

**VOLUME I**

**RESEARCH COMPONENT**

**RELATIONSHIP CONTINUITY AND UNDERSTANDING CHALLENGING  
BEHAVIOURS IN SPOUSES/PARTNERS OF THOSE WITH AN ACQUIRED BRAIN  
INJURY**

by

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A THESIS SUBMITTED TO THE UNIVERSITY OF BIRMINGHAM FOR THE DEGREE  
OF DOCTOR OF CLINICAL PSYCHOLOGY

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## **OVERVIEW**

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology at the University of Birmingham. The thesis consists of two volumes which illustrate research (Volume I) and clinical work (Volume II). All identifying information has been anonymised to ensure confidentiality.

### **Volume I**

This first volume contains three chapters. The first is a systematic review of the research literature regarding carers' attributions of challenging behaviour in care-recipients with dementia. The second is a research study examining the association between spousal carers' perceptions of relationship continuity, and their understanding and management of challenging behaviour, for partners with an acquired brain injury. The third is a public dissemination document providing an accessible overview of the research study.

### **Volume II**

This second volume contains four clinical practice reports (CPRs) and an abstract of a fifth CPR which was presented orally. The first CPR describes the assessment and formulation of a 48-year-old man with mild learning disabilities who was experiencing anxiety and low mood, from cognitive behavioural and systemic perspectives. The second is a service evaluation of a dementia-friendly inpatient unit, identifying the barriers and facilitators to good care. The third is a single-case experimental design of a 33-year-old man in a medium-secure forensic service who experienced anxiety. The fourth describes a piece of leadership and consultation work, regarding how hospice staff cope with grief. The final CPR is an abstract of an oral presentation of a case study of a graded exposure intervention with a 16-year-old female.

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**VOLUME I: SYSTEMATIC REVIEW**

**A systematic review of carers' attributions about challenging behaviour in individuals with dementia, and how carers' attributions impact their management of behaviour and their feelings**

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## **ABSTRACT**

### **Introduction**

Carers of those with dementia can find managing the care-recipient's behaviour challenging and may respond in a variety of ways, both emotionally and practically. In understanding challenging behaviour carers may attribute a range of explanations to that behaviour. Attribution Theory (Weiner, 1980, 1985) suggests that attributions to different causes, as well as whether behaviour is perceived as controllable or due to stable causes, can influence both a person's behaviour and their emotions.

### **Method**

The research literature was systemically searched to identify studies related to carers' attributions of challenging behaviour in people with dementia. Seventeen qualitative and quantitative peer-reviewed studies were identified and appraised using relevant quality frameworks (NICE, 2012).

### **Findings**

Carers tended to attribute challenging behaviour to causes that are internal to the care-recipient, and to dementia. Their perceptions of the controllability of behaviour were mixed, and behaviour attributed to internal causes or to dementia was often perceived as due to stable causes. Carers who attributed behaviour to dementia seemed to feel less negative feelings, but

those who perceived behaviour as controllable or unpredictable experienced more difficult feelings. Some evidence suggested that attributing behaviour to dementia leads to more person-centred care.

## **Discussion**

The studies varied in their definition of challenging behaviour and their measurement of carers' attributions, and had a number of methodological limitations. Little empirical research has been conducted to attempt to change attributions and measure the consequences of changes in attributions. Further empirical research should be conducted to identify what improves carers' wellbeing and their management of behaviour.

## INTRODUCTION

Individuals with dementia may be cared for in the community by family members or in residential care homes by nursing staff. Those with dementia commonly experience difficulties with their memory, cognitive functioning and communication, as areas of the brain decline. They may also exhibit a number of behavioural and psychological symptoms of dementia (BPSD), such as agitation, aggression, wandering, repetitive questioning, disinhibition, apathy and depression (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Savva et al., 2009). However, not all non-cognitive symptoms are linked to the individual's dementia, as they may be instead caused by socio-demographic factors (Savva et al.), the individual's environment or staff's care practices (Cunningham, 2006).

Family and staff carers often report experiencing caring for a person with dementia as challenging, and report emotional and psychological difficulties. For example, carers have been found to experience stress, burden, depression, anxiety, resentment and compassion fatigue (Adams, 2006; Brodaty & Donkin, 2009; Day & Anderson, 2011; Ory et al., 1999). Cerejeira, Lagarto and Mukaetova-Ladinska (2012) stated that it is the BPSD which lead to carers' distress, and some symptoms of dementia have been found to be more likely to produce difficult feelings in carers, such as aggression, disinhibition and irritability (Fauth & Gibbons, 2014). Some carers report experiencing more distress and burden than others, which has been found to be due to factors related to the carer, such as demographics, quality of life, personality, coping styles, perceptions of competence, and relationship factors (Brodaty & Donkin, 2009; Feast et al., 2017; Kim et al., 2011; Papastavrou et al., 2007).

A range of interventions are used by carers to manage behaviour which they find challenging (referred to as ‘challenging behaviour’), including person-centred interventions where the care-recipient’s personality, life history and situation may be considered, and more restrictive interventions such as physical restraint, environmental restraint and chemical intervention. National Institute for Health and Care Excellence guidelines (NICE, 2006) recommend person-centred non-pharmacological approaches for non-cognitive symptoms and challenging behaviour, unless the person is severely distressed or there is an immediate risk of harm. However, there is widespread use of pharmacological treatment for the behavioural and psychological symptoms of dementia (Margallo-Lana et al., 2001). Andrews (2006) suggested that if carers understood care-recipients’ challenging behaviour they may be more likely to use person-centred interventions.

One theory commonly used to understand the differences in carers’ emotional responses and their management of challenging behaviour is Attribution Theory (Weiner, 1980; 1985). Attribution Theory states that individuals often try to determine the causes of events and behaviours, and an attribution is the process of assigning a cause to something. Weiner stated that people’s attributions of behaviour can be understood in terms of three causal dimensions: internal/external attributions, the stability of attributions, and the controllability of attributions. Internal attributions are those internal to the person, such as their personality, feelings or beliefs. External attributions are those external to the person, such as the environment, the situation or other people. Attributions of stability reflect whether the cause of the behaviour changes over time: stable attributions remain constant. Attributions of controllability reflect whether the behaviour is under the control of the individual. When behaviours are attributed to factors internal to the person, they are often also perceived as

controllable by the person. Individuals often incorrectly determine the causes of behaviours, for example the fundamental attribution error is the tendency to attribute causes of others' behaviour to factors internal to that person, rather than to external factors. Weiner also suggested that a person's attributions could influence their emotions and their response to the behaviour of the other person.

Attribution Theory has been used to explore carers' understanding and responses to the challenging behaviour of people with learning disabilities, and it has been found that these carers tend to make more internal, stable and controllable attributions (Noone, Jones, & Hastings, 2006). It has also been found that their attributions influence their feelings and their management of challenging behaviour (Dagnan, Trower, & Smith, 1998). For example, carers who perceive challenging behaviour as caused by internal factors are likely to feel more anger and less sympathy, those who perceive behaviour as caused by stable factors are more likely to feel sympathy, and those who perceive behaviour as controllable by the care-recipient are more likely to feel anger (Dagnan & Cairns, 2005; Dagnan & Weston, 2006; Hill & Dagnan, 2002). When carers feel sympathy they are also more likely to engage in helping behaviour (Dagnan & Cairns; Hill & Dagnan). The type of challenging behaviour and whether a carer is experienced or inexperienced also influences their attributions (Hastings, Reed, & Watts, 1997; Hastings, Remington, & Hopper, 1995). However, some research has suggested that Attribution Theory only partly explains the relationship between carers' attributions, feelings and their management of challenging behaviour (Rose & Rose, 2005).

To summarise, individuals with dementia display a range of behavioural and psychological symptoms which can be experienced as challenging. To understand carers'

feelings and their management of challenging behaviour, Attribution Theory (Weiner, 1980; 1985) can be used, as seen in research in the field of learning disabilities. This systematic review therefore aims to review the current research literature to identify carers' attributions of challenging behaviour displayed by their care-recipients with dementia, and to explore the relationship between these attributions, carers' feelings and carers' management of that challenging behaviour.

## **METHOD**

### **Research question**

The aim of this systematic literature review was to systemically search the research literature to identify articles relevant to the research question, to appraise the quality of those articles and to summarise their findings in line with the research question. The research question was as follows: What attributions do carers of those with dementia make about challenging behaviour, and how do carers' attributions impact their management of behaviour and their feelings?

### **Method summary**

In line with the research question, the research literature was searched using relevant electronic databases and specific keywords. Inclusion criteria were applied and a number of studies were identified. Additional studies were identified by searching the reference lists of the identified articles, asking a researcher in the field, and by using Google Scholar. Seventeen articles were identified in total, including both quantitative and qualitative studies. The articles were appraised for their quality using the National Institute for Health and Care Excellence's (NICE, 2012) quality appraisal tools found in its Methods for the Development of NICE Public Health Guidance (third edition) guide. The appraisal of the studies was checked for reliability through a second rater who appraised five of the seventeen studies. The search strategy is described, as well as the findings including both the studies' characteristics and their quality.

## Literature searches

Four electronic databases were searched for relevant research literature. The databases were: Embase, MEDLINE, PsycINFO and Web of Science. Web of Science was searched first because of its large research database and its breadth of subject areas. The databases Embase, MEDLINE and PsycINFO were searched simultaneously through the Ovid database. PsycINFO was chosen for its psychology articles, Embase for its focus on public health and MEDLINE for its medical focus. It was hoped that these databases would find a good range of research literature related to the research question. Keywords were used to identify relevant articles, whilst also utilising Boolean operators AND and OR, and truncations to recognise linked words, i.e. *behav\** would identify behaviour, behavior, behaviours etc. More specific behaviours were not included as behaviour was added as a category term which automatically included references to specific behaviours such as aggression, antisocial behaviour and wandering. Behaviour was also considered a broad term which encompassed more specific kinds of challenging behaviour. Including other specific behaviours such as aggression did not produce any additional papers. Dementia was also a category term and included various types of dementia. As the review was focussed on Attribution Theory the search was conducted in this context, and so *'attribut\*'* and *'attribut\* theory'* were used as search terms, and the use of other terms such as *'beliefs'* or *'ideas'* was considered too broad, and likely to produce less efficient search results. Table 1 below shows the keywords and Boolean operators used for each search.

No start or end date was specified for the search; the articles found in the search ranged from those published in June 1985 to July 2015. A researcher in the field identified



another article which was not found through the database searches. The references of the identified studies were examined for any further relevant research literature, by reading their titles and abstracts. Any articles which were listed on Google Scholar as having cited the studies were also examined by reading their titles and abstracts. Any relevant studies were again examined for their own references and other studies which had cited that study. A number of further research studies were found using this method.

Table 1

*Research databases searched and key words used*

| Database                              | Keywords and Boolean operators  |
|---------------------------------------|---|
| Web of Science                        | attribut* OR attribut* theory<br>AND<br>carer* OR caregiv* OR care-giver* OR care<br>giver*<br>AND<br>dement* OR Alzheimer*<br>AND<br>behav* OR self-injur* OR BPSD |
| PsycINFO, MEDLINE & Embase (via Ovid) | attribut*<br>AND<br>carer* OR caregiv* OR care-giver* OR care<br>giver*<br>AND<br>dement* OR Alzheimer*<br>AND<br>behav* OR self-injur* OR BPSD                     |

## **Inclusion criteria**

The titles and abstracts of the research studies identified by the searches were read, and the following inclusion criteria were applied:

1. Found in peer-reviewed journals e.g. not research theses
2. In the English language
3. Researching carers (who may be either paid staff or family/friends)
4. Researching carers who care for a person with a type of dementia
5. Reporting original data relating to carers' attributions of the person with dementia's challenging behaviour
6. Researching behaviour which challenges carers, such as the behavioural and psychological symptoms of dementia (BPSD)
7. Accessible to the Trainee Clinical Psychologist

If it was unclear whether the study fit the criteria, the whole paper was read. A number of articles were found to not fit the criteria, and these were removed.

Both quantitative and qualitative studies were included in the review. The inclusion of both can be problematic in a review if they focus on different areas or ask different questions. However, the studies chosen were those which all focussed on carers' attributions of challenging behaviour in care-recipients with dementia. Further, Ryan et al. (2013) state that qualitative studies can be used in a systematic review alongside quantitative studies to provide a context, identify important patient-centred outcomes, provide in-depth descriptions of the characteristics regarding the review area and to generate future hypotheses. Therefore, in this review conclusions from quantitative studies have been prioritised when they relate to

quantitative matters, and qualitative studies are used to support suggested links between variables and to suggest how such links may be connected.

### **Quality framework**

The quality of the studies was evaluated in order to ascertain the confidence with which the results of the studies could be stated. It also allowed the comparison of similar aspects of different types of study design, such as their population and sampling methods.

NICE provides process and methods guides for developing its public health guidance. Its third edition of such guidance (NICE, 2012) includes checklists for quantitative intervention studies, quantitative correlation and association studies, and qualitative studies; these include the quality appraisal of the studies' designs and their internal and external validity. The checklists for quantitative interventions and quantitative correlation and association studies are adapted versions of Jackson et al.'s (2006) Graphical Appraisal Tool for Epidemiological Studies, which has been updated to be more relevant to public health interventions. The qualitative studies checklist is based on the quantitative studies checklists. Individual aspects of the studies are assessed, and an overall assessment of quality is also made based on those individual aspects, and the likelihood of those individual aspects to influence the overall conclusions of the study. The quantitative intervention studies checklist appraises study population, method of allocation to intervention or comparison, study outcomes, analyses, and the internal and external validity of its findings. The quantitative correlation and association studies checklist appraises study population, method of selection to exposure or comparison group, study outcomes, analyses, and the internal and external

validity of its findings. Section 1 assesses the studies' external validity, sections 2 to 4 the studies' internal validity, and section 5 provides a summary evaluation of both the external and internal validity of the study overall. The qualitative studies checklist appraises the studies' theoretical approach, design, data collection, trustworthiness, data analyses and ethics. The final part (section 15) of the checklist aims to provide an overall assessment of each qualitative study's quality.

These specific checklists were chosen as they provided similar checklists across different types of studies, which allowed for some comparison of the quality of studies across those identified for this systematic review. Further, the checklists are likely to be robust, given they are recommended by NICE, although no evaluation of the frameworks' inter-reliability has been conducted. They also provided detailed and clear explanations of each point in the checklist, and were free to access. Whilst the checklists were created to assess the quality of public health interventions, they are also applicable to the topic area of this systematic review.

To check for the reliability of the appraisal of the studies, another Trainee Clinical Psychologist used the same checklists to appraise five of the seventeen studies in this review. The Trainees then discussed their appraisals of the studies and their reasoning, talking through each criterion and each study that both had appraised. It was identified that the first rater (the author of this review) had been more lenient on a number of criteria than the second rater. For example, rating studies which were not based in the UK as 'relevant', and rating studies which used convenience sampling, only interview data or only briefly mentioned research ethics as 'acceptable'. A number of changes were therefore made to resolve these differences

following the discussion, and a number of further changes were made regarding the application of the criteria across all the studies. These are summarised below in Table 2. Inter-rater reliability was checked by calculating Cohen's kappa (Cohen, 1960). The value was low although significantly different compared to what would be expected by chance (kappa = .476; T = 7.41; p<.001). The low level of inter-rater reliability would suggest that the reliability of the frameworks is poor, and its application should therefore be tentative.

Table 2

*Changes made to quality appraisal of studies following discussion with second rater*

|                      | Number of studies both Trainees appraised | Total differences in appraisal ratings | Total number of changes made to the appraisal of studies both Trainees appraised | Total number of changes made to the appraisal of all studies following discussion with second rater |
|----------------------|---|--|--|---|
| Intervention studies | 1   | 8 (29.6%)                              | 5 (18.5%)  | 5 (11.1%)   |
| Correlation studies  | 1   | 8 (42.1%)                              | 4 (21.1%)  | 16 (16.8%)  |
| Qualitative studies  | 3   | 15 (33.3%)                             | 12 (26.7%)   | 26 (17.3%)  |

No papers were removed from this systematic review following the application of the checklists. None was judged as being of such poor quality that it merited removal.

## FINDINGS

### Search strategy

Searching the Web of Science database identified 70 research articles, of which six met the inclusion criteria. The article by Fopma-Loy and Austin (1997) led to the identification of three further papers which fitted the inclusion criteria, one from its references (Fopma-Loy & Austin, 1993) and two from examining the citations of the article as identified from the Web of Science (Todd & Watts, 2005; Parker et al., 2012). Searching Embase, MEDLINE and PsycINFO databases through Ovid resulted in 253 articles, which were reduced to 143 after the removal of duplicated articles. Following the application of the inclusion criteria the number of articles reduced again to seven, of which six had already been identified through the Web of Science database. No further articles were identified following the examination of the references of this additional paper and the articles which had cited it.

A further article was identified by a researcher in the field: Harvath (1994). Two further studies (Johansson, Norberg, & Lundman, 2002; MacAndrew et al., 2015) were found through examining articles which cited Harvath (1994), as identified through Google Scholar. A reference search of Johansson, Norberg and Lundman (2002) identified the article by Johansson, Zingmark and Norberg (1999). Google Scholar was used to examine articles which cited this 1999 paper, and Dupuis, Wiersma and Loiselle (2012) was found to fit the inclusion criteria. Finally, examining the references of Dupuis, Wiersma and Loiselle identified two further articles: Hallberg and Norberg (1990) and Roper, Shapira and Beck (2001), which both fitted the inclusion criteria. The search strategy is represented in Figure 1.

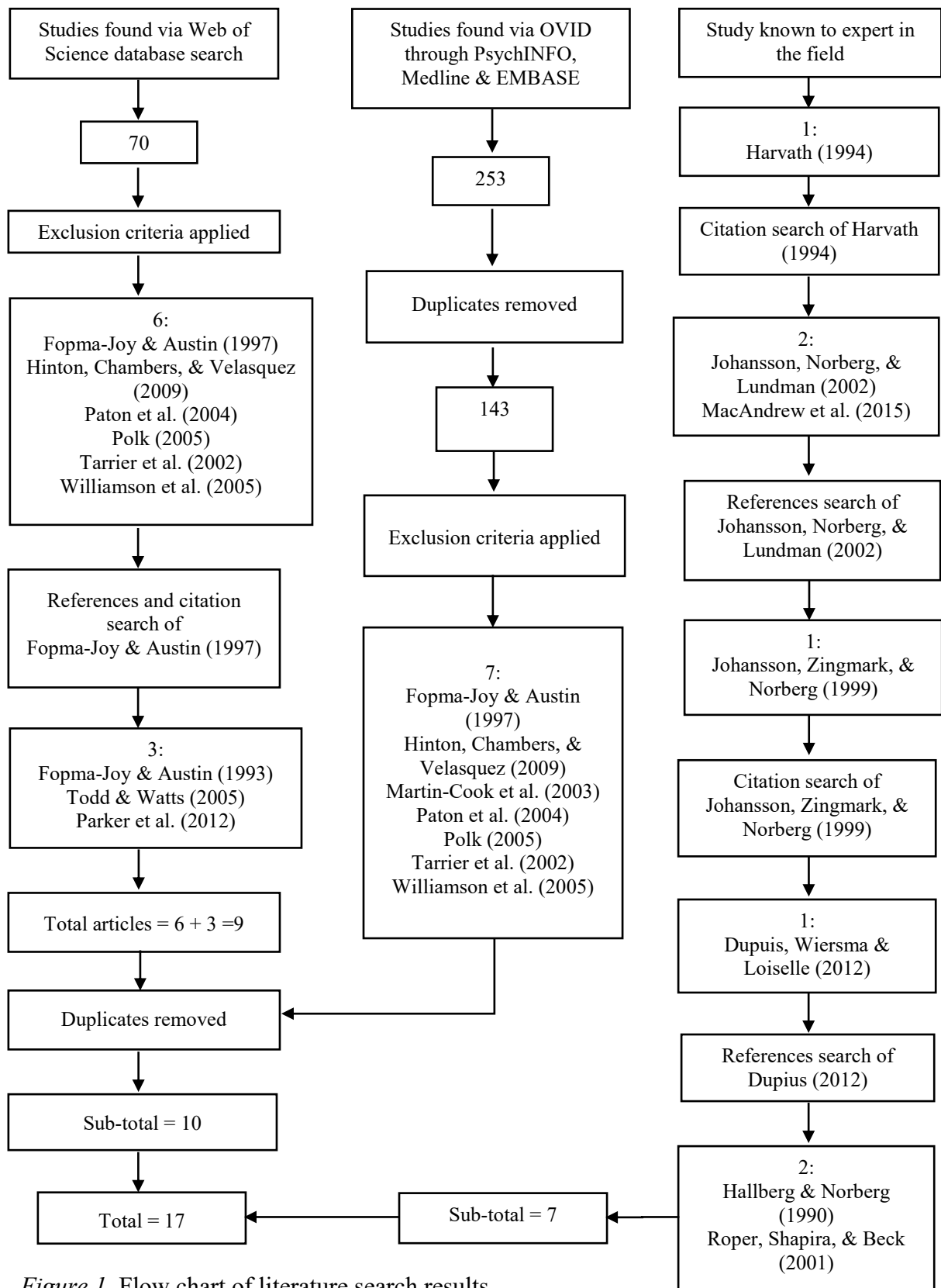


Figure 1. Flow chart of literature search results

## Study characteristics

The seventeen studies varied greatly in their methodology, setting, type of dementia and type of challenging behaviour. Ten of the studies identified were qualitative studies and seven were quantitative, five of which were studies which reported correlations and two were studies which reported the effect of an intervention on carers' attributions. To investigate whether carers' attributions could be changed, one study used a psycho-educational group (Martin-Cook et al., 2003) and another created an experimental condition to replicate the effect of competing cognitive demands on carers' attributions (Parker et al., 2012). The qualitative studies used a range of qualitative approaches and analyses. The characteristics of the seventeen studies are summarised below in Table 3.

Eight of the studies were conducted in the United States, four in the United Kingdom, three in Sweden, one in Australia and one in Canada. In ten of the studies the care-recipients were living in some sort of care/nursing home, in six studies they were living in the community, and in Polk's (2005) study their residence was unclear but is likely to also be the community as family members were the carers. Carers in eight of the studies were nursing staff (nurses and nursing assistants), although in one study they were only described as 'care providers'. One of these studies included psychologists as well as nursing staff (Todd & Watts, 2005) and another included a few maintenance staff and administration staff as well as nursing staff (Johansson, Norberg, & Lundman, 2002). Carers in six of the studies were a variety of family members, and in three of the studies carers were both staff and family members. Carers were both male and female, and were aged between 18 and 93 years old.



No information was provided on the type of dementia in eight of the studies, six studies exclusively focussed on carers of those with Alzheimer's Disease, two studies described care-recipients with different types of dementia, and one study described care-recipients as having 'severe' dementia. Challenging behaviour was defined in different ways. Ten studies did not specify specific behaviours overall but researched attributions of 'challenging behaviours' or 'behavioural disturbances'; two studies exclusively examined attributions of agitation, another two picking behaviour; and other behaviours included: self-feeding, vocally disruptive behaviour and wandering-related boundary transgression. Two studies used the Neuropsychiatric Inventory as a measure of behavioural and neuropsychiatric disturbance that carers struggled to manage.

Carers' attributions of challenging behaviour were measured in different ways. Twelve studies identified attributions through participants' responses during interviews, two of which then used the Leeds Attributional Coding system to code their attributions. The other five studies used standardised measures to determine carers' attributions. Eleven studies used interviews alone, two used interviews and questionnaires, and the remaining four used standardised and subjective measures. Two studies used vignettes, another two used video recordings of challenging behaviour, one used an audio recording of vocalisations, and the other studies asked participants to use their own experiences and memories of care-recipient behaviour. One study used a psycho-educational group and measured its impact on carers' attributions. In the qualitative studies attributions were sometimes described as carers' meanings, perceptions or understandings of the causes of behaviour.

Table 3a

*Quantitative intervention studies' characteristics*

| Reference   | Focus / aims of study  | Setting & sampling/ recruitment  | Participants  | Methodology   | Data collection/outcome measures  | Method of analysis  |
|---|--|--|---|---|---|---|
| Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner (2003) | To investigate the relationship between care-recipient 'behavioural disturbances' as measured by Neuropsychiatric Inventory (NPI) and resentment. To determine if a psycho-educational group can alter resentment, depression, and perceptions of care-recipients. | Family carers identified from The Clinic for Alzheimer's and Related Diseases at the University of Texas Southwestern Medical Center at Dallas, United States. | n = 33. Primary family caregivers: spouses and adult children. Care-recipient living at home, had a diagnosis of a 'dementing illness' and showed 'behavioural disturbance'.  | Four weekly two-hour psycho-educational group (n = 18), or standard care control group on waiting list (n = 15). Random assignment to group. Psychoeducation focused on dementia care, education about symptoms and behaviour management.   | Measures: Caregiver Resentment Scale, The Center for Epidemiologic Studies Depression Scale (CES-D), Steinmetz Control Scale to rate the presence and frequency of care-recipient problem behaviours seen by the carer as manipulative or used to gain control, NPI. Measures administered at baseline, weeks 6 (2 weeks post group) and week 14 (10 weeks post group). | T-tests of baseline measures. Correlations of outcome measures. ANOVAs for all variables, with time as a within factor variable, and group as a between-factor variable for resentment, depression, control, number of positive NPI symptoms, and total NPI. Assumptions for all tests were checked for violations. |
| Parker, Clarke, Moniz-Cook, & Gardiner (2012)               | To explore the effect of cognitive busyness on the attributions of stability and globality for aggressive and nonaggressive challenging behaviour in dementia.   | Homes providing residential and nursing care for people with dementia, homes varied in size (8-40 beds). United Kingdom.                                       | n = 30 (15 other participants dropped out). 26 healthcare assistants and 4 qualified nurses. 26 female, 4 male. Average age 34.9 years (SD = 14.4). Average time in current post 4 years (SD = 7.5), working in dementia 7.1 years (9.22), 10 had had no dementia training. Videos of actors playing roles of people with 'dementia'. | Conditions a week apart and were counterbalanced. Four groups - two videos (actors): aggressive, and non-aggressive (inappropriate urination, wandering), cognitive busy (answered questions about their home out loud during the clip) and non-busy conditions. Random allocation to groups. | Bespoke self-report measure: name a cause for the behaviour, rate attribution questions (Likert scale; Qs about internality, stability and globality). Controllability Beliefs Scale questionnaire. Participants reported subjective ability to concentrate on video.   | Paired samples t-tests. Compared mean changes observed in attribution measures over the two periods using independent samples t-tests.  |

Table 3b

*Quantitative correlational studies' characteristics*

| Reference                 | Focus / aims of study  | Setting & sampling/ recruitment   | Participants   | Methodology          | Data collection/outcome measures   | Method of analysis  |
|---------------------------|--|---|--|----------------------|--|---|
| Fopma-Loy & Austin (1993) | To investigate relationships between: attributions, feelings, expectations and caregiver behaviours regarding care-recipient agitation.  | Alzheimer's facilities and nursing homes with specialised dementia units, 14 settings, capacity 12 - 50 beds. United States. Recruited from larger study from the Alzheimer's Disease and Related Disorders Association (US). | n = 49. Staff carers (49 female; 18 - 67yrs, mean 35.8yrs; 6 - 16yrs of education; Hollingshead Four Factor Index of Social Position mean score 32.9 = semiskilled workers; employment length 1 month - 15yrs, mean = 2 years; unknown mix of nursing assistants, qualified medication aides, licenced practical nurses, registered nurses). Alzheimer's disease only. | Regression analysis. | Formal Caregiver Attribution Inventory (developed by researchers, series of statements rated on Likert scales). Two random orders of inventory used. Vignette of caregiving interaction. Carers equally assigned to two agitation scenarios of male and female care-recipient dependent on professional education. | Factor analysis of items to identify basic components of attributions, expectations, feelings, and behaviours. Vignette measured for validity by participants' believability scale ratings. |
| Fopma-Loy & Austin (1997) | To identify what influences carers' promotion of self-feeding. Exploring attributions of self-feeding behaviour, carer feelings and carer expectations of self-feeding behaviours. | Convenience sample using listings of Alzheimer's facilities and nursing homes with specialised dementia units from the Alzheimer's Disease and Related Disorders Association, United States.                                  | n = 54. Staff carers (all female, 18-68yrs (mean = 39.6yrs), education level 7-18 years (mean = 12.7, SD = 2.04), Hollingshead Four Factor Index of Social Position 18-51 (mean = 32.9, SD = 11), all nursing staff, 2 months to 11.5yrs experience (mean = 25.6 months), hours worked per week 8-53 (mean = 37.9, SD = 7.5)). Alzheimer's disease only.               | Regression analysis. | Formal Caregiver Attribution Inventory (developed by researchers, series of statements rated on Likert scales). Two random orders of inventory used. Vignette of resident with dementia either male (n = 26) or female (n = 28), who was not feeding themselves.   | Regression analyses and t-tests.  |

| Reference  | Focus / aims of study   | Setting & sampling/<br>recruitment  | Participants   | Methodology   | Data collection/outcome<br>measures   | Method of<br>analysis  |
|--|---|---|--|---|---|--|
| Tarrier,<br>Barrowclough,<br>Ward,<br>Donaldson,<br>Burns, & Gregg<br>(2002) | To investigate strain and distress in carers by examining cross-sectional relationships between carers' Expressed Emotion (EE), strain and distress, care-recipient symptoms and behaviours, and carers' beliefs about behavioural and psychological symptoms of dementia.                        | Manchester, UK. Person with Alzheimer's Disease living at home, cared for by participant for at least 4 occasions a week (lived with or visited). Convenience sample, identified from hospital databases, recruited from Old Age Psychiatric Service, approached by their Psychiatrist. | n = 100. Family carers: mean age 63.1 years (SD = 13.6), 57 female, 43 male; spouse (n = 53), offspring (n = 36), another relative (n = 11); mean duration of caring 35.2 months (SD = 28.7). Care-recipient: Alzheimer's Disease, mean age 77.3yrs (SD = 8.1); 70 female, 30 male; mean duration of dementia 47.9 months (SD = 34.2). | Quantitative correlation.   | Expressed Emotion and causal attributions (Leeds Attributional Coding System) measured from adapted version of Camberwell Family Interview. Carer wellbeing: Gilleard Strain Scale & General Health Questionnaire. Carer salivary cortisol. Clinical Dementia Rating, Mini-Mental State Examination, MOUSEPAD psychotic and behavioural symptoms, Cornell Scale for Depression in Dementia. | Content analysis of attributions about: illness, cognitive features, psychiatric symptoms, behavioural disturbances and activities of daily living. Mainly correlations and t-tests.         |
| Todd & Watts<br>(2005)   | To investigate the applicability of Weiner's (1980, 1985) attribution model to staff working with people with dementia who exhibit challenging behaviours (physical aggression, wandering and excessive verbal behaviour). To explore burnout and staff group responses to challenging behaviour. | Six settings for people with dementia across four regions of the Northwest of England. Nurses approached via managers, psychologists approached via links with specialist interest groups or by letter.   | n= 51. 25 nurses (23 registered mental nurses, one general nurse, and one learning disabilities nurse). 26 psychologists. 11 males and 40 females. Working with people with dementia for mean 11.4yrs, age 36–45 yrs. No specific type/s dementia specified.   | Quantitative correlation. Application of Weiner's cognitive-emotional model of helping behaviour. Two groups: nurses and psychologists. | Interviews to identify attributions using Leeds Attributional Coding System. Included: behaviour they had witnessed, why they thought it occurred, what they thought could be done to reduce it. Questions on Likert scales to identify: willingness to help, optimism and emotional responses; The Maslach Burnout Inventory—Human Services Survey.  | Content analysis: developing categories, transforming into codes, counting the occurrence of codes. Statistical analysis of variables and attributions, non-parametric tests of association. |

| Reference   | Focus / aims of study   | Setting & sampling/<br>recruitment  | Participants   | Methodology   | Data collection/outcome<br>measures   | Method of<br>analysis  |
|---|---|---|--|---|---|--|
| Williamson, Martin-Cook, Weiner, Svetlik, Saine, Hynan, Dooley, & Schulz (2005) | To explore how carers' attributions contribute to resentment and obligations for care, regarding 'disturbing' or 'problem' behaviour. | Community dwelling care-recipients. Areas of Georgia and Texas, United States. Participants identified from a longitudinal study, recruited from medical and community resources. Carers provided unpaid care for activities of daily living. | n = 103 (carer– care-recipient dyads). 74% carers women, 55% spouses, 35% adult children. Mean carer age 64yrs (SD = 13, range = 36–88). White (85%); most minority carers were African American (82%), remaining carers identified themselves as either Hispanic (14%) or members of other ethnic groups (4%). Providing care for mean 5yrs (SD = 5.8 years, range = 2 months–35 years). Care-recipients had either Alzheimer's Disease or another dementia (n = 72) or physically disabled without cognitive impairment (n = 31), mean care-recipient age 7yrs (SD = 8, range 60–94yrs). | Quantitative correlation. Interviews, two groups: cognitively impaired (dementia) or physical impaired (no dementia) care-recipients. | Cognitive Impairment measured by Neurobehavioral Cognitive Status Examination and clinical staff review of caregivers' reports. Seven items drawn from the CERAD Behaviour Rating Scale for Dementia, measured frequency of behaviours, and distinguished external and internal attributions. Measure of internally attributable care-recipient problem behaviour was adapted from the Steinmetz Control Scale. Caregiver resentment 17 item adapted measure. | Bivariate analysis, multivariate path analysis and exploratory mediational analyses. |

Table 3c

*Qualitative studies' characteristics*

| Reference                          | Focus / aims of study   | Setting & sampling/recruitment   | Participants  | Methodology  | Data collection/outcome measures   | Method of analysis  |
|------------------------------------|---|--|---|--|--|---|
| Dupuis, Wiersma, & Loiselle (2012) | To examine the meanings that staff attach to a variety of challenging behaviours and how meanings impact staff responses to those behaviours.                                   | 18 Long Term Care facilities, 3 locations, Southern Ontario, Canada. Selective and theoretical sampling, emerging themes used to guide sampling, continued recruitment until theoretical saturation. | n = 48. Staff carers (41 female, 7 male; 34 full-time, 11 part-time, 3 casual/unknown; 1-15yrs experience; admin/management = 6, nursing = 11, healthcare worker = 21, support staff = 7, maintenance/housekeeping = 3; shifts: day = 24, evening = 9, night = 1, day/evening = 5, day/night = 3, no regular shift/unknown = 6; age: 20-29yrs = 2, 30-39yrs = 9, 40-49yrs = 19, 50-59yrs = 13, 60+yrs = 0, unknown = 5). No information provided on type/s of dementia. | Constant comparative method (Charmaz, 2006) used to develop a substantive grounded theory. | Active interviews conducted by two research assistants, questions updated throughout. Interviews audio-recorded and transcribed.   | Team of researchers analysed data. Constant comparative method to develop a substantive grounded theory. Ideas, patterns then themes identified and then theoretical codes applied and organised.     |
| Hallberg & Norberg (1990)          | To explore how carers interpret the experiences of those with dementia with vocally disruptive behaviour, how carers experience care-recipients, and to explore carer feelings. | Psychogeriatric clinic in southern Sweden. Convenience sample on one day.  | n = 33. Staff carers (17 original participants plus 16 extra participants included later to check for theoretical saturation; 24 female, 9 male; 10yrs in care (median); 7yrs care dementia (median); 9 registered nurses, 16 licensed practical nurses and 8 enrolled nurses.) Participants experienced in caring for 'demented patients'.   | Qualitative. Open coding, categories identified.   | Tape-recordings of two unknown female dementia care-recipients were heard. Interviews about the emotions carers experience about their patients, care-recipients' experiences, meaning communicated by behaviour, emotions evoked, and what they would like to do. Participants also asked to free associate about their previous experiences. | Analysed from two perspectives: carers' interpretations of care-recipients' behaviour and emotions evoked in carers. Open coding, categories discussed and consensus reached between two researchers. |

| Reference                            | Focus / aims of study  | Setting & sampling/<br>recruitment  | Participants  | Methodology   | Data collection/outcome measures  | Method of analysis  |
|--------------------------------------|--|---|---|---|---|---|
| Harvath (1994)                       | To explore family carer perceptions and interpretations of a variety of problem behaviours related to dementia, and how that influences caregiving/management of problems. | Urban and rural communities, family carers. United States. Purposive sampling.  | n = 10. Family carers. (10 Caucasian female caregivers, 51-80yrs, 8 spouses to husbands, 2 daughters to mothers; 9 married, 1 widow; all lived with care-recipient aged 67 to 86, memory problems for 1 to 9 years, mean of 3.7 years, different perceptions of length of caregiving; carers struggling and carers managing. Multi-infarct dementia, Alzheimer's disease or mixed dementia. | Qualitative. Interactive process (Taylor & Bogdan, 1984), dominant themes identified. | Face to face semi-structured interviews, between 45 - 90 minutes.   | Interactive process (Taylor & Bogdan, 1984) - identified themes, coded using word processing software. Participant and peer review used.                  |
| Hinton, Chambers, & Velasquez (2009) | To describe the nature and frequency of Latino family carer attributions for dementia-related neuropsychiatric symptoms, including depression, agitation and irritability. | Family caregivers of community-dwelling Latino adults with dementia. Sacramento, California. Participant selection from an ongoing cohort study of older Latinos. | n = 30. Latino family or friends as main carers of community-dwelling Latino adults with dementia (mean age 60yrs (22-80yrs), 70% women, 60% spouses, half born outside of United States, 63% interviews conducted in Spanish). Care-recipient mean age 74 (60-97yrs), all had at least one symptom on NPI, no specific type of dementia stated.  | Qualitative. Content analysis.  | Semi-structured interviews using the Neuropsychiatric Inventory. Participants were asked what they thought was the cause of the symptom. Bilingual interviewer, interviews in English (37%) or Spanish (63%). | Content analysis, attribution categories and definitions created, participant responses coded by the research team. Frequency of attributions calculated. |

| Reference                              | Focus / aims of study  | Setting & sampling/ recruitment   | Participants   | Methodology   | Data collection/outcome measures   | Method of analysis   |
|--|--|---|--|---|--|--|
| Johansson, Norberg, & Lundman, (2002)  | To identify family carers and staff carers' descriptions and meanings of picking behaviour (carrying, folding and putting away, hiding, packing, picking at, rearranging, rolling, rubbing, tearing, stroking, and wrapping up). | 5 nursing homes and 12 group dwellings, two small towns, Northern Sweden. Participants (staff and family members) were identified by head nurses. | Family members (n = 5) and staff carers (n = 6, 'care providers') of five residents (4 female, 1 male) with 'severe dementia' who displayed picking behaviour. One family member interviewed for each resident and one or two staff carers were interviewed for each resident. | Qualitative. Content analysis.  | Two interviews per care-recipient - one with family and one (two in one case only) with staff carers. Asked to describe their experiences, care-recipient behaviour and their understanding of behaviour. Family asked about occupation, interests, habits of the care-recipient. 20-60 minute interviews. Interviews transcribed. | Content analysis, three categories created: picking behaviour, reasons for it, and underlying intentions. Researchers discussed categories to reach consensus. Comparison made between family and staff responses. |
| Johansson, Zingmark, & Norberg, (1999) | To identify the meanings carers make of repetitious picking behaviour at objects (picking at, rearranging, carrying about, tearing, and rolling things).   | Northern Sweden, two towns. Unclear recruitment/ sampling.  | 15 managers at nursing homes and group dwellings (8 nurses' aides and 7 licenced practical nurses, 1 male, 2.5-30years experience - mean 15 years). Type/types of dementia not specified.  | Qualitative. Structural analysis - phenomenologic hermeneutic philosophical method. | Interviews. 20-60 minutes, carers narrated experiences, questions asked about understanding of behaviours and set topics: behaviours, situations, reactions, thoughts and feelings.  | Analysis inspired by Ricoeur's (1976) phenomenologic hermeneutic philosophical method. Naive reading followed by coding; structural analysis of codes.   |



| Reference  | Focus / aims of study  | Setting & sampling/ recruitment   | Participants   | Methodology  | Data collection/outcome measures  | Method of analysis   |
|--|--|---|--|--|---|--|
| MacAndrew, Beattie, O'Reilly, Kolanowski, & Windsor (2015) | To explore carers experiences of caring for a person with dementia regarding wandering-related boundary transgression.   | Three aged secure care facilities. Queensland, Australia. Two not-for-profit and denomination affiliated care facilities, one private company care facility.  | n = 40. Family members and care staff. 28 nurses (8 registered nurses, 3 enrolled nurses, 17 assistants in nursing), (mean duration of employment at facility 6.97 years (SD = 6.08), range 20 years (1–21 years), 12 family members (3 spouses, 8 daughters, 1 sister), cared for relative at home previously. Type/s dementia not specified.   | Qualitative. Content analysis. Theoretical framework of study is need-driven dementia-compromised behaviour (NDB) model (Algase et al., 1996). | Four semi-structured focus groups with care staff (n = 28), and one with family members (n = 4). Individual interviews (n = 8) with family members. Focus groups watched 3-minute video of boundary transgression, then asked similar questions asked to those asked in individual interviews.                            | Content analysis, using an inductive approach. Open coding, concepts derived from data, themes identified, model of the phenomena developed from identified themes. Three researchers analysed data and discussed until consensus was reached. |
| Paton, Johnston, Katona, & Livingston (2004)               | To gain an insight into carers' understanding of the causes of various 'problematic behaviours', to identify whether carers believe the care-recipient has control over their behaviour. | North London and Essex, UK. Sample chosen to be representative of the whole population of Alzheimer's Disease in terms of severity, gender and living circumstances. Prospectively and recruited purposively through mental health teams. Part of a larger study. | n = 205. Family, friends or formal paid caregivers. Carers: 70% female, 30% male, 75 spouses (37%); 76 children (37%), 19 other relatives (9%); 10 friends (5%) and 25 paid carers (12%); 28–93yrs (mean 63yrs). Ninety (44%) lived with the care-recipient. Care-recipients: living in their own homes, in residential, nursing and hospital care, all with Alzheimer's Disease, 147 (72%) female; 55–98yrs old (mean 81yrs); 61 (30%) mild AD, 85 (41%) moderate AD and 59 (29%) severe AD; 164 (80%) were born in the UK. | Thematic analysis.   | Semi-structured interviews. Several interviewers. Asked what they thought causes of behaviour were, and to rate controllability. Outcome measures were caregivers' understanding of: the cause of problematic behaviour; the ability of the person with dementia to control this behaviour; the prognosis of the illness. | Carers' descriptions were divided into categories, then divided into themes. Two raters used.  |

| Reference                     | Focus / aims of study  | Setting & sampling/ recruitment   | Participants  | Methodology  | Data collection/outcome measures   | Method of analysis   |
|-------------------------------|--|---|---|--|--|--|
| Polk (2005)                   | To explore the nature of the family carer role, communication, and caregiving issues, using attribution theory and problematic integration theory regarding challenging behaviour. | Family carers of those with Alzheimer's Disease. United States. Unclear if person with Alzheimer's Disease lived with carer. Alzheimer's Association provided names of interested carers who met criteria.  | n =7. Family caregivers (blood/marriage); 3 male, 4 female; wife caring for her husband, three husbands caring for their wives, a daughter caring for her mother, and two sisters caring for an aunt; length of caregiving 1 - 3 years; 51 - 82yrs old. Care-recipients all had Alzheimer's Disease.                                  | Constant comparative method of grounded theory, inductively applying Problematic Integration theory.   | 6-month period of data collection with each participant through monthly open-ended interviews. One face-to-face interview, five monthly interviews 10-15 mins over telephone.  | Constant comparative method of grounded theory analysis, led to thematic analysis. Single coder used open coding and identified themes. Attribution theory and problematic integration theory used to understand the themes. |
| Roper, Shapira, & Beck (2001) | To explore the process of carers' assessment of agitation, carers' reactions, feelings about patients, and their management of agitation.  | 30 bed inpatient unit for individuals with behaviour problems, including those with Alzheimer's Disease, secure ward. 30 staff nurses overall. United States. Researchers were consultants on the ward, invited participants to study personally. | 17 nurses (6 registered nurses, 3 licenced vocational nurses, 8 psychiatric nursing assistants; 3 male 14 female; 23-5yrs (mean 38yrs), 5-132 months' experience on unit (mean 36 months), 24% high school diplomas, 47% high school graduates plus some college, 29% college graduates. Care-recipients all had Alzheimer's Disease. | Qualitative. Ethnographic interviews, participant observation, examination of medical records/policies/procedures (enabling study of how carers assess and respond to behaviour, their feelings, reported management of care). | Participant observation, records and documents used and formed interview questions. Ethnographic interviews. Asked about Alzheimer's Disease and problems, agitation, patient and carer behaviours and feelings. Records gave events and interventions regarding agitation, and policies/procedures about agitation. | Transcribed tapes were reviewed, coded and discussed by two researchers, patterns emerged.   |

## **Quality appraisal of studies: quantitative studies: intervention and correlational studies**

The appraised quality of the two quantitative intervention studies and five studies reporting correlations and associations is summarised in Tables 4 and 5 below. The quality was assessed using quality frameworks provided in NICE guidelines (NICE, 2012). None of the studies was excluded based on the appraisal of its quality, as none of the summary criteria in section 5 was rated as having significant sources of bias.

**Population:** Five of the quantitative studies described the source population well, however two studies did not adequately describe the demographics of the population. In five of the studies important groups were under-represented, for example, two studies only had female carers as participants. Further, the recruitment of participants appeared biased as a number of the studies used convenience samples, and in two studies managers of the care homes directly recruited the participants.

**Method:** In the correlational studies where participants were allocated into groups it was done by carer role, or described as participants being allocated into equal groups, but with no further description. In both the intervention studies the allocation was described as random, although the method of randomisation was not described in Martin-Cook et al.'s (2003) study. Further, in this study the intervention was not described in full, and it is unlikely that the participants and researchers were blind to the intervention. The intervention was also particularly different to the comparison, because the control group were those placed on a waiting list for the intervention, and so this provided unsatisfactory control over the non-specific components of the intervention. In the other intervention study (Parker et al., 2012)

participants were randomly allocated, but all four registered nurses ended up in one group which could have led to bias. Unfortunately, one third of the participants in Parker et al.'s study were lost mid-study, due to one nursing home having to withdraw from the study. All of the five correlational studies identified a number of confounding factors and either tried to adjust for them, or recognised them in light of their conclusions. It is likely that the studies based outside of the UK were in settings not reflective of UK practice, for example, there may be differences in training, policy and procedures.

**Outcomes:** All the quantitative studies used subjective outcome measures, which were a mixture of standardised and tailor-made measures for each study. Tarrier et al. (2002) also used an objective measure of stress: salivary cortisol. Follow-up measures were only used in one study. All relevant and important outcomes were assessed. The two intervention studies both experienced a loss of participants and consequently had some data missing, although the researchers tested for any effect of the loss of the data on the overall results.

**Analyses:** Often the power values and confidence intervals were not provided for the quantitative studies, but they could be calculated with the results provided, and many of the studies were underpowered. The analytical methods used in all the quantitative studies were appropriate, baseline data were checked between groups and the data of those who dropped out were either included or checked. The correlational studies considered a number of explanatory variables, but in two of the studies this was reported as only accounting for a small amount of the variance in the data.

**Summary:** The external validity of some of the studies could be biased due to the use of convenience sampling. The validity is also difficult to determine for some studies due to the experimental nature of the studies, for example with the use of vignettes. However, the studies all aimed to reduce bias where possible, and sought to understand the attributions carers make in their real-life scenarios.



Table 5  
*Quality appraisal of quantitative correlational studies*

| Study                     | Population  |   |  | Method of allocation to intervention/comparison                                     |  |   |   |  | Outcomes   |   |   |   |                                    | Analyses   |   |  | Summary  |   |  |
|---------------------------|---|---|--|---|--|---|---|--|--|---|---|---|------------------------------------|--|---|--|--|---|--|
|                           | 1.1 Is the source population or source area well described? | 1.2 Is the eligible population or area representative of the source population or area? | 1.3 Do the selected participants or areas represent the eligible population or area? | 2.1 Selection of exposure (and comparison) group. How was selection bias minimised? | 2.2 Was the selection of explanatory variables based on a sound theoretical basis? | 2.3 Was the contamination acceptably low? | 2.4 How well were likely confounding factors identified and controlled? | 2.5 Is the setting applicable to the UK? | 3.1 Were the outcome measures and procedures reliable? | 3.2 Were the outcome measurements complete? | 3.3 Were all the important outcomes assessed? | 3.4 Was there a similar follow-up time in exposure and comparison groups? | 3.5 Was follow-up time meaningful? | 4.1 Was the study sufficiently powered to detect an intervention effect (if one exists)? | 4.2 Were multiple explanatory variables considered in the analyses? | 4.3 Were the analytical methods appropriate? | 4.6 Was the precision of association given or calculable? Is association meaningful? | 5.1 Are the study results internally valid (i.e. unbiased)? | 5.2 Are the findings generalisable to the source population (i.e. externally valid)? |
| Fopma-Loy & Austin (1993) | ++  | +   | -  | ++  | ++   | ++  | +   | -  | +  | ++  | ++  | NA  | NA                                 | -  | +   | ++   | ++   | +   | +  |
| Fopma-Loy & Austin (1997) | +   | +   | -  | ++  | ++   | ++  | ++  | -  | +  | ++  | ++  | NA  | NA                                 | -  | +   | ++   | ++   | +   | +  |
| Tarrier et al. (2002)     | ++  | +   | -  | ++  | ++   | ++  | +   | -  | +  | ++  | ++  | NA  | NA                                 | -  | ++  | ++   | ++   | +   | ++   |
| Todd & Watts (2005)       | ++  | +   | +  | ++  | ++   | ++  | +   | ++                                       | ++   | ++  | ++  | NA  | NA                                 | -  | +   | ++   | ++   | +   | +  |
| Williamson et al. (2005)  | ++  | +   | +  | ++  | ++   | ++  | +   | -  | +  | ++  | ++  | NA  | NA                                 | -  | +   | ++   | ++   | +   | +  |

Key: ++ = study designed or conducted to minimise the risk of bias, + = unclear or all sources of bias not addressed, - = significant sources of bias, NA = not applicable

## **Quality appraisal of studies: qualitative studies**

The quality of the ten qualitative studies is summarised in Table 6 below. The quality was assessed using the quality framework for qualitative studies outlined in NICE guidelines (NICE, 2012). None of the studies was excluded based on the appraisal of its quality, as the overall criteria, number 15, was rated as fully or partially met for all studies.

***Approach and aims:*** A qualitative approach was appropriate in all the qualitative studies, with the studies often aiming to explore the meanings carers attribute to challenging behaviour, and their experiences as carers. In all but one study the aims were very clearly stated, and only one study did not specifically state which qualitative approach or methodology it used.

***Design:*** The design of all the qualitative studies was assessed as appropriate, but in some of the studies the use of convenience sampling was not justified by the authors. In one study the rationale of using its particular qualitative approach was not justified by the authors.

***Data collection and method:*** Data collection was well described and suitable to the aims of all the studies. Eight of the studies clearly described the context of the setting and the participants. However, in one study this was described only broadly, and in another study the description was limited. Two areas of weakness were that only two studies used additional other methods to collect data rather than only interviews, and only one study clearly described the role of the researcher. In four studies the interaction between the researcher and the



participants was described, but not the relationship or the role of the researcher. In five studies there was no description of the consideration of the role of the researcher.

**Analysis:** The analysis was appropriate in all the studies, although the description of the analysis was limited in some studies, making it difficult to say if it was suitably rigorous. In five of the studies the analysis was completed by more than one researcher and their method for ensuring reliability and resolving differences was described. However, in four studies this process was not well described, and in one study only one person analysed the data.

**Findings:** The findings presented were rich in five of the studies, but in the other five studies less detail was provided. The findings were all relevant to the aims of the study, and all the findings were clearly presented and convincing, except in two studies where there was little detail provided about carers' individual attributions and the differences between carers' attributions.

**Conclusions:** Two studies did not recognise any limitations in their conclusions, and in another study the lack of detail about participants' responses and the methodology made it difficult to evaluate whether its conclusions were plausible. However, all the studies made clear links between their findings and the theory or research literature. A number of studies discussed the implications of the findings and made recommendations for future research and/or improvements to services.

***Ethics:*** A number of the qualitative studies did not directly mention ethics, but there appeared to be no major issues regarding ethics in any of the studies. Most of the studies described some of the processes applied to ensure the studies were conducted appropriately.

***Overall assessment of quality:*** All the studies were assessed overall as being relevant, and the majority were well conducted overall.

Table 6  
*Quality appraisal of qualitative studies*

| Study  | 1. Is a qualitative approach appropriate? | 2. Is the study clear in what it seeks to do? | 3. How defensible/rigorous is the research design/methodology? | 4. How well was the data collection carried out? | 5. Is the role of the researcher clearly described? | 6. Is the context clearly described? | 7. Were the methods reliable? | 8. Is the data analysis sufficiently rigorous? | 9. Is the data 'rich'? | 10. Is the analysis reliable? | 11. Are the findings convincing? | 12. Are the findings relevant to the aims of the study? | 13. Conclusions | 14. How clear and coherent is the reporting of ethics? | 15. Is the study relevant? As far as can be ascertained from the paper, how well was the study conducted? |
|--|---|---|--|--|---|--------------------------------------|-------------------------------|--|------------------------|-------------------------------|----------------------------------|---|-----------------|--|---|
| Dupuis, Wiersma, & Loiselle (2012)           | ++  | ++  | ++   | ++   | +   | ++                                   | +                             | ++   | ++                     | +                             | ++                               | ++  | +               | +  | ++  |
| Hallberg & Norberg (1990)                    | ++  | ++  | +  | ++   | -   | ++                                   | +                             | +  | +                      | ++                            | +                                | ++  | ++              | -  | +   |
| Harvath (1994)                               | ++  | ++  | ++   | ++   | +   | ++                                   | +                             | ++   | ++                     | ++                            | ++                               | ++  | ++              | +  | ++  |
| Hinton, Chambers, & Velasquez (2009)         | ++  | ++  | ++   | ++   | -   | ++                                   | ++                            | ++   | +                      | ++                            | +                                | ++  | ++              | -  | ++  |
| Johansson, Norberg, & Lundman (2002)         | ++  | ++  | +  | ++   | -   | -                                    | +                             | ++   | ++                     | ++                            | ++                               | ++  | +               | -  | +   |
| Johansson, Zingmark, & Norberg (1999)        | ++  | ++  | +  | +  | -   | +                                    | +                             | +  | +                      | +                             | ++                               | ++  | +               | -  | +   |
| MacAndrew et al. (2015)                      | ++  | ++  | ++   | ++   | -   | ++                                   | +                             | ++   | ++                     | ++                            | ++                               | ++  | ++              | ++   | ++  |
| Polk (2005)                                  | ++  | +   | +  | +  | +   | ++                                   | +                             | +  | ++                     | -                             | ++                               | ++  | ++              | +  | +   |
| Paton, Johnston, Katona, & Livingston (2004) | ++  | ++  | ++   | ++   | ++  | ++                                   | +                             | +  | +                      | +                             | ++                               | ++  | ++              | ++   | ++  |
| Roper, Shapira, & Beck (2001)                | ++  | ++  | ++   | ++   | +   | ++                                   | ++                            | +  | +                      | +                             | ++                               | ++  | ++              | ++   | ++  |

Key: ++ = met the criteria well, + = unclear or mostly meets the criteria well, - = criteria not met

## **Study findings**

### **Carers' attributions of the causes of challenging behaviour in care-recipients with dementia**

The research literature was reviewed to identify what carers of those with dementia attribute the causes of challenging behaviour to, and to identify any differences across the types of behaviour and the characteristics of the carer.

According to many both quantitative and qualitative studies, carers at times and sometimes often, attribute the cause of challenging behaviour to the care-recipient's dementia, (Dupius, Wiersma, & Loiselle, 2012; Harvath, 1994; Hinton, Chambers, & Velasquez, 2009; MacAndrew et al., 2015; Roper, Shapira, & Beck, 2001; Williamson et al., 2005). Family and staff carers believed that challenging behaviour was caused by the disease process of dementia, or dementia-related impairments. In three well conducted qualitative studies carers specifically described interpreting challenging behaviour based on what they perceived to be behaviours appropriate to the person's stage of dementia (Dupius, Wiersma, & Loiselle; MacAndrew et al.; Roper, Shapira, & Beck). Dupius, Wiersma and Loiselle found that for most staff challenging behaviour was first interpreted in terms of the person's dementia, such as the deterioration of the brain, and then further attributions were considered through this 'lens of pathology'.

However, in all but two studies (Martin-Cook et al., 2003; Roper, Shapira, & Beck, 2001) carers also attributed factors not related to the care-recipient's dementia as the cause of challenging behaviour. Family and staff carers identified a range of factors internal to the

care-recipient, such as normal aging, personal loss, negative life experiences, premorbid personality, frustration and depression (Paton et al., 2004). Seven studies, both quantitative and qualitative, found that carers also perceived external factors, such as overwhelming demands from others and the environment as a cause of challenging behaviour (Fopma-Loy & Austin, 1997; Hallberg & Norberg, 1990; Harvath, 1994; Johansson, Norberg, & Lundman, 2002; Johansson, Zingmark, & Norberg, 1999; TARRIER et al., 2002; Todd & Watts, 2005). Although external factors were recognised by both family and staff carers, they were not cited as a cause more often than internal factors in any of the studies.

Attributing the causes of challenging behaviour was not a clear-cut process for carers, as shown in some of the qualitative studies. For example, in Dupius, Wiersma and Loisel's (2012) study staff interpreted challenging behaviour firstly as due to dementia, and then in terms of secondary factors internal to the care-recipient. Alternatively, family carers in Harvath's (1994) study saw dementia as a secondary factor compared to various internal and external factors. Further, some family carers struggled to identify the cause of challenging behaviours, and thought there could be multiple reasons for single behaviours (Polk, 2005). In Roper, Shapira and Beck's (2001) study, some carers had the tendency to interpret care-recipients' agitation through their own life experiences, especially those of their own relatives' experiences of dementia, and the authors suggested that these carers missed a number of important potential reasons for behaviour.

The type of behaviour and the characteristics of the carer appear to influence carers' attributions, across both quantitative and qualitative studies. Some behaviours were more likely than other behaviours to be perceived as due to dementia, such as vocalisations

(Dupius, Wiersma, & Loisel, 2012) and irritability (Hinton, Chambers, & Velasquez, 2009). Vocalisations, wandering and aggression were all found to be attributed to dementia more often than any other factor (Todd & Watts, 2005). However, in one qualitative study aggression was rarely discussed in terms of dementia, but was more likely to be perceived as due to internal factors such as the care-recipient's childhood and personality (Paton et al., 2004). In terms of the differences between family and staff carers, family carers tended to describe attributions to the care-recipient's personal history and emotional needs (Johansson, Norberg, & Lundman, 2002), especially when family carers scored highly on measures for displaying criticism and hostility (Tarrier et al. 2002). Staff carers were more likely to consider environmental factors than family carers (Johansson, Norberg, & Lundman). Further, staff carers were found to perceive aggression as due to more internal than external causes when the staff were 'cognitively busy', suggesting that attributions may be influenced when increased demands are placed on carers; although this result was found using an artificial experimental condition (Parker et al., 2012).

In conclusion, across the quantitative intervention, quantitative correlation and qualitative studies all but two studies found that carers made attributions to factors internal to the care-recipient. As six of the studies which shared this finding were quantitative studies, including one of which was an intervention study, some confidence can be placed in this conclusion. However, regarding carers attributing behaviour to dementia, only five qualitative and one correlational study had this finding, and only five qualitative and two quantitative studies reported carers recognising the role of external factors. Whilst the studies raise the possibility that carers may hold these attributions, they cannot be stated with great confidence due to their limited number and their methodological deficits. For example, the studies

discussed a range of challenging behaviours and measured attributions in different ways, some of which were less representative of carers' experiences due to convenience sampling and small sample sizes. Further, the evidence coming from mostly qualitative studies is less robust as the description of their methodologies was limited, they only used interviews and did not triangulate the data, and they often failed to describe the role of the researcher. A small number of qualitative studies also suggested that the process of making attributions may be complex, and one correlational and a small number of qualitative studies suggested that individual differences and the type of behaviour may influence attributions. These limited findings also require further and more robust research.

### **Perceptions of controllability and intentionality**

When attributions of behaviour are made to internal causes, individuals may then make attributions of controllability: whether the care-recipient has been able to choose that action and is able to perform that action (Weiner, 1985; 1986). Judgements of responsibility are then made, which reflects the perception of whether the person should or ought to have acted in that way (Shaver, 1985; Weiner, 1995). If a person is in control of their behaviour, and no mitigating circumstances are perceived, they are likely to be viewed as responsible for that behaviour. If a person is perceived as being responsible for their behaviour they may then also be perceived as to blame. Responsibility is a neutral attribution, whereas blame tends to be negative and reflects the magnitude of the consequences of the behaviour. Further, after someone is perceived as being responsible for their behaviour, that behaviour is then likely to be perceived as intentional, deliberate and even manipulative, whereas behaviour a person is

not responsible for is likely to be seen unintentional (Shaver). The research literature was reviewed in terms of these concepts, and is summarised below.

Carers mostly perceived challenging behaviour as not under the care-recipient's control, according to both quantitative and qualitative studies (Dupius, Wiersma, & Loisel, 2012; Fopma-Loy & Austin, 1993, 1997; Hinton, Chambers, & Velasquez, 2009; MacAndrew et al., 2005; Paton et al., 2004; Tarrier et al., 2002; Todd & Watts, 2005). When behaviour was described as uncontrollable by care-recipients, carers also perceived the care-recipients as not responsible and not to blame (Dupius, Wiersma, & Loisel). Behaviour was often perceived as uncontrollable when it was seen as being caused by dementia, and Fopma-Loy and Austin (1993) found that attributions to causes such as dementia were predictive of carers' beliefs that agitation was uncontrollable. In contrast, even though the majority of family carers in Paton et al.'s study perceived challenging behaviour as uncontrollable, they were more likely to attribute the causes of challenging behaviour to non-dementia-related factors.

Even though behaviour was mostly perceived as uncontrollable, some family and staff carers in three qualitative studies described care-recipients' behaviour as an intentional way of communicating something meaningful to the carer about their feelings and their inner world (Hallberg & Norberg, 1990; Johansson, Norberg, & Lundman, 2002; Johansson, Zingmark, & Norberg, 1999). For example, care-recipients in Johansson, Norberg and Lundman's study were perceived as intentionally communicating their needs, such as to connect with others, feel alive and strive for an 'ordinary' life. Similarly, in Hallberg and Norberg's study vocally disruptive behaviour was perceived as a communication of the care-recipient's physical and



practical needs, their difficult emotions such as loss and abandonment, and their responses to disturbing environments. However, the behaviour was also perceived as imitative, automatic and not always conscious, suggesting it may have been perceived as uncontrollable even if intentional. These qualitative findings give a rich yet mixed picture of perceptions of intentionality and their relationship to perceptions of controllability. However, these studies only used interviews, and the findings could have been more detailed, and therefore the relationship between intentionality and controllability should be explored further.

Both Harvath (1994) and Polk (2005) found mixed reports of perceptions of controllability, which may have been due to family carers' mixed and uncertain perceptions about the causes of challenging behaviour overall. When family carers did perceive the care-recipient to have control over their behaviour, this was mostly linked to carers perceiving behaviour as being caused by factors internal to the care-recipient (Hinton, Chambers, & Velasquez, 2009; Martin-Cook et al., 2003; Williamson et al., 2005). These carers then also tended to perceive the behaviour as manipulative: that care-recipients were attempting to gain control, get 'their own way', or make the carer feel guilty (Martin-Cook et al.; Williamson et al.).

Two of the quantitative studies found that the characteristics of the carer could influence their perceptions of controllability and intentionality. Behaviour was more likely to be perceived as controllable when family carers displayed high levels of criticism, hostility and emotional overinvolvement (Tarrier et al., 2002), and when staff had less years of experience working with people with dementia (Todd & Watts, 2005). Two other quantitative studies attempted to alter attributions of controllability and intentionality. Staff put under an

artificial ‘cognitively busy’ condition were found to be more likely to perceive aggression as controllable (Parker et al. 2012), however this study lacks ecological validity and has not been replicated. Martin-Cook et al. (2005) attempted to alter family carers’ perceptions of controllability through a psycho-educational group, but found no significant changes, and suggested that family carers’ attributions were complex given their personal connection to the care-recipient. None of the studies identified any impact of specific behaviours on perceptions of controllability and intentionality.

In summary, the evidence regarding carers’ attributions of controllability and intentionality is limited due to the small number of studies reporting findings in this area, and by the quality of the studies. Evidence from the two quantitative intervention studies, whose findings should be more robust, was mixed. One study found that carers’ attributions of controllability could not be altered by a psycho-educational group, but the other found that attributions could be altered under a cognitively busy condition, yet this study lacked ecological validity. A larger number of studies, four correlational and four qualitative, suggested that carers perceived care-recipients as not in control of challenging behaviour, and the support from correlational studies suggested this was particularly so when they attributed the behaviour to dementia, although these studies were underpowered. In contrast, limited evidence in three studies across different types of methodology found that behaviour can be perceived as controllable and even manipulative. Quantitative evidence from just two correlational studies suggested there may be other factors, such as carer personality, which influence attributions of controllability and intentionality, and these should be explored further with larger sample sizes. A small number of qualitative studies also gave some insight

into carers who described perceiving the behaviour as an intentional communication, and attempts should be made to replicate these findings using quantitative methodology.

Therefore, these studies raise the possibility that carers perceive behaviour as not in the care-recipient's control, but due to the quality of evidence and small number of studies this cannot be stated with great confidence. Further, the other evidence which suggests that carers may hold other attributions regarding controllability and intentionality is limited, and the evidence from intervention studies regarding altering attributions is mixed. Further research which can ascertain the reasons for different attributions, and under what conditions they can be altered, should be conducted using quantitative methodology.

### **Attributions of stability and perceptions of predictability**

Attribution theory states that attributions to stable causes are those which are unchanging and stable over time, and lead to expectations of that behaviour reoccurring in the future in that situation (Weiner, 1986; 1995). Internal attributions, such as a person's personality, are likely to be perceived as stable, and predictive of future behaviour. If behaviour is attributed to an unstable cause, such as noise in the environment, then the behaviour may be viewed as less likely to occur in the future, as the noise would fluctuate. Even when behaviours are perceived as due to stable causes and likely to reoccur, they can be perceived as predictable or unpredictable in terms of being able to anticipate *when* the behaviour will re-occur. A summary of the research literature's findings regarding attributions of stability and perceptions of predictability is given below.

Four studies identified that challenging behaviour was mostly perceived by family and staff carers as stable over time. These were carers who perceived behaviour as being caused by either the care-recipient's dementia in two qualitative studies, (Paton et al., 2004; Roper, Shapira, & Beck, 2001) or carers who perceived challenging behaviour as being caused by factors internal to the care-recipient, in two quantitative studies (Tarrier et al., 2002; Todd & Watts, 2005). Eighty six percent of carers in Paton et al.'s study thought that the care-recipient's challenging behaviour - which was mostly attributed to dementia - would continue, and would not get better or return to 'normal'. However, some staff carers did attribute challenging behaviour to unstable factors in two correlational studies (Fopma-Loy & Austin, 1993; 1997). For example, carers reported that the care-recipient would display "no agitation if routine followed consistently" and "no agitation if rests or naps" (Fopma-Loy & Austin, 1993, p. 221), and these comments also suggested that carers were making attributions to causes external to the care-recipient. The attributions to unstable causes were also predictive of carers' perceptions that agitation and poor self-feeding could be prevented and even reversed (Fopma-Loy & Austin, 1993; 1997).

When challenging behaviour was attributed to dementia, family and staff carers in three qualitative studies also described perceiving that behaviour as unpredictable (Dupius, Wiersma, & Loiselle, 2012; MacAndrew et al., 2015; Polk, 2005). This may be because they perceived dementia itself as unpredictable (Dupius, Wiersma, & Loiselle; Polk). Carers were more likely to perceive wandering as unpredictable if it was also seen as risky or difficult to manage (MacAndrew et al.). Some quantitative evidence was provided for the link between attributions of stability and perceptions of predictability: Fopma-Loy and Austin (1993) found

that making attributions to stable causes, such as dementia, was predictive of carers perceiving challenging behaviour as unpredictable.

A number of other factors were found to influence carers' attributions of stability. In Tarrier et al.'s (2002) quantitative study when family carers perceived challenging behaviour to be severe they were more likely to make attributions to unstable causes, and perceive the behaviour as less likely to reoccur. However, if the carer perceived the behaviour as having a great influence over many areas of their life, they were more likely to perceive it as likely to reoccur. The carer's role also appeared to influence attributions of stability, for example, registered nurses were more likely to perceive behaviour as likely to reoccur compared to nursing assistants (Fopma-Loy & Austin, 1993), although no differences were found between psychologists' and nurses' attributions of stability (Todd & Watts, 2005). Carers who had a lower socio-economic status were more likely to perceive behaviour as enduring, compared to those with a higher socio-economic status (Fopma-Loy & Austin). In terms of the characteristics of the care-recipient, when the care-recipient was male, carers were more likely to expect their behaviour to remain constant, whereas female care-recipient behaviour was more likely to be expected to change in the future (Fopma-Loy & Austin, 1997).

Only half of the studies in this systematic review explored carers' attributions of stability and/or perceptions of predictability. A very limited amount of evidence from two correlational and two qualitative studies suggests that when behaviour is attributed to dementia or internal causes it is perceived as stable, and two other correlational studies suggested when behaviour is attributed to external causes it is perceived as unstable. These findings are in line with Attribution Theory (Weiner, 1986; 1995), however caution should be

taken as the studies are few in number, they investigated different types of challenging behaviour, measured attributions in different ways, and no causation can be implied between the types of attributions due to a lack of quantitative intervention studies. The correlational studies also all used convenience samples, were mostly outside of the UK and did not provide information regarding each study's power or expected effect size. A limited amount of well conducted qualitative research suggested that attributing challenging behaviour to dementia was linked to perceptions of unpredictability, but this should be replicated using quantitative methods. Other areas for further research include those factors specific to the carer and the care-recipient which appear to influence perceptions of stability.

### **Carers' attributions and their feelings**

Carers experience a range of difficult feelings when caring for a person with dementia. The majority of the studies discussed these feelings, and explored how carers' attributions about challenging behaviour are related to those feelings. The findings are discussed below.

The difficult and negative feelings a family or staff carer experiences can include: resentment (Williamson et al., 2005; Martin-Cook et al., 2003), depression (Martin-Cook et al.), anger and frustration (Fopma-Loy & Austin, 1993), and strain and irritability (Johansson, Zingmark, & Norberg, 1999). Powerlessness and irritation were the most commonly reported feelings in Hallberg and Norberg's (1990) study, and led to guilt, anxiety, fatigue and emotional outbursts at home and work. However, carers have been found to experience some less negative feelings, such as feeling puzzled, and feeling sorry for the care-recipient (Fopma-Loy & Austin). Positive feelings can also be experienced, for example, some carers

perceived picking behaviour to be making “the ward more alive” (Johansson, Zingmark, & Norberg, p. 29), and sometimes carers felt compassion and empathy towards the care-recipient (Hallberg & Norberg).

This review has found that many carers attribute challenging behaviour to dementia. When this happens, staff describe less difficult feelings and not taking the behaviour personally (Dupius, Wiersma, & Loisel, 2012), and feeling more confident in their work and more satisfied (Roper, Shapira, & Beck, 2001). However, when staff do not attribute challenging behaviour to dementia, they have been found to describe more difficult feelings, such as frustration, helplessness and hopelessness (Roper, Shapira, & Beck). Whilst this relationship was only reflected on in two qualitative studies, it was also replicated in a quantitative study in which family carers felt more resentment when they attributed behaviour to factors internal to the care-recipient rather than to dementia (Williamson et al., 2005); although this study had limited validity due to its convenience and non-representative sample, and non-UK setting.

This review has also suggested that challenging behaviour attributed to dementia is often also perceived as not under the control of the care-recipient. In these cases, carers in three qualitative studies described experiencing challenging behaviour as less stressful and feeling fewer difficult feelings (Dupius, Wiersma, & Loisel, 2012; Harvath, 1994; Polk, 2005). However, carers in MacAndrew et al.’s (2015) qualitative study perceived wandering as uncontrollable and found the behaviour intolerable and frustrating. On the fewer occasions when challenging behaviour was perceived as controllable and/or manipulative, staff and family carers reported experiencing more difficult feelings such as stress, depression, anger,

blame and resentment across a number of qualitative and quantitative studies (Fopma-Loy & Austin, 1997; Harvath, 1994; Hinton, Chambers, & Velasquez, 2009; Martin-Cook et al., 2003; Polk, 2005; Tarrier et al., 2002; Williamson et al., 2005). Investigating the relationship further, Williamson et al. found that family carers' perceptions of controllability were predictive of feeling resentment.

There is a little evidence that attributions of stability and perceptions of predictability are linked to carers' feelings. When physical aggression was perceived as likely to reoccur, carers felt more disgust, depression and anxiety (Todd & Watts, 2005). However, Fopma-Loy and Austin (1997) found no relationship between attributions of stability and carers' feelings in relation to self-feeding behaviour. When staff and family carers reported perceiving aggression (Dupius, Wiersma, & Loisele, 2012), agitation (Polk, 2005) and wandering (MacAndrew et al., 2015) as unpredictable, they also described feeling frustrated and anxious. For example, one carer in Polk's study reported "the unpredictable behavior causes me to react in a state of edgy alertness, causes stomach aches and nervousness in me. I have to be ready to move every minute" (p. 265). The link between feelings and unpredictability was only reported in qualitative studies which had some limitations in their methodologies, but did provide rich and convincing findings.

In contrast to the previously cited research, two correlational studies did not find any relationship between staff carers' attributions and their feelings (Fopma-Loy & Austin 1993; 1997). It may be that the relationship between carers' feelings and their attributions is also dependent on other factors, such as the type of challenging behaviour. For example, in Todd and Watts' (2005) correlational study a relationship was found between higher levels of



disgust and attributions of stability for physical aggression, but no relationships were found between emotions and attributions for wandering or excessive vocal behaviour. Other factors, such as the carers' professional role may also influence their feelings, as nurses were found to have stronger emotional responses than psychologists, such as more anger for physical aggression (Todd & Watts).

This review found that carers experience difficult feelings, as has often been suggested previously in the research literature, although this review also identified some neutral and positive feelings. One quantitative intervention study found that perceptions of controllability were linked to negative feelings, and whilst the quantitative methodology is more robust, the study itself was limited by poor allocation to groups, and the study not reflecting usual practice in the UK. Evidence from quantitative correlational studies was limited, with only one or two studies reporting similar findings. For example, one study suggested that attributing behaviour to dementia was associated with positive feelings, two studies that perceptions of controllability was linked to negative feelings, and another two reported different findings regarding carers' feelings and perceptions of stability. Individual correlational studies also found that the type of behaviour and the carers' role may be linked to carers' feelings, but two other correlational studies reporting finding no relationship between attributions and feelings. Making any conclusions from the correlational studies regarding this area is difficult, due to the limited number of studies reporting similar findings, their lack of representative samples, the settings being outside the UK, and the studies' limited power. A small amount of qualitative evidence adds some support to the quantitative findings, regarding attributions of dementia being linked to positive feelings, and attributions of controllability being linked to negative feelings. A limited amount of other qualitative

evidence also suggested other links that were not explored in the quantitative literature, such as varied findings related to feelings and perceptions of uncontrollability, and negative feelings associated with attributions of unpredictability. This qualitative evidence is small but well conducted, and perhaps points to where further quantitative research could be conducted. Overall, in terms of quantity and quality there is limited evidence that carers' feelings may be associated with attributions. Much more research needs to be conducted, preferably with intervention studies to explore whether there are any causal relationships between attributions and feelings.

### **Carers' attributions and their management of challenging behaviour**

Carers respond to challenging behaviour in a variety of ways to manage that behaviour. The introduction to this review stated that both previous research and current guidelines for care recommend that carers should use person-centred interventions when managing challenging behaviour, rather than physical or chemical restraints (Andrews, 2006; Margallo-Lana et al., 2001; NICE, 2006). The research literature described the specific approaches and interventions that carers used, and some of the literature explored the role of carers' attributions regarding their management of challenging behaviour. If carers have an understanding of the causes of care-recipients' behaviour, it could be expected that their understanding would influence their management of that behaviour, and some carers in the studies described using their understanding as a way of helping them to respond appropriately. For example, carers described considering the behaviour in terms of the care-recipient's previous life experiences (Johansson, Zingmark, & Norberg, 1999), or in terms of specific situations the care-recipient was in so that they could help them to avoid the situation

(Harvath, 1994). The findings regarding the relationship between carers' attributions and their management of behaviour are described below.

Carers used a wide range of strategies for managing challenging behaviour, such as monitoring, going along, diversions, delaying, reasoning/convincing, guiding and managing the environment (Harvath, 1994; Johansson, Zingmark, & Norberg, 1999). Family carers described trying to eliminate and compensate for behaviours, avoiding situations, and using trial and error (Harvath; Polk, 2005). Some studies described staff behaving in particularly containing and calming ways, for example, staff carers gave examples such as “put in geri-chair and talk to him/her about how is feeling” and “ask what he/she is afraid of” (Fopma-Loy & Austin, 1993, p. 221) when managing agitation; and trying to show tact and respect (Johansson, Zingmark, & Norberg). The most effective strategies were found to be the more subtle, indirect and non-confrontational interventions, as opposed to challenging and confrontational strategies (Harvath).

However, some family and staff carers in both qualitative and quantitative studies were found to use challenging and confrontational techniques as standard interventions, particularly when they needed to minimise harm and serious risk (Dupius, Wiersma, & Loiselle, 2012; MacAndrew et al., 2015). Staff carers described telling the care-recipient that “behaviour will not be allowed and must sit down to eat” and described that they would “call for other staff members to help restrain” when managing agitation (Fopma-Loy & Austin, 1993, p. 221). Some staff also reported blocking out and ignoring challenging behaviour (Hallberg & Norberg, 1990; Dupius, Wiersma, & Loiselle), and this was more likely if

calming and containing interventions had been tried repeatedly but had been unsuccessful (Hallberg & Norberg).

Some studies found links between carers' attributions of the causes of behaviour and carers' management of that behaviour. For example, in three qualitative studies when carers attributed challenging behaviour to the care-recipient's dementia they reported using more non-confrontational approaches such as the use of distraction, diversion, verbal and nonverbal strategies (Dupius, Wiersma, & Loiselle, 2012; MacAndrew et al., 2005; Roper, Shapira, & Beck, 2011), and less physical or chemical restraint (Roper, Shapira, & Beck). One qualitative study linked carers' attributions to the use of chemical and physical restraint. Roper, Shapira and Beck found that staff who interpreted the causes of care-recipient behaviour using their understanding of their own or their relatives' experiences, were more likely to describe using restraint and medication.

Two qualitative studies found that when carers perceived challenging behaviour as uncontrollable they were more likely to use non-confrontational approaches (Harvath, 1994), or allow the behaviour to occur with little or no intervention (MacAndrew et al., 2015). Likewise, carers who believed the behaviour was controllable were found to report using more confrontational approaches (Harvath). Similarly, in Polk's (2005) study one family carer talked about finding it difficult not to 'lash out' when they perceived the care-recipient's behaviour as controllable. However, in Williamson et al.'s (2005) quantitative study when family carers perceived behaviour as controllable they reported providing more care, including being more vigilant and attentive; although this was only the case if behaviour occurred frequently. In contrast to these findings, in another quantitative study Fopma-Loy

and Austin (1993) found no relationship between perceptions of controllability and carer interventions.

Attributions of stability appear to influence staff behaviour, according to three quantitative and qualitative studies. When behaviour was perceived as constant, carers thought that it should be managed rather than ignored (Dupius, Wiersma, & Loisel, 2012), and perceiving agitation as persistent was predictive of containing and calming responses, but not punitive responses (Fopma-Loy & Austin, 1993). When carers believed that behaviours were due to unstable causes and likely to change in the future, they provided more support for care-recipient self-feeding (Fopma-Loy & Austin, 1997). Perceiving behaviour as unpredictable may also play a role in carer behaviour, according to two qualitative studies. When carers described challenging behaviour as unpredictable they reported being more vigilant (MacAndrew et al., 2015; Polk, 2005), using redirection, and removing environmental cues or objects (MacAndrew et al.). However, in Fopma-Loy and Austin's (1993) quantitative study perceiving agitation as unpredictable was not predictive of how carers responded.

The literature described a range of other potential reasons for carers' differing interventions. Carers factors, such as their ability (Fopma-Loy & Austin, 1997), burnout (Todd & Watts, 2005), and emotional strain and emotional overinvolvement with the care-recipient (Roper, Shapira, & Beck, 2001) were described as influencing their behaviour. However, Fopma-Loy and Austin found that carers' feelings did not predict their behaviour. For staff carers, the demands of the job (Dupius, Wiersma, & Loisel, 2012; MacAndrew et al., 2015), the speciality of the employing facility and the organisation's practices, procedures

and resources (Fopma-Loy & Austin; MacAndrew et al., 2015) were reported as factors which could limit staff's responses. Further, shift-workers were found to be less likely to display containing/calming behaviours than non-shift workers (Fopma-Loy & Austin, 1993).

To summarise, carers use many varied strategies to manage behaviour. Neither quantitative intervention study investigated carer management of behaviour. Substantially limited evidence from correlational studies made some links between perceptions of controllability and stability and carer behaviour, although the findings were contradictory, with some correlational studies suggesting there were no links. These correlational studies were also underpowered, unrepresentative and not applicable to the UK. Qualitative evidence was also very limited, but suggested that non-confrontational and containing responses were linked to attributions of behaviour to dementia, as well as to attributions of uncontrollability, stability and unpredictability. Whilst these studies provided specific examples of carers sharing their attributions and their management of behaviour, no causal relationships can be assumed, and the samples were small. Limited research from both qualitative and correlational studies suggested a range of other factors which may influence carer behaviour, and these should be investigated with well-designed quantitative studies, with representative samples in settings applicable to care in the UK and where training and procedures are likely to be similar. The studies investigating carer behaviour also had other methodological limitations because the studies used varying subjective measures of carer behaviour, and it may have been difficult for carers to identify and describe how they might respond, especially when a number of the studies used vignettes to elicit responses. Only Roper, Shapira and Beck (2001) additionally observed carer behaviour. Therefore, it is very difficult to draw any

conclusions about the relationship between carers' attributions and their management of behaviour from this limited evidence.

## DISCUSSION

### Summary of findings

All of the correlational studies, nine of the ten qualitative studies, and one of the two intervention studies in this review raised the possibility that carers of those with dementia attribute challenging behaviour to internal factors. Mainly qualitative studies suggested that carers may also attribute behaviour to dementia, and to external factors. Both qualitative and correlational studies also provided some evidence that carers perceive behaviour to not be in the care-recipient's control. One study from each type of methodology found that carers could perceive behaviour as manipulative and controllable by the care-recipient, and a few qualitative studies suggested behaviour was perceived as an intentional communication. The evidence from both correlational and qualitative studies regarding carers' attributions of the stability or predictability of challenging behaviour was very limited and the findings were mixed. The limited evidence reported in intervention, correlational and qualitative studies regarding the relationship between carers' attributions and carers' feelings and management of behaviour also had mixed findings. Across the intervention, correlational and qualitative studies the evidence for the role of individual differences was suggested regarding different types of attributions, carers' feelings and carers' behaviour, but the number of studies reporting findings in this area was very limited.

The limited evidence provided means that making conclusions with confidence is very difficult, and this is also compounded by a number of methodological issues across the studies. Only seven quantitative studies were identified, and only two of these were



intervention studies, with five only providing findings regarding associations between variables as opposed to causal relationships. One of the intervention studies was particularly impaired by its method of allocation to groups and its lack of applicability to UK practice, whilst the other had limited ecological validity. The correlational studies were poorly powered, had limited applicability and the participants poorly represented the target population. The qualitative studies provided limited support for some of the quantitative findings, but at other times the evidence was contradictory or provided new insights not yet explored in the quantitative literature. The qualitative studies were also limited by not describing the role of the researcher or their ethical procedures, and whilst the data was often rich they mostly drew on interviews. Further methodological limitations across the types of studies and the limitations of the review itself are discussed below.

## **Limitations**

There is little consistency across the studies in this systematic review. They measure and define challenging behaviour in various ways, with some studies investigating specific behaviours and others focussing on challenging behaviour in general. The studies also used different methods of measuring and identifying carers' attributions, and all the measures were subjective. Descriptions of how studies defined internal or stable attributions were often unclear, and appeared to differ. For example, whilst Parker et al. (2012) and Todd and Watts (2005) described stability as the extent a cause is believed to influence behaviour in the future, Fopma-Loy and Austin (1993) described it as "causes along an invariant versus variant continuum" (p. 218) and TARRIER et al. (2002) defined stability as "whether the cause of the negative event is enduring—and therefore likely to be present if a similar situation occurred in the future—or is merely transient" (p. 342). In identifying attributions, some studies asked

carers to respond to vignettes, videos or tapes, reducing the ecological validity. However, studies asking carers to rely on their own past experiences to identify their attributions may have been subject to biases in recall and reporting. Unfortunately, these differences lead to difficulties in making conclusions across the studies, even when similar results were found.

There is little experimental research across the studies, only two attempted to alter carers' attributions, and only one found any significant change. One study did this through a psycho-educational group (Martin-Cook et al., 2003), but was unsuccessful in finding any significant change in carers' attributions or feelings. The other study (Parker et al., 2012) found some changes in carers' attributions when carers were under a 'cognitively busy' experimental condition. However, the replicability of this study to carers' real life experiences is likely to be limited. There is no research that shows that altering attributions can impact carers' feelings or their management of challenging behaviour. The lack of experimental research and findings makes it difficult to draw any firm conclusions regarding identifying what specifically causes or predicts carers' attributions, and any causal role those attributions may have in terms of carers' feelings or management of behaviour.

The quality frameworks used to appraise the studies highlighted several limitations which reduce the reliability and validity of the evidence provided. Specifically across the quantitative studies, convenience samples were often used, many studies were based outside of the UK, the majority used subjective outcome measures and many were underpowered. Across the qualitative studies the majority used only single interviews and did not consider the role of the researcher. Further experimental and naturalistic studies should be designed with good levels of statistical power reported, objective measures should be used, and

attempts to replicate findings should be conducted. If subjective measures are used, the validity of those measures should be investigated.

Some information was provided in the studies about the carer and the setting, but less was provided about the care-recipient/s, the relationship between the carer and the care-recipient, and the carer's relationship to their carer role, and these could all be important factors. Further, the experience of a family carer compared to a trained and paid staff carer is likely to be very different, and such factors were only partially explored in studies with both staff and family carers. Many studies also used convenience samples, and larger and more representative samples should be sought. Some of the studies identified some individual differences across carers and it would be useful for further research to be conducted to identify the individual factors which can predict carers' attributions.

Only seventeen studies were found which investigate carers' attributions of challenging behaviour in care-recipients with dementia, which is limited. Just a few studies explored attributions of stability and perceptions of predictability, and only a few discussed other potentially important aspects about the care-recipient, including their pre-morbid personality, experiences and relationships. As the research so far offers mixed and limited findings regarding carers' attributions, it may be that the broad constructs found in Attribution Theory (Weiner, 1980; 1985) are less applicable to this area, and more specific theories that relate to dementia may be more helpful in understanding carers' feelings and behaviours. Due to the limitations of the studies and perhaps the applicability of Attribution Theory, it is not possible to say what the relationships are between carers' attributions, feelings and/or behaviour.

This systematic review only used peer-reviewed studies, and there may be more research and papers in this field which could provide further insight into the area. It is possible that using a wider range of search terms, for example also using ‘belief’ or ‘understanding’ rather than just ‘attribution’ and ‘attribution theory’, may have produced further relevant research studies. The use of Attribution Theory (Weiner, 1980; 1985) itself to explore the findings may also have limited the review, as discussed above.

The appraisal tool used (NICE, 2012) was originally made for public health intervention studies, and so there may be aspects which have been missed that should have been appraised. The reliability of the appraisal tool itself is questionable, as an evaluation of the framework’s inter-rater reliability has not been published, and in this review there was disagreement between the two raters, and the calculated Cohen’s kappa (Cohen, 1960) value showed that inter-rater reliability was poor. The tool does not lead to an overall score of each study’s quality, and does not provide a way of comparing the quality across the three types of study. Some appraisal tools do attempt to provide a way of comparing the overall quality of studies that used different methodologies (e.g. Downs & Black, 1998). However, it could be argued that this is a questionable approach, particularly when reviewing both qualitative and quantitative research. A preferable approach is to acknowledge a hierarchy of methodologies such as that proposed by Ryan et al. (2013) in which, for example, experimental studies are ranked higher than observational studies and the evidence they provide is given greater weight. An attempt was made to reflect this in the conclusions drawn in this review. Where there was any discrepancy or inconsistency in the findings, greater weight was given to the intervention studies compared to the quantitative observational studies, and greater weight to the latter over the qualitative studies. Alternatively, the review of the literature could have

focussed on only quantitative or only qualitative literature, such as completing a meta-synthesis of the qualitative studies.

## **Implications**

Many of the studies recommended providing training and education about attributions, dementia, and managing challenging behaviour, in order to raise awareness of and improve the accuracy of attributions, and in turn to improve carers' experiences and care-recipient care (Dupius, Wiersma, & Loiselle, 2012; Fopma-Loy & Austin, 1993; Parker et al., 2012; Paton et al. 2004; Roper, Shapira, & Beck, 2001; Williamson et al., 2005). For example, carers who do not attribute challenging behaviour to dementia may be less likely to seek and receive support from professionals (Paton et al., 2004), and carers may also miss important factors relevant to the care-recipients if their attributions are incorrect (Roper, Shapira, & Beck). The studies also recommended support, supervision and training for staff (Dupius, Wiersma, & Loiselle; Hallberg & Norberg, 1990; Hinton, Chambers, & Velasquez, 2009; Parker et al.; Roper, Shapira, & Beck; Todd & Watts, 2005), and a few recommended that policies, practices and the culture in care services should be reviewed (Dupius, Wiersma, & Loiselle; Hallberg & Norberg; Parker et al.).

However, there is limited evidence in this review to suggest that such training, education, support or any review of policies/practices would be beneficial to carers or care-recipients. Martin-Cook et al.'s (2003) study used a psycho-educational group about dementia care to alter family carers' attributions and difficult feelings, but did not find any significant changes. This may be because the relationship between the carer and care-recipient may be

more complex, especially between family members. Once further research about carers' attributions, feelings and behaviour has been conducted, appropriately planned interventions must then also be measured and evaluated, before making any recommendations for carer interventions.

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**VOLUME I: EMPIRICAL PAPER**

**Relationship continuity and understanding challenging behaviours in spouses/partners  
of those with an acquired brain injury**

by

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## **ABSTRACT**

### **Introduction**

Spouses of those with an acquired brain injury (ABI) can experience distress in caring for a partner if they behave in ways which is challenging to the spouse. Spouses' perceptions of the change in their partner and their relationship since the injury (relationship continuity or discontinuity) have been shown in the context of dementia and in qualitative literature in ABI to play a role in spouses' experiences of caring for their partner, and in understanding and managing their behaviour. On the basis of this literature, it was hypothesized that perceptions of greater continuity in the relationship would be associated with a more person-centred approach to understanding and managing challenging behaviour.

### **Method**

Twenty-six spouses of individuals with an ABI completed the Birmingham Relationship Continuity Measure (Riley et al., 2013) and a semi-structured interview about how they understand and manage challenging behaviour. The interviews were transcribed and coded using factors related to understanding and managing behaviour in terms of taking a person-centred approach.

## **Results**

In accordance with the hypotheses, perceptions of greater continuity in the relationship were associated with a more person-centred approach to the understanding and management of challenging behaviour.

## **Discussion**

This study adds quantitative evidence to the largely qualitative research in this field. Further research is required to investigate why relationship continuity is associated with how spouses understand their partner's behaviour and how they manage that behaviour.



## INTRODUCTION

### **Caring for a spouse with an ABI**

When a person has an acquired brain injury (ABI) their behaviour in the following months, and in many cases for years to come, can be challenging for those who care for them, including their spouses (Wood, Lioffi, & Wood, 2005). (The term spouse is used loosely throughout to refer to both marital spouses and those who are partners and live together). For example, those with an ABI may experience various neuropsychological care needs including cognitive deficits such as with memory and problem solving, emotional changes such as mood swings, and behavioural changes such as aggression and loss of initiative (Jennekens, de Casterle, & Dobbels, 2010). These behaviours which carers may experience as difficult are referred to as ‘challenging behaviours’.

Carers of those with an ABI have been shown to experience distress, including burden, anxiety and depression (Kreutzer, 2009; Smeets et al., 2012). When the care-recipient displays challenging behaviour such as through changes in their personality or behaviour, carers are more likely to experience such distress compared to when the care-recipient has physical or cognitive difficulties (Mitchley, Gray, & Pentland, 1996). The impact of an ABI can affect spousal carers more than other family carers (Verhaeghe, Defloor, & Grypdonck, 2005), and spousal carers report more anxiety, stress and depression, and reduced quality of life and life satisfaction compared to the general population (Doyle et al., 2013; Riley et al., 2015).

Spouses take on more responsibility as they gain the role of carer in addition to that of spouse, and this may lead them to neglect their own needs and impact their personal finances and activities, all of which can add to their sense of loss, burden and feelings of stress (Riley, 2016). They may also struggle to cope with the behavioural and personality changes which may be undesirable, and this can lead to a sense of losing the intimacy and connection once found in the spouse and in the relationship (Riley). Spouses can then feel dissatisfied in their relationship, and experience a range of conflicting feelings about remaining in the relationship and about their spouse (Blais & Boisvert, 2005; Godwin et al., 2011).

### **Relationship continuity**

However, there is variation in how carers respond, both emotionally and practically, to challenging behaviour in care-recipients with ABI (Riley, 2007; Verhaeghe, Defloor, & Grypdonck, 2005). Whilst many spouses report difficulties, some cope with the changes in their partner and their relationship, and report few difficulties in their mental health or relationship following the ABI (Riley, 2016). One factor associated with such variation in coping is the concept of relationship continuity. Relationship continuity is a person's perception of the continuity of their partner and their relationship following a diagnosis or event, such as dementia or ABI. Where relationship discontinuity is perceived, and the relationship and the spouse are perceived as different, a person may experience loss, different feelings and a sense of no longer being a couple.

The Birmingham Relationship Continuity Measure (BRCM, Riley et al., 2013) was created as a quantitative measure of relationship continuity for spouses with dementia, which

has been shown to have good reliability and validity. It includes five subscales: relationship redefined, same/different person, same/different feelings, couplehood and loss. Relationship redefined measures the extent to which the relationship has been redefined by the spouse (e.g. item 16: Despite all the changes, our relationship has remained much the same as it was). Same/different person measures the perception of the care-recipient as the same or a different person compared to before (e.g. item 13: Sometimes, I feel it's like living with a stranger). Same/different feelings measures the extent the spouse has the same or different feelings towards the care-recipient (e.g. item 4: I care for him, but I don't love him the way I used to). Couplehood measures the perception of being a couple, such as sharing decision making and having established patterns of interaction and communication (e.g. item 23: It doesn't feel like a partnership any more). Loss measures the extent of the experience of loss of the person and/or the relationship (e.g. item 12: I miss having someone to share my life with). The measure has recently been adapted for use with ABI (N. Yasmin, personal communication, April 6, 2017).

### **Relationship continuity in the context of dementia and ABI**

Relationship continuity and discontinuity have been observed in spouses of those with dementia in qualitative (Chesla, Martinson, & Muwaswes, 1994; Lewis, 1998; Walters, Oyebode, & Riley, 2010) and some recent quantitative studies (Poveda et al., 2017; Riley, Evans, & Oyebode, 2016). A spouse is more likely to perceive relationship discontinuity when their partner with dementia displays more challenging behaviours, especially when those behaviours are apathy, disinhibition or agitation (Poveda et al.). The greater the presence, frequency and severity of such behaviours, the more likely spouses are to

experience relationship discontinuity. Although the association between discontinuity and challenging behaviour is not explained by the spouses' level of anxiety and/or depression (Poveda et al.).

Spouses who perceive discontinuity may be more likely to experience negative emotions including distress, guilt and loss, whereas spouses who experience continuity appear less likely to feel such feelings, and more likely to feel empathy (Walters, Oyebode, & Riley, 2010). This has been supported by quantitative research: relationship continuity has been found to be significantly associated with fewer negative reactions to emotional caregiving including burden, stress, resentment, anger and guilt; and relationship continuity has also been found to be significantly associated with more positive emotional responses to caregiving, such as gratitude, satisfaction and achievement (Riley, Evans, & Oyebode, 2016). Poveda et al. (2017) also found that the more distress challenging behaviour causes a spouse, the more likely they are to experience discontinuity.

Less research has been conducted regarding relationship continuity in the context of ABI, compared to the context of dementia. One qualitative study (Bodley-Scott & Riley, 2015) found that perceptions of relationship discontinuity were linked to feelings of frustration and helplessness, and considering ending the relationship; whereas those who experienced continuity reported becoming closer following the injury. Another qualitative study (Villa & Riley, in press) also identified that spouses of those with an ABI could experience relationship discontinuity, and those who did reported experiencing more loss and distress regarding the changes in their partner and their relationship.

## **Relationship continuity and understanding challenging behaviour**

Qualitative research suggests that relationship continuity may also be associated with spouses' understanding of challenging behaviour. Spouses who experience continuity seem to understand their partner and their behaviour in terms of their knowledge of their partner's pre-injury behaviours and character, and in terms of aspects of their partner's individual intentions and interests, for care-recipients with dementia and ABI (Bodley-Scott & Riley, 2015; Lewis, 1998; Villa & Riley, in press). These spouses appear to draw on their pre-existing knowledge of the person pre-injury to understand their behaviour (Villa & Riley), but those who perceive discontinuity appear to struggle to understand their partner's behaviour (Bodley-Scott & Riley). Those who perceive discontinuity in their partner and their relationship also appear to perceive their behaviour as radically different compared to the premorbid person, and as not purposeful or personalised (Chesla, Martinson, & Muwaswes, 1994). They appear to redefine their partner and the relationship in terms of the dementia or the ABI, and when understanding challenging behaviour they have been observed using depersonalised and objectifying language regarding their partner, such as 'people like that' or 'one of them' (Lewis; Villa & Riley; Walters, Oyebode, & Riley, 2010).

## **Relationship continuity and managing challenging behaviour**

This qualitative research also suggests that spouses' experience of relationship continuity and discontinuity may be linked to the type of care they provide. Spouses who perceive continuity seem to adopt a more person-centred view and respond more empathically (Villa & Riley, in press; Walters, Oyebode, & Riley, 2010). These spouses tend to find more

practical solutions to managing behaviour (Walters, Oyebode, & Riley), and tend to be more successful (Bodley-Scott & Riley, 2015). In comparison, spouses who perceive relationship discontinuity appear to provide care which is less personalised and less tailored to their partner's individual past or present needs (Chesla, Martinson, & Muwaswe, 1994). They may look to more external sources to manage behaviour and rely more on guidance and advice from medical professionals (Villa & Riley). Further, spouses who perceive discontinuity appear more likely to provide care that is more controlling and restrictive (Lewis, 1998). Their management of behaviour also appears to be less successful compared to those who perceive continuity in the person and the relationship (Bodley-Scott & Riley).

### **The link between relationship continuity and understanding and managing challenging behaviour**

Whilst these qualitative studies make links between relationship continuity and understanding and managing behaviour, they do not elaborate on why such links may exist. It may be that it is spouses' use of an internal system of meaning about their partner and their relationship to them, that helps them to understand their partner despite any changes related to their dementia or ABI. In Villa and Riley's (in press) study spouses of those with an ABI who perceived relationship continuity reported drawing on their own premorbid knowledge and understanding of their partner to understand and manage their behaviour, which seemed to result in more person-centred, empathic and individualised approaches to managing behaviour. Further, for a spouse who perceived continuity in Bodley-Scott and Riley's (2015) study, it was suggested that their understanding of the spouse in terms of their premorbid character was what enabled them to be more successful in managing behaviour. Spouses who

experience continuity therefore appear to use an internal model of the past characteristics of the person to help them to understand their challenging behaviour.

In contrast, when spouses perceive discontinuity and understand and redefine their partner in terms of their dementia or their ABI, they seem to put aside their past knowledge of the person and consequently no longer use a familiar model of the person to understand them, because they are no longer perceived to be that person. Because spouses have redefined their partner and view them as different, they seem to instead utilise their knowledge of dementia or ABI, or their understanding of ‘people with dementia’ (Walters, Oyebode, & Riley, 2010), or ‘people with ABI’ (Villa & Riley, in press), to understand and manage the partner’s challenging behaviour. The spouses’ responses and approach to their partner therefore appears to not be informed by their partner’s pre-injury characteristics or current circumstances, but by their knowledge of dementia or ABI. Consequently, care appears to be less tailored to the individual’s needs and less person-centred, and spouses may instead utilise a medical model to understand behaviour (Villa & Riley).

These suggestions from qualitative research, that perceptions of relationship continuity influence how spouses understand and manage challenging behaviour, need support from quantitative methods. One piece of quantitative research by Achiampong (2011) regarding care-recipients with dementia has provided support that relationship continuity is associated with spouses’ understanding and management of challenging behaviour. Spouses completed the BRCM to measure perceptions of relationship continuity and responded to a semi-structured interview about their understanding and management of challenging behaviour. Responses from the interviews were coded using a method based on the Leeds Attributional

Coding System (Stratton, Munton, Hanks, Heard, & Davidson, 1988). The codes included understanding the behaviour in terms of the care-recipient's neurological impairment, as well as a number of person-centred factors which were those where the spouse considered the partner's individual premorbid personal history and/or personality, or considered in depth their partner's thoughts and/or feelings. Perceptions of relationship continuity were found to be positively correlated with understanding challenging behaviour in terms of these person-centred factors. Perceptions of relationship continuity were also found to be negatively correlated with understanding challenging behaviour in terms of neurological factors.

### **Person-centred care as a framework for investigating spousal responses to challenging behaviour**

Kitwood (1997) introduced the idea of person-centred care in the context of providing care for people with dementia. He emphasised that individuals need to be cared for in a manner that takes account of their individuality, that respects and values the individual as a person, and that highlights the importance of a sharing a positive and rewarding relationship with the person with dementia. The well-being of the person with dementia depends on social interactions that promote a sense of individuality and agency, and on being valued and respected. Across healthcare settings person-centred care is considered best practice in the UK (Department of Health, 2010). Although much of the work around person-centred care has focused on the care provided in residential care settings, the ideas are also applicable to family and informal carers (e.g. Ellis-Gray, Riley, & Oyebode, 2014). Brooker (2004) described four key elements of person-centred care: “valuing people with dementia...(V), treating people as individuals (I), looking at the world from the perspective of the person with



dementia (P), and a positive social environment in which the person living with dementia can experience relative wellbeing (S)” (p. 216).

The differences in the understanding and management of challenging behaviours between those perceiving continuity and those perceiving discontinuity that have been highlighted in the qualitative research reviewed earlier, can be mapped onto the conceptual framework provided by the construct of person-centred care. The depersonalization and objectification of the person receiving the care (Lewis, 1998; Walters et al., 2010), lack of a personalized approach to care (Chesla et al., 1994) and the controlling and restrictive approach to care provision (Lewis, 1998) would be examples of care that is not person-centred; whereas understanding behaviour in terms of the person’s individual needs and history (Bodley-Scott & Riley, 2016; Lewis, 1998; Villa & Riley, in press) and care that is focused on individual needs (Villa & Riley, in press; Walters et al., 2010) would be examples of person-centred care.

There are advantages to using the conceptual framework of person-centred care to guide further investigation of the links between relationship continuity and responses to challenging behaviour. Person-centred care is an overarching construct that traces different features of care delivery back to the core feature of whether the person receiving the care is being respected as an individual. It thereby provides, to some degree at least, an explanation of why these different features of care (such as those characterising the care provided by those who perceive discontinuity) may tend to cluster together. It thereby also suggests other features of care that one may expect to be associated with a person-centred or a non-person-centred approach, features that have not, as yet, been highlighted in the qualitative literature

about continuity and dealing with challenging behaviour. For example, from the perspective of person-centred care, one feature that follows from treating the other as a person is the enhancement of their sense of agency and involvement. This raises the possibility that relationship continuity may be associated with an approach to dealing with challenging behaviour that emphasizes the role of the person with the brain injury in deciding how to try to deal with the challenges created by the behaviour. A final advantage of adopting the person-centred framework is that the VIPS approach provides a systematic indication of what aspects of care should be associated with a person-centred approach, and thereby provides guidance in developing a method of measuring person-centred care in the present context.

### **Aims and hypotheses**

The research literature described shows that behavioural changes following an ABI are particularly difficult for a spouse, and are linked to greater burden compared to other changes. The emotional impact of the changes on the spouse and how they manage them varies amongst spouses. Relationship continuity has been suggested as an explanation for these individual differences, and particularly so in how spouses understand challenging behaviour and how they consequently manage that behaviour. In primarily qualitative studies it has been suggested that when spouses perceive relationship continuity they take a more person-centred and empathic approach to their understanding and management of challenging behaviour. Those who perceive relationship discontinuity on the other hand, may take a more depersonalised approach to understanding and managing behaviour, based instead on neurological and circumstantial explanations to behaviour. These suggestions need support from quantitative research, and therefore this study aims to use a quantitative approach to

investigate the association between relationship continuity and the understanding and management of challenging behaviour for spouses of those with an ABI.

*Aim of the study:* to investigate the relationship between perceptions of relationship continuity and how spousal carers of a person with an ABI understand and manage challenging behaviour, using quantitative methods to support what has been suggested so far in the qualitative research literature.

To meet the aim of the study, twenty-six spouses of a person with an ABI completed an adapted version of the BRCM and were interviewed about two behaviours which they personally found particularly challenging. They were asked about how they understood those behaviours and how they managed them. The interviews were transcribed, and spouses' approaches to understanding and managing the behaviours were coded using a measure, developed specifically for the present study, that was based on the VIPS model of person-centred care. The measure involved coding the interview according to how the person understood and responded to the behaviour. Person-centred understanding was conceptualised in terms of making sense of the behaviour by using knowledge about the pre-injury personal history, relationship and personality of the person, and in terms of showing a depth of understanding about the specific motivations, thoughts and feelings of the other person by taking their perspective on the situation. Previous research has shown that taking the perspective of another is a key part of empathy and person-centred care (Batson, Early, & Salvarani, 1997; Brooker, 2004; Lamm, Batson, & Decety, 2007; McCormack & McCance, 2006). A person-centred approach to managing and responding to the behaviour was conceptualised in terms of whether the response promoted the agency and freedom of the

other person (V), whether the management took account of the individual needs of the person (I), whether there was evidence of a compassionate response (P), and whether the response and management promoted a positive social environment (S).

Hypothesis 1: Greater perceptions of continuity in the relationship (as measured by the BRCM) will be associated with a more person-centred approach to understanding challenging behaviour (as evaluated by a system, devised for this study, for the coding of interview responses).

Hypothesis 2: Greater perceptions of continuity in the relationship (as measured by the BRCM) will be associated with a more person-centred approach to responding to and managing challenging behaviour (as evaluated by a system, devised for this study, for the coding of interview responses).

## METHOD

### Recruitment

G\*Power (version 3.1.5; Faul, Erdfelder, Lang, & Buchner, 2007) was used to complete a power analysis for the required sample size. With the power set at 0.80 and the alpha level (two-tailed) at 0.05, a sample of 26 would be required to detect a large effect correlation ( $r = 0.50$ ) and a sample of 82 would be required to detect a moderate effect correlation ( $r = 0.30$ ). The intention, therefore, was to recruit a minimum of 26 spouses. This target was achieved and 26 spouses took part.

Ethical approval was given by the University of Birmingham Science, Technology, Engineering and Maths Ethics Committee (Appendix 1). The inclusion criteria for spouses were that: their partner had an ABI at least 9 months ago but no more than 15 years ago, they lived together before the ABI, were still living together and had been in a relationship at least 5 years prior to the ABI. Participants were recruited through the national and local services provided by Headway (a non-governmental organisation providing support for people after brain injury).

Staff and/or volunteers in the organisations emailed a research flyer (Appendix 2) to carers whom they believed would fit the recruitment criteria and would have an interest in the project, and some also displayed the flyer as a poster at their premises. The researcher attended carers' groups at the organisations where possible to promote the research by distributing flyers and answering questions. The national Headway Brain Injury Association

promoted the study through an online advert of the research flyer on their website, and tweets on Twitter which linked to the advert. The research flyer contained the researcher's telephone number and email address for spouses to make contact if they wished to receive further information. Spouses were asked to provide their name, telephone number and email or postal address. Some Headways received direct contact from spouses wishing to take part following receiving the research flyer. In these cases, with permission of the potential participant, Headway staff forwarded the contact details of those spouses to the researcher.

When a spouse contacted the researcher to express an interest in the study they were sent a Participant Information Sheet (Appendix 3) and the Participant Consent Form (Appendix 4) to help them decide if they wished to take part. They were contacted by the researcher by telephone or email at least 48 hours later, to answer any questions and to find out if they wished to participate. For those who wanted to take part, an appointment was booked at a convenient time and place. Three spouses who had expressed an interest in the study and received the Participant Information Sheet and the Participant Consent Form chose not to take part. Spouses who were interviewed face-to-face were met either in their home, at local Headway premises, or at the University of Birmingham. Nine of the twenty-six spouses were interviewed by Skype or telephone, due to their location across the United Kingdom. Written consent was gained by spouses completing the Participant Consent Form at the start of the research interview. This was received by post or via email for those taking part by Skype or telephone.

## **Participants**

Twenty-six participants took part in the study, 19 females and 7 males, who were either the partner or the spouse of a person with an acquired brain injury (ABI). Their ages ranged from 36 to 71 years old (mean =56.23). The majority were White-British (24), and one carer was of Asian ethnicity and one of non-British White ethnicity. The care-recipients were 7 females and 19 males, aged between 41 and 76 years old (mean =55.81), 21 were White British, 4 were from another White background, and 1 was from a Black/African/Caribbean background. The majority had experienced a stroke (19), but there were also care-recipients who had experienced a Traumatic Brain Injury (TBI, 6), a haematoma (1) or an abscess (1). The time since their ABI ranged from 11 months to 162 months (13 years, 6 months; mean = 68.42 months). The length of relationship between the spouse and their partner ranged from 10 years to 57 years (mean = 28.42 years). Participants came from across the UK, with most being recruited from centres in the Midlands and South West of England. Another spouse also took part in the study, but their results were excluded from the analysis, as their partner's ABI exceeded the criterion set for time since injury (15 years).

## **Data collection**

Spouses answered some demographic questions (Participant Demographics Questionnaire, Appendix 5), completed an adapted version of the Birmingham Relationship Continuity Measure (BRCM, Appendix 6) and took part in a semi-structured interview about their understanding and management of two frequently experienced challenging behaviours. The methodology followed that in Achiampong's (2011) research study.

## **Adapting the BRCM**

The Birmingham Relationship Continuity Measure (BRCM, Riley et al., 2013) was created as a quantitative measure of relationship continuity for spouses with dementia, which has been shown to have good reliability and validity. Cronbach's alpha for the full scale was 0.947, and test-retest reliability was 0.932; and similar levels of reliability have been found in another study (Riley, Evans, & Oyebode, 2016). Evidence of construct validity was provided by a predicted patterns of subscale correlations with the Closeness and Conflict Scale (Schofield et al., 1997) and the Marwit-Meuser Caregiver Grief Inventory (Marwit & Meuser, 2002). The BRCM consists of 23 items across five subscales, which are: relationship redefined (the extent to which the relationship has been redefined by the spouse), same/different person (the perception of the care-recipient as the same or a different person), same/different feelings (the extent the spouse has the same or different feelings towards the care-recipient), couplehood (the sense of being a couple, such as sharing decision making and having established patterns of interaction and communication), and loss (the extent of the experience of loss of the person and/or the relationship). Each item is rated on a five point Likert scale ('strongly agree' – 'strongly disagree'), with some items reverse scored. A higher score on the BRCM indicates a greater sense of continuity.

As the BRCM has been shown to have good reliability and validity, and because dementia is a disease of the brain which affects cognition, behaviour and personality similar to the consequences of an ABI, it was adapted for use with spouses of those with an ABI. A group of five experts by experience, some of whom were spouses, from a Headway carers group took part in a focus group in order to adapt the BRCM for use with spouses of those



with an ABI. They were asked for feedback on the clarity of the instructions to the BRCM, and for general feedback on the overall measure (see Appendix 7 for focus group script and questions). For each subscale the focus group participants were shown the relevant items and asked if the statements were clearly worded, whether they thought it was a good way of asking about that subscale, and from their experience whether they could imagine some spouses of people with a brain injury strongly agreeing with the statement, but others strongly disagreeing.

A small number of changes were made to the BRCM following the focus group. The group thought that the statements were all clearly worded and were a good way of asking about that subscale. However, they thought the instructions could be clearer, and so a short introductory paragraph was added to confirm that the measure is about changes in the spouse and the relationship since the ABI, and requesting spouses to think about how things were before the ABI and how they are presently. The group also identified two statements which they thought were less reflective of the experiences of spouses of those with an ABI. To reflect the differing nature of ABI compared to dementia, the following items were reworded: “he’s in a world of his own most of the time” was changed to “he is more interested in himself now than he is in me or our relationship” (item 1, couplehood subscale), and “he’s a shadow of his former self” was changed to “since the brain injury, his personality is very different” (item 7, same/different person subscale). This revised version of the BRCM has recently been evaluated and was found to have good reliability and construct validity (N. Yasmin, personal communication).

## **Semi-structured interviews**

Semi-structured interviews (Appendix 8) were used to allow spouses to talk freely about their experiences and to gain a rich picture of both their understanding and management of challenging behaviours. Spouses were first given three examples of common challenging behaviours (verbal/physical aggression, being unenthusiastic and sudden mood changes) and asked whether they occurred, and if so, how frequently. If these examples were not relevant to the spouse or occurred infrequently, they were asked to describe other challenging behaviours which occurred frequently. Spouses were then asked to choose two issues that they personally found particularly challenging.

Some of their choices did not include what would typically be considered as ‘challenging behaviours’, such as fatigue and not recognising people. However, it was considered that giving them the choice to discuss issues that they found challenging would provide more useful data than restricting their choice to what would typically be considered as challenging behaviours. Issues that they found particularly challenging seemed more likely to generate information about how they understood and tried to manage those issues, than ‘challenging behaviours’ that they did not experience particularly often or find particularly difficult. For the same reason, participants were asked to talk about what they individually found challenging, rather than asking all participants to talk about the same two issues. Participants chose to talk about a wide range of issues, for example angry outbursts, lacking motivation, obsessions about particular objects, being emotionally cut-off, avoiding places, and being socially inappropriate.

Taking each behaviour in turn, spouses were asked to describe that behaviour and/or a recent situation where the behaviour had occurred. They were then asked why they thought their partner behaved in that way, how they managed that behaviour, and whether they thought their strategies were successful or unsuccessful and why. They were also asked how their partner tried to manage that behaviour, as a way of prompting them to expand on their responses. Spouses were given the opportunity to share anything else about the behaviour, their understanding and their management of it which they thought would be useful to share with the researcher. It was hoped that these open questions would enable spouses to share the uniqueness of their experiences.

The semi-structured interviews were recorded using a digital recorder, and the recordings were transcribed and then deleted following transcription. The transcripts were anonymised and pseudonyms were used in the transcripts and in the reporting throughout this paper.

### **Data coding**

The VIPS model of person-centred care was used as the framework for coding the interview transcripts. The VIPS model reflects: “Valuing people with dementia and those who care for them (V), Treating people as individuals (I), Looking at the world from the perspective of the person with dementia (P), A positive social environment in which the person living with dementia can experience relative wellbeing (S)” (Brooker, 2004; p. 216). In developing the coding system, the aim was to create codes that captured 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. Creation of the codes involved an iterative process: A code and its definition were developed; two researchers then applied this to the coding of some interview data; the two researchers then met to compare the ratings and to discuss areas of uncertainty and lack of clarity. In the light of this discussion, the definition was revised and clarified. Once the final version of the codes was established, two researchers independently rated three whole interviews.

The codes and their definitions are shown in Table 1. For each code, there is an indication of which aspect of the VIPS model it addressed and whether it assessed the understanding of the behaviour or its management. There were 13 codes altogether; six addressed the understanding and seven addressed management. The Valuing aspect of the model is described by Brooker (2004) as being about respecting the care-recipient as a unique person and giving them power and control in their life. In coding the interview data, this was translated into consideration of whether there was a joint approach to managing behaviour and the situation, whether independence and decision making were encouraged, and the absence of a restrictive, controlling, authoritarian or paternalistic approach.

The Individual aspect of the model as described by Brooker (2004) concerns treating the other person as an individual and taking into account their individual needs, personal history, personality etc. Applying this to the present context, the interview data were evaluated for evidence of whether, in trying to understand the behaviour, the spouse had considered their partner's pre-injury personal history, relationship or personality, as well as evidence that they were responding in ways which were tailored to the individual's wishes, values, strengths and needs.

Brooker's (2004) account of the Perspective aspect of the VIPS model described seeing and understanding the world from the frame of reference of the care-recipient, and taking their point of view. This was translated in the present context into an evaluation of whether, in attempting to understand the behaviour, the participant engaged in an extensive reflection on their partner's personal motivations, thoughts, feelings or emotions and provided evidence of thinking or feeling about the situation from the perspective of their partner.

The final part of the VIPS model (Social) is described by Brooker (2004) as the need to create an environment that promotes positive relationships between people, recognising the therapeutic value of social and loving relationships, and connection with others. The interview data were evaluated in terms of whether the management of behaviour was causing distress to the care-recipient; whether there was an absence of a blaming or critical response which may also highlight the individual's difficulties; and whether management involved the spouse actively encouraging and facilitating their partner's involvement in valued social roles (such as parenting).

Table 1

*VIPS model codes and definitions*

| VIPS Category + code number | Understanding or Management |  | + 1 point | 0 point | - 1 point |
|-----------------------------|-----------------------------|--|-----------|---------|-----------|
| <b><u>V</u></b>             |                             |  |           |         |           |
| 1                           | <b><u>Management</u></b>    | <b><u>Partnership</u></b><br><u>Positive score:</u> Evidence that person with ABI has been actively involved in discussions about how best to deal with the issue; evidence that they are trying to deal with the issue as a couple rather than the partner alone; evidence that the person with the ABI is encouraged to self-manage the behaviour; evidence of the adjustments being joint adjustments, rather than individual; evidence of working together on solutions to the problems.   |           |         |           |
| 2                           | <b><u>Management</u></b>    | <b><u>Restrictive</u></b><br><u>Negative score:</u> Management/response to the issue is restrictive, controlling, authoritarian and/or paternalistic; involves denial of choice and freedom (but do not score as negative if limitation of choice is in context of providing a choice within a restricted range on the basis that the person struggles to cope with too much choice). Person with ABI is treated in ways more appropriate to a child rather than an adult. Participant takes over doing things because it is easier than letting the person with ABI do it. Deceit or manipulation is used to manage the situation (i.e. participant induces person with ABI to do something without the person with ABI being aware of being induced to do it; distraction doesn't typically involve manipulation or deceit because the person with the ABI knows they are being asked to do something else).<br><u>Positive score:</u> Explicit statement about wanting to avoid restrictive and controlling ways of dealing with the problem, or about the desire to strike the right balance; participant actively encourages independence and decision-making in their approach to the problem (even if this is within the context of introducing some limitations to the choice so that the person is not overwhelmed by too much choice). |           |         |           |
| <b><u>I</u></b>             |                             |  |           |         |           |
| 3                           | <b><u>Understanding</u></b> | <b><u>Pre-injury personal history</u></b><br><u>Positive score:</u> Understanding of the highlighted issue is partly in terms of pre-injury personal history - events, roles, activities or circumstances. Include jobs, traumas, achievements etc. For example, about lack of motivation: "I don't tell him straight out to do something, or to stop  |           |         |           |

|                 |                             |  |  |  |  |
|-----------------|-----------------------------|--|--|--|--|
|                 |                             | doing something. He did National Service and hated every minute of it. He really doesn't like being told what to do. I put it in terms of me asking for his help if I want him to do something." The implication here is that part of the reason for his unwillingness to do things is his dislike of being told what to do, and this, in turn, arises from his experience of doing National Service.  |  |  |  |
| 4               | <b><u>Understanding</u></b> | <b><u>Pre-injury relationship</u></b><br><u>Positive score:</u> Understanding of the highlighted issue is partly in terms of the <u>pre-injury</u> relationship that the participant shared with the person with the brain injury. For example, about person being argumentative "Our relationship was always a bit one-sided. He made all the decisions and I followed. But now I have to make so many of the decisions. And he can't handle it. He won't go along with what I suggest, even when he knows it's right."   |  |  |  |
| 5               | <b><u>Understanding</u></b> | <b><u>Pre-injury personality</u></b><br><u>Positive score:</u> Understanding is partly in terms of the <u>pre-injury</u> personality of the person with the brain injury. Personality refers to general patterns of behaviour, thoughts and feelings that characterize the individual (e.g. being fussy, outgoing, moody etc.). For example, about aggression "We stick to a routine. He was always a control freak, and wanted to know who was doing what when. If something happens now out of the ordinary, he can't cope with it because he doesn't know what's going on and he gets all confused if you try to tell him. That's when he can get aggressive."  |  |  |  |
| 6               | <b><u>Management</u></b>    | <b><u>Individually-tailored management</u></b><br><u>Positive score:</u> Management/response takes account of the individuality of the person with the ABI. Management strategy or response is tailored to the other's wishes, interests, values, strengths, individual psychological or social needs, and/or life history. Do not award a plus mark if the response directly addresses some worry or concern expressed by the person with the ABI: The wishes, worries or concerns of the other person should only be awarded a credit when the participant makes a connection between managing the behaviour and an expression on another occasion of these wishes, worries or concerns.   |  |  |  |
| <b><u>P</u></b> |                             |  |  |  |  |
| 7               | <b><u>Understanding</u></b> | <b><u>Deep understanding of personal motivations:</u></b><br><u>Positive score:</u> Understanding is in terms of beliefs about what motivates the person with the brain injury - likes and dislikes, goals, values etc. These should be distinguished from emotions (see below). Motivations are things that the person aspires to or works towards, or activities that the person does (avoids) because they enjoy/value (do not enjoy/reject)) Award plus mark only when the account suggests a deep understanding of the personal motivations of the other person, suggesting they have taken the perspective of the other person in trying to understand their behaviour. Do not award the mark if the evidence suggests only a surface understanding that |  |  |  |

|    |                             |  |  |  |  |
|----|-----------------------------|--|--|--|--|
|    |                             | does not involve any extensive reflection or knowledge about what motivates the other person. Example: <i>Surface</i> (do not award plus mark) - “I take him out for a walk to try to calm him down. He likes walking. It helps him relax.” <i>Deep</i> (award plus mark) - “He was, and still is, a very independent person, doesn’t like being reliant on anyone else, doesn’t like to be beholden to other people. Having to rely on other people so much gets to him.”   |  |  |  |
| 8  | <b><u>Understanding</u></b> | <b><u>Deep understanding of the thought processes of the other person:</u></b><br><u>Positive score:</u> Understanding is in terms of the content of the thoughts of the person with the brain injury. Thoughts include appraisals and interpretations of the situation, and only specific cognitions should be considered. Do not include references to general cognitive states or impairments (e.g. references to being ‘confused’ or ‘forgetful’). Award the plus mark only when there is evidence that the participant has thought in depth about what the other person is thinking, and has tried to take their perspective on the situation. Do not award the mark if the description of the cognitions is vague; does not refer to specific thoughts that the other person may have; or does not require the participant to take the perspective of the other person. Do not award the mark for instances where the participant is just repeating or paraphrasing what the person with the injury has said about what they are thinking, and there is no evidence that the participant has reflected on this to any meaningful extent.<br>Example: <i>Surface</i> reference (do not award plus mark) “I suppose it’s just the way he thinks about these things.” <i>Deep</i> reference (award the mark): “I try never to raise my voice when we get into that kind of situation. Loud voices to her mean that you’re getting at her, that you hold her responsible, and I don’t want her to think that I’m blaming her. Because I don’t blame her – it’s not her fault.” |  |  |  |
| 9  | <b><u>Understanding</u></b> | <b><u>Deep understanding of the emotional experience of the other person:</u></b><br><u>Positive score:</u> As for (8), but understanding is in terms of the emotions (as opposed to the cognitions) of the person with the brain injury. Distinguish from motivations (see code 7).<br>Example: <i>Surface</i> reference (do not award the plus mark): “He gets mood swings, and when he’s in a downer that’s when it will all kick off.” <i>Deep</i> reference (award the mark): “Sometimes when she starts banging on about something, I just try to give her a hug. I think the whole thing gets on top of her sometimes – you can see a look of panic in her eyes. I think then that she just needs a bit of TLC.”  |  |  |  |
| 10 | <b><u>Management</u></b>    | <b><u>Compassion:</u></b><br><u>Positive score:</u> Explicit expression of the participant’s own feelings of compassion for the person arising from consideration of their situation. Evidence that the partner is emotionally moved by a consideration of how difficult things are from the perspective of the person with the ABI.   |  |  |  |



| <b>S</b> |                          |   |  |  |  |
|----------|--------------------------|---|--|--|--|
| 11       | <b><u>Management</u></b> | <p><b><u>Causing distress:</u></b><br/> <u>Negative score:</u> Evidence that the partner’s way of managing the situation is causing distress to the person with the ABI and/or that that person is unhappy with the way they are dealing with it. Do not award negative score if person with ABI is distressed but is reported by participant to have explicitly endorsed the approach taken by the participant.</p>  |  |  |  |
| 12       | <b><u>Management</u></b> | <p><b><u>Blaming:</u></b><br/> <u>Negative score:</u> Evidence of a blaming, critical response, or a response that highlights the deficits and inadequacies of the person with the ABI to that person, or that highlights how much difficulty they are causing to those around them; evidence of angry, hostile or threatening responses. Only award negative score if there is evidence that the participant expresses this to the person with the ABI. Do not award negative score if participant expresses frustration in the interview, but there is no evidence that they express this to the person with the ABI.<br/> <u>Positive score:</u> Evidence of an encouraging positive approach (e.g. praise) in response to the highlighted behaviour; evidence that they reassure the person with the ABI and tell them they are not to blame, or that they normalise the behaviour.</p>   |  |  |  |
| 13       | <b><u>Management</u></b> | <p><b><u>Valued social roles:</u></b><br/> <u>Positive score:</u> Evidence that, as a means of managing the behaviour highlighted, 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. Do not award plus score simply because the person with the brain injury engages in these roles or activities – only score if there is evidence that the participant is active in bringing this about. Also do not award positive scores for engaging in activities that are related to the treatment or rehabilitation of the brain injury (e.g. attending Headway).<br/> <u>Negative score:</u> Award a negative score if there is evidence of the participant actively steering the person with the ABI away from these roles and from engaging with wider society. Do not award a negative score if the participant gives a clear justification of this action in terms of the needs and wishes of the person with the ABI (including safety issues).</p> |  |  |  |

To facilitate the coding of the data, a researcher went through the transcripts and highlighted passages that related to the understanding or management of the behaviours. The transcripts were then reviewed for evidence relating to each of the 13 codes. For each code, the participant was given a score of +1, 0 or -1. Scores of +1 indicated that there was some evidence in the interview of person-centred care in relation to that code. Scores of -1 indicated that there was some evidence of care that was at variance with a person-centred approach (e.g. a restrictive or paternalistic management strategy). Scores of zero indicated there was either no evidence in the interview relating to that aspect of person-centred care, or there was evidence of both a person-centred and a non-person-centred approach (in which case the positive and minus scores cancelled each other out and a zero was awarded). These scores were awarded according to the presence or absence of evidence matching the code; no account was taken of the frequency or extent of the evidence relating to the code. The number of times a participant referenced a particular factor was not incorporated into the analysis because of wide individual differences in the length and depth of the interview data provided by the different participants.

Two scores were derived from the coding process. A 'person-centred understanding' score was derived by adding together the scores for the individual codes relating to understanding (i.e. codes 3, 4, 5, 7, 8 and 9 in Table 1); for example scores of +1, 0, 0, +1, -1, and 0 on these six codes would result in a total person-centred understanding score of +1. Higher scores indicated a more person-centred approach. A 'person-centred management' score was derived by adding together the scores for the other individual codes (i.e. codes 1, 2, 6, 10, 11, 12 and 13 in Table 1), and again higher scores indicated a more person-centred approach.

Two examples are given here to illustrate the process of coding. One of the challenges highlighted by the participant in the following excerpt from the interview was her husband's poor memory and tendency to get confused.

“P: He gets quite anxious to do the right thing, so if he saw me bustling about in the kitchen, he might think it's tea time and he'd start laying the table; he's got no concept at all, it's like three o'clock in the afternoon and you've had your lunch two hours ago... and this is another example, last September, we were going to XXXX for a few days and we were meeting some friends there but my sister was coming with us as well. We'd had breakfast and cleared up and everything was ready and the cases were in the hall, and she arrived. So he saw her and started laying the table, because he thought she'd come for lunch or something, and yet, we were going away for four nights, and you're just about to leave and...

R: what do you do then?

P: I got really impatient with him, which is the worst thing you can do because by then he is, you know, he is trying to help, but, mmmm....”

This was coded as an example of 'blaming' (code 12, Table 1). The participant's response to dealing with the challenge was judged to involve a negative and angry response. In the second example, the two challenges selected by the participant were his wife's socially disinhibited behaviour and her lack of motivation, including her unwillingness to engage in social activities. In the extract, he links the two challenges:

“She was never an outgoing person, prior to the head injury; she would do enough in social circumstances, and enjoy friends and do stuff, but she wasn’t what you call an outward person. So that in itself is very different [i.e. the fact that she is now very reluctant to engage in any social activities with friends]. I don’t know whether she holds herself back because she knows the way she does react now [i.e. in a socially disinhibited way], and she has enough of a thought process going on in her head to evaluate that and understand that.”

This was coded as evidence of a ‘deep understanding of the thought processes of the other person’ (code 8, Table 1). The participant’s account indicated that he had reflected in some depth about his wife’s thought processes that might explain her reluctance to engage in social activities, and that he had considered the situation from her perspective.

Parts of a highlighted transcript and an accompanying coding form can be found as a further example of the coding process in Appendix 9.

## **Data analysis**

The hypotheses were tested by calculating the correlations between the BRCM scores, the *person-centred understanding* scores and the *person-centred management* scores. Prior to the analysis, these variables were checked for any missing data or outliers, and the normality of the distributions (using the Shapiro-Wilk test). There were no missing data or outliers, but all three variables showed a modest positive skew. Spearman’s rho was accordingly used for the correlation analysis.

Other analyses included calculating Cronbach's alpha for the three variables to assess the internal reliability of the measures. Three transcripts were rated independently by two researchers, and Cohen's kappa was used to estimate the inter-rater reliability. Finally, Mann-Whitney U-tests were used to compare scores on the three variables across different categorical demographic variables (specifically, gender and type of injury, but not ethnicity because there were insufficient numbers in the different categories) and Spearman's rho was used to correlate scores on the three variables with scores on continuous demographic variables (specifically, age of participant, age of person with the brain injury, time since injury and length of their relationship).

## RESULTS

### Descriptive data

Table 2 summarises the descriptive data for the BRCM scores, the *person-centred understanding* scores and the *person-centred management* scores. In terms of Cronbach's alpha, the BRCM showed very good internal consistency and the *person-centred management* variable was satisfactory, but the *person-centred understanding* variable was not. The latter result may reflect the very restricted possible range of this variable (0 to 4), the fact that most participants (22 out of 26) scored 0, 1 or 2 on it, and the fact that all but three participants obtained a score of zero on the 'pre-injury relationship' and 'deep understanding of the emotional experience of the other person (see Table 1).

Table 2

*Descriptive statistics for the BRCM, person-centred understanding and person-centred management*

| Total variables/factors      | Mean  | Standard deviation | Possible range | Obtained range | Cronbach's alpha |
|------------------------------|-------|--------------------|----------------|----------------|------------------|
| BRCM                         | 62.11 | 26.87              | 23 to 115      | 30 to 112      | 0.98             |
| Person-centred understanding | 1.38  | 1.17               | 0 to +6        | 0 to +4        | 0.29             |
| Person-centred management    | 1.15  | 2.26               | -4 to +7       | -2 to +6       | 0.71             |

Three interviews were rated independently by two researchers to evaluate the inter-rater reliability of the interview coding system. The level of agreement of coding was good

(kappa = .694; T = 4.889; p <.001), and would be considered ‘substantial agreement’ according to the categorization suggested by Landis and Koch (1977).

### Testing the hypotheses

Spearman’s rho correlations between the three variables (BRCM, *person-centred understanding* and *person-centred management*) are shown in Table 3. In support of the two hypotheses, BRCM scores showed a significant positive correlation with both the *person-centred understanding* and the *person-centred management* variables. Higher BRCM scores (indicating greater perceptions of continuity in the relationship) were associated with higher *person-centred understanding* scores (indicating a more person-centred approach to understanding challenging behaviours) and higher *person-centred management* scores (indicating a more person-centred approach to managing challenging behaviours)

Table 3

*Correlations between BRCM, person-centred understanding and person-centred management*

|                           | Person-centred understanding           | Person-centred management              |
|---------------------------|--|--|
| BRCM                      | 0.698; 95% CI: .489 to .835;<br>p<.001 | 0.614; 95% CI: .328 to .811;<br>p=.001 |
| Person-centred management | .491; 95% CI: .114 to .768;<br>p=.011  |  |

## Analysis of the demographic variables

Mann-Whitney U-tests were used to evaluate whether there were any differences between gender and type of injury (stroke vs. traumatic brain injury) on the BRCM, *person-centred understanding* and *person-centred management* variables. Ethnicity was not included because there were insufficient numbers of non-White British participants to make a meaningful comparison. No significant differences across these demographic groups were observed. Spearman's rho was used to correlate scores on the three variables with scores on 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 showed a significant negative correlation with time since injury ( $\rho = -.479$ ;  $p=.013$ ); that is, higher BRCM scores (i.e. perceptions of greater continuity) were associated with less time since injury. The *person-centred management* scores were significantly negatively correlated with participant age ( $\rho = -.418$ ;  $p=.033$ ) and with the length of the relationship ( $\rho = -.430$ ;  $p=.029$ ): that is, showing a more person-centred approach to management was associated with younger carers and with a shorter length of their relationship. No other correlations were significant. Not too much confidence should be placed in these significant findings because they were the product of multiple unplanned tests.



## DISCUSSION

This study aimed to examine the association between relationship continuity and spouses' understanding and management of challenging behaviour in partners with an ABI. In line with the qualitative research about relationship continuity (Bodley-Scott & Riley, 2016; Chesla et al., 1994; Lewis, 1998; Villa & Riley, in press; Walters et al., 2010), perceptions of greater continuity in the relationship were associated with a more person-centred approach to the understanding and management of challenging behaviours. The study thus provides some quantitative support for the suggestions made within the qualitative literature.

The BRCM had not been used previously with spouses of those with an ABI, although relationship continuity itself had been explored in qualitative studies (Bodley-Scott & Riley, 2015; Villa & Riley, in press). The current study therefore provides quantitative evidence of the role of relationship continuity in spouses of those with an ABI. Further, this revised version of the BRCM was found to have good internal reliability in this study and has recently been evaluated and found to have good reliability and construct validity (N. Yasmin, personal communication), and appears to be a useful tool for examining this concept in ABI.

### **Relationship continuity and understanding behaviour**

Part of the explanation of the link between relationship continuity and a person-centred approach to understanding challenging behaviour may be due to the fact that spouses who perceive relationship discontinuity no longer see their partner as the same person and that this may have an effect on the schemas they use to try to understand the behaviour. Whilst they

will have knowledge about their partner's pre-injury character and experiences, if they perceive their partner to have changed significantly they are unlikely to view this knowledge as relevant when trying to understand their partner's current behaviour. Therefore, the association found between continuity and the premorbid factors may be because spouses who perceive discontinuity may not use their pre-injury schema of their partner to understand current behaviour. In contrast, spouses who perceive continuity and therefore perceive their partner as mostly unchanged, are likely to view their pre-injury schema as still relevant to their understanding of their partner, and they appear to use that knowledge to explain current behaviour.

This fits with previous qualitative research which found that spouses who perceived continuity were more likely to use their pre-injury knowledge and understanding of their partner to understand their behaviour, and that those who perceived discontinuity were less likely or appeared less able to apply such knowledge, in both the context of dementia (Chesla, Martinson, & Muwaswe, 1994; Lewis, 1998; Walters, Oyebode, & Riley, 2010) and ABI (Bodley- Scott & Riley, 2015; Villa & Riley, in press).

Reduced use of explanatory schema about the pre-injury person may also contribute to the increased probability that those perceiving discontinuity fail to take the perspective of the person with the brain injury (i.e. to show deep understanding of personal motivations, thoughts and emotions – Table 1). Without a familiar schema of their partner to use to help them to understand their current behaviour, they may resort to more generic and medicalised schema. For example, to make sense of their behaviour they may use information they have been provided with about the 'symptoms' of ABI. In the context of dementia, spouses who

experience discontinuity have referred to their partner in depersonalised and objectifying ways, such as referring to ‘people with dementia’ and “people like that” (Walters, Oyebode, & Riley, 2010, p. 174). In ABI, spouses who perceived discontinuity also referred to their partners using depersonalised language, and understood behavioural changes in their partner in terms of the damage to the brain, and seemingly linked to this was their reliance on external support in terms of the behavioural changes (Villa & Riley, in press). If spouses who perceive discontinuity are using more generic and medicalised explanations of behaviour, rather than individual and personalised knowledge of their partner, they may be less likely to try to understand behaviour from their partner’s perspective.

Previous research about intimate relationships in general has suggested a link between the general quality of the relationship and attributions made about more challenging aspects of the relationship. For example, it has been found that in a poorer relationship, negative behaviours are more likely to be attributed to internal, global and stable causes, and to be perceived as intentionally hurtful, motivated by selfish concerns, and blameworthy, whereas the opposite attributions are made in relationships of a better quality (Bradbury & Fincham, 1990; Davey et al., 2001). As relationship discontinuity is associated with a reduction of positive feelings such as love and affection, and less satisfaction with the relationship, it may be that people who perceive discontinuity are less likely to engage in attributional thinking that seeks to understand the behaviour empathically. This could explain why spouses who perceived discontinuity in this study were less likely to take an empathic and person-centred approach and appeared to not consider their partner’s perspective when making sense of their behaviour. Instead, they may be more likely to engage in attributional thinking that involves blaming and negative attributions.

## **Relationship continuity and managing challenging behaviour**

Spouses who perceived continuity were more likely to respond to behaviour and manage behaviour in ways which were tailored to and value the individual, understood the individual's perspective and created a positive social environment for the person with an ABI. Spouses who perceived relationship discontinuity were less likely to respond using a person-centred approach.

Previous qualitative research has suggested that the management of behaviour is influenced by relationship continuity, where discontinuity tended to be linked with less person-centred and less individualised approaches to managing behaviour (Chesla, Martinson, & Muwaswe, 1994), and with responses that could be restrictive or controlling (Lewis, 1998). Villa and Riley's (2015) study of spouses of those with an ABI suggested that perceiving continuity may lead to using knowledge of the pre-injury partner to understand and consequently manage behaviour, and that perceiving discontinuity may lead to spouses relying on their knowledge of ABI to understand and manage behaviour.

The findings of the current study are in line with this previous research. It may be that for spouses who perceive their partner as relatively unchanged, they are more likely to use their previous knowledge of the person when responding to them, seeing that knowledge as still relevant; whereas spouses who perceive their partner as significantly different compared to pre-injury, may not draw on this knowledge to manage behaviour. Spouses who perceive continuity may also be more likely to view their partner as an individual, and respond with individualised interventions. Individualised interventions would likely consider the

individual's thoughts, feelings and personal motivations. This would be in contrast to spouses who perceive discontinuity and perhaps view their partner as a 'person with ABI' (Villa & Riley, in press), these spouses may instead draw on medicalised or general interventions for 'people with ABI' rather than reflecting on the partner's individual needs. Perceiving continuity in the relationship also includes continuing to perceive the relationship as a partnership, and this fits with responding to behaviour as a couple, which is part of the framework used that was adapted from the VIPS model of person-centred care (Brooker, 2004).

### **Demographic variables**

A number of significant correlations were found between demographic variables and the relationship continuity and person-centred variables. Perceptions of greater continuity were associated with less time since injury. Interestingly, a similar finding has been reported in dementia: Riley et al. (2013) reported that a longer time since diagnosis was associated with reduced perceptions of continuity. An explanation of this is, perhaps, more readily available in dementia. As the person with dementia deteriorates in terms of their abilities, it may be more difficult to hang on to the perception that the person and the relationship are essentially the same. However, in acquired brain injury, at least over the first few years, improvements in ability and function would be expected, rather than decline. Some other explanation of the association between time and continuity is required. Further exploration of this issue is merited. Also in the present study, a person-centred approach to the management of challenging behaviour was associated with the participant being younger in age, and their relationship with the person with the brain injury being shorter (both of which were,

unsurprisingly, also correlated highly with one another). Again, no ready explanation of this finding is available and further exploration of this issue is merited. Possibly, it reflects a cohort effect. The younger generation may be more likely to have pre-injury relationships characterised by equality in decision-making and more equal participation in valued social roles such as child care. These characteristics may be more likely to persist after the brain injury, which would have resulted in higher scores on the *person-centred management* variable. However, too much confidence should not be placed on these findings as a high number of these analyses were conducted without any expectation of the outcome the family-wise error rate is high, and some significant findings are likely to have occurred by chance.

### **Limitations**

The sample was not representative of the general population and therefore the generalisability of the findings is limited. The sample was largely White British and the couples were all in heterosexual relationships. Researching how couples from different backgrounds experience relationship continuity and challenging behaviour could be of interest. The quality of the relationship before the injury was not measured in this study, but the BRCM assumes that the previous relationship was of reasonable quality and Riley et al. (2013) recommended using a measure of pre-morbid relationship quality alongside the BRCM. Previous research has also suggested that the quality of the relationship pre-injury may play a role in relationship continuity (Lewis, 1998; Walters, Oyebode, & Riley, 2010). For example, it has been suggested that those with less positive premorbid relationships may be more likely to experience discontinuity (Chesla, Martinson, & Muwaswe, 1994). The type of brain injury experienced by the partners was not homogeneous and included both stroke and traumatic

brain injury, as well as other types of injury. The relatively small sample size precluded a meaningful exploration of whether diagnosis made a difference to the relationship between continuity and response to challenging behaviour.

This was a correlational study, and therefore only associations and not any causal relationships can be identified from the findings. Further quantitative research should be conducted to ascertain if perceptions of relationship continuity have a causal relationship with understanding and managing partners' challenging behaviour. Identifying any mediating variables would be beneficial, as it may be that maintaining an internal working model of the partner is what links relationship continuity with understanding and managing behaviour, as suggested previously.

The BRCM was adapted for use with an acquired brain injury population and there is only limited evidence for its validity and reliability when used in this context (N. Yasmin, personal communication). The person-centred coding system was devised specifically for this study. Although inter-rater reliability was good, further evidence is required to establish confidence in this. Furthermore, the internal reliability for the *person-centred understanding* variable was poor. Although a possible account of this was offered earlier that may explain the outcome in terms that do not undermine the accuracy of the measure as an indicator of the extent to which the participant's attempts to understand are person-centred, nevertheless confidence in results involving this variable is reduced.

In order to measure spouses' understanding and management of challenging behaviour, they were scored in terms of whether or not they had provided an explanation referring to that

factor at any point during their interview. Using a frequency count of the number of times spouses used a particular explanation was considered problematic. The length and depth of interview data provided by participants varied greatly, meaning an absolute frequency count was inappropriate. Further, some participants repeated the same explanation in different ways during their interview, meaning that using the relative frequency of explanations was also problematic. Therefore, whilst the measure used was a fairly crude index of the extent that spouses used pre-morbid or person-centred explanations for behaviour, and is likely to have reduced the likelihood of finding significant results, it was considered the most appropriate.

The study's methodology meant that the procedure was not the same for all participants. For example, spouses chose which behaviours they talked about, and there was a lot of variation in the behaviours described, including some which were more cognitive or physical, such as fatigue and confusion. Previous research has suggested that non-personality and non-behavioural changes are less challenging than physical or cognitive changes (Mitchley, Gray, & Pentland, 1996), and that relationship continuity may be influenced more by particular behaviours compared to others (Poveda et al., 2017). Further, some behaviours, such as lack of motivation, may more readily lend themselves to explanations which draw on the spouse's knowledge of the person pre-injury, compared to behaviours which are caused by cognitive deficits, such as confusion. Although in enabling participants to discuss the behaviours which they found challenging and did experience, rather than more typically expected challenging behaviours, spouses were probably more likely to have provided more useful information around their understanding and management of the behaviours. The breadth of behaviours discussed is a potential limitation of the results, and it may be beneficial to



explore the association between continuity and spouses' understanding of specific types of behaviours.

The study used semi-structured interviews which provided spouses with the opportunity to think in-depth about their understanding and management of challenging behaviour, and to share their own unique experiences in their own words. However, by following each spouse's unique description of their experiences meant that the questions in the interviews were asked in different orders and in slightly different ways, and different follow-up questions were asked. Further, in talking about challenging behaviour and relationship discontinuity, spouses were sharing difficult aspects of their everyday experiences, and may have limited or altered their responses to be more socially desirable. However, this did not appear to be the case as many spouses described difficult feelings and experiences, and perceptions of discontinuity.

In giving explanations for challenging behaviour, several spouses initially responded by stating they did not know the reasons for their spouse's behaviour. With further prompting all the spouses identified some explanations for behaviour, although some identified only a few reasons compared to other spouses. Spouses of ABI have previously been found to struggle to understand their partner's behaviours (Bodley-Scott & Riley, 2015). It may be useful to investigate how frequently spouses try to understand their partner's challenging behaviour, and the factors influencing this. It may be that spouses who are particularly stressed and overwhelmed with caring for their partner may be less able to reflect on the reasons for challenging behaviour. Research has shown that the impact of the ABI on a spouse's daily life can be great, and can influence their feelings and their sense of relationship continuity

(Bodley-Scott & Riley; Poveda et al., 2017; Walters, Oyeboode, & Riley, 2010). However, spouses' feelings and their perception of their coping ability were not explored in this study.

## **Implications**

This research has shown that spouses of those with an ABI can vary in their experience of relationship continuity, and that relationship continuity is associated with how spouses understand, manage and respond to their partner's challenging behaviour. If these findings are subsequently replicated and found to be robust, healthcare professionals could support spouses to perceive continuity in their partner and relationship where possible. Spouses could also be supported to understand their partner's behaviour through reflecting with them on the partner's past character and their partner's current experiences and perspective. These aspects of the individual could also be shared with healthcare professionals who may benefit from understanding the person with the ABI in this manner. A number of spouses remarked at their surprise that they were not the only person who experienced discontinuity, and increased awareness of the concept of relationship discontinuity may be beneficial. Being the spouse of a person with an ABI can be a challenging experience, and general emotional and practical advice is likely to also be valued.

In terms of managing behaviour, it appears that spouses' experiences of relationship continuity may affect the quality of care and support they provide to their partner. If the person with ABI receives less person-centred care the management of behaviour may be less effective (Bodley-Scott & Riley, 2015), and may lead to a negative impact on the sense of agency, personhood and self-worth of the person with the ABI. If this is the case, it would be beneficial

to further explore the impact of interventions designed to help spouses maintain a sense of relationship continuity following an ABI, both in terms of the impact on the level of person-centred care and the outcomes for the person with the ABI.

## **Conclusions**

This study provides some quantitative support that spouses who perceive relationship discontinuity understand challenging behaviour less in terms of their knowledge of their partner's premorbid character, and less in terms of considering their partner's perspective, compared to spouses who perceive continuity. Further, that perceptions of relationship continuity are associated with managing behaviour in a person-centred manner. However, a larger sample size would have been preferable and further research should be conducted to replicate these findings. It should also be noted that much of the research about relationship continuity and understanding behaviour is taken from the research literature regarding spouses of those with dementia, and further research with spouses of ABI should be conducted.

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## **PUBLIC DISSEMINATION DOCUMENT**

This document provides a summary of the research study included in the thesis submitted by Hayley Keeble for the degree of Doctorate of Clinical Psychology at the University of Birmingham.

### **Relationship continuity and understanding challenging behaviours in spouses/partners of those with an acquired brain injury**

#### **Introduction**

Acquired brain injuries (ABI) include damage to the brain such as through a traumatic event (e.g. a road traffic or sports accident), or through other causes such as a stroke. Individuals with an ABI may experience physical, cognitive, behavioural and/or personality changes. Spouses (including partners who are not married) of those with an ABI can experience distress in caring for their partner regarding these changes, especially if the changes are experienced as challenging, such as if a partner is lacking motivation or is aggressive.

Given these potential changes in the partner following the ABI, the spouse may experience their partner and their relationship as particularly different, for example they may feel like they are living with a stranger and feel more like a carer than a spouse. Perceptions of change in the partner and/or the relationship is called relationship discontinuity, and perceptions of little or no change is called relationship continuity. Previous research has found that for spouses of a person with dementia, relationship continuity and discontinuity is linked



to how spouses understand their partner's challenging behaviour and how they manage that behaviour. Some research in ABI has also suggested these links. It appears that spouses who experience continuity in their partner and relationship may use their knowledge of their partner pre-injury to understand their challenging behaviour, and may, as a result, take a more person-centred perspective when understanding their behaviour (e.g. thinking about the situation from their partner's perspective). For example, a spouse who perceives their partner as mostly unchanged may understand their new aggressive behaviour in terms of their previous character of being irritable and short-tempered, or in terms of their partner feeling frustrated and upset about their current situation. However, those who perceive their partner and their relationship to be very different following the ABI may instead take a more medical understanding of their behaviour, using their knowledge about ABI in general. These differences in understanding behaviour may also influence how spouses manage challenging behaviour.

The current study aimed to explore the relationship between spouses' perceptions of relationship continuity and their understanding and management of challenging behaviour.

## **Method**

Twenty-two spouses of individuals with an ABI took part in this study. They completed the Birmingham Relationship Continuity Measure which is a questionnaire that measures perceptions of relationship continuity. The questionnaire was used previously with spouses of those with dementia, and was adapted for use with spouses of those with ABI following a focus group at a local Headway (an organisation providing support for people after brain injury). Participants also answered some questions about how they understood and

managed two of their partner's behaviours which they found challenging. The transcripts were reviewed to examine whether spouses used their past knowledge of their partner or if they thought about the situation from their partner's perspective, when trying to understand their partner's behaviour.

## **Results**

The results found that spouses who experienced relationship continuity rather than discontinuity understood their partner's challenging behaviour more in terms of:

- their knowledge of their partner pre-injury, and specifically in terms of their partner's pre-injury personal history e.g. they behave like that because they always did that for their job
- taking their partner's perspective such as considering their partner's emotions and personal motivations (likes, dislikes, goals, values) e.g. they behave like that because they feel they are missing out and feel upset about it

## **Discussion**

This study found a relationship between how a spouse perceives their partner and their relationship to be different or the same following an ABI, and how they understand their partner's challenging behaviour. It may be that spouses who perceive their partner to be similar to before the ABI are more likely to use their knowledge of them pre-injury to understand their

behaviour because they perceive it as still relevant. Spouses who perceive their partner to be very different since their injury may not see their knowledge of their partner pre-injury as relevant, and may therefore ignore such knowledge when trying to understand their partner's behaviour. In doing so they may resort to using more generic and medical knowledge of ABI to understand their behaviour. This could lead to a less personal understanding of their partner, and spouses being less likely to consider their partner's perspective. In future research it would be useful to explore whether the differences in how spouses understand behaviour lead to differences in how they try to manage that behaviour.

**VOLUME I: APPENDICES**

**Appendices for empirical paper**

**Appendix 1: Letter Of Ethical Approval Of Research Study**

Removed for confidentiality

Removed for confidentiality

## Appendix 2: Research Flyer/Poster

# LIVING WITH A PARTNER WITH A BRAIN INJURY?

We are looking for people to take part in a research project about relationships following brain injury.

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School of Psychology  
Frankland Building  
University of Birmingham  
Edgbaston, B15 2TT  
Tel: XXXXXXXXXXXX  
Email: XXXXXX

### What is the research about?

How wives/husbands/partners of someone with a brain injury feel about their relationship following the injury, and how this has an impact on how they understand and manage difficult situations that may arise with their spouse/partner.

### What will you have to do?

- Meet with the researcher (myself) for between 45 and 75 minutes
- At a time and date suitable to you
- By telephone/Skype or face-to-face where possible, in a private and convenient location
- Complete a questionnaire and answer some questions

### Am I eligible to take part?

You can take part in this research if you answer 'yes' to all of the following questions:

- Does your wife/husband/partner have a brain injury (including traumatic brain injury (head injury), stroke (including haemorrhagic strokes), brain tumours, brain infections (e.g. encephalitis) and anoxic brain injury (i.e. brain has been starved of oxygen such as by drowning))
- Did you live together before the brain injury?
- Are you still living together?
- Were you in a relationship for at least 5 years prior to the brain injury?
- Did your wife's/husband's/partner's brain injury happen at least 9 months ago?
- Did your wife's/husband's/partner's brain injury happen less than 10 years ago?

### I am interested, what do I do next?

Please contact Hayley by email: XXXXXX or telephone:

XXXXX XXX XXX (message may be left on answerphone). Please provide your:

- Telephone number
- Email or postal address

Further information about the project will be sent after receiving your request.

**With many thanks, Hayley Keeble**, Trainee Clinical Psychologist, University of Birmingham  
Supervised by Gerry Riley, University of Birmingham

## Appendix 3: Participant Information Sheet

Participant Information Sheet version 2: 04.01.16

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### PARTICIPANT INFORMATION SHEET

*Title of Project:* Experiences of spousal carers of those with a brain injury.

*Researchers:* Hayley Keeble, Trainee Clinical Psychologist, supervised by Gerard Riley

This participant information sheet provides information regarding a research project that is part of my Clinical Psychology Doctorate course.

#### **What is the purpose of this research?**

The purpose of the research is to find out more about the experiences of spouses/partners of those with a brain injury. More specifically, I am interested in spouses'/partners' experiences of managing difficult situations and how this is linked to their experience of their relationship.

#### **Why have I been invited to take part?**

You have been invited to take part because you are a spouse/partner of a person with a brain injury. The other criteria for taking part are that you will have been in a relationship with your spouse for at least 5 years prior to the brain injury and you will have lived together both before their brain injury and now. Your spouse's brain injury will have occurred more than nine months prior to you taking part in this study.

#### **Do I have to take part?**

Participation is completely voluntary, you do not have to take part. If you choose to not take part this will not affect your or your spouse's/partner's care in any way.

#### **What will happen to me if I agree to take part?**

I will contact you by telephone/email at least 24 hours after you have received this information sheet, in order to give you time to consider your participation. When I telephone/email you I will aim to answer any questions that you may have, discuss the study and find out if you wish to take part. If you do, we will arrange to meet at a convenient time and location. If you do not wish to meet at your home, we may be able to make alternative arrangements and I am able to offer travel expenses of up to £10 per carer. If we are geographically far apart, the research can take place by telephone or Skype.

It is recommended that your spouse/partner is not present during the visit due to the nature of the questionnaires and interview. Therefore, if we are meeting face-to-face and your spouse



requires round-the-clock care and there is no alternative care available for your spouse/partner, unfortunately you will be unable to take part in the study.

During the meeting I will complete two questionnaires with you, and an interview. The questionnaires will include questions such as the length of your relationship, the length of time since your spouse/partner had their brain injury, and how you experience your relationship. The interview will be based on situations you have experienced whilst caring for your spouse/partner. I will ask you about difficult situations you may have experienced with your partner, such as them becoming verbally aggressive or lacking motivation. I will ask you some questions about such situations, specifically, why you think your partner responded in that manner and what you have found helpful in dealing with the situation.

The time of the meeting is estimated to take between 45 and 75 minutes. The interview part of the meeting will be audio recorded, to ensure that nothing you say will be missed. You will have the opportunity to ask questions during the meeting and I will check at the beginning and end that you are happy to participate. Further, information regarding support for yourself will be provided during the meeting.

I will provide you with my email address and telephone number, and you may choose to withdraw all or part of your interview by contacting me within two weeks of completing the interview. If you withdraw you will not be asked why and it will not impact on the care you or your spouse/partner receives. Once the research is complete you will receive a summary of the results, if you wish.

### **How will my information be stored?**

I will record the part of our meeting where I ask you some questions. I will record this on a password protected audio recorder. The audio files will be encrypted and once transcribed the recording will be deleted. Paper files, such as your Consent Form and completed questionnaires will be kept secure in a locked cabinet at the University of Birmingham. Data files such as the results from the questionnaires will be anonymised and password protected on a computer. Transcripts of the audio tapes will also be anonymised.

After the research is complete the transcripts of the audio-tapes and the data from the questionnaires will be held securely by the academic supervisor at the University of Birmingham for 10 years (up until September 2027). This is in line with the American Psychological Association and the University of Birmingham guidelines. Paper documents such as the questionnaires, Consent Forms and Contact Details Forms (a sheet of paper where I will write your contact details as given to me by you) will be destroyed once the research is completed.

### **Will my responses be confidential?**

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Your responses will be anonymised and pseudonyms will be used. I will have access to your responses and the other personal information that you will have given me (e.g. your contact details). Only relevant staff at the University of Birmingham would also have access to this information, for example my academic supervisor. The anonymised transcripts will also be seen and analysed by another person, such as another Clinical Psychology Doctorate Course trainee.

If I am concerned about any risk to you or your spouse/partner I will discuss this with my academic supervisor and may need to pass on information to other relevant professionals. For example, I may speak to your local Headway if I believe you or your partner/spouse would benefit from further support. They may choose to speak with you and/or your partner/spouse further to offer further advice and/or support. If I have concerns that there are serious risks to yourself or another I may be obliged to contact the local social services safeguarding department. I would always aim to speak to you about this before I took any further action. If there appeared to be an immediate and serious risk to any person I would report this straightaway to the emergency services and to the local social services safeguarding department.

### **What are the benefits and disadvantages of taking part?**

There are no direct benefits to taking part. Alternative care for your spouse/partner will need to be arranged by yourself, and unfortunately we cannot support you with this or provide expenses for this. I can offer £10 per carer for travel expenses where the carer is not met in their own home. The total time taken for participation could be between 1 hour 15 minutes and 1 hour 45 minutes depending on the time taken during the home visit and time taken to read the relevant materials (such as this information sheet). Individuals may find it helpful to discuss their experiences during the interview. However, answering questions and discussing the changes in your spouse/partner and your relationship, as well as the difficult situations you experience may be upsetting. Information for further support is provided below and will be provided during the meeting.

### **What will happen if I do not want to carry on with the study?**

You can withdraw from the research at any time before, during or after the study. You may telephone or email me up to two weeks after the visit if you would like to withdraw your interview in part or in full. However, after that time once anonymised data is analysed it is not possible to withdraw that data. If you withdraw you will not be asked why and it will not impact on the care you or your spouse/partner receives. You can withdraw by contacting me on the details below.

## **Expenses and payments**

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If we do not meet at your home, I am able to offer up to £10 per carer as travel expenses to another location that would be more suitable and convenient, such as a local Headway.

## **What will happen to the results of the research study?**

The anonymised results will be published as part of my doctoral thesis, which will be stored at the University of Birmingham. The results may also be published in a peer-reviewed journal and/or presented at a conference. If you wish, you will receive a summary of the research results. Carers groups may also receive a summary of the results. Any direct quotes used will be anonymised and pseudonyms will be used.

## **What happens if I have any further concerns?**

If you have any further concerns or questions, please contact me on the details below, or speak to me when I contact you.

## **How do I make a complaint?**

If you wish to make a complaint about any part of this research, you can do so by contacting my supervisor, Gerry Riley at the University of Birmingham. Alternatively, you can contact Kimron Shapiro, Head of Psychology, at the University of Birmingham. The contact details for both are by telephone: 0121 414 4932 or by post: School of Psychology, Frankland Building, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

## **What do I do if I need further support?**

If at any time you require further support, please contact your GP or your local Headway (please visit <http://headway.org.uk/>).

Thank you for your time in reading this information sheet.

If you would like to discuss any aspect of this research please contact myself, Hayley Keeble, by:

Email: XXXXXX  
Telephone: XXXXX XXX XXX  
Post: Hayley Keeble, Trainee Clinical Psychologist, University of Birmingham,  
School of Psychology, Edgbaston, Birmingham B15 2TT

**Appendix 4: Participant Consent Form**

**CONSENT FORM** version 2: 04.01.16

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Participant Identification Number:.....

*Title of Project:* Relationship factors and understanding difficult behaviours in spouses/partners of people with an acquired brain injury

*Researcher:* Hayley Keeble, Trainee Clinical Psychologist, supervised by Gerard Riley

Please initial box

1. I confirm that I have understood the information sheet dated 4 January 2016 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my own or my partner/spouse's medical/social care or legal rights being affected.
3. I understand that the research interview will be audio-recorded, and that it will be transcribed by the researcher or a professional transcriber.
4. I understand that the personal and research data held will be kept securely and deleted within recommended time frames.
5. I understand that following the research interview I will have a two-week period for reflection. The researcher will provide me with their contact details and up to two weeks after the interview I may contact them to withdraw my interview entirely or in part, without giving any reason, without my own or my partner/spouse's medical/social care or legal rights being affected.
6. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to relevant professionals but only if any previously undisclosed issues of risk to me or my family member's safety should be disclosed.
7. I understand that direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.
8. I agree to take part in the above study.

.....  
Name of participant                      Date                      Signature

.....  
Name of researcher                      Date                      Signature

**Appendix 5: Participant Demographic Questions**

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**Demographic Questions**

Participant code:

Your gender:

Your spouse/partner's gender:

Your age:

Your spouse/partner's age:

Your ethnicity:  
(please choose from list below)

Your spouse/partner's ethnicity:  
(please choose from list below)

**White**

1. English/Welsh/Scottish/Northern Irish/British
2. Irish
3. Gypsy or Irish Traveller
4. Any other White background, please describe

**Mixed/Multiple ethnic groups**

5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed/Multiple ethnic background, please describe

**Asian/Asian British**

9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background, please describe

**Black/ African/Caribbean/Black British**

14. African
15. Caribbean
16. Any other Black/African/Caribbean background, please describe

**Other ethnic group**

17. Arab
18. Any other ethnic group, please describe

How long have you been in a relationship with (spouse/partner's name)?:

How long has it been since (spouse/partner's name) brain injury?:

What kind of brain injury did your partner have?

Traumatic brain injury (head injury) / stroke / infection of the brain /

Other (please specify).....

**Appendix 6: Adapted Birmingham Relationship Continuity Measure**

**Birmingham Relationship Continuity Measure**

This questionnaire is about changes in your husband (partner), and in your relationship with him, since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully. Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response. Please answer ALL the questions.

**Example**

|  |  |                |       |          |          |                   |
|--|--|----------------|-------|----------|----------|-------------------|
|  | Caring for my partner can be difficult | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
|--|--|----------------|-------|----------|----------|-------------------|

|   |  |                |       |          |          |                   |
|---|--|----------------|-------|----------|----------|-------------------|
| 1 | He is more interested in himself now than he is in me or our relationship.       | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 2 | The brain injury has brought us closer together emotionally.                     | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 3 | I miss having someone to turn to when I need some comfort or support.            | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 4 | I care for him, but I don't love him the way I used to.                          | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 5 | We still do things together that we both enjoy.                                  | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 6 | I feel like his carer now, not his wife (partner).                               | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 7 | Since the brain injury, his personality is very different.                       | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 8 | I don't feel about him the way I used to.  | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 9 | Our relationship has changed beyond recognition since the brain injury happened. | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |

|    |   |                |       |          |          |                   |
|----|---|----------------|-------|----------|----------|-------------------|
| 10 | Despite all the changes, he's still his old self.                               | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 11 | The bond between us isn't what it used to be.                                   | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 12 | I miss having someone to share my life with.                                    | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 13 | Sometimes I feel it's like living with a stranger.                              | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 14 | I feel shut off from him.   | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 15 | We face our problems as a couple, working together.                             | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 16 | Despite all the changes, our relationship has remained much the same as it was. | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 17 | Compared to how he used to be, he's a different person altogether now.          | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 18 | I feel like I've lost the person I used to know.                                | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 19 | It's like there's a barrier between us now.                                     | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 20 | I don't feel I really know him any more.  | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 21 | The bond between us is as strong as ever.                                       | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 22 | He still has many of the same qualities that first attracted me to him.         | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
| 23 | It doesn't feel like a partnership any more                                     | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

## **Appendix 7: Focus Group Script and Questions**

### **INTRODUCTION**

#### **Who am I?**

I am a Clinical Psychologist in Training at the University of Birmingham and with the XXX NHS trust. As part of my doctorate research I am looking at the experiences of carers of those with a brain injury, and this focus group is part of an introductory piece of work I am completing before I begin interviewing people about their experiences. After the new year I will start telling people about that bit of work, if they want to take part or find out more.

#### **What is the purpose of the study?**

We want to investigate whether a questionnaire called the Birmingham Relationship Continuity Measure, which was developed for use in dementia, can be used in traumatic brain injury as well. In this stage of the study, we want to ask some spouses/partners of people with a traumatic brain injury what they think of the questionnaire. We will then revise the questionnaire in response to the feedback we get. In a later stage of the study, we will ask people to complete the questionnaire, along with some other questionnaires, to see how useful it is as a measure of what happens to relationships after a brain injury. Once we have revised the questionnaire and evaluated its effectiveness, we hope we will have a questionnaire that can be used to investigate more effectively what happens to relationships after a traumatic brain injury.

#### **What will I have to do?**

You will be shown the Birmingham Relationship Continuity Measure and asked for your opinion about it. This should take no more than 60 minutes of your time. You will not be asked to fill in the questionnaire. If you think something isn't clear or isn't relevant to carers of those with a brain injury I may ask you to say a bit more about why it doesn't seem relevant or isn't clear.

#### **Do I have to take part?**

No, there is no obligation on you to take part. You can leave this group or not answer the questions at any time.

#### **Are there any risks to taking part?**

The information you give will be anonymous.

The questionnaires do ask personal and sensitive questions about relationships after brain injury. You will not have to answer these questions, but if you think that you may find reading them too upsetting, please do not take part.

#### **What will happen to the information I provide?**

The information will be used to decide whether the questionnaire needs revising or rewording before it is assessed in a later stage of the study.

There are two versions of the Birmingham Relationship Continuity Measure, one for use when the person with the brain injury is male, and one for use when the person with the brain injury



is female. Only the male version is shown here. The female version is identical, but uses ‘she’ instead of ‘he’.

### Instructions

Show the group the instructions

This questionnaire is about your husband (partner) and your relationship with him since the brain injury. Please do not answer the questions with reference to how husband (partner) or your relationship was before the injury.  
 Please read each question carefully.  
 Circle the response that best expresses your view (as shown in the example).  
 If you change your mind, cross it out and circle another response.  
 Please answer ALL the questions.

### Example

|   |                    |                       |                |                          |                       |
|---|--------------------|-----------------------|----------------|--------------------------|-----------------------|
| <b>Caring for my partner can be difficult</b> | <b>Agree a lot</b> | <b>Agree a little</b> | <b>Neither</b> | <b>Disagree a little</b> | <b>Disagree a lot</b> |
|---|--------------------|-----------------------|----------------|--------------------------|-----------------------|

### Ask

Do you feel these instructions are clear? Yes / No

If you answered ‘No’, please explain your answer

### Items

Next you will see all the items from the questionnaire. These are grouped according to what they are supposed to be measuring. An explanation will be given of what each set of questions is supposed to be measuring. Please give your opinion about each item. If you say ‘no’ to any of the questions, I’ll ask you a bit more about that.

#### Feels like the same/different kind of relationship

The first set of items is meant to measure whether, since the injury, the relationship no longer feels like a husband/wife/partner relationship, but feels like a different sort of relationship (discontinuity) or still feels basically like the same kind of relationship (continuity)

|   |   |             |                |         |                   |                |
|---|---|-------------|----------------|---------|-------------------|----------------|
| 9 | Our relationship has changed beyond recognition since the brain injury. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the relationship feels different/ basically the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered 'No' to any of these questions, please explain your answer

|   |  |             |                |         |                   |                |
|---|--|-------------|----------------|---------|-------------------|----------------|
| 6 | I feel like his carer now, not his wife (partner). | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the relationship feels different/ basically the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered 'No' to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 16 | Despite all the changes, our relationship has remained much the same as it was. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the relationship feels different/ basically the same? Yes/No

- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered ‘No’ to any of these questions, please explain your answer

Spouse/partner feels like a different/the same person

This set of items is meant to measure whether the person feels that, since the injury, the spouse/partner feels like they have changed in some fundamental way (discontinuity) or is essentially the same person despite the changes (continuity).

|   |                                   |             |                |         |                   |                |
|---|-----------------------------------|-------------|----------------|---------|-------------------|----------------|
| 7 | He’s a shadow of his former self. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|-----------------------------------|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered ‘No’ to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 10 | Despite all the changes, he’s still his old self. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

- If you answered ‘No’ to any of these questions, please explain your answer

|    |  |             |                |         |                   |                |
|----|--|-------------|----------------|---------|-------------------|----------------|
| 13 | Sometimes I feel it’s like living with a stranger. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|    |  |             |                |         |                   |                |
|----|--|-------------|----------------|---------|-------------------|----------------|
| 17 | Compared to how he used to be, he’s a different person altogether now. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 20 | I don't feel I really know him anymore. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 22 | He still has many of the same qualities that first attracted me to him. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

Feelings for the person are the same/very different

This set of items is meant to measure whether, since the injury, the feelings that the person has for their spouse/partner have changed in some fundamental way (discontinuity) or are essentially the same (continuity).

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 19 | It's like there's a barrier between us now. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No

- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

|   |  |             |                |         |                   |                |
|---|--|-------------|----------------|---------|-------------------|----------------|
| 2 | The brain injury has brought us closer together emotionally. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

|   |   |             |                |         |                   |                |
|---|---|-------------|----------------|---------|-------------------|----------------|
| 4 | I care for him, but I don't love him the way I used to. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No

- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|   |   |             |                |         |                   |                |
|---|---|-------------|----------------|---------|-------------------|----------------|
| 8 | I don't feel about him the way I used to. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 11 | The bond between us isn't what it used to be. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|    |                           |             |                |         |                   |                |
|----|---------------------------|-------------|----------------|---------|-------------------|----------------|
| 14 | I feel shut off from him. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---------------------------|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 21 | The bond between us is as strong as ever. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

#### Whether it feels like a partnership or not

This set of items is meant to measure whether, since the injury, the relationship no longer feels like a partnership (discontinuity) or still feels like a partnership (continuity).

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 15 | We face our problems as a couple, working together. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No



- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|   |   |             |                |         |                   |                |
|---|---|-------------|----------------|---------|-------------------|----------------|
| 5 | We still do things together that we both enjoy. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership?? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|    |   |             |                |         |                   |                |
|----|---|-------------|----------------|---------|-------------------|----------------|
| 23 | It doesn't feel like a partnership any more | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership?? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|   |  |             |                |         |                   |                |
|---|--|-------------|----------------|---------|-------------------|----------------|
| 1 | He’s in a world of his own most of the time. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership?? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

Whether the person feels a sense of loss for what has changed

This set of items is meant to measure whether or not the person feels a sense of loss for how things used to be in the relationship.

|   |   |             |                |         |                   |                |
|---|---|-------------|----------------|---------|-------------------|----------------|
| 3 | I miss having someone to turn to when I need some comfort or support. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|---|---|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether or not the person feels a sense of loss for how things used to be in the relationship? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

|    |  |             |                |         |                   |                |
|----|--|-------------|----------------|---------|-------------------|----------------|
| 12 | I miss having someone to share my life with. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether or not the person feels a sense of loss for how things used to be in the relationship? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

|    |  |             |                |         |                   |                |
|----|--|-------------|----------------|---------|-------------------|----------------|
| 18 | I feel like I've lost the person I used to know. | Agree a lot | Agree a little | Neither | Disagree a little | Disagree a lot |
|----|--|-------------|----------------|---------|-------------------|----------------|

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether or not the person feels a sense of loss for how things used to be in the relationship? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

Thank you for your participation. Your assistance will be invaluable in developing this questionnaire. We hope that having the questionnaire will enable researchers to study more effectively what happens to relationships after traumatic brain injury.

### **One final question**

As part of my main research study I would like to talk to carers about their experiences and situations they find difficult to manage regarding caring for their partner. I want these situations to be relevant to the cares, and so I wondered...

### **Which situations do you think carers of those with a brain injury find difficult or challenging to manage?**

I'm not asking for personal examples please, but from your knowledge and experiences of carers, in general....

**Appendix 8: Semi-structured Interview Questions**

**Carer Responses Questionnaire**

**UNIVERSITY OF  
BIRMINGHAM**

**Participant code:**

“I’m going to read to you a few situations and I would like you to tell me whether you have experienced these with your spouse/partner since their brain injury.”

**Example situation 1:** Have you experienced your partner being verbally abusive, such as shouting or swearing?

YES/NO

If yes, how often have you experienced this situation?

Everyday      At least once a week      At least once a month      Only occasionally

**Example situation 2:** Have you experienced your partner being unenthusiastic and reluctant to take part in activities? (Prompts: perhaps withdrawing or refusing to participate)

YES/NO

If yes, how often have you experienced this situation?

Everyday      At least once a week      At least once a month      Only occasionally

**Example situation 3:** Have you experienced your partner’s mood suddenly and unexpectedly changing? (Prompts: for example, becoming unresponsive, indifferent or moody)

YES/NO

If yes, how often have you experienced this situation?

Everyday      At least once a week      At least once a month      Only occasionally

The two most frequently occurring situations are identified: .....

If the situations occur only occasionally or not at all, the following question will be asked:

**Situation 4:** “Tell me about a difficult situation that frequently occurs with your spouse/partner.”

.....  
.....

How often have you experienced this situation?

Everyday      At least once a week      At least once a month      Only occasionally

**Situation 5:** “Tell me about a difficult situation that frequently occurs with your spouse/partner.”

.....  
.....

How often have you experienced this situation?

Everyday      At least once a week      At least once a month      Only occasionally

Check participant is happy to answer questions regarding the situations that they have the most experience with. (The participant will be answering questions for two situations.)

Inform the participant that you will be audio-recording the rest of the responses to this questionnaire: “I would like to record our discussion about your experience of these situations to ensure all that you share is noted- is that ok?”

Behaviour – please describe -----  
-----  
-----  
-----

1. Why do you think your partner does this?

-----  
-----  
-----

2. What do you do to deal with/manage the situation/behaviour?

-----  
-----  
-----  
-----

3. Why do you think this strategy works/why do you choose this strategy?

-----  
-----  
-----  
-----  
-----

4. How has your partner been dealing with it?

-----  
-----  
-----  
-----  
-----

(optional) What are your thoughts and feelings at the time?

-----  
-----

## Appendix 9: Example Transcript and Coding Record Form

Lines 47- 63

R: that's fine... so what do you do to let him be less disengaged, what have you tried

What have we tried, we go out with the dogs so you know we do things like that, when I'm busy, we have two different care workers who alternate and come, they take him out and about for the day on the bus, he's got a bus pass for plus one, so he's out and about doing stuff, and then in the evenings we sit down and watch the tele, we watch a lot of quiz shows, because it's general knowledge, a lot of his general knowledge is still there and he actually will engage and answer the questions, whereas he won't have a conversation with me

1

R: something about quizzes and

He was an incredibly intelligent man you know, and he still is, you just don't spot it very often these days, yer, yer, old general knowledge is still there, he still plays a better game of chess than anybody we know, come see on a Friday, the number of people he's tried to teach to play chess, he forgets the next person he's taught, he forgets he's got a beginner with him, and he plays at his level (laughs)

2

Lines 115-128

R: is there anything that he ever does to try to engage himself in things or people

Not really, no

R: or that other people have ever tried?

One of his care workers is a bit more proactive than the other one, they occasionally got to like technique, they went to doctor who exhibitions and stuff, I've taken him to the cinema a couple of times to see a film, that basically I've wanted to see, last one I took him to was the Steven Hawking one, because he's he's a very science-y sort of person and he remembers Steven Hawking and that, sort of thing, so he actually enjoyed the film, on the way back I was asking him questions, just generally talking about, because I'd enjoyed the film you know, and by the time we had got home he had forgotten what we had been to see, and it was only a quarter of an hour journey, but that's his memory's bad, while I keep talking about something he'll keep remember, but while I keep talking about something he'll keep remembering, but as soon as I stop talking about it, say if there's a busy junction coming up or something, or round the roundabout or whatever, he will have forgotten we were talking about it, so that's where the memory's gone... he did enjoy it at the time he was laughing the in the right places so I knew he was understanding it, I think that's probably why he er, the care workers take him out, it's a quality of life thing isn't it, he might not remember that he's done something nice, but at the time he felt nice, so whatever

3

Lines 191-205

R: so, he's not able to support or help with decision making

No, no, not at all, give him a choice of two things, it could be anything from making a sandwich to writing a will, it doesn't matter what it is, given a choice of two things he'll always choose the first one, which is handy when you've only got ham and you've given him an offer of ham or cheese, I do play it to my advantage

4

R: so, in giving him that choice

He thinks he's got some sort of control

R: and that's nice for him

I do try to give him some sort of independence, or think that he's got control over some parts of his life, because it's important, yer,

5

| Record form    |   | Participant ID: 15             |                |
|----------------|---|--------------------------------|----------------|
| Section number | Category  | Understanding / Management     | Comments       |
| 1              | <u>Individually-tailored management</u>                             | Management                     |                |
| 2              | <u>Pre-injury personal history</u><br><u>Pre-injury personality</u> | Understanding<br>Understanding |                |
| 3              | <u>Individually-tailored management</u>                             | Management                     |                |
| 4              | <u>Restrictive practice</u>   | Management                     | Negative score |
| 5              | <u>Restrictive practice</u>   | Management                     |                |