifying and depersonalizing approach. By contrast, continuity has been linked to a more tolerant response that takes the perspective of the person with dementia in trying to understand why they are behaving in that way (Murray & Livingstone, 1998; Walters et al., 2010) and with care that is more tailored to the individual needs of the other person (Chesla, Martinson, & Muwaswes, 1994; Walters et al., 2010).

Person-centred care

Walters et al. (2010) used the construct of *person-centred care* to characterise these differences in partner reactions to challenging care needs. They suggested that continuity was associated with more person-centred care, and discontinuity with a less person-centred approach.

The construct of person-centred care was developed within dementia research (Kitwood, 1993, 1997). In essence, person-centred care is care provided in the context of a relationship in which the carer values and respects the person receiving the care; in care that is not person-centred, the diagnosis overshadows the personal identity of the individual, who becomes devalued and disempowered. This central characteristic has various components which Brooker (2004) summarised in the acronym *VIPS*. The *Valuing* component is about valuing the personhood of the person receiving the care and according them the same moral and social status as everyone else in society, with equal rights such as the right to autonomy and control. The *Individual* component is about treating the person as an individual with a unique personal history and personality; with their own wishes, values and goals; and with strengths as well as needs. The person is not to be defined simply in terms of their diagnosis or disabilities. The *Perspective* component refers to the need for the carer to respond with empathy and try to understand the world from the perspective of the person receiving the care. The *Social* component is about creating a positive social environment and experience for the other person, and avoiding negative and critical responses that might undermine self-worth.

The partner responses to challenging care needs associated with relationship continuity/discontinuity in the qualitative literature can readily be mapped onto the VIPS framework. The less tolerant and more negative emotional responses associated with discontinuity (Bodley-Scott & Riley, 2015; Murray & Livingstone, 1998; Walters et al., 2010) can be viewed as a non-person-centred aspect of the *social* component. The more empathic response associated with continuity that tries to see the challenges from the perspective of the other person (Murray & Livingstone, 1998; Walters et al., 2010) can be categorised under the *perspective* component. Continuity is also associated with the partner making use of their pre-injury knowledge and understanding of their partner to develop a

richer understanding of the needs (Bodley-Scott & Riley, 2015; Villa & Riley, 2017) and with tailoring care to the individual needs of the other person (Chesla et al., 1994). These can be classified under the *individual* component. So, too, can the tendency to depersonalize the other and to identify them with their diagnosis (Villa & Riley, 2017; Lewis, 1998; Walters et al., 2010). The more controlling and restrictive management associated with discontinuity (Lewis, 1998, Walters et al., 2010) can be classed under the *valuing* component because it involves constraining the choice and freedom of the other person.

The present study

In summary, partners providing care to those with an ABI differ in terms of how they respond to challenging care needs such as aggression and lack of motivation. General characteristics of the relationship are likely to impact on these responses. Relationship continuity/discontinuity has been suggested as an influence on how partners react emotionally to these needs, how they make sense of them and how they try to manage them. Continuity has been linked with a more person-centred response, and discontinuity with a less person-centred response.

The present study aimed to provide a more robust test of the suggestion that there is a link between continuity/discontinuity and a more person-centred response to challenging care needs. The qualitative studies described earlier were not primarily focused on the link, and the link was not explored or justified in any detail. Moreover, although qualitative studies are valuable, the small number of participants involved and the subjectivity involved in the interpretation of the data can sometimes undermine confidence in the conclusions and make it difficult to draw general conclusions (Johnson & Onwuegbuzie, 2004). Corroborating the findings of qualitative studies with evidence from quantitative or mixed-methods studies can enhance generalizability and provide more robust conclusions (Johnson & Onwuegbuzie, 2004).

In the absence of an existing quantitative measure of person-centred care in a family context, the present study adopted a mixed-methods approach. A sample of partners of people with an ABI completed a questionnaire measure of continuity/discontinuity. They also took part in a semi-structured interview about their response to specific challenging care needs. A set of person-centred codes was derived using the VIPS framework and applied to interview data, giving a quantitative measure of how person-centred the participant was in their response to the challenging care needs. The hypothesis tested was that continuity would be associated with a more person-centred response.

Method

Ethical approval was given by the University of Birmingham Ethics Committee. All participants provided written consent. None can be identified from this paper.

Participants

Participants were recruited through Headway, a non-governmental organization providing support for people with an acquired brain injury and their families. Sampling was non-random. Participants opted into the study after responding to a presentation, flyer, poster or on-line advertisement about the research. Participants were required to be the partner of someone who had an ABI at least 9 months, but no more than 15 years, prior to the participant's involvement in the study; to be living with the person with the ABI at the time of both the injury and their participation; and to have been in a relationship with them for at least 5 years prior to the ABI. Participants were also required to provide a substantial level of ongoing care to the person with the ABI, and to manage 'difficult situations' (the wording used in the recruitment material) with that person.

Twenty-six participants were recruited to meet power requirements. The analysis involved correlations. According to G*POWER (Faul, Erdfelder, Lang, & Buchner, 2007),

detection of a large correlation (r=.5), with an alpha set at .05 (two-tailed) and power at .80, requires a sample of 26. Demographic details about the sample were as follows: All participants were in heterosexual relationships. There were 19 females and 7 males, whose ages ranged from 36 to 71 years old (mean = 56). The majority (24) were White-British. The care-recipients were aged between 41and 76 years old (mean = 56), and again the majority (21) were White-British. Nineteen had experienced a stroke, six a traumatic brain injury and one a brain abscess. The time since their ABI ranged from 11 months to 162 months (mean = 68 months). The length of relationship ranged from 10 years to 57 years (mean = 28).

Assessment of relationship continuity/discontinuity

Participants completed the Birmingham Relationship Continuity Measure - Acquired Brain Injury (BRCM-ABI). This is an adaptation of a questionnaire that assesses the experience of relationship continuity/discontinuity in partners of people with dementia (Riley et al., 2013). An evaluation study of the BRCM-ABI (Yasmin, Keeble, & Riley, *submitted*) reported high internal consistency (alpha = .96) and test-retest reliability (intra-class correlation = .96); and evidence of construct validity was provided by significant correlations with the Closeness and Conflict Scale (Schofield et al., 1997) and the Marwit-Meuser Caregiver Grief Inventory (Marwit & Meuser, 2002) (both correlations were above 0.7). The questionnaire has 23 items scored on a scale from 1 to 5, and higher scores indicate higher continuity. Items include "It doesn't feel like a partnership anymore" and "Sometimes I feel it's like living with a stranger."

Assessing person-centred care

There are no existing quantitative measures of person-centred care that would have been appropriate in the present context. Nearly all the measures in dementia focus on employed carers (Martinez, Suarez-Alvarez, & Yanguas, 2016), and none has been validated for use in ABI. Instead, the present study adopted a mixed-methods approach widely used in

attributional research (Stratton, 1997). The method involves extracting, from semi-structured interviews, statements concerning the participant's understanding of the causes of the behaviour of others. These statements are then coded using pre-determined categories derived from attributional theory (specifically, internal vs. external, controllable vs. uncontrollable, personal vs. universal and stable vs. unstable). The numbers of statements falling under each category are then used in a statistical analysis.

Interest in the present study was on how person-centred participants were in terms of their emotional reaction to challenging care needs, their efforts to understand the needs and their efforts to manage them. So they took part in a semi-structured interview that focused on these three issues. Statements about the issues were then extracted from the interviews. Whereas in attributional research, the codes are derived from attributional theory, in this study the person-centred codes were derived a priori from the VIPS theoretical framework. The statements were then classified using these codes, and the numbers falling under each code were used in the statistical analysis.

Interview

At the start of the interview, three common challenging care needs were described to the participants (aggression/irritability, loss of motivation/inactivity and low mood/emotionality). These were selected because they are reported to be among the more common and challenging situations faced by family carers (Marsh et al., 1998). Participants were asked to identify two of these that they experienced on a regular basis (at least once a month) and that they were willing to talk about. If they did not experience at least two on a regular basis, they were asked to identify one (or two) other challenging care needs that did occur at least once a month, that they found challenging, and that they were willing to talk about. The reason for preferring them to select two of the three common care needs was to try to minimise confounding that may arise because certain types of caring need may be more likely to be

dealt with using a person-centred approach (e.g. compared to low motivation, memory difficulties may less often be understood in terms of the unique characteristics of the individual). On the other hand, participants needed to talk about needs that they were regularly faced with, and so there needed to be some flexibility in terms of what they discussed.

Each participant was interviewed about the two care needs they had nominated in this way. For each situation, participants were asked to describe the problem and give a detailed account of a recent occurrence of it. They were asked why they thought their partner was behaving in this way; how they managed the care need; why they dealt with it in this way; whether these strategies were successful or not; what they attributed this success/failure to; how they thought the person with the ABI coped with the problem; and their general thoughts and feelings in reaction to the care need. Interviews were recorded and transcribed.

Derivation of the coding system

The VIPS model of person-centred care (Brooker, 2004) was used as the theoretical basis for deriving a set of codes (V=valuing; I=individual; P=perspective; S=social). The aim was to create codes that operationalized these four dimensions in the context of rating how the participant understood, responded to and managed the behaviours that they had chosen to speak about.

[Table 1 about here]

Table 1 provides a brief definition of each code and indicates whether the code addressed the emotional reaction to the care need, the attempt to understand the need or the attempt to manage the need. The *Valuing* aspect of the VIPS model is about according the person equal moral and social status, with equal rights such as the right to autonomy, choice and freedom. This was operationalized in terms of whether there was a joint approach to managing the challenging care need (*partnership* – Table 1); whether independence and

decision making in relation to the need were encouraged (*promoting independence*); and whether there was a restrictive, controlling or authoritarian approach (*restricting independence*). The *Individual* component is about not defining the person in terms of their disability, but treating them as an individual with a unique personal history and personality, with their own wishes, values and goals, and with strengths as well as needs. Applying this to the present context, the interview data were evaluated for evidence of whether, in trying to understand the behaviour, the participant had considered their partner's *pre-injury personal history*, *relationship* or *personality*; and whether they tried to manage the behaviour in ways which was tailored to the individual's wishes, values, strengths and needs (*individually-tailored management*). The *Perspective* component refers to the need for the carer to try to understand the situation from the perspective of the person receiving care. This was translated in the present context into an evaluation of whether, in responding to the behaviour, the participant considered the situation from their partner's perspective by engaging in a relatively in-depth reflection on their partner's *personal motivations*, *thoughts*, or *emotions*; and whether they expressed *compassion* for their partner's situation. The *Social* component is about creating a positive social environment and experience for the person receiving care, and avoiding negative and critical responses. The interview data were evaluated in terms of whether the management of behaviour was causing distress to the care-recipient (*causing upset*); whether there was a blaming or angry reaction to the care need (*negative reaction*) ; whether management involved helping the person with ABI to manage their negative emotions about the care need (*emotionally supportive reaction*); and whether the participant promoted or restricted engagement in valued social roles (such as parenting and employment) as a way of managing the behaviours (*restricting* and *promoting access to valued social roles*).

Three other codes were also created to allow the classification of extracted statements that did not fit into any of these person-centred codes (Table 1). In terms of understanding the care need, a *brain injury* code was created for attempts to explain the need in terms of the symptoms of the brain injury. The *other explanation* code was used for attempts to explain that did not fall into any other category (e.g. an explanation in terms of a recent post-injury event or circumstance). The *other management/reaction* code was used for ways of managing the need or reacting to it that did not fall into any other category.

Developing instructions for coders

An initial set of coding instructions, including explanations of each code, was drawn up. Two members of the research team then applied this to the coding of some interview data, and then compared their codes. The instructions were elaborated and clarified to address any areas of uncertainty and lack of clarity. Similarly, when the inter-rater reliability exercise was conducted (see below), the rater who was unaware of the study hypothesis used the instructions to code two interviews as part of her training. As a result, some further clarifications were added to the instructions. The final version of the instructions is available from the first author.

Application and scoring of the coding system

The first author first read through the interview transcript and highlighted any passage that related to the participant's understanding, management or emotional reaction to the care needs being discussed. Any passages that repeated the same idea were highlighted as repeats of the same idea. This idea was counted only once in calculating the *person-centred care* score used in the analysis (i.e. repetitions did not increase the score). Any passage where two or more distinct ideas were intermingled was highlighted for coding with two or more codes. The coder then decided which code(s) were relevant to the passage, and for each selected code assigned a score of +1 (indicating evidence of a person-centred approach), -1 (evidence

of an approach inconsistent with person-centred care) or 0 (insufficient or irrelevant evidence) according to the rules in Table 1. The *person-centred care* score was derived by adding up the scores for all the interview passages for each participant. For example, a participant who obtained 13 scores of +1 scores, three scores of -1, and 12 scores of 0, would be given a *person-centred care* score of +10.

Inter-rater reliability

To assess the reliability of the coding system, all the interviews were also coded by another psychologist who is familiar with the concept of person-centred care, but who was unaware of the aims and hypothesis of the research and had no access to the BRCM-ABI scores.   The second rater was first instructed in use of the coding system and practised with two transcripts. As noted earlier, some further clarification and elaboration of the instructions was carried out as a result of this. The second rater then coded all of the remaining interviews, and recoded the two practice interviews in the light of these clarifications. The second rater worked from transcripts in which relevant passages had already been highlighted by the first rater, and in which it was indicated whether to code the passage with reference to the participant's efforts to understand the needs (i.e. codes 1 to 8) or with reference to the remaining codes (codes 9 to16). The coding was completed independently (i.e. not in collaboration with any of the other researchers involved).

The statistics reported in the Results section used the ratings of the first author. However, as a check against bias, the correlation that tested the hypothesis was also calculated using the scores of the second rater, and this correlation is also reported.

Results

Interview data

Just over half of the topics selected by the participants for discussion belonged to one of the three challenging needs described at the start of the interview. Other chosen topics included social needs such as communication difficulties and being self-absorbed (20%); specific cognitive impairments such as memory loss (10%); compulsive behaviours and preoccupations (10%); and fatigue (9%). Excluding the part of the interview that involved selecting the topics for discussion, the interviews were on average 3,579 words in length (approximately 6 single-typed pages of A4), with the longest being 5,380 words and the shortest 1,250.

In total, 409 excerpts from the interviews were highlighted for coding, with a mean of 16 excerpts per participant and a range of 5 to 31. Table 2 provides excerpts from the interviews to illustrate the kind of material that was categorised under each of the codes, along with an indication of the frequency with which each code was used.

[Table 2 about here]

Several measures of inter-rater reliability for the interview data were calculated. The kappa coefficient for the choice of code for a highlighted excerpt was 0.807, indicating good agreement. Considering only the 290 excerpts for which there was agreement about the allocation of a person-centred code (i.e. all the codes in Table 1 except the 'other codes'), the kappa relating to agreeing or disagreeing about the score (agreement = both scores were +1 or -1; disagreement = one rater scored as 0 but the other as +1 or -1) was 0.583. Although smaller, a kappa of this magnitude is still considered 'moderate' according to the bandings suggested by Landis and Koch (1977). The correlation between the total *person-centred care* scores calculated from the two sets of codings provided by the two raters was high; $r = .944$, $p<.001$.

Descriptive statistics

Table 3 summarises the descriptive data for the BRCM-ABI scores and the *person-centred care* score. In terms of Cronbach's alpha, the BRCM-ABI showed very good internal consistency but the person-centred care score showed only modest internal consistency.

[Table 3 about here]

Test of the hypothesis

No univariate or multivariate outliers were detected, and the distributions of the two variables did not depart significantly from the normal distribution. Pearson's correlation was therefore used to test the hypothesis. In support of the hypothesis, BRCM-ABI scores showed a significant positive correlation with the *person-centred care* score; r = .619; p = .001; 95% confidence intervals = .305 to .811. Higher BRCM-ABI scores (indicating greater perceptions of continuity in the relationship) were associated with higher *person-centred care* scores. Because of the potential bias arising from the coding of the first author who was aware of the hypothesis, the correlation was also calculated for the data provided by the second rater, who was unaware of the hypothesis and had no access to the BRCM-ABI scores. Again, a moderate-sized correlation was obtained; r = .580; p = .002; 95% confidence intervals = .249 to .789.

Analysis of demographic variables

Because of unequal group sizes, Mann-Whitney U-tests were used to evaluate whether there were any differences between genders and between types of injury (stroke vs. traumatic brain injury) on the BRCM-ABI and *person-centred care* score. Those in the stroke group scored significantly lower on the BRCM-ABI than the traumatic brain injury group (mean for stroke = 58; mean for traumatic brain injury = 80; p=.043). Pearson's correlation was used to

investigate the relationship of the two main variables with the continuous demographic variables (specifically, age of participant, age of person with the brain injury, time since injury and length of their relationship). The BRCM-ABI showed a significant negative correlation with time since injury (r = -.425, p = .031); that is, perceptions of greater continuity were associated with less time since injury. The *person-centred care* score was significantly negatively correlated with participant age (r =-.516; p=.007); partner age (r = -.430, p = .028) and length of the relationship (r = -.412; p=.036): Showing a more person-centred approach was associated with younger couples and with a shorter length of the relationship. No other correlations were significant.

Discussion

Partners providing care to those with an ABI differ in terms of how they respond to challenging care needs such as aggression and lack of motivation. Previous qualitative research has suggested that relationship continuity/discontinuity may influence their emotional response, how they make sense of these needs, and how they try to manage them. The present study provided a triangulating mixed-methods test of the claim. Person-centred care was used as a framework for conceptualising and measuring partner responses. The findings supported the hypothesis. Continuity was associated with a more person-centred response to challenging care needs. This is in line with broader research on intimate relationships that suggests that general characteristics of the relationship are a major influence on how people respond to the negative behaviours of their partner (Regan, 2011).

Why might continuity and person-centred care be linked? The association with person-centred understanding may be partly explained by a difference in the schemas carers use to try to understand the behaviour of their partner (Villa & Riley, 2017). When the person experiences continuity (i.e. the person and relationship are viewed as continuous with the

past), presumably they carry on making sense of the behaviour of the person with the ABI using many of the same schemas that they used before the injury. These schemas are likely to involve their extensive knowledge of the individual characteristics, attributes and history of that person and of their history together (i.e. the *pre-injury personal history, pre-injury relationship* and *pre-injury personality* codes in Table1). Making use of this extensive knowledge of the other person may also facilitate efforts to understand the care need from the perspective of the other person– i.e. they are able to come up with deeper and more complex explanations focusing on the internal states of the person with the injury (i.e. the codes referring *personal motivations*, *thoughts,* and *emotions* – Table 1). By contrast, in discontinuity the other person and the relationship no longer feels the same and these longstanding ways of understanding them may seem less relevant. The carer is faced with the task of constructing a new identity for the person with the injury and their relationship, and finding new ways of understanding them. Because of the prominence of the injury and its impact on their life, it may be that this construction focuses on the other as a person with a brain injury, and that, in attempting to understand challenging care needs, the carer overlooks the schemas used in the past in favour of a more generic understanding of how people are affected by brain injury (Villa & Riley, 2017).

Several explanations can also be offered of the link between continuity and both the emotional response to challenging care needs and the attempts to manage them. First, if the carer experiencing continuity makes more use of their knowledge of their partner as an individual in trying to make sense of challenging care needs, then they are presumably also more likely to come up with ways of managing the needs that are tailored to meet the needs of the individual (i.e. the *individually-tailored management* code, Table 1). Second, because the relationship still feels the same as before the injury in continuity, then, unless the pre-injury relationship was dysfunctional, the carer is more likely to treat the person with the

injury as an equal partner, seeking their opinion and working together in tackling the challenging care needs; and less likely to adopt a paternalistic, controlling or restrictive response (i.e. the *partnership* and *restricting/promoting independence* codes, Table 1). Third, continuity involves the retention of the same feelings of love and affection within the relationship, whereas in discontinuity these are replaced by other general feelings towards the other person, which may sometimes be negative and hostile (Bodley-Scott & Riley, 2015; Villa & Riley, 2017). Broader research on intimate relationships suggests that, once these general negative feelings have entered into a relationship, instances of negative behaviour are likely to elicit negative emotional reactions such as anger and irritation, and negative attributions about the behaviour (e.g. that it is motivated by malice). By contrast, in loving relationships, partners are more likely to make positive attributions, and to tolerate and forgive the behaviour (Bradbury, Fincham, & Beach, 2000; Fincham, Paleari, & Regalia, 2002; McCullough et al., 1998). This might contribute to an association between discontinuity and a blaming, hurtful and less compassionate response (i.e. the *causing upset*, *compassion*, *negative reactions* and *emotionally supportive reaction* codes, Table 1). Some of this research (e.g. McCullough et al., 1998) also indicates that a more loving relationship is associated with more effort to understand negative behaviours from the perspective of the other person, which may also shed light on the association between continuity and a person-centred approach to understanding.

Limitations

 The findings of this exploratory study need to be treated with caution. Although the individual components of relationship continuity have often appeared in the ABI literature (Villa & Riley, 2017), the generic construct and the questionnaire used to measure it are novel. Similarly, although the general methodology of coding interview data is widely used in attributional research (Stratton, 1997), its particular application in the present context is

also new. There are several more particular limitations relating to the method for deriving the person-centred care variable:

- Participants were given a choice about what challenging care needs they chose to talk about, rather than all discussing the same needs. This was unavoidable because of the difficulty in finding challenging needs that all participants had experience of. However, it did introduce a potential source of confounding. Certain types of care need may prompt a more person-centred response than others. For example, compared to low motivation, fatigue may less often be understood in terms of the unique characteristics of the individual and more often attributed exclusively to the brain injury itself.

- The interview consisted of general open questions (e.g. 'Why do you think your partner behaves in this way?') and participants were not asked specific questions about the different aspects of person-centred care (for example, they were not asked whether they ever tried to make sense of the behaviour in terms of their knowledge of the personality of their partner). This is a strength in that it avoids leading questions and associated response biases; indeed, it is difficult to conceive how more specific questions could be asked without leading the participant. It is also likely that the interview data reflected the dominant way in which the participant thought about and reacted to the behaviour. However, it is possible that the scores did not reflect some aspects of the participants' responses relevant to person-centred care because they just happened not to be mentioned in the interview.

- Although inter-rater reliability was reasonable, there is inevitably a subjective element to the coding process that introduces a source of error variance and the possibility of more systematic bias. To reduce the possibility of systematic bias, the hypothesis was also tested using the scores obtained from the codes provided by the rater who was

unaware of the aims and hypotheses of the study, and had no access to the BRCM-ABI scores.

- With the exception of the *personal motivations*, *thoughts* and *emotions* codes in which vague or superficial references were scored as zero (Table 1), there was no attempt in the codes to differentiate participant responses in terms of the *extent* to which they reflected a person-centred approach. Such differences were apparent in the interview data. For example, references to *personal history* ranged from brief unelaborated references to previous employments that shed some light on the care need to more detailed efforts to make sense of the need in terms of a range of negative events and circumstances in the person's part life. The coding system could perhaps be improved by incorporating more weighting of responses according to the extent of person-centeredness shown, although this might be at the risk of undermining its reliability by increasing the degree of subjectivity involved in using the system.

Other limitations include the fact that the sample was self-selected and not representative of the general or ABI population. For example, the sample was largely White British and the couples were all in heterosexual relationships. This restricts the generality of any conclusions that can be drawn. The type of brain injury experienced by the partners was not homogeneous and included both stroke and traumatic brain injury. The relatively small sample size prevented an adequately powered evaluation of whether type of injury or other demographic and injury-related variables may have influenced the link between continuity and the response to challenging care needs.   Two of these variables merit particular attention in any future investigation of this issue: Continuity (but not person-centeredness) decreased significantly as the time since injury increased, and a more person-centred approach (but not continuity) was significantly associated with younger couples.

Finally, the non-experimental design of the study prevents any definite causal conclusions about the association between the two main variables. The correlation between the BRCM-ABI scores and the person-centred variable is open to other interpretations. For example, it is possible that the correlation is spurious due to continuity and person-centred care both being dependent on the type or severity of the care needs: It may be that more severe or particular kinds of care need both undermine continuity and make it more difficult for the carer to adopt a person-centred approach. Another possibility is that both variables are dependent on the quality of the pre-injury relationship: A better pre-morbid relationship might lead to greater continuity and a more person-centred response to challenging care needs. It is also possible that the level of brain-injury education and therapeutic input received by the participants may have had an impact on both their relationship and the way in which they dealt with the challenging care needs. Related to this, it has also been suggested that the degree of social support received by a family may impact on the degree of expressed emotion evident in their relationship with the person with the brain injury (Flanagan, 1998). Expressed emotion has some overlap with the person-centred care variable used in this study in that both include an assessment of how hostile and critical family members are to the person with the brain injury. Future investigation would need to try to control for these other variables that might explain the association. However, as befits its status as an exploratory study, it seems appropriate that the current study focused on establishing that there is an association worth investigating before resources are invested in a larger more complex investigation that addresses potential confounding variables.

Implications

Promoting person-centred care is an important goal. Such care is in line with the moral values of many societies (Brooker, 2004; Epp, 2003). Research in dementia also indicates that person-centred care has beneficial outcomes for both the person providing and the person

receiving the care. Interventions to enhance person-centred care (albeit in the context of paid carers) have led to decreases in carer stress (Barbosa, Nolan, Sousa, & Figueiredo, 2015; Fazio, Pace, Flinner, & Kallmyer, 2018) and, for the care receiver, increases in quality of life and self-esteem, and decreases in agitation and other neuropsychiatric symptoms (Ballard et al., 2018; Epp, 2003; Fazio et al., 2018; Kim & Park, 2017). Symptom decrease may be due in part to more effective management of these challenging care needs as a result of a person-centred understanding of why they are occurring. The important role played by person-centred understanding of challenging care needs in their effective management underlies several clinical approaches to dealing with these needs and the resulting behaviours, such as the Newcastle model (James & Stephenson, 2007). Previous qualitative research in ABI has similarly suggested that a more individualised understanding of these needs may result in management that is more effective in meeting challenging care needs and reducing the associated behaviour (Bodley-Scott & Riley, 2015; Villa & Riley, 2017).

Person-centred care is essentially about the quality of the personal relationship between the care giver and the care receiver (Kitwood, 1993, 1997). Promoting person-centred care may therefore best be addressed through a focus on that relationship. The findings of the present study suggest that promoting relationship continuity merits further investigation as a way of promoting person-centred care.

Disclosure of interest

The authors report no conflict of interest.

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Table 1

Brief definition of codes and scoring options

Understanding codes	**Possible scores**
Pre-injury personal history: Participant attempts to understand the care need in terms of pre-injury personal history - events, roles, activities or circumstances. Zero scored if participant is just stating a difference between how things were before the injury and how they are now.	0 or +1
Pre-injury relationship: Participant attempts to understand the care need in terms of pre-injury relationship with the person with the ABI. Zero scored if participant is just stating a difference between how things were before the injury and how they are now.	0 or +1
Pre-injury personality: Participant attempts to understand the care need in terms of the pre-injury personality of the person with the ABI. Zero scored if participant is just stating a difference between how things were before the injury and how they are now.	0 or +1
Personal motivations: Participant attempts to understand the care need in terms of their beliefs about what motivates the person with the ABI - likes and dislikes, goals, values etc. Zero scored if reference is vague or superficial.	0 or +1
Thoughts: Participant attempts to understand the care need in terms of their beliefs about specific content of the thinking of the person with the ABI. Zero scored if reference is vague or superficial.	0 or +1
Emotions: Participant attempts to understand the care need in terms of their beliefs about the emotions of the person with the ABI. Zero scored if reference is vague or superficial.	0 or +1

Management codes	
Partnership: Evidence that the person with ABI has been actively involved in discussions with the participant about how best to deal with the care need; evidence of working together on solutions, of a joint approach.	0 or +1
Individually-tailored management: The participant's way of dealing with the care need takes account of the individuality of the person with the ABI - e.g. their wishes, interests, values, strengths, individual psychological or social needs, and/or life history.	0 or +1
Causing upset: Evidence that the participant's way of managing the care need is causing distress to the person with the ABI.	0 or -1
Emotionally supportive reaction: The participant tries to assist the person with the ABI to manage their negative emotions about the situation and/or encourages positive feelings about the situation (e.g. they praise the efforts of the person to deal with the issue).	0 or +1
Restricting independence: Participant's way of managing the care need is restrictive, controlling, authoritarian or involves denial of choice and freedom.	0 or -1
Promoting independence: Participant makes an explicit statement about wanting to avoid restrictive and controlling ways of dealing with the problem; participant actively encourages independence and decision-making for the person with ABI in their approach to the issue.	0 or +1
Restricting access to valued social roles: Participant actively steers person with the ABI away from valued social roles (e.g. parenting, employment) and from engaging with wider society. Zero is scored if justification is provided in terms of the needs and wishes of the person with the ABI (including safety issues).	0 or -1
Promoting access to valued social roles: As a means of managing the care need, the participant actively encourages, facilitates or supports the person with the ABI to resume/ participate in valued social roles (e.g. being a parent, being employed) or to engage with wider society.	0 or +1

Emotional reaction codes

Compassion: The participant explicitly expresses their own feelings of compassion for the person with the brain injury arising from consideration of their situation. 0 or +1

Negative reaction: The participant reacts to the care need in an angry, hostile or threatening way; or there is evidence of a blaming or critical response. 0 or -1

Other codes

Brain injury: The participant refers to the brain injury, or to some cognitive, physical or other symptom arising from the brain injury, in explaining the care need. 0

Other explanation: This code is applied if the highlighted passage offers an explanation of the care need that does not fall under any other understanding codes. 0

Other management/emotional reaction: This code is applied if the management or emotional reaction to the care need described by the participant does not fall under any of the other management/emotional reaction codes. 0

Table 2

Excerpts from interviews to illustrate codes

Understanding codes	**Frequency of code use (N=409)**
Pre-injury personal history: Participant is explaining reasons for her partner's irritability: "X has always been someone who has exercised, and someone who has used exercise - I think it helps everyone's mood and temperament; and I think that was part of the trouble, was that, you know, not getting the chance to exercise."	3%
Pre-injury relationship: Participant is explaining how a regular routine, including frequent rests, has helped reduce her partner's irritability: "In a way we're lucky because we are the type of people who like a routine, and you know, we've never been those free spirits who dash off and things; we've always been very traditional routine people so it's probably been a good thing… you know we don't stay up late and go off places, or you know we're very regular with our meal times with the family and that sort of thing, so that's got a good framework in place anyway."	<1%
Pre-injury personality: Participant is talking about her understanding of why her husband is self-absorbed: "He always was quite introvert so he wouldn't always say it, and that might be why you would think he was self-absorbed but actually, just, he's quite introverted anyway…he's always been the kind of guy that when he comes home at night if he wants to talk he will, but more often than not he doesn't want to talk about it at all."	4%
Personal motivations: Participant is talking about difficulties in dealing with partner's fatigue: "She's driven and thinks she's bigger than the fatigue. I mean we spent eight weeks in rehab learning about fatigue and putting in place strategies, all that sort of stuff, and she just plays lip service to it. Basically, she won't do it…She has to be busy all the time. And she knows what she should be doing, but she doesn't do it. She's bloody minded about it…"	7%
Thoughts: Participant is discussing why her partner gets irritable: "The thing that makes him irritable, brings him to this point, is when, is, people not understanding, and it's often nearest and dearest, or friends who knew him before, don't get that he can't cope with busy environments. They'll suggest things like, 'oh let's go out for a drink and watch the football', but he couldn't do that, he couldn't be in a pub that was noisy. Or they'll say let's meet up and then they'll turn up really late. And a thing that makes him very tense and irritable, they're not meaning to be hurtful to him but it does affect him so I think he gets very irritable, you know - why do people who get me and know me, not understand my situation and how difficult they are making it for me? That in itself makes him very irritable and frustrated, that they don't seem to get the fact that he can't cope with it."	10%
Emotions: Participant is discussing some of the reasons for her partner's low mood: "I know when I'm busy he finds that really difficult…I can see it is making him feel 'can't she stop what she's doing and just come and sit with me' you know and, again, it makes him feel pathetic. Even if I offer to drive, that can make him feel a bit pathetic sometimes… it's almost like him being a bit needy."	7%

Management codes

Partnership: Participant has described the use of routines to manage her partner's fatigue: "I think we just try and make the best of life as it is; I mean this is what I think drives us to manage things tightly because we know the better we can manage things the better he'll feel."

3%

Individually-tailored management: Participant is describing some of the strategies she uses to help lift her partner's mood: "X loves holidays - we tend to go away a bit; I'm off now…I've got twelve days off. I say to X well okay I'd like to go away, so to occupy his mind he'll start, I'll get him looking on the computer, and he'll find a holiday."

8%

Causing upset: Participant is describing how he prompts his partner to do different things as a way of dealing with her lack of motivation: "When we've pushed her, it gets her very upset, very emotional, if she thinks it's too much, and you don't just give up the first time, you try and keep it going but you get to a point where it's obvious she isn't going to do this thing - so you try the next thing."

3%

Supportive reaction: Participant is discussing what helps her partner control his irritability: "But I've realised in my role, I am that person there for him …he needs to let that frustration out and things, and have someone to talk to about it, you know, that's part of his dealing strategy, that I will listen and I totally understand and let him know it's not his fault."

3%

Restricting independence: Participant is discussing how she deals with her partner's aggression: "So, if we have to now, we put him into time-out, like you would a child."

2%

Promoting independence: Participant is discussing his partner's difficulties with planning and her intention to go on an unaccompanied train journey: "You've got to think - I've got to step back from that and let her make her own mistakes, as long as she's safe, because that's how we all learn anyway, we make mistakes, that's how we learn, that's how we learn about how we get places."

7%

Restricting access to valued social roles: Participant is explaining how he deals with his partner's antisocial behaviour to family and neighbours (e.g. turning her back on them): "I just stop them coming in, or I warn them beforehand how she's going to be, and then it's up to them [to decide whether they want to come]."

1%

Promoting access to valued social roles: Participant is discussing her partner losing his temper with the children: "[so I said] 'well you need to find other ways of getting your point across without shouting'…he wants to be a parent, and I want him to be a parent and he has to be a parent, and it can't always be me, you know good cop, bad cop; but it has to be, we want it to be, the same as it was before."

1%

Emotional reaction codes

Compassion: Participant is discussing reasons for her partner's anger: "He obviously had an awareness that he wasn't coping, that he couldn't remember things. He would, people would take all kinds of things, you know, which I realise now are horrendous, you know bringing around films of when we were on holiday before the accident, hoping that something would trigger it, you know like magically bring everything back…imagine that you don't remember any of this and you don't remember it, and you can't relate to it, and yet you know that that is you in the picture…his memory was so bad, must have been horrendous for him."

2%

Negative reaction: Participant is discussing her reaction to the difficulties her partner   3%
has in making conversation: "Sometimes I get very frustrated and I get snappy with him,
because, you know, I want to have a conversation. So if I see I'm getting snappy I just
give up and say 'let's not have this conversation' because I'm frustrated, and I'll go talk
to someone else about something."

Other codes

Brain injury: Participant is describing his understanding of why his partner gets so   16%
fatigued: "Because of the way stuff is with the brain injury, with taking in information
you don't realise how much stuff you blot out, erm, but shops is deliberately made to be
just boom, right in your face, you can't, special offer this, and bright coloured packages
the other. But whereas you go in and think I'm not interested in that, washing powder
or whatever, biscuits, she would go along there and you can't just look at the biscuits,
there's the music and the lights, it's really overpowering …a combination of not being
able to turn off, so you've got all this information coming at you constantly, it would be
like trying to watch three televisions at once, and not only have you got to do it, you
can't turn them off, so it gets very tiring very quickly."

Other explanation: Participant is discussing reasons for his partner's fatigue: "When   4%
she's been sleeping she wakes up and feels tired from sleeping, because you're probably
not active and your joints stiffen up."

Other management/emotional reaction: Participant is describing her strategies for   10%
dealing with his partner's moodiness: "My key strategy is that I have to bite my lip
before I open my mouth; because if I use the wrong words, or if they are perceived as
the wrong words, we're at the point where I make the situation worse in a nanosecond."

Table 3

Descriptive statistics for the main variables

Main variables	Mean	Standard deviation	Possible range	Obtained range	Cronbach's alpha
BRCM-ABI	62.12	26.87	23 to 115	30 to 112	0.98
Person-centred care score	4.50	5.58	not applicable	-4 to +17	0.73

BRCM-ABI: Birmingham Relationship Continuity Measure for Acquired Brain Injury