VOLUME 1: RESEARCH ELEMENT

A LITERATURE REVIEW OF RESEARCH INTO WHAT FAMILY CAREGIVERS DO IN SUPPORT OF THEIR LOVED ONE WITH DEMENTIA, AND RESEARCH EXAMINING LINKS BETWEEN PERCEPTIONS OF CONTINUITY AND THE LEVELS OF PERSON-CENTRED CARE PEOPLE GIVE TO THEIR SPOUSE WITH DEMENTIA

By

Julie Achiampong (née Singleton)

School of Psychology, University of Birmingham, England

Address Correspondence to:

Julie Achiampong, School of Psychology, University of Birmingham,

Edgbaston, Birmingham, B15 2TT, Tel: [redacted]

[redacted]

For Granddad, Granny

& Mum

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OVERVIEW OF THESIS

The following work has been completed as part of the Birmingham University Clinical Psychology Doctorate. The thesis is presented in two parts: the Research element and the Clinical element.

Volume One contains three research papers: a literature review on work exploring care-giving approaches in family carers of people with dementia; an empirical paper exploring the link between perceptions of continuity in spouses caring for someone with dementia and person-centred care; and an executive summary of the empirical paper.

Volume Two contains the following clinical practice reports (CPR) completed whilst on placements within the NHS. The models CPR describes the assessment, Cognitive-Behavioural and Psychodynamic formulation of a twenty-year old young man with a diagnosis of Somatoform Disorder. The service evaluation CPR is a qualitative exploration of staff experiences and needs in the use of Cognitive Behavioural Approaches in Community Mental Health Teams. The Single Case CPR describes and evaluates an intervention for visual neglect conducted with a 55 year-old man. The Case study CPR presents cognitive-behavioural therapy work conducted with a teenage girl with appearance-related social anxiety. The abstract for the Clinical Presentation CPR is included and this described work with a 79 year old man in a general hospital, referred for low mood.

LITERATURE REVIEW

Approaches to caring for a family member who has dementia: Themes within the literature

By

Julie Achiampong

School of Psychology, University of Birmingham, England

WORD COUNT: 7031

Address Correspondence to:

Julie Achiampong, School of Psychology, University of Birmingham,

Edgbaston, Birmingham, B15 2TT, Tel: [redacted]

[redacted]

ABSTRACT

As the population ages, the effective support of family carers of people with dementia, has become a priority for services, to promote care in the community and reduce the burden on professional care services. The ways in which people support their family member are therefore important to explore in order to identify areas of potential difficulty and promote person-centred care to improve outcomes. This literature review was conducted to identify themes within research into the ways in which people care for their family member and to highlight implications for clinical practice interventions and further research. A literature search was conducted between September 2010 and October 2011. The method of search is discussed and nineteen studies are reviewed and evaluated. The papers were predominantly qualitative. Themes identified and discussed are: ‘managing behaviour’, ‘managing social situations’, ‘preserving self-esteem’, ‘promoting engagement in activities’, ‘maintaining continuity’, and ‘preserving the person’. Implications for practice and further research are suggested.

Rationale

As the population ages, the number of people with dementia is set to double. In 2008 the number of people in the UK with dementia was 700,000 with an expected rise to 1.4 million in 2038. The cost of care is predicted to rise from £17 billion to over £50 billion (Department of Health, 2009). As a consequence, services will need to support family carers to provide care in the home for as long as possible.

At present family members tend to care for PWD at home until they are no longer able to cope. A decision for the person with dementia to go into care is usually based on them having behaviour the family carer cannot manage (O'Donell et al. 1992, cited in de Vugt et al., 2004) or reaching the later stages of dementia and therefore requiring a higher level of nursing care. Carers need to respond effectively to challenging behaviour in order to maintain both the person with dementia (PWD)'s and their own wellbeing and in many instances, manage risk. Carer responses can potentially perpetuate or escalate challenging behaviour as suggested by de Vugt et al. (2004) who noted that caregivers who reported higher levels of hyperactivity in the PWD also used higher levels of confrontation and ignoring the PWD. In this context, it is therefore valuable for professionals to understand the ways people support their family member. Strategies that meet the PWD's needs have the potential to reduce agitation and challenging behaviour. Such sensitive care may have benefits for both the caregivers' wellbeing and that of the PWD. As a consequence, family caregivers may be less likely to admit their relative to institutional settings and this, in turn, would reduce the cost to the state. Research that uncovers the various ways that carers naturally respond to the day-to-day challenges of caring for a relative with dementia may be valuable in guiding the development of interventions to support and enhance care-giving strategies and maintain people with dementia in their own homes. The aim of this paper is therefore to review research that has investigated the ways in which family carers support relatives with dementia in their own homes and environments.

To set this review in context, the existing body of carer research is briefly summarised below. Carer research has focused predominantly on burden in family caregivers, with the psychological and physical impact on the carer being thoroughly explored and summarised in reviews and meta-analyses. Pinquart and Sörensen (2003) conducted a meta-analysis on studies of levels of depression in carers of frail older adults finding a large significant difference in the prevalence of depression between carers and non-carers. Shultz et al (1995) conducted a review finding that over 33% of carers of PWD had depression, stress or general psychological difficulties. Over 50% of dementia carers scored at a level of 'caseness' on the General Health Questionnaire (GHQ; Gilleard, 1984; Donaldson, Tarrier & Burns et al, 1998). Russo et al (1995) also found higher rates of depression in dementia carers compared with those caring for a person with other conditions. More recently, a further systematic review of depression in dementia carers was conducted by Cuijpers (2005) who concluded that both the prevalence and the incidence of depression are increased in caregivers of dementia patients

In addition to poor mental health, carers of people with dementia also report poorer physical health (Baumgarten et al, 1992) and are on higher levels of medication than age-matched controls (Schofield et al, 1999). Sixty-one percent of people caring for over 20 hours a week have reported ill health due to their caring role (General Household Survey, 2000). A meta-analysis looking at the impact of dementia care-giving on physical health (Vitaliano, Zhang, & Scanlan, 2003), found a higher risk of health problems in caregivers compared with non-caregivers. Measures such as the Care-giving Burden Scale (Gerritsen & Van der Ende, 1994), BASOLL (Brooker et al., 1993), Carers' Assessment of Managing Index (CAMI;

Nolan, Keady & Grant, 1995) and Ways of Coping with Caring (Matson, 1994) have been developed to quantify objective and subjective burden and the coping strategies carers use.

More recently, the research area has evolved to also look at caregiver wellbeing and satisfaction (Carbonneau, Caron & Desrosiers, 2010) and to evaluate interventions for family caregivers. Various interventions aimed at caregiver mental health have led to significant improvements including: behavioural approaches to depression (Selwood et al, 2007), relaxation and cognitive-behavioural therapy for anxiety (Cooper et al, 2007b) and group-based psycho-education (Thompson et al, 2007). Sorensen, Pinquart and Duberstein (2002) and Pinquart and Sorensen (2006) reviewed 127 studies of interventions including psycho-education, CBT, support, counselling, day care, and training of care-recipient, finding that only multi-modal interventions reduced institutionalisation. Significant but small therapeutic outcomes were found for carer burden, depression, subjective well-being, and ability or knowledge. Significant improvements were also found in the symptoms of the PWD and institutionalisation was significantly reduced where the caregiver had accessed a support group (Spijker et al., 2008). A meta-analysis by Brodaty, Green and Koshera (2003) indicated that individualised, intensive couple-based interventions were the most effective and in some cases, institutionalisation was delayed. There was no reduction in carer burden but there were positive effects on distress and general outcome for the carer with a positive impact on the PWD’s mood. However, there is room for improvement as Smits et al (2007) reviewed combined carer and PWD interventions and found that under 50% benefited both the caregiver and PWD.

Aside from carer research, there is also psychological research focusing on the person with dementia and on the relationship between care-recipient and caregiver. This has followed Kitwood’s seminal work on person-centred care (Kitwood & Bredin, 1992). Kitwood highlighted the impact of the social environment on the level of impairment of people with dementia living in institutional settings, shifting dementia understanding from a medical/psychiatric model to a biopsychosocial model. Person-centred care has become the focus for professional care-giving, with quality of care being evaluated using Dementia Care Mapping (see Brooker, 2005 for a review), which has sprung from the person-centred ethos. Person-centred care is considered good practice to promote psychological wellbeing in PWD and is recommended in policy frameworks (National Service Framework for Older People, 2001). The emphasis on maintaining the personhood of the PWD i.e. acting on their behalf to ensure that their preferences are taken into account and their retained abilities are facilitated and valued, has lead to an increase in research looking at the PWD's experience (Beard 2004; Hulko 2009), family caregiver experiences (Loukissa, Farran & Graham 1999; Quinn, Clare & Woods 2009; Butcher, Holkup & Coen Buckwalter 2001) and spousal relationships (Perry & O'Connor, 2002; Hellström, Nolan & Lundh, 2007; Vikström, Josephsson, Stigsdotter-Neely & Nygård, 2008).

It is not the aim of this paper, to further review carer burden, wellbeing or mental health and neither is it to re-review caregiver-based interventions as these areas have been extensively reviewed previously. Rather, this paper focuses specifically on the ways in which family members naturally care for the PWD. The way in which family members interact with the PWD during care-giving activities, may promote psychological wellbeing, reduce agitation and maintain the person's identity or may undermine well-being, leading to reduced self esteem and increased challenging behaviour in the PWD. This area closely links to research on relationship dynamics and could inform the basis of future work in promoting quality care by family members at home. Therefore, this literature review asks: 'What do we know about the ways in which dementia family carers care for the PWD?' Care encompasses responding to the PWD in all aspects of daily living including challenging behaviour, assisting with activities, and supporting the person in social environments.

Inclusion and Exclusion criteria

A search was conducted to identify articles exploring the day-to-day strategies used by carers in looking after a relative with dementia. This focused on family care-giving in all types of dementia in relation to quality of care, quality of life, activities of daily living, behavioural difficulties or agitation, and the use of strategies and tactics in relation to interactions with the PWD. The literature search is limited to papers published from 1992-2010 with the start date being set to coincide with Kitwood and Bredin's (1992) seminal work on person-centred care.

Discursive papers, dissertations, editorials and case studies were excluded as peer-reviewed empirical studies were the main focus of the review. Papers were limited to the English language. Research with a primary focus on: nursing and residential care, levels of carer burden, carer mental health, the subjective experience of carers or the evaluation of therapeutic intervention was excluded.

Search Methodology

Initial literature searches were conducted between September 2010 and October 2011 in the following databases: Medline, CINAHL, Web of Science and PsycINFO to locate papers of interest. A final systematic search using subject headings, keywords and phrases was then conducted in PsycINFO (see Appendix 1). This was found, in the initial searches, to be the most appropriate database for the topic of the review.

This search initially focused on the following subject headings, identifying 966 papers: ‘vascular dementia’ OR ‘dementia’ OR semantic dementia’ OR presenile dementia’ OR ‘dementia with lewy bodies’ OR ‘senile dementia’ OR ‘Alzheimer’s Disease’ AND ‘caregivers’ OR ‘family members’ OR ‘family’ OR ‘spouses’ OR ‘couples’ AND ‘quality of care’ OR ‘coping behaviour’ OR ‘behaviour problems’ OR ‘agitation’ OR‘behaviour disorders’ OR ‘symptoms’ OR ‘quality of life’ OR ‘daily activities’ OR ‘strategies’ OR ‘activities of daily living’

In keeping with the exclusion criteria, the following terms were then excluded: NOT ‘nursing homes’ OR ‘residential care institutions’ OR ‘therapy (maximises sensitivity)’ or ‘therapy (maximises specificity)’ or ‘therapy (best balance of sensitivity and specificity’. In addition papers were excluded if they had the following keywords in their title: ‘carer burden’ OR ‘caregiver burden’ OR ‘caregiving burden’ OR care*adj (health or depression or stress). With these exclusions the number of papers was reduced to 456.

The titles were visually inspected to ensure that they met the inclusion criteria and were excluded by hand if they met the exclusion criteria. 73 remaining papers were then inspected by abstract to ensure they were relevant, following the same process. The following papers were identified, as meeting the inclusion criteria:

Table1: Relevant papers identified in search.

Corcoran (1994)

Dodds (1994)

Matson (1995)

Richter, Roberto & Bottenberg (1995)

Taft, Matthiesen, Farran, McCann & Knafl (1997)

MacRae (2002)

Perry & O'Connor (2002)

Gitlin, Winter, Dennis, Corcoran, Schinfeld & Hauck (2002)

Ward, Opie & O'Connor (2003)

De Vugt, Stevens, Aalten, Lousberg, Jaspers, Winkens, Jolles & Verhey (2004)

Vikström, Borell, Stigsdotter-Neely & Josephsson (2005)

Hasselkaus & Murray (2007)

Hellström, Nolan & Lundh (2007)

Vikström, Joselhson, Stigsdotter-Neely & Nygard (2008)

The references of the papers above were examined yielding a further two papers:

(Hinrichsen & Niederehe, 1994; Jansson, Nordberg & Grafstrom, 2001). Finally, three additional papers (Buri &Dawson, 2000; Harvath, 1994; Blum, 1991) were retained from the initial broad searches as they met all inclusion criteria. (NB: All other papers located through the initial searches were also identified through the focused psycINFO search). In total 19 papers were identified and included in the review.

Evaluating the studies

Given the predominance of qualitative research identified, standards specifically developed for reviewing qualitative work rather than criteria used to critique quantitative papers, were used to evaluate the papers. Fossey, Harvey, McDermott & Davidson (2002) highlight that criteria used to evaluate research *'need to be consistent with the philosophical position... and aims informing the research method' (p 723).* The qualitative studies are evaluated using the Critical Appraisal Skills Programme (CASP) appraisal tool for qualitative research (see Appendix 2). These were developed by a national CASP collaboration for qualitative methodologies published by the Public Health Resource Unit in England (2006). These criteria fundamentally address whether studies are sufficiently rigorous, credible and relevant. Similarly, for the purpose of this review, the evaluation of the quantitative studies (and quantitative aspects of the mixed method studies) seeks to address the same issues: rigour or 'appropriateness' of methods and analysis; credibility or 'validity & reliability'; and relevance or 'generalisability' (see Tables 1 and 2 for a summary and evaluation of papers). Following tables 1 and 2, an overview of the papers will be given along with a summary relating to rigour and credibility.

Table 2: Description and Evaluation of Qualitative and Mixed Design Studies. (standard font= descriptive aspects, italic font= evaluative aspects)

Authors, Date & Aim of Study *Are method & design appropriate to meet aims?*	**Sample** *Recruitment strategy appropriate?*	**Method of Data Collection** *Adequately addresses research issue? Reflexivity & ethical issues addressed?*	**Analysis** *Sufficiently rigorous?*	**Findings** *Clear and credible?*	**Value of Research** *Implications & Transferability*
Blum (1991) To explore caregivers' management of stigma associated with Alzheimer's Disease (AD). *Strong theoretical base. Qualitative approach appropriate.*	US. 34 spouse/offspring caregivers (of people with AD & 'related disorders') accessing support group over 3 years. *No recruitment, demographic or ethnicity data supplied.*	Observation of support group, 'in-depth interviews'. *No information regarding interview structure, form of data, ethical issues or researcher's relationship with participants.*	*No information regarding analysis of data or measures to ensure credibility of data.*	2 phases found in m'ment of stigma. 1) collusion with person with AD 2) collusion with others & associated m'ment strategies. *Range of participant quotes. Clear links to theory. No reflection on possible researcher bias.*	Links back to sociological theory. *No attempts to link to implications for practice/ transfer to other clinical populations or recommendations for further research.*
Corcoran (1994) To explore Bowers' (1987) categorisation of care-giving with spousal caregivers. *Context of caregiver shortage described. Sociological approach.*	US. 26 spouses of people with moderate AD. *Detailed demographic information & eligibility criteria supplied.*	Responses regarding solutions to 3 vignettes. Taped & transcribed by independent interviewer. Repeated 3 months later. *Ethical issues not considered.*	Grounded Theory analysis. *Good description of steps taken to manage saturation, analytic process & reflexivity.*	Bowers' (1987) categories supported by data, differences also identified. *Direct quotes used, range of participants unclear.*	Exploration of preferred strategies & ways to promote carer satisfaction suggested. Recommends research to build models of care-giving and evaluate interventions.

Authors, Date & Aim of Study *Are method & design appropriate to meet aims?*	**Sample** *Recruitment strategy appropriate?*	**Method of Data Collection** *Adequately addresses research issue? Reflexivity & ethical issues addressed?*	**Analysis** *Sufficiently rigorous?*	**Findings** *Clear and credible?*	**Value of Research** *Implications & Transferability*
Dodds (1994) To identify types of 'wandering' carers experience & how they manage this. *Relevance to people with dementia identified.*	UK. 6 family caregivers. *Recruitment process explained, some demographic information supplied.*	Semi-structured interviews with use of Hope & Fairburn (1990) typology of wandering. *No information on data format, relationship with participants & ethical issues.*	*No explanation of analysis or steps taken to maintain rigour.*	Ten different management strategies were identified. *Includes a range of direct quotes from different participants.*	Recommendations to promote range of management strategies, non-judgemental approaches and openness to shared learning. *No further research avenues identified.*
Harvath (1994) To explore family caregiver perceptions & interpretations of difficult behaviour and how these affect how they manage these. *Links with previous research and appropriate approach used.*	US. 8 wives & 2 daughters of people with dementia. *Sampling strategy & demographics given.*	Semi-structured interview. *Detailed description of process, questions asked and data collected. Ethical issues addressed.*	Interactive thematic process of analysis (Taylor & Bogdan, 1984). *Participant & peer reviewed to ensure validity.*	Links between perception, interpretation, management & consequences explored. Range of caregiver interventions identified. *Direct quotes used, range of participants unclear. Reflects on limitations of the sample* .	Implications for practice include increasing range of strategies & understanding caregivers' reasoning behind responses to behaviour.

Authors, Date & Aim of Study *Are method & design appropriate to meet aims?*	**Sample** *Recruitment strategy appropriate?*	**Method of Data Collection** *Adequately addresses research issue? Reflexivity & ethical issues addressed?*	**Analysis** *Sufficiently rigorous?*	**Findings** *Clear and credible?*	**Value of Research** *Implications & Transferability*
Matson (1995) To explore coping in the context of behavioural difficulties occurring. Mixed qualitative/questionnaire based design. *Thorough exploration of context of current intervention & research.*	UK. 36 stroke and 37 AD/MID live-in, non-professional carers. *Some demographic information but no ethnicity information.*	Vignettes to generate coping responses in taped interview & 'Ways of Coping with Caring Questionnaire'. *Extensive information about pilot work preceding study. Consideration given to efficacy of process.*	Categorisation of responses to vignettes. *Appropriate analysis of psychometric and quantitative aspects.*	Describes general 'strategies' of coping and 'tactical' coping in response to particular behaviours, developing a typology for this aspect which appears credible.	Suggests observation-based research to inform interventions in practice.
Richter, Roberto & Bottenberg (1995) To explore verbal & non-verbal communication by family & professional staff when dealing with fearfulness, agitation & wandering. *Relevance clear from communication issues presented.*	US. 23 family caregivers of people with AD living in long term care & 22 staff. *Demographics described.*	Focus groups. Staff asked to talk about current communication they use. Data taped & non-verbal interactions noted. *Relationship of moderator with group considered. Carers asked to respond in hindsight & time since caring at home is not stated.*	Thematic analysis process described. *Conducted by research team to ensure validity.*	Family responded with environmental adjustments & reassurance; staff responded with environmental adjustments, engaging in conversations & physical contact. *Direct quotes used, range of participants unclear.*	Suggested interventions in both home and professional care settings. *No specific recommendations for further research.*

Authors, Date & Aim of Study *Are method & design appropriate to meet aims?*	**Sample** *Recruitment strategy appropriate?*	**Method of Data Collection** *Adequately addresses research issue? Reflexivity & ethical issues addressed?*	**Analysis** *Sufficiently rigorous?*	**Findings** *Clear and credible?*	**Value of Research** *Implications & Transferability*
Taft, Matthiesen, Farran, McCann & Knafl (1997) Mixed design. Describes findings from previous study. Explores links between perceived strengths of the person with dementia, use of approaches & type of behavioural difficulties.	US. Primary family carer & staff involved with 20 people with dementia. *Some demographics for people with dementia & carers.*	Behaviour identified by Cohen-Mansfield Agitation Inventory (1986). *Data sources & methods: staff & family interviewed about person. Information given about questions asked. Process of data collection & ethical issues addressed. Responsive to data during process.*	Constant Comparative Analysis using computer software. Visual comparison of means to analyse links between behaviour & approaches. *Correlational analysis would indicate if findings are significant. Peer & participant reviewed.*	Links made between type of behaviour and approaches used. *Direct quotes used, range of participants unclear. Thorough consideration of limitations. Conclusions appear credible.*	Links made back to theory. Recommendations for further use of social & psychological interventions. *No recommendations for further research.*
Buri & Dawson (2000) To explore how family carers of people with dementia experience the risk of falls. *Builds on previous research with a relevant research question. Appropriate method used given social constructionist approach.*	UK. Pre-study focus group to inform theoretical sampling of 6 family carers. *Detail given.*	Critical Incident Technique (Flanagan, 1954) adopted during taped interviews.	Grounded Theory approach. Alternating data collection and analysis. *Triangulation of data sources, shared findings with participants, reflexivity. Comparative analysis across participants.*	Emergent categories from focus group stated. Thorough discussion of strategies identified in the interviews in response to ‘being on the edge of chaos’. *Range of participants quoted unclear.*	Links made back to theory. Collaborative approach and the use of Critical Incident Technique suggested for clinical practice.

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Jansson, Nordberg & Grafstrom (2001) To describe spousal care-giving activities. *Relevance of research question is clear.*	Sweden. Thorough description of 8 participants & their spouses who have dementia. *Initial visit to establish rapport & trust.*	Observation of activities over two half-days. Open-ended interviews & conversations used to supplement information. *Brief notes made during observation & further notes made following conversation/interviews. Initial data collected by 2 researchers & analysed before proceeding. Ethical issues considered and approval obtained.*	Detailed description of analysis drawing on Grounded Theory & Thematic analysis. Data saturation was reached resulting in the sample size. *Follow-up interviews conducted to improve credibility.*	Themes identified & sub-categories explored. *Observational descriptions for a range of participants. Quotes from informal interviews provided may not be rigorous. Limitations considered.*	Findings linked back to theory. *No discussion regarding implications for interventions.*
MacRae (2002) To explore how family caregivers respond to the 'loss of self' of the PWD.	Canada. 53 family caregivers of people with AD. *Relationship to PWD supplied, no information regarding other characteristics.*	Semi-structured tape-recorded interviews. *Some information given regarding specific questions asked. Reflexivity & ethical issues not considered.*	Interactionist perspective of' identity as a social product' used as framework. Inductive analysis techniques used to perform thematic analysis. *No information regarding steps taken to ensure findings were valid.*	Strategies to maintain PWD's identity: 'concealing information', 'medicalizing inappropriate behaviour','fostering independence', 'managing appearance', 'perceiving selectively'. *Points supported by thorough quoting of P's but unclear if range included.*	Some discussion of implications of findings regarding interpretation of behaviour, continuity and handing over care to others. *Some suggestion for further research.*

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Perry & O'Connor (2002) To explore how spouses act to preserve the personhood of their partner who has dementia. *Relevance of question clear.*	US & Canada. 26 wives & 12 husbands participating in one of three studies.	Unstructured interviews, tape-recorded. Up to 4 interviews per participant over extended period.	Secondary constant comparative analysis of transcripts from first two studies, verified using interviews from current third study. *Analysed jointly by two authors.*	Strategies identified: Maintaining Continuity, Supporting Competencies, Protecting from Incompetence & Strategising Encounters. Gender differences explored. *Findings supported by detailed quotes but unclear whether they represent a range of participants.*	Suggests therapeutic interventions such as asking the spouse to 'tell the story' of their partner and supporting spouses' efforts to sustain competence and protect from incompetence. Suggestions for further research.
Ward, Opie & O'Connor (2003) To further knowledge of the ways in which family carers manage behavioural & psychological symptoms. *Limited exploration of related research.*	Australia. 30 family carers who had previously been involved in a GP survey & 20 accessed through mental health services.	Participants gave their responses to symptoms, (identified with Manchester & Oxford University Scale for the Psychopathological Assessment of Dementia) that had occurred in the preceding month. *It is unclear in what format the data was collected. Information about the validity & reliability of the MOUSEPAD is supplied.*	Responses were classified according to Dodd's (1994) typology. Further categories were identified. Responses then categorised as 'reactive' or 'assertive'. *Little information regarding analysis, results presented in percentages.*	Range of frequently used responses identified. *Findings lacked a depth of exploration in comparison to other qualitative studies. Explores limitations including the use of a structured interview schedule.*	Study raises further questions for subsequent research. *Limited conclusions or suggestions for clinical practice.*

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De Vugt et al (2004) To identify caregiver strategies & whether these predict behavioural problems and caregiver distress. Mixed questionnaire/qualitative design. *Relevance of research question clear.*	Netherlands. 99 informal primary caregivers. *Comprehensive demographic information given plus explanation regarding those who declined to participate.*	Semi-structured interviews re management strategies were taped. A range of questionnaires were utilised. Data collected at multiple time points over a year. Well established questionnaires used. *Internal reliability calculated. Data collected by independent psychologists to ensure objectivity.*	Interview data analysed using Grounded Theory with assistance of software. Participants assigned to 1 of 3 groups and data analysed using MANOVAs. *Kappa value for agreement between 2 coders given. Statistical analysis appropriate. Alpha level adjusted to minimise risk of Type 1 errors. Data clearly presented.*	Three types of management strategies: 'Non-adaptors', 'Nurturers' & 'Supporters'. *Findings clearly explained.*	Links made with previous research. *Comprehensive exploration & evaluation of limitations including sample size. Implications for clinical practice briefly suggested.*
Vikström, Borell, Stigsdotter-Neely & Josephsson (2005) To explore the ways caregivers support the PWD in an everyday activity. *Relevant research and rationale adequately explained..*	Sweden. 30 co-habiting couples where one has mild to moderate dementia. *Participant information re. education & cognitive function supplied.*	Observation- video recording with supplementary notes of the couple preparing afternoon tea. *Conducted in natural home setting.* *Notes written following observation. Data accuracy checked by 1st &4th author.*	Constant comparative analysis. *Considers implications of presence of researcher & steps taken to reduce this. Codes checked back with data by 1st & 4th authors and then peers within research group.*	'Creating a supportive working climate', 'supportive practical involvement' and 'negative aspects in caregiver support' described in detail. *Quotes supplied as evidence but unclear whether a range of participant quotes used.*	Highlights the importance of tailoring approaches to the individual and suggests approaches for clinicians to help the caregiver to do this. *Emphasis on implications for clinical practice.*

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Hasselkus & Murray (2007) To explore caregivers' perceptions of wellbeing in relation to their work as a caregiver. *Provides thorough descriptive context of other research.*	US. 33 family caregivers. *Care support services in place and nature of relationship with PWD described.*	Telephone interviews regarding satisfying and dissatisfying caregiving experiences. *Two researchers conducted initial analysis independently and then together. 8 participants called back with initial interpretations for clarification and elaboration.*	Thematic analysis of narratives. *More full description of process of analysis would be useful, Acknowledges researcher position in relation to clinical profession.*	'Everyday occupation' as 'representation of care receiver's state of being'; reflecting 'caregiver's state of being'; as 'a means for the caregiver to seek & maintain relationship' with PWD. *Rich descriptions provided but unclear whether a range of participant quotes used.*	Suggests the importance for clinicians, of validating caregivers' efforts. *Some suggestions for further research.*
Hellström, Nolan & Lundh (2007) To further body of knowledge about experience of 'couplehood' where one partner has dementia. Constructivist approach. *Relevant research & theories described.*	Sweden. 20 couples interviewed at five points in time, over a period of 5 years.	152 interviews. *Spouses interviewed separately by 2 different researchers. Themes for discussion, process regarding ethics & steps taken to promote rapport stated.*	Grounded Theory. *Constant Comparative analysis used to inform subsequent interviews. Understandings co-constructed by researcher & participants over time.*	3 phases identified: 'Sustaining couplehood', 'maintaining involvement' & 'moving on'. *Specific participants not identified, but quotes from both partners, clearly evidencing conclusions.*	Links made to other research & suggests interventions for couples may be beneficial. *Limitations explored in terms of the number of couples who participated, with suggestions for further research.*

Authors, Date & Aim of Study *Are method & design appropriate to meet aims?*	**Sample** *Recruitment strategy appropriate?*	**Method of Data Collection** *Adequately addresses research issue? Reflexivity & ethical issues addressed?*	**Analysis** *Sufficiently rigorous?*	**Findings** *Clear and credible?*	**Value of Research** *Implications & Transferability*
Vikström, Josephsson, Stigsdotter-Neely & Nygård (2008) To explore how couples perceive their engagement in everyday activities. *Relevance to quality of life issues identified.*	Sweden. 52 couples where one person has dementia. *Criteria for participation explained.*	Tape-recorded semi-structured interviews prior to intervention stage of main study.	Constant comparative analysis. *Early & later data descriptions were compared as saturation was not used to limit the sample. Two authors & the research group & subsequently peer review utilised to ensure credibility.*	Themes identified: perceived changes in activity engagements, consequences of changes, dilemmas experienced by caregivers & management approaches to handle changed life. *Breadth of participants quoted is unclear. Clear discussion of findings. Detailed consideration given limitations of the study.*	Suggests clinician consider ways of promoting couple collaboration. *Relates findings to previous research.*

Table 3: Evaluation of Quantitative Studies (normal font used for descriptive aspects; italic for evaluative aspects)

Authors, Date & Aim of Study *Are method & design appropriate to meet aims?*	**Sample, including country** *Recruitment strategy appropriate & power of sample sufficient?*	**Data Collection** *Did it address research issue?*	**Analysis** *Are appropriate tests used?*	**Findings** *Are they clear, reliable & valid?*	**Value of Research** *Implications & Transferability*
Hinrichsen & Niederehe (1994) To examine whether behaviour management strategies are associated with caregiver adjustment. *Relevance to research on coping identified.*	US. 152 primary informal carers. *Detailed demographic information for carers & people with dementia. No information regarding power of sample.*	Range of questionnaires to measure: strategies used, coping styles, desire to institutionalise, carer psychiatric symptoms, extent of memory, behavioural problems and difficulties with activities of daily living. *Details reliability of measures & the development of the 'Dementia Management Strategies Scale'.*	Hierarchical regression: carer adjustment on characteristics of the person with dementia, the carer, their coping style & management strategies. *Results presented clearly, appropriate analyses conducted.*	Three strategies identified- 'Criticism', 'Encouragement' & 'Active management' were associated with level of carer burden & desire to institutionalise. *Findings clearly summarised.*	Recommendations for further research made with regard to longitudinal work to address possible limitations of the study. *Implications for clinical practice not explored.*
Gitlin et al (2002) To report psychometric properties of Task Management Strategy Index (TMSI), measuring the ways carers simplify self-care tasks for people with dementia. *TMSI developed from theory base & previous research.*	US. Baseline data from 2 intervention study samples: 202 & 255 primary family caregivers of people with dementia & related disorders, respectively. *Criteria for participation & exclusion adequately explained. No information regarding power of sample.*	Interview covering the TMSI, caregiver health & wellbeing & functioning of person with dementia. *Authors direct reader to further information regarding measures.*	Construct validity assessed and principle axis factor analysis conducted. Correlation & multiple regression also used to explore links between person characteristics & strategy. *Choice of analyses is justified clearly.*	TMSI was reliable & valid. Greater use of task strategies was associated with higher levels of caregiver education. *Results adequately described with limitations identified.*	Recommendations for longitudinal study made with brief suggestions for clinical practice.

Overview of papers

Fourteen qualitative studies, three mixed methodologies and two purely quantitative papers were evaluated. There is a good spread of methods of data collection across the qualitative papers ranging through interviews, focus groups and observation. A social constructionist approach has been used in many which reflects the progress made in recent years from a bio-medical model to a biopsychosocial approach to dementia which recognises the value of subjective experience and relational aspects of living with dementia (Kitwood, 1993). The majority of papers located seek to further the understanding of care-givers' experiences in caring and managing the changes in their relationship that dementia brings. All papers made links to previous research and the relevance of the research aims was apparent. The studies included in the review were conducted across 6 countries (Australia, Canada, Netherlands, Sweden, the UK and the US) reflecting a shared need to increase knowledge of family caregiver experiences in order to better support them to care for their family member within the community.

The papers evaluated in Tables 1 and 2 are summarised below under the broad categories of rigour and credibility.

Rigour

Within the qualitative papers reviewed sample size ranged from 6 family carers of people with dementia (Buri & Dawson, 2000) to 52 couples where one person had dementia (Vikström, Josephsson, Stigsdotter-Neely & Nygård, 2008) and included family or spousal carers and additionally, in some instances, formal caregiver perspectives (Richter, Roberto & Bottenberg, 1995). Matson (1995) is the only paper reviewed which included carers of non-dementia related chronic conditions, with approximately half the sample comprised of carers of people with a stroke. Although neurological changes can potentially be similar in stroke and dementia, the progressive deterioration associated with dementia may bring different issues into caregivers' experiences such as a more ambiguous experience of loss that those caring for people with a stroke may not necessarily encounter to the same extent. Therefore the findings of this paper must be viewed with this in mind. The extent of demographic information provided by the papers varied with few papers giving information on ethnicity of participants. A number of papers went into particular detail with regards to analytic process (Corcoran, 1994, Buri & Dawson, 2000). With the exception of Blum (1991) and Dodds (1994), the studies provided enough information about their methodology to suggest that the data collection and analysis were sufficiently rigorous.

Credibility

Generally, steps were taken to ensure the credibility of the findings with the exception of Blum (1991) who provides no information in regards to this. Qualitative data was frequently by multiple researchers and peer or participant review was also utilised eg. Hellström, Nolan & Lundh, (2007); Taft, Matthiesen, Farran, McCann & Knafl, (1997); Harvath, (1994). Corcoran (1994) was one of the few papers that made reference to considering the impact of researcher assumptions and position (reflexivity) on the results. Although the studies made use of participant quotations, in most studies (with the exception of Blum, 1991) it was unclear whether a breadth of participants were quoted. Only one paper also utilised quotations from people with dementia (Hellström, Nolan & Lundh, 2007) which reflects the paucity of studies conducted with people with dementia. Findings were linked back to theory in many but not all papers and the majority of papers related findings to implications for clinical practice, thus strengthening the credibility of the findings.

Synthesis of Findings

Looking at the findings of the reviewed papers, it was apparent there were common themes regarding the way in which family carers care for someone with dementia. These have been drawn into six sub-sections below which cover findings relating to the ways that carers have been found to:

- manage behaviour
- manage social situations
- try to preserve the self-esteem of the person with dementia
- promote engagement in activities
- act to try to maintain continuity/normality
- try to maintain personhood for the person with dementia

Managing behaviour

Not surprisingly, given the prominence of behavioural changes in dementia, a number of papers explored the ways in which carers seemed to try and manage behaviour such as agitation or gaining co-operation.

Taft et al (1997) suggest that carers employ medical and behavioural approaches to manage agitated behaviours in their relative with dementia. They describe behavioural approaches as ‘interventions to reinforce or promote desirable behaviours or alter undesirable behaviours’ including ‘diversion, non-interference, going along, time away, delaying, confrontation, and avoiding the truth’ (p199). They also found that carers tended to use cognitive approaches more frequently in response to verbally agitated or aggressive behaviour, suggesting that this may be in response to the need for reassurance. Matson (1995) similarly noted that in response to behavioural difficulties, carers were more likely to utilise cognitive or avoidant strategies, whilst managing functional difficulties was associated with responses that were planned. He suggests that carers would use a number of strategies simultaneously or in succession if initial responses did not successfully resolve the situation. Harvath (1994) suggested that trial and error approaches were associated with a greater breadth of strategies employed by caregivers. Non-confrontational approaches tended to be more effective than confrontational responses and these were linked to the perception that the PWD was unable to control their behaviour. Harvath (1994) identified seven types of responses to challenging behaviour: ‘monitoring’, going along’, diversions’, ‘putting off’, ‘reasoning or convincing’, ‘guiding’ and ‘managing the environment’ (p18-19).

Hellström et al (2007, p398) describes how spouses attempt to ‘keep the peace’ by ‘knowing the triggers’ and ‘not responding’. These triggers were avoided by ‘providing some form of reassurance or distraction’ and ‘acceptance and a neutral response’ were often utilised. Dodds (1994, p754) suggests some responses that caregivers use such as ‘walking away’, ‘ignoring the behaviour’ and ‘collusion with wrongly held beliefs’ which, although non-confrontational, may not be person-centred. Ward, Opie & O’Connor (2003) also found similar approaches to responding to behaviours noting that these were often ignored if possible. Again, they also found carers used reassurance, distraction, reducing triggers and collusion. Reality orientation was also used by some carers in their study. Ignoring, distracting, reassurance and avoiding triggers were also identified as responses by carers in Matson’s (1995) study.

Reassurance was found by family caregivers in the Richter et al (1995) study, to be the most effective strategy when the person with dementia (PWD) was perceived to be frightened. The use of logic or arguing was found to be unhelpful and carers utilised reassurance, distraction, redirection and acknowledgement of the PWD’s emotional state. Richter et al (1995) suggested that although caregivers appeared to understand that the PWD needed to wander, this was also interpreted as a sign of fearfulness.

De Vugt et al (2004) categorised care-giving approaches primarily into acceptance or non-acceptance of the dementia-related problems and care-giving situation. ‘Non-adapters’ (p88) showed a ‘lack of understanding’, describing interacting with the PWD with ‘impatience, irritation or anger’ and used confrontational or ignoring responses to behaviour. The ‘adaptive’ caregivers were categorised as either ‘nurturers’ or ‘supporters’. ‘Nurturers’ (p88) tended to adopt a ‘parent-child approach’, being protective and taking on activities on behalf of the PWD whilst ‘supporters’ (p88) tended to use a supervise and assist approach, thereby encouraging the PWD to use his/her remaining abilities and using patient and calm responses.

Hinrichsen and Niederehe (1994, p98) also categorise care-giving approaches, identifying three: ‘Criticism’, ‘Encouragement’, and ‘Active Management’ which involved the carer doing a lot of activities to support and manage the behaviour of the person with dementia. They found that ‘Active Management’ was associated with higher levels of burden and greater desire to institutionalise.

It seems from these descriptions that carers could be seen as having quite a sophisticated understanding, acquired through trial and error perhaps, of behavioural psychology, using judgement about when to respond to behaviour and when not, as well as a range of reinforcement and anxiety management strategies.

<u>Managing social situations</u>

Another set of circumstances that carers and those with dementia face is the management of social situations where there is potential for high demand, embarrassment and misunderstanding. A number of studies gathered information about how carers managed such situations.

Taft et al. (1997) describe ‘social approaches’ as ‘interventions that encourage interpersonal interaction and support continued social functioning of the person with dementia’ including ‘empathic caring, supportive touch, providing activities, and relating’ (p198). Vikstrom et al (2008) reported that the PWD tended to value remaining in close proximity but caregivers found this problematic both practically and emotionally.

Vikstrom et al (2008) describe a decrease in social contact for both the person with dementia and their spouse. They found that this was due to caregivers feeling that they needed to be at home for their spouse and the person with dementia losing friends as a result of the diagnosis and experiencing a loss of confidence in maintaining friendships. Some friendships had been lost as a result of dementia-related changes such as forgetfulness or angry outbursts. Vikstrom et al (2008) also reported that some engagement in social activities had been deliberately stopped as a result of no longer feeling able to entertain guests as the person had done previously but also due to in the mixed feelings provoked by seeing friends who were happy and well. Vikstrom et al (2008) found that spouses were unsure whether to act on behalf of their spouse to try to maintain relationships, in situations where the dementia had caused difficulties. Those who did not intervene appeared to reflect on whether they could have prevented the loss of relationships on behalf of their spouse. Vikstrom et al. also describe carers lowering demands on the couple by engaging in fewer activities and also through the choice of social activity, doing things as a couple, as opposed to joining a large group of people. Blum (1991) however conceptualises this differently, describing ‘avoidance covering' (p270) whereby the person with dementia and their carer avoid situations in which attention would be drawn to the person with dementia's difficulties, thus managing stigma. This is echoed by MacRae (2002), who describes how some carers avoid difficult situations where the PWD' s identity may be at risk.

Managing social situations may also occur through 'supervisory care', illustrated by Corcoran (1994, p42) in highlighting how spouses report ensuring that their spouse is dressed appropriately, thereby also maintaining their dignity. MacRae (2002) suggests that help with grooming and dressing is part of identity maintenance work, enabling the presentation of 'a favourable and unchanged image of self...to others' (p. 411). Perry and O'Connor (2002) describe managing appearance as being aimed at maintaining 'a facade of normalcy' (p59). They acknowledge that this may '...support the notion that dementia is a source of shame' (p61). However, alongside Blum (1991) and MacRae (2002), they also found that some spouses decided to be quite open about the dementia attempting to set a context of understanding in others.

Blum (1991) develops Goffman's (1963) concept of 'passing' where the person with dementia withholds 'undisclosed discreditable information about self' (Goffman, 1963 p 41, cited by Blum, 1991). She describes 'collusive passing' where family become aware of the person's difficulties and 'align' themselves becoming 'a partner in passing, helping to preserve both the public face of the family member and of the family (or 'couple') as a collective unit' (p267). She notes that some spousal caregivers appeared to see it 'as a natural extension of the way...they had always protected the other's face' (p267). Three types of collusive passing are described, i.e. 'standing by' when the person with dementia is 'passing' in order not to undermine this and to monitor whether any intervention is necessary; 'preventative passing' such as managing the person's appearance so the person did not appear to have difficulties with self-care; and ‘active passing’ (p. 268-269) which may include prompting. Although these approaches can be seen as supervisory, facilitative or attempts to preserve self-esteem or dignity, they are reconceptualised by Blum as measures taken to manage stigma, effectively hiding the dementia. This is similar to Perry and O’Connor’s (2002) finding that efforts were made to present a ‘facade of normalcy’ (p59). Blum (1991) describes ‘remedial covering’ (p272) where carers act quickly to reduce the likelihood of embarrassment andMacRae (2002) uses similar terms of ‘covering up’ or ‘disguising’ (p. 408) to describe the ways spousal caregivers had reported the symptoms of dementia, in order to protect the PWD.

Blum (1991) goes on to describe a gradual shift in family carers from hiding to disclosing, suggesting that this occurs when ‘passing’ and ‘covering’ are ineffective due to the person with dementia’s increasing inability to co-operate with the strategies used. She suggests that disclosing to close others may be ‘as a means of enlisting their help’, to ‘validate their own observations’ (p275) or in response to the other person seeing the behaviour that is considered a problem. Blum also talks about disclosure to strangers as tending to be in the form of ‘disclaimers’, ‘apology’ or ‘reassurance’ which pre-empt or follow behaviours that are seen as unacceptable and embarrassing (p278). She suggests that by disclosing the person’s diagnosis the ‘caregiver takes control of the other party’s definition of the situation’ (p279), shifting it to a medical position as opposed to a moral one.

These studies illuminate the impact that dementia can have on both carer and the PWD’s social life and the implications for the carer in dealing with social encounters within a society in which there is stigma attached to dementia.

Preserving self-esteem

A number of papers give particular attention to the ways that carers attempt to preserve the self-esteem of the PWD. The Task Management Strategy Index (TMSI) (Gitlin et al 2002), for example, includes items such as 'try to ignore care receiver's mistakes' and the provision of 'failure free repetitive tasks'. Buri and Dawson (2000) noted that 'protecting' (p287) the PWD's self-esteem was important to carers. Corcoran (1994) describes 'protective care' as acting to defend against consequences such as 'threats to self-esteem, sense of wellbeing and dignity' (p42). The study found that caregivers considered 'protective care' to be an important aspect of care-giving. Corcoran (1994) suggested that self-esteem was preserved through engaging the person with dementia in 'productive activities, distraction, error-proofing the environment, strategic time use' (such as stretching out tasks to avoid opportunities to become bored and anxious, and creating a routine), and 'maintained involvement with friends and family' (p 42-43).

Perry and O'Connor (2002) describe 'protecting from incompetence' (p58) which incorporated strategies such as normalising difficulties and hiding efforts to compensate for difficulties from their spouse eg. re-washing dishes after their husband had gone to bed. Other strategies were to manage the physical and social environment to reduce the likelihood of experiencing negative feedback. In some cases this extended to the caring spouse attempting to hide their feelings to avoid upsetting their spouse. Vikström et al (2005) describe in detail the ways that caregivers attempted to 'create comfort' for their partners by drawing attention to the PWD's strengths, making light of their own shortcomings, being 'permissive' or 'discreetly' correcting mistakes (p. 153). MacRae (2002) described how caregivers would 'influence the definition of the situation' (p. 410) and 'play along' (p. 411) with the PWD in order to protect them from the awareness of how much support they were being given.

Perry and O'Connor (2002) highlight the potential for a 'paternalistic environment' (p59) to develop and suggest that a balance needs to be kept between protective measures and supporting strengths. They report that at times husbands would make efforts to protect their wives 'at the expense of protecting the personhood' (p59).

Vikstrom et al (2008, p265) observed that acting to maintain their spouse's 'continued sense of competence' appeared to be beneficial to the care-giver. Hellstrom et al (2007, p399) noted the importance of 'maintaining involvement' for the spouse with dementia even if this required more effort from the care-giving spouse. They describe how the care-giving spouse may ''work alone', both to 'protect' their partner from becoming fully aware of just how much support they were getting and eventually because the PWD was unable to contribute' (p402). From the studies described, it appears that preserving self-esteem is an important and demanding task for family, particularly spousal, carers.

Promoting engagement in activities

Closely linked to preserving self-esteem is the way in which the studies describe how spouses try to engage the PWD in activities. MacRae (2002) observed that some caregivers reported attempting to keep the PWD active in an effort to maintain independence and increase a sense of self-esteem. Perry and O'Connor (2002) noted that spouses were 'modifying expectations and setting up tasks for success'(p.57) and allowing their spouse to do things for themselves that they were still able to manage. In one study, the highest factor loadings for the items on the TMSI (Gitlin et al 2002, p66) suggested ways in which carers do this practically: 'introduce an activity that uses the same motion over and over such as sweeping, raking, dusting', 'give short instructions (2 or 3 words)', 'use pictures or labels to identify objects in rooms' and 'keeping talking to care receiver when he/she is doing something so he/she knows what to do'. Dodds (1994, p753) noted that caregivers 'felt guilty if they encouraged meaningless activities' and appeared embarrassed when discussing these.

Taft et al (1997) talk about a 'functional approach' (p199) category of care-giving that supports the person to complete activities of daily living, promoting 'physical functioning', 'providing cues', 'supervision', 'rest periods' and 'assistance'. Taft et al (1997) also talk about how 'cognitive approaches' (p206) such as 'reorienting' and 'reminders' 'maintain independence and involvement'. 'Error-proofing' has been suggested by Corcoran (1994, p43) as a means to protecting self-esteem and promoting engagement in productive activity. She suggests that this is done through presenting the required items, completing some steps in the task and relaxing rules about what is required to complete a task successfully. Vikström et al (2005) describe the ways in which caregivers support the PWD in preparing afternoon tea, noting that the task was more successful if they took 'responsibility for the task,' 'provided guidance', 'adapted the environment' (including presenting items that were needed) and 'altered the activity to make it easier' (p. 153). They noted that a 'collaborative approach' also became more time consuming for the caregiver as they would need to 'go back and check that the agreed tasks in the activity were fulfilled' (p. 156). Many caregivers were also observed to give the PWD time to think about what they needed to do next whilst indicating that they were available if assistance was needed, promoting supported independence and empowering the individual.

Dodds (1994) also suggested that caregivers may avoid disturbing the PWD when they are engaged in activities even though a decline in functioning may be a source of frustration in caregivers. Gitlin et al (2002) found that the use of strategies to support the completion of tasks was significantly associated with level of caregiver education. De Vugt et al (2004) also linked the use of supportive strategies with care-giver education. Vikström et al (2005) explored the ways in which caregivers may provide ‘insufficient’ or ‘inappropriate’ support to the PWD, describing how a ‘lack of attentiveness’ and ‘disproportional’ support ‘created confusion’ for the PWD (p. 155). They also describe instances where the caregiver fails to recognise the PWD’s need for support by questioning why they are unable to do the task or ‘taking over’ (p. 156).

Perry and O’Connor’s (2002) ‘supporting competencies’ strategy is described as ‘identifying retained abilities and setting up situations that encouraged the spouse with dementia to do as much as he or she could do’ (p.57). The authors attribute this to having ‘the important function of demonstrating that the person with dementia was like other people and able to act independently to some extent’ (p.57) which links with the theme of managing social settings. However, it could be suggested that spouses may facilitate engagement with activities to encourage cognitive stimulation (Jansson, Nordberg & Grafström, 2001) in the absence of other people. Buri and Dawson (2000) also recognised a ‘need to preserve independence’ (p287) in relation to managing falls.

Vikstrom et al (2008) describe how decreased engagement by the person with dementia was linked to their spouse taking on more responsibility. They describe a balance between care-givers ‘encouraging initiatives’ and ‘taking over chores’ to save time or reduce chances of conflict (p.262). This conflict arose in response to the person with dementia being unable to successfully complete a task and therefore this may link to efforts to protect self-esteem, although the authors did not identify this explicitly. Concern about a decrease in initiative appeared to lead to spouses providing a lot of encouragement in response to small signs of engagement. Care-givers communicated a collaborative perspective in describing their activities, for example, using the description, ‘we do’, even when their spouse had little practical involvement (p.263). They also described ‘engaging in the same task at the same time’ (p263), as opposed to interfering with how the spouse completed the task. Although this is not identified by the authors, this may have the effect of allowing supervision whilst modelling the task to reduce the risk of failure, thus protecting self-esteem.

Hasselkus & Murray (2007) found that caregivers equated the PWD’s ability to carry out ‘everyday occupations’ (p. 12) with wellbeing in the PWD. Witnessing retained abilities was a source of satisfaction and wellbeing for the caregiver.

The studies discussed here indicate that carers have quite a variety of ways in which to engage or maintain the engagement of the PWD. This may at times require them to make more effort in order to support the person but the associated importance of preserving self-esteem may motivate the carer to make these continued attempts.

Continuity/normality

Continuity refers to the notion that the person, relationship and associated feelings have remained fundamentally unchanged from before and since the diagnosis of dementia. Perry and O’Connor (2002) highlight that care-giving for spouses is seen as an ‘extension of the marital relationship’. They talk about the position of the caring spouse in relation to the spouse with dementia and link it to themes of personhood and continuity ie: ‘If I am a caregiver because I am his wife, then he must still be my husband’ (p.56). Continuity was maintained by the spouse ‘‘telling the ways’ of his or her partner’ (p57) and ‘interpreting current behaviours based on previous habits and personality styles’ (p.57) thus allowing them to separate out which behaviours were linked to the person and what was part of the dementia. Jansson et al (2001) also observed carers ‘preserving as much as possible of the past’ (p810). Dodds (1994) noted, however, that none of the carers she interviewed were engaging actively in reminiscence approaches with the PWD, which could be a key part of maintaining a sense of continuity.

Hasselkus & Murray (2007) noted that dementia could lead to ‘discontinuity of self’ (p. 13) for the caregiver, due to the ‘occupational disruption’ (p. 13) of dementia. A‘continued shared identity’ (p. 17) with the PWD was linked to the continuation of activities that the PWD had always done. The caregivers were reported to have ‘developed occupational strategies to help hold onto whatever sense of relationship and remnants of ‘normalcy’ remained in their daily lives’ (p. 14). They suggest that everyday occupations may help to maintain relationship continuity and help the caregiver retain a sense of their own identity.

Hellstrom et al’s (2007) work talks about ‘sustaining couplehood’ (p392) which can be seen as a form of effort to maintain continuity in the relationship. They describe the shift from ‘remaining a ‘we’’ to ‘becoming an ‘I’’ which represents a move from continuity to discontinuity in the relationship (p.403). Richter et al (1995, p282) noted that many of the caregivers described the PWD as ‘lost’ a long time prior to the PWD going into long term care, indicating the carer’s sense of discontinuity.

Within the papers reviewed, continuity has been briefly considered in connection to spousal caregivers as opposed to other family members. Little about how carers work to maintain normality has been explored.

Preserving the person

In an area related to attempts to maintain continuity in the relationship, carers also work to preserve the personhood of the person with dementia. Jansson et al (2001) described carers’ attempts to preserve the person’s sense of self as an important part of care observed in their study. They suggest that this is an important aspect of working to maintain the PWD’s self-esteem. MacRae (2002) noted how change in the PWD distressed carers and describes the 'identity maintenance work' (p. 405) that family members do on behalf of the PWD. She suggests that they do this through avoiding stigma as long as possible by not disclosing the diagnosis to others, by attributing challenging behaviours to the dementia, by maintaining the PWD's appearance and promoting engagement with activities. Some caregivers reported that they had not told the PWD the diagnosis in an attempt to protect the PWD's sense of self.

MacRae (2002) described how carers 'drew attention' (p. 412) to aspects of the person that had remained despite the dementia. Perry and O'Connor (2002) noted that care-giving spouses would refer back to their husband or wife, providing a description of how they used to be and ensuring that others 'connected the person of the present with the person of the past' (p.57). They argue that for the spouses, 'preserving personhood' is a 'primary... directive' of care-giving (p.56). This 'appears to benefit both spouses', providing 'coherence and meaning' to the caring spouse, and enabling them to attribute behaviour 'as either consistent with the past or attributable to the disease' (p.60). Hasselkus & Murray (2007) talks about 'identity keeping' where the caregiver uses occupation as 'a unique symbol of biographical and social identity... and an enabler of continuing moments of unity and purpose in one's life' (p. 17). The act of preserving the person through tailoring activities to meet long standing preferences of the PWD, is a source of satisfaction and wellbeing for the caregiver.

Corcoran (1994) noticed how spouses appeared to 'place a high value on anticipating the needs, responses, and wishes' of the PWD (p41). Taft et al (1997) categorised 'interventions that recognise and support the individuality and continued psychological functioning of the person with dementia' as 'psychological approaches'. Within this would be specific approaches: 'being responsive, taking the other's perspective, offering choices, and reframing' (p. 189-199).

Overview of synthesis

The studies reviewed use a wide range of approaches to research a number of different aspects of care-giving beyond practical assistance with basic activities of daily living. There have been a number of studies looking specifically at responses to challenging behaviour- both quantitative and qualitative, with attempts made to categorise general approaches. Several studies have noted particular strategies used by carers- avoidance of triggers, ignoring the behaviour, distraction and reassurance. In terms of managing social situations, there have been a few studies which highlight the impact of dementia on the person's social experience and issues for the carer in relation to these. Although Blum (1991) supplied little information to give a sense of rigour and credibility of the study, the paper provides a descriptive account of the way in which the family caregiver may need to work to manage the social impact of the dementia, within a society that marginalises people with mental health difficulties. Several papers noted the efforts carers make to protect the PWD's self-esteem and this was linked with engaging them in activities that they were likely to be successful in completing. A couple of papers have captured insights into spouses working to preserve continuity of the person and the relationship. In some respects, working to maintain social and activity engagement could be seen as ways in which spouses attempt to maintain normality and continuity but this has not been fully explored as yet.

Clinical implications from the work reviewed include the following. Harvath (1994) has emphasised the impact of carer attributions on the management of challenging behaviour, suggesting that the perception that the person is responsible for their behaviour may make it harder for the carer to resolve the behaviour effectively making the care-giving experience more stressful. Supporting carers to understand the behaviour and minimise triggers was suggested as helpful (also Hinrichsen & Niederehe, 1994). Collaboration and couples work

(Hellström, Nolan & Lundh, 2007; Vikström et al., 2008) is suggested by a number of studies but little detail is given on how this might be done in practice. Work with carers to consolidate and expand their range of ways to support the PWD in activities is also suggested (Corcoran, 1994).

Further research could focus around the ways in which normality and continuity are maintained by both spousal carers and other family members. It would be interesting to explore the purposes carers identify in what they are trying to achieve. Much of the literature takes a positive altruistic interpretation of behaviour, particularly with regards to promoting engagement in activities and preserving personhood and self-esteem. This focus may be to a lesser degree in managing behaviour, which Matson (1995) conceptualises as carer coping strategies rather than work to improve wellbeing.

The studies reviewed have noticed similar things about caregivers- that they appear to regard preserving self-esteem as very important, they appear to use a similar range of approaches to manage challenging behaviour, and they may have a range of ways to promote engagement and this appears to link to their level of psycho-education. Several papers have attempted to categorise types of care-giving approaches. However, a cohesive model of care-giving has not yet been developed. Many of the studies emphasise positive ways that carers act to promote wellbeing in the PWD.

The research reviewed indicates that carers work hard to maintain the PWD’s wellbeing, using person-centred approaches such as individualised approaches, creating a facilitative environment and valuing the person. As yet, person-centred care delivery by informal carers has not been the primary focus of studies. Given the ageing population and push to support PWD at home for as long as possible, this is an important next step for research in dementia. Quantitative research could consolidate some of the qualitative study findings, such as exploring which conditions encourage carers to use approaches that preserve personhood. The ways in which spouses and family caregivers work to maintain continuity and normality deserves further attention. Research should also develop and evaluate therapeutic approaches and interventions that improve or increase person-centred care by family and spousal caregivers.

References

Baumgarten, M., Battista, R. N., Infante-Rivard, C., Hanley, J. A., Backer, R. & Gauthier, S. (1992) The psychological and physical health of family members caring for an elderly person with dementia. *Journal of Clinical Epidemiology, 45*(1), 61-70

Beard, R. L. (2004) In their voices: Identity preservation and experiences of Alzheimer's disease *Journal of Aging Studies*

18(4), 415-428

Blum, N. S. (1991) The management of stigma by Alzheimer family caregivers. *Journal of Contemporary Ethnography. 20,* 263-284

Brodaty, H., Green, A., & Koshera, A. (2003) Meta-analysis of psycho-social interventions for caregivers of people with dementia. *JAGS, 51,* 657-664

Brooker, D. J. R., Sturmey, P, Gatherer, A. J. H. & Summerbell, C. (1993) The behavioural assessment scale of later life (BASOLL): A description, factor analysis, scale development, validity and reliability data for a new scale for older adults. *International Journal of Geriatric Psychiatry 8(9), 747-754*

Brooker, D. (2005) Dementia Care Mapping: A review of the research literature. *The Gerontologist*. *45*(1), 11-18.

Buri, H. & Dawson, P. (2000) Caring for a relative with dementia: a theoretical model of coping with fall risk. *Health, Risk & Society., 2*(3), 283-293

Butcher, H. K., Holkup, P. A. & Coen Buckwalter, K. (2001) The experience of caring for a Family member with Alzheimer's Disease. *Western Journal of Nursing Research, 23*(1), 33-55

Carbonneau, H., Caron, C. & Desrosiers, J. (2010) Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia, 9*(3), 327-353

Cooper C., Balamurali T., Selwood A., & Livingston G. (2007b).
A systematic review of the treatment of anxiety in caregivers of people with dementia. *International Journal of Geriatric Psychiatry, 22* 181–188.

Corcoran, M. A. (1994) Management decisions made by caregiver spouses of persons with Alzheimer's Disease. *American Journal of Occupational Therapy. 48*(1), 34-45

Cuijpers, P. (2005) Depressive disorders in caregivers of dementia patients: a systematic review. *Aging & Mental Health, 9*(4), 325-330

Critical Appraisal Skills Programme (CASP). (2006) 10 questions to help you make sense of qualitative research. Public Health Resource Unit in England.

Department of Health (2001) National Service Framework for Older People. www.dh.gov.uk/publications

Department of Health (2009) The Dementia Care Strategy. www.dh.gov.uk/publications

De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles,J. & Verhey, F. R. J. (2004) Do caregiver management strategies influence patient behaviour in dementia? *International Journal of Geriatric Psychiatr., 19,* 85-92

Dodds, P. (1994) Wandering : A short report on coping strategies adopted by informal carers. *International Journal of Geriatric Psychiatry. 9,* 51-756

Donaldson, C., Tarrier, N. and Burns, A. (1998) Determinants of carer stress in Alzheimer's Disease. *International Journal of Geriatric Psychiatry, 13,* 248-256

Fossey, E., Harvey, C., McDermott, F. And Davidson, L. (2002) Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatr., 36,* 717-732.

Gerritsen, J. C. & Van der Ende, P. C. (1994) The development of a care-giving burden scale. *Age and Aging, 23*(6), 483-491

Gilleard, C. J. (1984) *Living with dementia: community care of the elderly mentally infirm.* London: Croom Helm

Gitlin, L.N., Winter, L., Dennis, M. P., Corcoran, M., Schinfeld, S. & Hauck, W. W. (2002) Strategies used by families to simplify tasks for individuals with Alzheimer's Disease and related disorders: A psychometric Analysis of the Task Management Strategy Index (TMSI). *The Gerontologist. 42*(1), 61-69

Harvath, T. A. (1994) Interpretation and Management of Dementia-Related Behaviour Problems. *Clinical Nursing Research. 3*(1), 7-26

Hasselkus, B.R. & Murray, B. J. (2007) Everyday Occupation, Well-being, and Identity: The Experience of Caregivers in Families with Dementia. *The American Journal of Occupational Therapy. 61,* 9-20

Hellstrom, I., Nolan, M. & Lundh, U. (2007) Sustaining ‘couplehood’: Spouses’ strategies for living positively with dementia. *Dementia, 6,* 383-409

Hinrichsen, G. A. & Niederehe, G. (1994) Dementia Management Strategies and Adjustment of Family Members of Older Patients. *The Gerontological Society of America, 34*(1), 95-102

Hulko, W. (2009) From ‘not a big deal’ to ‘hellish’: Experiences of older people with dementia. *Journal of Aging Studies, 23,* 131-144

Jansson, W., Nordberg, G. & Grafstrom, M. (2001) Patterns of Elderly spousal caregiving in dementia care: an observational study. *Journal of Advanced Nursing, 34*(6), 804-812

Kitwood, T., (1993) Towards a Theory of Dementia Care: The Interpersonal Process. *Ageing and Society, 13,* 51-67

Kitwood, T. & Bredin, K. (1992) Towards a theory of dementia care: Personhood and well-being. *Ageing & Society, 12,* 269-287

Loukissa, D., Farran, C. J. & Graham, K. L. (1999) Caring for a relative with Alzheimer’s Disease: The experience of African-American and Caucasian caregivers. *Am J Alzheimers Disease & other dementias, 14*(4) 207-216

MacRae, H., (2002) The Identity Maintenance Work of Family Members of Persons with Alzheimer’s Disease. *Canadian Journal on Aging, 21*(3), 405-415

Matson, N. (1994) Coping, caring and stress: a study of stroke carers and carers of older confused people. *British Journal of Clinical Psychology, 33,* 333-344

Matson, N. (1995) Coping in Context. Strategic and tactical coping in carers of stroke survivors and carers of older confused people. *Journal of Community & Applied Social Psychology, 5,* 89-104

Nolan, M., Keady, J. & Grant, G. (1995) CAMI: a basis for assessment and support with family carers. *British Journal of Adult/Elderly Care Nursing,1,* 822-826

Office for National Statistics (2000) *General Household Survey.* Scotland: Crown

Pinquart, M., and Sörensen, S. (2003) Differences between caregivers and non-caregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267

Pinquart, M. and Sörensen, S. (2006) Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr., 18*(4), 577-95

Perry, J. & O'Connor, D. (2002) Preserving Personhood: (Re)Membering the Spouse with Dementia. *Family Relations, 51,* 55-62

Quinn, C., Clare, L. & Woods, B. (2009) The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental Health, 13*2), *143-154*

Richter, J. M., Roberto, K. A., & Bottenberg, D. J. (1995) Communicating with persons with *Alzheimer's* Disease: Experiences of Family and Formal Caregivers. *Archives of Psychiatric Nursing, IX*(5), 279-285

Russo, J., Vitaliano, P. P., Brewer, D. D., Katon, W. & Becker, J. (1995) Psychiatric disorders in spouse caregivers of care recipients with Alzheimer's disease and matched controls: A diathesis-stress model of psychopathology. *Journal of Abnormal Psychology, Vol 104*(1) 197-204.

Schofield., H. L., Bloch, S., Nankervis, J., Murphy, B., Singh, B. S. & Herrman, H. S. (1999) Health and wellbeing of women family caregivers: a comparative study with a generic focus. *Australian and New Zealand Journal of Public Health, 23*(6), 585-589

Schulz, R., O'Brien, A. T., Bookwala , J. & Fleissner, K. (1995) Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist, 35*(6) 771-91

Selwood, A., Johnston, K., Katona, C., Lyketsos, C., Livingston, G., (2007) Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders, 101,*75-89

Smits, C. H. M., de Lange, J., Dröes, R-M., Meiland, F., Vernooij-Dassen, M. & Pot, A. M. (2007) Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry, 22*(12), 1181-1193

Sõrensen, S., Pinquart, M. & Duberstein, P. (2002) How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356-372

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R. & Verhey, F. (2008) Effectiveness of Nonpharmacological Interventions in delay in the institutionalisation of patients with dementia : A meta-analysis. *Journal of the American Geriatric Society,56*(6), *1116-1128*

Taft, L. B., Matthiesen, V., Farran, C. J., McCann, J. J. & Knafl, K. A. (1997) Supporting strengths and responding to agitation in dementia care: An exploratory study. *American Journal of Alzheimer's Disease, 12*(5), 198-208

Thompson, C. A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C. & Adamson, J. (2007) Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics,7,* 18

Vikström, S., Borell, L., Stigsdotter-Neely, A. & Josephsson, S. (2005) Caregivers' self-initiated support towards their partners with dementia when performing an everyday occupation together at home. *OTJR: Occupation, Participation and Health, 25*(4), 149-159

Vikström, S., Josephsson, S., Stigsdotter-Neely, A. & Nygård, L. (2008) Engagement in activities: Experiences of persons with dementia and their caregiving spouses. *Dementia, 7,* 251-270

Vitaliano, P. P., Zhang, J. & Scanlan, J. M. (2003) Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*(6), 946-972

Ward, S., Opie, J. & O'Connor, D. W. (2003) Family carers' responses to behavioural and psychological symptoms of dementia. *International Journal of Geriatric Psychiatry, 18,* 1007-1012

EMPIRICAL PAPER

Perceptions of Relationship Continuity/Discontinuity in caring for a spouse with Dementia: Implications for Person-Centred Care.

By

Julie Achiampong

School of Psychology, University of Birmingham, England

WORD COUNT: 7260

Address Correspondence to:

Julie Achiampong, School of Psychology, University of Birmingham,

Edgbaston, Birmingham, B15 2TT, [redacted]

[redacted]

ABSTRACT

Objectives: To explore whether there is a link between levels of perceived relationship continuity in people caring for a spouse with dementia and the extent to which person-centred factors are considered when responding to challenging behaviour. A secondary aim is to examine whether relationship continuity is linked to caregiver demands reported by the spouse.

Method: Twenty spouses of people with dementia completed the Birmingham Relationship Continuity Measure (BRCM) and an adapted version of the Care-giving Hassles Scale (CHS). A semi-structured interview explored factors considered when responding to challenging behaviours. The interview data were analysed using an approach based on the Leeds Attributional Coding System (LACS).

Results: Levels of perceived continuity and consideration of person-centred factors were significantly positively correlated (r= 0.49, p=0.03). Levels of perceived continuity and consideration of the neurological impairment factor were significantly negatively correlated (r= -0.48, p=0.03). There were mixed findings in exploring the relationship between continuity and subscales of the CHS. Reported cognitive and behavioural difficulties were significantly negatively associated with levels of continuity (r= -0.65, p= 0.002 and r= -0.74, p=0.000 respectively). Male spouses reported significantly higher levels of continuity than females (Z= -3.15, p= 0.002).

Conclusions: The findings support the hypothesis that perception of continuity is linked with the degree to which the carer’s consideration of challenging behaviour focuses on person-centred or disease-related factors. Limitations and implications for clinical practice are explored and suggestions for further research made.

Key words: ‘behaviour’, ‘management’, ‘approaches’.

INTRODUCTION

This study draws together two strands of research in dementia - the continuity of relationships following the onset of dementia and person-centred approaches to care. The National Service Framework for Older People (Department of Health, 2001) stipulated that service-provided care should be person-centred (standard 2). Given the increasing age of the population, understanding which factors facilitate and support person-centred care at home is increasingly important. The predicted figures of people in the UK with dementia in 2038 are 1.4 million (in 2008 there were 700,000) with the cost of care rising from £17 billion to over £50 billion (Department of Health, 2009).

Through exploring how spouses experience the progression of dementia and its impact on their perception of their spouse and the relationship, a number of qualitative studies (Chesla, Martinson & Muwaswes, 1994; Kaplan, 2001; Walters, Oyebode & Riley, 2011) have developed the concept of relationship continuity/discontinuity. This refers to whether the person perceives the relationship since the onset of dementia to be a continuation of their pre-morbid relationship (continuity) or perceives it to be essentially different (discontinuity). The concept incorporates 'feelings of togetherness', 'feelings of loss', 'expressions of affection', 'same or different feelings', 'same or different perceptions of the person' and 'same or different perceptions of the relationship' (Shercliff, 2010). It has been suggested that the perception of continuity is on a continuum (Kaplan, 2001, Chesla et al., 1994) and that the perception may be elastic (Walters et al., 2011) i.e., the degree of perception of relationship continuity may fluctuate for the same person, at times being seen as more discontinuous than others. MacRae (2002) noted that whilst some carers perceived continuity in family members with severe dementia, others reported perceiving a major change in family members in the earlier stages of dementia. This concept of continuity differs from that of a general model of stages of adjustment through the progression of dementia suggested by others (Keady, 1999; Keady & Nolan, 2003; Hellström, Nolan & Lundh,

2007) in that it suggests that couples may differ in the extent to which continuity or discontinuity is perceived, regardless of the stage of progress in the dementia.

Perceptions of continuity/discontinuity may have an impact on how carers respond emotionally to the person they are looking after, their role as carer, and on how they manage the challenges presented by this role. Findings suggest that people who perceive discontinuity seem to feel progressively less emotional connection to their spouse (Chesla et al., 1994), having a sense that the person is gone (Kaplan, 2001). Walters et al. (2010) found that wives who experienced their spouse as changed, appeared to experience more negative feelings in relation to caring, such as guilt or feeling trapped. It was suggested that those who viewed the relationship as continuous may experience better adjustment to care-giving. MacRae (2002) suggested that variation in perception of the person with dementia (PWD) as the same or changed may be linked to ‘how family members perceived and responded to the effects of the disease’ (p. 408).

MacRae (2002) suggested that spouses may be particularly ‘motivated to hold onto the former selves of their partners because a meaningful part of their own identities (‘husband’ or ‘wife’) is in danger of being lost’ (p413). Hasselkus and Murray (2007) have also suggested that dementia may present a threat to the continuity of care-givers’ identities. Family caregivers reported a sense of satisfaction from seeing the PWD continue with activities that they had participated in prior to the dementia. The maintenance of these activities were thought to be linked to a ‘continued shared identity’ (p. 17) for the caregiver and the PWD, suggesting the importance of continuity for both individuals. Qualitative research into family caregivers’ ‘ways’ of caring has illustrated how some caregivers work to maintain continuity. Hellström, Nolan & Lundh (2007) talk about the work the spousal caregiver conducts in order to ‘sustain couplehood’ (p. 392) through communication, affection and their responses to challenging behaviour. Jansson, Nordberg and Graftsröm (2001) observed that carers made attempts to ‘preserve’ the past as far as possible (p. 810) by trying to keep life as ‘normal’ and engaging their spouse in activities they previously enjoyed. The ways in which family caregivers promote engagement in activities and the maintenance of self-esteem has been described in detail (see Corcoran, 1994; Gitlin et al., 2002; Vikström et al., 2008).

Continuity may also be maintained through working to maintain the PWD's personhood. Buron (2008) has emphasised that, through communication and cognitive losses, the person's sense of self is eroded. He argues that professional carers need to actively retain the individual's personhood on their behalf. This is done by knowing the person as an individual and using empathy to understand the person. Without an understanding of the person, attempts to communicate needs are misinterpreted as challenging behaviour and the carer takes a parental approach to the person, 'infantalising' them. This results in the person's isolation at a social level, loss of confidence and skills, and a deterioration in wellbeing. MacRae (2002) points out that seeing the loss of the PWD's sense of self is distressing to family caregivers, suggesting that they focused their attention on signs that the person was still there 'preserving the former self of one's loved one *for oneself*' (italics as per original quote, p. 412). She found that they also work to maintain the PWD's identity through concealing the diagnosis, attributing challenging behaviour to the dementia, attending to signs of the pre-morbid identity of the person, and managing their appearance. Perry and O'Connor (2002) re-analysed three qualitative studies about spouses' experiences of care-giving, looking for ways that spouses maintain personhood for their spouse. They observed caregivers 'tell the ways' of their spouse, 'connecting the person of the present with the person of the past' (p. 57). Maintaining the personhood of the PWD appeared to provide 'coherence and meaning' (p. 60) to the caregiver. Hasselkus and Murray (2007) used the term 'identity keeping' (p. 17).

The work of 'preserving personhood' (p. 56, Perry & O'Connor, 2002) enabled the caregivers to discern whether or not behaviour was attributable to the dementia as they 'interpreted current behaviours based on previous habits and personality styles' (p. 57). The consistent consideration of the knowledge about the PWD would also promote the caregiver's ability to consider the PWD's perspective, a strategy identified by Taft, Matthiesen, Farran, McCann and Knafl (1997). The extent to which caregivers have a sense of discontinuity may impact on their ability to take into account the PWD's feelings and pre-morbid personality when responding to challenging behaviour.

From predominantly qualitative research, family caregivers have been found to use a wide range of strategies when responding to challenging behaviour. These strategies range from confrontation (Hinrichsen and Niederehe, 1994; Taft et al., 1997; de Vugt, et al 2004) and attempts to reason with the PWD (Harvath, 1994), through ignoring (Dodds, 1994; Matson,1995; Ward, Opie and O'Connor, 2003; de Vugt et al., 2004; Hellström et al., 2007), 'walking away' from the PWD (Dodds, 1994; Taft et al., 1997) or 'going along' with the PWD (Harvath, 1994; Taft et al., 1997). Collusion (Dodds, 1994; Ward et al., 2003) and 'avoiding the truth' (Taft et al., 1997) were used in addition to reality orientation (Ward et al., 2003). Delaying (Taft et al., 1997) or 'putting off' (Harvath, 1994) has also been described by carers. Carers reported using distraction (Matson, 1995; Richter, Roberto and Bottenberg, 1995; Ward et al., 2003), diversion (Harvath, 1994; Taft et al., 1997) and redirection (Richter et al., 1995). Steps are taken by many carers to avoid triggers (Matson, 1995; Ward et al., 2003; Hellström et al., 2007). Responding to the PWD with reassurance, has often been described in the literature (Matson, 1995; Richter et al., 1995; Ward et al., 3003; Hellström et al., 2007). It has been suggested that trial and error approaches lead caregivers to develop a breadth of different strategies (Harvath, 1994) and that these are sometimes employed simultaneously or in succession (Matson, 1995). Hinrichsen and Niederehe (1994) and de Vugt et al., (2004) have categorised the strategies under three different approaches. Hinrichsen and Niederehe (1994) conceptualised these approaches as 'Criticism', 'Encouragement' and 'Active Management'. The latter was found to be associated with higher levels of burden and a greater desire to institutionalise. De Vugt et al (2004) described the approaches in relation to acceptance of the PWD’s difficulties: ‘Non-adapters’ were found to respond to the PWD with impatience and confrontation and ‘adaptive’ caregivers were found to have either a ‘supervise and assist approach (‘supporters’) or a ‘parent-child approach’ (‘nurturers’). How these strategies and more general approaches fit with current service ideals of dementia care deserves further attention and exploration.

A key development in recent years for in wider research into dementia care has been Kitwood’s work on person-centred care in care services (Kitwood, 1990). He suggested that dementia is a process that results from the combined effects of neurological deterioration and depersonalising approaches to care. He argued that approaches that retain the person’s sense of personhood, and which support and enable retention of skills and relationships are vitally important for wellbeing. He discussed ten approaches which constitute ‘malignant social psychology’ and undermine personhood. Person-centred care embodies ‘valuing the person’, providing individualised care, taking into account the perspective of the person with dementia and creating a supportive social environment (Brooker, 2007). Person-centred approaches are now considered good practice and feature as standards in both the Alzheimer’s Society standards for care homes document (Alzheimer’s Society, 2001) and the National Service Framework for Older People (Department of Health, 2001).Research into person-centred care has focused on care service settings. However, most care is delivered to people with dementia at home by family, predominantly spouses (Lewis, 1998). As the population ages, this is set to continue and increase as services will be insufficient to meet need (Department of Health, 2009). It therefore seems important to explore person-centred care in the home and what enables this to take place. Although research has started to explore the ways that caregivers work to maintain personhood and continuity, and respond to challenging behaviour, research has not explicitly focused on the use of person-centred care approaches by non-professional caregivers in the home environment. In order to explore the degree to which person-centred care is present, it is important to have an understanding of the factors the caregiver takes into consideration when responding to the PWD and the circumstances in which this occurs. Harvath (1994) found that caregiver attributions about the nature, cause and the PWD's ability to control their behaviour, influenced how the caregiver responded to challenging behaviour and contributed to carer burden.

A case can be made for suggesting that person-centred care and relationship continuity may be linked, and that those carers who perceive continuity in their relationship may find it easier to adopt a person-centred approach to the person they are caring for. A person-centred approach requires the carer to view the person with dementia as an individual with their own history, their own personality, their own preferences and so on. It requires the carer to adopt the perspective of the other and to empathize with them. When the carer perceives continuity in the relationship, they perceive the person with dementia as being essentially the same person as before, the relationship to be the same and they still feel a bond of affection with the other person. Because the carer perceives the person and the relationship to be essentially the same, one might expect that they will continue to relate to them in, in many respects, in the same way as they have always done. For most relationships, this will involve seeing the other as a person as an individual, empathizing and being able to adopt the perspective of the other (i.e. being person-centred in how they relate to the other person). By contrast, when the carer perceives radical discontinuity, they have no familiar framework within which they can relate to the other person. Instead, they are faced with the task of reconstructing the identity of the other person and the nature of their relationship. Because of the prominence of the dementia and its impact on their life, it may be that this reconstruction focuses on the other as a person with dementia, and that the other person and their relationship are essentially defined in terms of the dementia. Instead of being an individual, the other person may be defined by their diagnosis. The loss of a sense of the other's individuality may also make it more difficult to take the perspective of the other and to empathize. Person-centred care, with its emphasis on the individuality and uniqueness of the other and on empathy and perspective-taking, may thus prove more difficult for those who perceive discontinuity in the relationship.

The current study explored this idea (that relationship continuity and person-centred care are connected) in the context of the response of carers to the challenging behaviour of a spouse with dementia. Twenty participants completed the Birmingham Relationship Continuity Measure (Shercliff, 2010) and the Caregiver Hassles Scale (Kinney & Parris Stephens, 1989). They also completed a semi-structured interview that explored how they responded to and managed the challenging behaviour of their spouse. This interview material was then coded using a set of categories that attempted to capture what factors the person had considered in choosing, devising or implementing strategies for dealing with that behaviour. Examples of these categories included a code relating to evidence that the carer had considered the neurological impairments associated with the dementia and a code relating to evidence that the carer had taken the perspective of the other and thought about what they would be feeling in the situation they were in. The hypothesis was that the considerations of those who scored low on relationship continuity would relate primarily to neurological impairment (on the supposition that they have re-defined the other person primarily in terms of their dementia); whereas those who scored high on relationship continuity, although they may consider neurological impairment, would also report considerations that were evidence of taking account of the individuality of the other and taking their perspective. In other words, it was hypothesized that low scores on the BRCM would be associated with a high percentage of considerations relating to neurological impairments; whereas high scores would be associated with a high percentage of person-centred considerations.

As noted earlier, there is some disagreement in previous literature about whether relationship continuity follows a fixed series of stages that depend on the level of impairment of the person with dementia; or whether spouses vary greatly in the degree to which they perceive continuity or discontinuity regardless of the degree of deterioration in the person with dementia.

Dementia involves a progressive loss of independence in completing activities of daily living, loss of communication and increased confusion which often results in challenging behaviour. As such it is multi-facetted and creates a range of demands for the carer. These demands include giving the PWD practical support as well as responding to challenging behaviour. Therefore a secondary aim of the study was to investigate whether perceived relationship continuity is linked to the type and level of demands reported by the caregiving spouse. . The issue was investigated by examining the correlation between an adapted version of the CHS and the BRCM.

METHOD

Participants

Eleven husbands and nine wives of people with dementia participated in the study. All of the spouses were Caucasian and lived with their spouse except for one husband, whose wife had moved into a nursing home shortly before the study took place. Length of relationship ranged from 20-75 years (mean=48.45 years). Time since diagnosis of the dementia ranged from 1-10.5 years (mean=3.66 years). The diagnoses of the spouses were: Alzheimer's Disease (7), Vascular Dementia (6), Mixed Dementia (4), Fronto-temporal dementia (2) and Lewy Body Dementia (1).

The original aim was to recruit at least 26 participants. This figure was based on a power analysis conducted using the G-POWER program (Faul & Erdfelder, 1992). The main component of the analysis was correlations. According to the power calculation, detection of a large correlation (r=.5), with an alpha set at .05 (two-tailed) and power at .80, would require a sample of 26.

Ethical approval was obtained through an NHS Research Ethics Committee (see Appendix 3 for ethics approval letter and research and development approval from NHS Trusts involved in participant identification). Participants were recruited through a number of services. The researcher attended Alzheimer's Cafes run by a local voluntary organisation and spoke to groups of people about the research. Those who were interested were given an information pack with a consent form to return by post (see Appendix 4). The majority of people were happy to be contacted a week later to see if they had any questions, with no obligation to participate. If they wished to participate, an appointment was made over the telephone at this point. Another voluntary organisation delivered a mail shot with brief information about the study and those who wished to participate returned a request to receive the information pack along with their telephone contact details if they were happy to be contacted. The researcher then telephoned people a week after they received the pack to answer any questions, again with no obligation to participate. If they were happy to go ahead, a meeting was then arranged at this point. In addition two local NHS older adult mental health services were supplied with information packs to give to interested spouses of people accessing the service. Participants were contacted by telephone to answer any questions they had and to arrange to meet if they wished to participate. No participants were contacted by the researcher unless they had given their contact details and consent to be contacted. Participants were given at least a week to look at the participant information pack before they contacted. The majority of participants were seen in their homes at a time that allowed a private meeting. Where this was not possible, participants were met on NHS trust premises. In all cases written consent to participate was obtained.

Data Collection

Each participant completed the BRCM (Shercliff, 2010), an adapted version of the Caregiver Hassles Scale (CHS, Kinney & Parris Stephens, 1989) and a semi-structured interview concerning their management of challenging behaviour. They also answered some demographic questions.

Birmingham Relationship Continuity Measure (Appendix 5): The BRCM (Shercliff, 2010) was based on domains of relationship continuity identified by Walters et al (2010). The measure is comprised of twenty-six items covering the following domains: ‘feelings of togetherness’, ‘feelings of loss’, expressions of affection’, ‘same or different feelings’, ‘same or different perceptions of the person’ and ‘same or different perceptions of the relationship’. Each item is rated on a 5 point Likert scale (‘agree a lot’- ‘disagree a lot’). The BRCM had good concurrent validity (Shercliff, 2010). The internal reliability was found to be good (α = .94) as was the test-retest validity (α= 0.96).

Caregiver Hassles Scale (Appendix 5): The CHS (Kinney & Parris Stephens, 1989) is a 42-item scale featuring events that could occur in the day-to-day care-giving for someone with dementia. The scale asks whether an event has occurred within the past week, and to what extent it was considered a hassle on a scale of 0-4 (not at all –a great deal of hassle). The scale consists of items belonging to the following categories: ‘hassle assisting with basic activities of daily living (BADL), ‘hassle assisting with instrumental activities of daily living’ (IADL), ‘hassle with care-recipient’s cognitive status’ (COG), ‘hassle with care-recipient’s behaviour’ (BEH) or ‘hassle with caregiver’s support network’ (SN). The scale was reported to have good internal consistency (α=0.91) (Kinney & Parris Stephens, 1989). For this study, the participants were asked only if the event had occurred in the previous week and not to what extent it was considered a hassle. The scale was used in order to give a picture of the perceived demands reported by the caregiving spouse. This was considered more informative than relying on cognitive assessment scores or symptoms measures which would miss the day-to-day aspects of the caregiving experience. Item 28 was accidentally omitted prior to data collection and therefore the value entered into statistical analysis was the mean value for the subscale the item belonged to.

The CHS was given in order to provide information about the demands placed on the participants in looking after their spouse, and thus provides a fuller description of the sample. Furthermore, in the Introduction, it was noted that there is some disagreement in previous literature about whether relationship continuity follows a fixed series of stages that depend on the level of impairment of the person with dementia; or whether spouses vary greatly in the degree to which they perceive continuity or discontinuity regardless of the degree of assistance needed by the person with dementia. The CHS provided an opportunity to investigate this issue further, within the limitations of self-report.

Semi-structured interview (Appendix 5): It was decided that a semi-structured interview utilising vignettes would be the most appropriate way to address the research question. Direct observation has been a useful approach in examining the use of person-centred care in professional care environments (for example, Dementia Care Mapping, see Brooker, 2005) but has been applied less frequently to studies with family caregivers. The presence of an observer during spousal care interactions may significantly impact on the interaction, in terms of the spouse with dementia's behaviour and the way in which the caring spouse may respond to it. A desire to appear to respond in socially desirable ways may undermine the validity of observed person-centred interactions. In order to ensure that the influence of the researcher is minimised, observations were therefore eliminated as a data collection option. Additionally, questionnaires previously used with professional carers of people with dementia may assume a breadth of knowledge resulting from working with many people with dementia over a number of years, and would not take into account the personal nature of a spousal relationship into account. Producing a new tailored questionnaire for spouses presenting a range of responses to challenging behaviour would introduce a researcher bias and potentially undermine the ecological validity of what was being captured by the questionnaire. Therefore a semi-structured interview that was open enough to accommodate the uniqueness of each spouses' experience seemed most appropriate.

At the start of the interview, participants were read a series of vignettes which were used to help identify difficult situations that the participant regularly experienced with their spouse. The vignettes were scenarios featuring four commonly stressful behaviours drawing on Donaldson, Tarrier and Burns' (1998) research with carers of people with dementia. The situations featured pacing, night-time waking, risk-taking behaviours and repetitive questioning.

The participant was asked whether they had experienced the difficulty with their spouse and how frequently this occurred. The participant was then asked to talk about two of these situations (in four cases only one situation was discussed and in one case three situations were discussed). Participants were asked to talk about the last time a situation similar to that of the vignette happened. The participant was then asked about their thoughts and feelings at the time; why they thought their spouse had behaved in that way; how they responded to the behaviour: why they responded in that way; and about helpful and unhelpful responses to the behaviour that they had used in the past or still currently use. The behaviours discussed were as follows (the number of participants who discussed them are in brackets): repetitive questioning (8), risky behaviour (5), lack of co-operation (2), pacing (3), forgetfulness (2), losing things (1), difficulties with specific activity (1), unsettled at night (3), not recognising home (3), being disruptive (1), and word-finding difficulties (1). The discussion was tape-recorded and then transcribed. The recordings were then deleted to protect participants' anonymity.

Semi-structured interviews and a coding system have been widely used in research investigating how people understand and attribute the behaviour of others -for example, Bolton et al., (2003) and Barrowclough et al., (2001) use the Camberwell Family Interview to measure expressed emotion. This methodology generates qualitative data, but also quantitative data that can be entered into a statistical analysis. The method of coding transcripts in this study is based on the Leeds Attributional Coding System (Stratton, Munton, Hanks, Heard, & Davidson, 1988) which was developed in response to the difficulty in measuring causal beliefs with questionnaires.

To establish the coding system, transcripts of two interviews were examined and an initial list of categories was drawn up to encode factors participants considered in how they managed or responded to the behaviour. These categories were defined and a set of instructions drawn up for their application. The instructions were then tried out by the research team (including those unaware of the research hypothesis) and further refined to clarify areas of uncertainty and ambiguity. Ten codes were established as shown in Table One which provides the definitions of the factor and an example (the final set of instructions for coding and the record form on which codes were entered are provided in Appendix Six).

Table 1 Factor definitions and examples from transcripts

Factor and definition	**Example of influence on management of the behaviour from transcripts**
Neurological impairment Evidence that the choice/implementation of strategy is influenced by beliefs about disabilities in language, cognition, physical or social functioning arising from the dementia. Include here any examples where the participant refers to "dementia" generally as an influence on their choice of a specific management tactic.	Participant1: Strategy: 'It's no good asking him straight out (about his concerns)' (line 43) Factor: '...he doesn't know himself...he can't get the word out' (lines 43-47)
Other health conditions Evidence that the choice/implementation of strategy is influenced by consideration of other health conditions that may have an impact on the person with dementia.	Participant 3: Strategy: Using distraction techniques when his wife asks for cake repetitively: 'we are going to the day centre this morning' (lines 28-30). Factor: '...I have to control that (her snacking)... she's not using any calories, very sedentary...try to keep the weight down.' (lines 23-25)
Pre-morbid personal history Evidence that the choice/implementation of strategy is influenced by consideration of events or circumstances that happened to the person with dementia before the onset of the dementia. Also, jobs, activities or achievements that occurred before the onset of the dementia.	Participant 16: Strategy: Reduce chances of forgetting by continuing with longstanding routine of going out for a meal on the same day of the week. Factor: 'That's connected with the time when she used to play golf... it used to be to have a complete day off and we've done that for years'. (lines 65-69)
Current events, activities and environment Evidence that the choice/implementation of strategy is influenced by consideration of events that have taken place since the onset of the dementia; features of the current social or physical environment in which the person with dementia finds themselves; and/or current activities.	Participant 3: Strategy: Using distraction techniques when his spouse wants to buy a new girdle. Factor: His wife now requires assistance to get dressed and is unstable when standing: '...it would be absolutely impossible...the slightest pull on her and she'd go down.' (lines 345-7)
Personality Evidence that the choice/implementation of strategy is influenced by the carer's beliefs about the long-standing pre-morbid personality of the person with dementia. Personality refers to general patterns of behaviour, thoughts and feelings that characterize the individual (e.g. being fussy, outgoing,	Participant 11: Strategy: 'It wouldn't help to ...stop him from going out or doing things independently.' (lines 144-5) Factor: 'He's ...a very dominant personality, it wouldn't help at all to prevent him from doing what he wanted to do.' (144-147)

ambitious). The evidence needs to be clear that the carer is thinking about what the person's personality was like before the onset of the dementia.	
Likes and dislikes Evidence that the carer has considered the likes and dislikes of the person with dementia in their choice/implementation of a strategy.	Participant 7: Strategy: Answering her repetitive questions about their grandson. Factor: 'She likes him most of all the family.' (lines 22-24)
Thoughts (surface vs deep) • Evidence that the carer, in choosing or implementing a strategy, has considered what are/might be the thoughts of the person with dementia (both their thoughts relating to the situation that triggers the challenging behaviour and their possible thoughts should a particular management tactic be used). Thoughts include appraisals and interpretations of the situation/tactic, and goals and intentions. • **Deep** when the reference is to specific thoughts that the person with dementia has and there is evidence that the carer has thought about what the other person is thinking (i.e. that the participant has engaged in theory of mind activity). • **Surface** means that the reference is vague; does not refer to specific thoughts that the person with dementia may have; and did not require the participant to take the perspective of the other person and think about what they are thinking.	Deep Thought: (Participant 9) Strategy: 'I've had to stand up by her (in the bus) because she can't see me' (lines 22-23) Factor: 'It's like 'where am I? I'm lost' and she's looking at me blank...because 'what am I doing here' or 'why ain't nobody with me?'' (lines 28-30) Surface Thought: (Participant 15) Strategy: Give him his keys when he repetitively asks whether they have the keys when they go out. (lines 97-112) Factor: '...he still thinks about keys...' (line 100)
Feelings (surface vs deep) • Evidence that the carer, in choosing or implementing a strategy, has considered the feelings, mood or emotions of the person with dementia (both their feelings relating to the situation that triggers the challenging behaviour and their possible feelings should a particular management tactic be used). • **Surface** means that the reference is vague; does not refer to specific feelings that the person with dementia may have; and did not require the participant to take the perspective of the other person and think about what they are feeling. • **Deep** refers to specific feelings and/or evidence that the participant has thought about what the other person is thinking.	Surface Feeling: (Participant 2) Strategy: She avoids 'bawling and shouting' (line 137) Factor: It 'aggravates' him. (line 138) Deep Feeling: (Participant 6) Strategy: She responds to repetitive questioning with the same answer (lines 81-83) Factor: 'I think in some ways he's showing that he's concerned and he wants to know that things are alright.' (lines 94-95)

To assess the reliability of the coding system, all interviews were coded separately by the main researcher and one of two people who had been trained to use the coding system but who were unaware of the aims and hypothesis of the research. A meeting was then held with both coders, plus a third member of the research team (who was aware of the research hypothesis). Disagreements in the coding were highlighted in this meeting, and, through discussion, an agreed set of codes was achieved. This agreed set of codes was used in the analysis that tested the hypothesis. The two individual sets of codes were used to calculate the inter-rater agreement and thus give an indication of the reliability of the coding system.

The hypothesis was that the considerations of those who scored low on relationship continuity would relate primarily to neurological impairment (on the supposition that they have re-defined the other person primarily in terms of their dementia); whereas those who scored high on relationship continuity, although they may consider neurological impairment, would also report considerations that were evidence of taking account of the individuality of the other and taking their perspective. For the analysis, the total number of codes recorded for a participant across the two situations was calculated and then the percentage of those that belonged to the 'neurological impairment' was calculated. The expectation was that this percentage would be negatively correlated with the BRCM score (i.e. that those scoring lower on relationship continuity would have a higher percentage of their codes falling into the 'neurological impairment' category). Four of the other codes were considered to be particularly representative of a person-centred approach. These were 'pre-morbid personal history' and 'pre-morbid personality' (because these suggest that the participant considered the individuality and uniqueness of the other person); and 'deep thoughts' and 'deep feelings' (because these demonstrated that the participant was attempting to empathize and take the perspective of their spouse). The category 'likes/dislikes' was considered for inclusion in the person-centred factors.

However it was omitted as the ‘likes/dislikes’ reported by participants appeared to be superficial and general (eg: liking ice cream) and not reflective of a unique individualised knowledge of the spouse. For each participant, the number of codes falling into these four categories was totalled and this total was expressed as a percentage of the total number of all codes for that participant. The expectation was that this percentage would correlate positively with the BRCM (i.e. that those scoring higher on relationship continuity would have a higher percentage of their codes falling into these four person-centred categories). The remaining factors, ‘health’ and ‘current events, activities and environment’ were rarely considered by participants leading to very low data for these categories and therefore these were not analysed.

RESULTS

Descriptive Data

Table Two summarises the continuous variable data gathered from the 20 participants.

Table 2: Descriptive Data

Total Variables/Factors	**Mean**	**Std Deviation**	**Possible Range**	**Actual Range**
Demographics				
Length of R’ship	48.45	15.03	-	20-75
Time since Diagnosis	3.66	2.42	-	1-10.5
CHS				
Basic ADL	4.3	2.87	0-9	0-8
Instrumental ADL	5.15	1.42	0-7	1-7
Cognitive	6.35	1.78	0-9	2-9
Behaviour	5.4	2.73	0-12	1-10
Support Network	2.25	1.07	0-5	0-4
CHS Total	23.45	4.84	0-42	12-30
BRCM				
Total	78.2	22.84	26-130	46-116
Factors:				
Neurological Impairment	3.50	1.73	-	1-6
Other Health	0.20	0.62	-	0-2
Pre-morbid Personal History	0.50	0.83	-	0-3
Current events, activities/	0.60	0.75	-	0-2

Environment				
Personality	0.15	0.37	-	0-1
Likes/Dislikes	0.70	0.86	-	0-3
Surface Thoughts	0.30	0.57	-	0-2
Deep Thoughts	0.75	1.29	-	0-4
Surface Feelings	2.30	1.69	-	0-5
Deep Feelings	0.85	0.88	-	0-2
N I percentage	40.00	22.32	-	9.09-100
Person-Centred Percentage	20.65	11.06	-	0-41.67

The descriptive statistics for the BRCM (mean = 78.2, SD = 22)are similar to those reported in the original development of the study (mean= 76.90, SD=23.55; Shercliff, 2010).

Suitability for analysis

The data were inspected for suitability for analysis through inspecting the values for skewness and kurtosis of each distribution; running the Shapiro-Wilk test (see Appendix 7) to examine whether the distribution departed significantly from normality; and searching for univariate and multivariate outliers. The only variable to depart significantly from the normal distribution was time since diagnosis. An outlier score was identified on both percentage of neurological impairment and time since diagnosis. Given the size of the sample, removing the outliers was considered unsatisfactory. Therefore non-parametric tests were conducted. However, it was deemed useful to ensure that the correlations were not significantly influenced by the outliers and therefore this was checked by performing additional correlations after removing participants three and seventeen.The removal of these outliers did not change the pattern of statistically significant findings obtained for the whole sample. Accordingly, in what follows only the analysis for the whole sample is reported (see Appendix 7 for correlations for whole sample and with outliers removed).

Internal Reliability

Cronbach's alpha for the BCRM was 0.93 indicating good internal consistency. This is similar to that reported in its development (α= 0.94, Shercliff, 2010). Cronbach's alpha for the

Caregiver Hassles Scale Basic Activities of Daily Living (α= 0.84) and the Behaviour subscale (α= 0.74) indicate good levels of internal reliability. The full scale CHS internal reliability was 0.65. The Instrumental Activities of Daily Living (α= 0.48), Cognitive subscale (α=0.49), and Social Network subscale (α=-0.08) showed poor internal reliability (see Appendix 7 for SPSS output).

Inter-rater Reliability

Inter-rater reliability of the coding system was assessed using Cohen's kappa (Cohen, 1960). There were two types of non-agreement: one in which the two raters differed in the coding they gave to a particular statement made by the participant ('a disagreement' – e.g. one rater coded it as 'neurological impairment', but the other as 'personality'); and the other in which one rater coded a piece of the transcript, but the other coder missed this piece and did not encode it at all ('a miss'). Table Three shows the agreements, disagreements and misses for the two raters. When all three of the categories were included, Cohen's kappa was quite low, although it showed that the level of agreement was significantly different from what would be expected by chance (kappa = .353; T = 11.87; p<.001). According to the suggestions of Landis and Koch (1977), a kappa of 0.353 would be rated as 'fair' (fair = kappas within the range 0.21 – 0.40). When only agreements and disagreements were included in the calculation, the kappa suggested a good level of agreement (kappa = .722; T = 16.77; p<.001) ('good' range according to Landis and Koch: 0.61-0.80). Therefore there was good agreement on the actual rating of a piece of the transcript, but there was a marked tendency for the raters to fail to code a piece that the other rater had coded.

Correlations

Bivariate correlations were conducted using Spearman's rho with the following variables: Length of Relationship, Time since Diagnosis, Basic ADL, Instrumental ADL, CHS Behavioural subscale, CHS Social Network subscale, CHS Cognitive subscale, CHS Total items, BRCM, Neurological Impairment Percentage and Person Centred Factors Percentage.

The main hypotheses were supported. There was a significant positive correlation between the BRCM score and the person-centred percentage score (rho= 0.49, p=0.03). Also as predicted, there was a significant negative correlation between the BRCM score and the neurological impairment percentage score (rho= -0.48, p=0.03). The results support the suggestion that perception of continuity is linked to the degree to which person-centred and neurological factors are considered in determining responses to difficulties. As noted earlier, the removal of the outlier data lead to the same conclusion (see Appendix 7 for correlations with participants three and seventeen removed).

Table 3: Inter-Rater coding agreements and disagreements

		Main Researcher coding											
		Neuro	Health	History	Current	Person	Like/Dislikes	Surface Thought	Deep Thought	Surface feelings	Deep feeling	Missed	Totals (Other)
Other Coder	Neuro	37	0	0	0	0	0	1	1	0	2	22	63
	Health	0	2	0	1	0	0	0	0	0	0	1	4
	History	0	0	5	0	0	0	0	0	0	0	0	5
	Current	0	0	0	2	0	0	0	0	1	0	5	8
	Personality	0	0	0	0	1	0	0	0	0	0	0	1
	Likes/ Dislikes	0	0	0	0	0	7	0	0	0	0	1	8
	Surface thought	0	0	0	0	0	1	2	0	0	0	2	5
	Deep thought	0	0	0	0	0	0	1	8	0	0	3	12
	Surface feeling	0	0	0	0	0	1	0	0	15	4	9	29
	Deep feeling	0	0	0	0	0	0	0	0	12	9	4	25
	Missed	8	0	6	2	0	5	0	2	4	2	0	29
	Totals (Main Researcher)	45	2	11	5	1	14	4	11	32	17	47	189

A secondary aim of the research was to address the issue of whether the level of relationship continuity is linked to the level of demands reported by the caregiver. . Correlations between the BRCM score and each of the subscales of the CHS are shown in Table Four. An inconsistent picture emerged: The BRCM score had significant negative correlations with the Cognitive (rho= -0.65, p=0.002) and Behaviour subscales (rho= -0.74, p=0.000) (indicating that more frequent reported cognitive and behavioural difficulties were associated with less continuity); there was no significant correlation with the instrumental ADL subscale (rho= -0.16, p=0.488); and a positive correlation with the basic ADL subscale (rho= 0.41, p=0.077) that approximated significance (indicating a tendency for greater basic ADL demands to be associated with more continuity). Another finding of potential relevance here is that the correlation between time since onset of dementia and the BRCM (rho= 0.4, p=0.083) was also positive and approximated significance (indicating a tendency for greater continuity to be associated with a longer duration of dementia).

Table 4: Correlations of perceived continuity (BCRM) with degree of support required by person with dementia (CHS sub-scales and total)

Sub-scale	**Correlation Co-efficient**	**Significance**
Basic ADL	0.41	0.077
Instrumental ADL	-0.16	0.488
Behaviour	-0.74	0.000
Social network	-0.35	0.135
Cognitive	-0.65	0.002
Total score	-0.58	0.007

There were some other findings of interest emerging from an analysis of the demographic variables in relation to the BRCM scores. There was a positive (but non-significant) correlation between length of relationship and the BRCM score (rho= 0.4, p=0.087), suggesting that perceptions of continuity may be more preserved in couples who have been together for longer. A Mann-Whitney U-test indicated that the male participants reported significantly higher BRCM scores than the females (mean for male participants = 92.55 and females= 60.67, Z = -3.15, p=0.002). There may be some confounding of gender with type of dementia-related needs in that the female participants scored significantly higher on the Cognitive subscale of the CHS. (mean for male participants = 5.64 and females = 7.22, t =-2.21, p=0.041).

DISCUSSION

The results support the hypothesis that spouses who perceive a low level of continuity in their relationship are more likely to look to neurological impairment explanations for challenging behaviour. Additionally, spouses who perceive a higher level of continuity in their relationship draw on more person-centred factors when dealing with challenging behaviour. As previously argued, this difference may be due to the continued consideration of their spouse's pre-morbid personality, history, and the ability to recognise and empathise with their spouse's thoughts and feelings. In the case of discontinuity, this prior knowledge of the person is not considered to the same extent and therefore non-person-centred factors form the basis of an interpretation of the behaviour. This lacks individuality and therefore makes it difficult for the spouse to empathise with the other's experience. MacRae (2002) suggested that there was a risk that carers who attributed behaviour as being caused by the dementia, in order to preserve the continuity of the PWD's identity, would overlook other explanations for the behaviour. However, it appears that those who perceive continuity, consider other explanations for the behaviour in addition to neurological ones.

The second aim for this study was to further understand how continuity links with the reported demands placed on the caregiver. We hypothesised that, based on previous research (Chesla et al 1994; Kaplan 2001; Walters et al 2011), continuity could be different for different couples as opposed to being linked with the trajectory of the dementia (Keady 1999; Keady & Nolan 2003; Helström, Nolan & Lundh 2007). The results provided some support for this suggestion. Scores on the relationship continuity measure had a complex relationship with the self-reported demands placed on the carer (as measured by the CHS). The results were consistent with the suggestion that it is not simply the case that relationship continuity declines as carer demands increase. Instrumental and Basic ADL were not significantly correlated with the relationship continuity measure. Indeed, Basic ADL had a positive correlation with relationship that approximated significance (p=.08); and a negative correlation would be expected if relationship continuity simply declined as carer demands increased. However, the relationship continuity did show a significant negative correlation with both the Cognitive and the Behaviour subscales of the CHS. The subscales of the CHS indicate that discontinuity may be more likely in couples where the person with dementia is perceived to generate a higher level of cognitive or behavioural demands. It is possible that discontinuity is more likely in instances where carers are under an increased level of stress due to the nature of the difficulties. Donaldson, Tarrier & Burns (1998) identified that behavioural disturbances were a strong predictor of subjective burden in carers and, cognitive impairment predicted carer distress. One of the items within the behavioural subset is about undesirable changes in personality and again, Donaldson, Tarrier & Burns (1998) identified that mood and behavioural changes in the person also predicted subjective burden. Another possibility is that the changes evaluated by the Cognitive and Behaviour subscales fundamentally challenge the carer's perception of the identity of their spouse (e.g. aggressive behaviour might be difficult to reconcile with a gentle pre-morbid disposition) and relationship continuity becomes difficult to maintain when the perceived identity of the other is challenged in this way.

High levels of continuity were also linked with a longer duration of the relationship (although non-significant), suggesting that continuity may be partly predicted by the nature of the relationship. One possible explanation for this is that the spouse's own identity may be inextricably linked with the relationship and the identity of the other. Hasselkus and Murray (2007) talked about dementia as a threat to the caregivers' identity and research has highlighted the ways that caregivers work to maintain continuity (Jansson, Nordberg & Grafström, 2001; MacRae, 2002; Perry & O'Connor, 2002; Hellström, Nolan and Lundh, 2007). The investment in a 'continued shared identity' (Hasselkus & Murray, 2007) may strengthen perceptions of continuity and protect them against the impact of dementia-related changes, particularly in instances where people have been together since adolescence. Conversely, couples who have met later in life will have formed their own identities prior to the relationship. This identity, independent of the context of the relationship, may be more readily reverted to when continuity is threatened by behavioural cognitive changes in their spouse. Further research to explore this explanation is required, as there is not enough data in this study to decisively draw that conclusion.

Another interesting area for further research springs from the notion that caregivers work to maintain the PWD's identity for the PWD and for themselves. MacRae (2002) suggests that 'whether identity is lost or retained is very much dependent on 'the eye of the beholder'' (p. 414) and that her 'findings suggested that the self may not be so much 'lost' as prematurely relinquished, highlighting the significance of subjective reality and self-fulfilling prophecy' (p. 414). The circumstances in which caregivers cease to work towards maintaining the identity of the person- and thus their perception of continuity- need further exploration.

Matson (1995) has suggested that problem solving interventions for carers have produced moderate results, indicating that the care giving experience is not sufficiently understood to ensure effective intervention. As Walters et al (2011) have previously suggested, spouses with perceptions of discontinuity are more likely to experience poorer adjustment to care giving. From our study it seems that they may also be more likely to report higher levels of cognitive and behavioural difficulties in their spouse, and they may also struggle to understand challenging behaviour. The findings of the study indicate that spouses with perceptions of discontinuity focus on neurological explanations for behaviours. It is possible that this restricts the range of management and coping strategies that they can draw on in their response to the behaviour. In order to support spouses to manage challenging behaviour, it may be helpful for clinical interventions to be focussed around the ways in which spouses make sense of behaviour, supporting the spouse to recognise person-centred factors that may be contributing. This is likely to result in a better understanding of the behaviour and the use of more effective and person-centred management strategies. Work particularly focussed on developing the ability to recognise the person with dementia's retained pre-morbid personality and preferences would be expected to lead to more person-centred care. From Kitwood's (1990) work we would expect that the use of person-centred care approaches would have potentially acted to reduce challenging behaviour and promote wellbeing in the person with dementia, reducing the subjective burden on the spouse.

A significant limitation of this study is the power of the analysis as a result of the small number of participants recruited. Further data are required to increase confidence in the study's conclusions. As this is a correlational study, the direction and nature of any causal relationships are unclear. Another limitation is that the interview was only semi-structured and there was variability in the questions and probes used across individuals. This may have reduced the reliability and validity of the encodings obtained from the interview data, though it should be noted that every care was taken to avoid the use of leading questions.Further research is required to establish how perceptions of continuity influence responses to behaviour or whether responses to behaviour influence perceptions of continuity. The extent of behaviour and personality change may also be involved in this dynamic, making it difficult to maintain perceptions of continuity, but also potentially leading to responses focused primarily on the dementia. Although there seemed to be a tendency for coders to miss factors in the transcripts, there was a reasonably good agreement between coders and the discussion between three researchers strengthened the validity of the data. There was a low level of codes for particular factors in the data, for example current events, activities and environment, and other health difficulties as a result of the limited range of factors identified by participants. The use of questionnaires would have been prescriptive and the factors considered may have remained undetected. The use of an adapted version of the CHS has created a picture of the current demands reported by the caregiving spouse but, the extent to which it is an objective measure of impairment is questionable as it is a self-report measure and some items are more subjective than others eg, item 1: ‘your spouse criticising/complaining’. Therefore our findings are linked to perceived demands and do not account for a mismatch between the caregivers’ perceived demands and the objective burden or actual level of functioning the PWD has.The IADL and Cognitive sub-scales of the CHS indicated poor internal reliability and therefore some of the conclusions relating to these particular subscales should be accepted with caution. Consideration has been given to whether participants gave socially-desirable responses to the questions in the interview. However spouses generally expressed feelings of frustration which would indicate relatively honest responses. This paper has focussed primarily on the factors taken into consideration with regards to responding to challenging behaviour. It has not been possible to explore and code the strategies themselves for levels of person-centred care. Further analysis of this aspect could be useful in building a better understanding of person-centred care in informal care-giving. This research has also not addressed the quality of the relationship prior to the onset of dementia. We have argued that perceptions of continuity are more likely to be linked to person-centred responses on the basis that there is a continued context of a loving respectful relationship. However a relationship that has pre-morbidly been difficult with a loss of feelings of affection prior to the dementia may not provide a context for empathic or person-centred care. Clearly the impact of the quality of the relationship needs further explanation.

In conclusion relationship continuity where there has been a loving and supportive relationship is likely to result in continued person-centred care. Clinicians may support spouses more effectively by working on understanding how spouses perceive their relationship and the person with dementia, this may work towards supporting improved outcomes for person-centred care at home.

References

Alzheimer's Society (2001) Quality dementia care in care homes: person-centred standards. London.

Barrowclough, C., Haddock, G., Lowens, I, Connor, A., Pidliswyj, J., Tracy, N. (2001) Staff expressed emotion and causal attributions for client problems on a low secure unit: An exploratory study. *Schizophrenia Bulletin, 27,* 517-526

Bolton, C., Calam, R., Barrowclough, C., Peters, S., Roberts, J., Wearden, A., Morris, J. (2003). Expressed emotion, attributions and depression in mothers of children with problem behaviour. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 44*(2) 242-254

Brooker, D. (2005) Dementia Care Mapping: A review of the research literature. *The Gerontologist*. *45*(1), 11-18.

Brooker, D. (2007) Person-centred Dementia Care. Making Services Better. *Jessica Kingsley Publishers,* London.

Buron, B. (2008) Levels of Personhood: A model for dementia care. Geriatric Nursing 29 p324-332

Chesla, C., Martinson, I. and Muwaswes, M. (1994) Continuities and Discontinuities in Family Members' Relationships with Alzheimer's Disease Patients. Family Relations. 43, 1. p3-9

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement 20* (1): 37–46.

Corcoran, M. A. (1994) Management decisions made by caregiver spouses of persons with Alzheimer's Disease. *American Journal of Occupational Therapy. 48*(1), 34-45

Department of Health (2001) National Service Framework for Older People. www.dh.gov.uk/publications

Department of Health (2009) The Dementia Care Strategy. www.dh.gov.uk/publications

De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles,J. & Verhey, F. R. J. (2004) Do caregiver management strategies influence patient behaviour in dementia? *International Journal of Geriatric Psychiatry., 19,* 85-92

Dodds, P. (1994) Wandering : A short report on coping strategies adopted by informal carers. *International Journal of Geriatric Psychiatry. 9*, 51-756

Donaldson, C., Tarrier, N. and Burns, A. (1998) Determinants of carer stress in Alzheimer's Disease. *International Journal of Geriatric Psychiatry, 13*, 248-256

Faul, F. & Erdfelder, E. (1992). *G-POWER: A priori, post-hoc and compromise power analyses for MS-DOS* [computer program]. Bonn, FRG: Bonn University, Dept of Psychology.

Gitlin, L.N., Winter, L., Dennis, M. P., Corcoran, M., Schinfeld, S. & Hauck, W. W. (2002) Strategies used by families to simplify tasks for individuals with Alzheimer's Disease and related disorders: A psychometric Analysis of the Task Management Strategy Index (TMSI). *The Gerontologist. 42*(1), 61-69

Harvath, T. A. (1994) Interpretation and Management of Dementia-Related Behaviour Problems. *Clinical Nursing Research. 3*(1), 7-26

Hasselkus, B.R. & Murray, B. J. (2007) Everyday Occupation, Well-being, and Identity: The Experience of Caregivers in Families with Dementia. *The American Journal of Occupational Therapy. 61,* 9-20

Hellstrom, I., Nolan, M. & Lundh, U. (2007) Sustaining ‘couplehood’: Spouses’ strategies for living positively with dementia. *Dementia, 6,* 383-409

Hinrichsen, G. A. & Niederehe, G. (1994) Dementia Management Strategies and Adjustment of Family Members of Older Patients. *The Gerontological Society of America, 34*(1), 95-102

Jansson, W., Nordberg, G. & Grafstrom, M. (2001) Patterns of Elderly spousal caregiving in dementia care: an observational study. *Journal of Advanced Nursing, 34*(6), 804-812

Kaplan, L. (2001) A Couplehood Typology for spouses of institutionalised persons with Alzheimer’s Disease: Perceptions of ‘We’-‘I’. Family Relations, *50,* 87-98

Keady, J. (1999). *The Dynamics of dementia: A modified grounded theory study.* PhD Thesis, University of Wales, Bangor.

Keady, J and Nolan, M R (2003) The dynamics of dementia: working together, working separately, or working alone? In Nolan, M R, Lundh, U, Grant, G and Keady, J (Eds) *Partnerships in Family Care: understanding the caregiving career.* Open University Press, Maidenhead, 15-32.

Kinney, J,M. & Parris Stephens, M.A (1989) Caregiving Hassles Scale: Assessing the Daily Hassles of Caring for a Family Member with Dementia. *The Gerontologist 29,* 3. 328-332

Kitwood, T. (1990) The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease. Ageing and Society, 10 177-196

Landis, J.R. & Koch, G.G. (1977). The measurement of observer agreement for categorical data. *Biometrics* ***33*** (1): 159–174.

Lewis, R. D. H. (1998). The impact of the marital relationship on the experience of caring for an elderly spouse with dementia Ageing and Society *18* 209-231

MacRae, H., (2002) The Identity Maintenance Work of Family Members of Persons with Alzheimer's Disease. *Canadian Journal on Aging, 21*(3), 405-415

Matson, N. (1995) Coping in Context. Strategic and tactical coping in carers of stroke survivors and carers of older confused people. *Journal of Community & Applied Social Psychology, 5,* 89-104

Perry, J. & O'Connor, D. (2002) Preserving Personhood: (Re)Membering the spouse with dementia. *Family Relations 51* 55-62

Richter, J. M., Roberto, K. A., & Bottenberg, D. J. (1995) Communicating with persons with *Alzheimer's* Disease: Experiences of Family and Formal Caregivers. *Archives of Psychiatric Nursing, IX*(5), 279-285

Shercliff, G. (2010) *Construction and Initial Validation of an Instrument to measure Relationship Continuity when Caring for a Spouse with Dementia.* ClinPsyD Thesis. University of Birmingham, Birmingham.

Stratton, P., Munton, A.G., Hanks, H.G.I., Heard, D.H. and Davidson, C. (1988) Leeds Attributional Coding System (LACS) Manual. Leeds: LFTRC. Available on www.psyc.leeds.ac.uk/staff/p.m.stratton/

Taft, L. B., Matthiesen, V., Farran, C. J., McCann, J. J. & Knafl, K. A. (1997) Supporting strengths and responding to agitation in dementia care: An exploratory study. *American Journal of Alzheimer's Disease, 12*(5), 198-208

Vikström, S., Josephsson, S., Stigsdotter-Neely, A. & Nygård, L. (2008) Engagement in activities: Experiences of persons with dementia and their caregiving spouses. *Dementia, 7,* 251-270

Walters, A., Oyebode, J., & Riley, G.A. (in press). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. Dementia: The International Journal of Social Research and Practice.

Ward, S., Opie, J. & O'Connor, D. W. (2003) Family carers' responses to behavioural and psychological symptoms of dementia. *International Journal of Geriatric Psychiatry, 18,* 1007-1012

EXECUTIVE SUMMARY

Perceptions of Relationship Continuity/Discontinuity in caring for a spouse with Dementia: Implications for Person-Centred Care.

Background

Person-centred care is considered good practice in dementia care settings (Department of Health, 2001). As the number of people with dementia increases, it is important for services to support family caregivers, particularly spouses, to use person-centred approaches: taking the person with dementia's perspective into account, valuing them as individuals, and facilitating their independence (Brooker, 2007).

Continuity/discontinuity describes the extent to which the care-giving spouse perceives change in the person with dementia, the relationship and associated feelings (Walters, Riley & Oyebode, 2010). This study's aim was to explore whether levels of continuity/discontinuity are linked to how much the carer considers person-centred factors when responding to a spouse's challenging behaviour. Viewing the person with dementia as fundamentally the same (continuity) may enable the spouse to draw on more longstanding knowledge of the person: their perspective, personality and personal history when responding to challenging behaviour. Viewing the person as changed (discontinuity) may result in the spouse focusing more on the dementia and drawing less on longstanding knowledge of the individual when considering how to respond to them.

Method

Twenty spouses completed the Birmingham Relationship Continuity Measure, the Caregiver Hassles Scale (CHS) and a semi-structured interview that explored how they responded to challenging behaviour. Factors considered in responding to the behaviour were coded into various types (e.g. neurological or personality). These were entered along with the questionnaire data, for statistical analysis.

Results and Discussion

The main hypotheses were supported. Higher levels of person-centred factors were considered by spouses who perceived higher levels of continuity in their relationship. Lower levels of continuity (discontinuity) were associated with greater consideration of the dementia. The link between continuity and level of support required by the person with dementia was also explored. Discontinuity may be more likely to occur in couples where there is a higher level of perceived cognitive or behavioural difficulties. Higher levels of perceived continuity were found in couples who had been together longer and particularly in husbands.

Limitations of the study include the small number of participants and the poor reliability of some of the subscales of the CHS. Further research is needed to consolidate secondary findings. Implications for clinical practice include supporting spouses to understand behaviours in the context of past personal history, personality and preferences so that they can provide person-centred care. Future research into links with the quality of the relationship prior to the dementia will be important in understanding what may improve perceptions of continuity in care-giving spouses.

References

Brooker, D. (2007) Person-centred Dementia Care. Making Services Better. *Jessica Kingsley Publishers,* London.

Department of Health (2001) National Service Framework for Older People. www.dh.gov.uk/publications

Walters, A., Oyebode, J., & Riley, G.A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. Dementia: The International Journal of Social Research and Practice.

APPENDICES

Appendix 1

Literature Search

Search summary from PsycINFO 1987~, conducted 30th September 2011

1. exp Vascular Dementia/ or exp Dementia/ or exp Semantic Dementia/ or exp Presenile Dementia/ or exp Dementia with Lewy Bodies/ or exp Senile Dementia/
2. exp Alzheimer's Disease/
3. 1 or 2
4. exp Caregivers/
5. exp Family Members/ or exp Family/
6. exp Spouses/
7. exp Couples/
8. 4 or 5 or 6 or 7
9. 3 and 8
10. exp "Quality of Care"/
11. exp Coping Behavior/
12. exp Behavior Problems/
13. exp Agitation/
14. exp Behavior Disorders/
15. exp Symptoms/
16. exp "Quality of Life"/
17. exp Daily Activities/
18. exp Strategies/
19. exp "Activities of Daily Living"/
20. behavior management.mp.
21. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22. 21 not 20
23. 9 and 22
24. exp Nursing Homes/ or exp Residential Care Institutions/
25. 23 not 24
26. limit 25 to ("therapy (maximizes sensitivity)" or "therapy (maximizes specificity)" or "therapy (best balance of sensitivity and specificity)")
27. 25 not 26
28. limit 27 to (all journals and english language)
29. carer burden.m_titl.
30. caregiver burden.m_titl.
31. caregiving burden.m_titl.
32. 29 or 30 or 31
33. 28 not 32

34. (care* adj3 (health or depression or stress)).m_titl.

35. 33 not 34

36. from 35 keep 14,79,81,86,93,99,103-105,110,117,135,137,149-150,172,179,181,195,204,212,221,226,229,238,241-242,247,251,255-258,262,268,271,275,280,284,289,302,309,323,326,329,331-332,338,347-348,350,352,356,358,370,372,376,381-382,395-397,402,404-405,415,424,426,428,436,445,447-448

Abstracts of these papers (73) were then inspected resulting in the 14 papers featured in Table 1 of main text (see page 22).

Appendix 2

Criteria for Evaluation of Papers

Critical Appraisal Skills Programme (CASP)

making sense of evidence

10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is *not a definitive guide* and extensive further reading is recommended.

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

! **Rigour: has a thorough and appropriate approach been applied to**

! **key research methods in the study?**

! **Credibility: are the findings well presented and meaningful?**

! **Relevance: how useful are the findings to you and your organisation?**

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

Screening Questions

1. Was there a clear statement of the aims ! Yes ! No

of the research?

Consider:

– what the goal of the research was

– why it is important

– its relevance

2. Is a qualitative methodology appropriate? ! Yes ! No

Consider:

– if the research seeks to interpret or illuminate
the actions and/or subjective experiences of
research participants

Is it worth continuing?

Detailed questions

Appropriate research design

3. Was the research design appropriate to Write comments here

address the aims of the research?

Consider:

– if the researcher has justified the research

design (e.g. have they discussed how they

decided which methods to use?)

Sampling

4. Was the recruitment strategy appropriate Write comments here

to the aims of the research?

Consider:

– if the researcher has explained how the

participants were selected

– if they explained why the participants they

selected were the most appropriate to provide

access to the type of knowledge sought by the

study

– if there are any discussions around recruitment

(e.g. why some people chose not to take part)

Data collection

5. Were the data collected in a way that Write comments here

addressed the research issue?

Consider:

– if the setting for data collection was justified

– if it is clear how data were collected (e.g. focus

group, semi-structured interview etc)

– if the researcher has justified the methods

chosen

– if the researcher has made the methods explicit

(e.g. for interview method, is there an indication

of how interviews were conducted, did they

used a topic guide?)

– if methods were modified during the study. If so,

has the researcher explained how and why?

– if the form of data is clear (e.g. tape recordings,

video material, notes etc)

– if the researcher has discussed saturation of

data

Reflexivity (research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and Write comments here

participants been adequately considered?

Consider whether it is clear:

– if the researcher critically examined their own

role, potential bias and influence during:

– formulation of research questions

– data collection, including sample recruitment

and choice of location

– how the researcher responded to events during

the study and whether they considered the

implications of any changes in the research

design

Ethical Issues

7. Have ethical issues been taken into Write comments here

consideration?

Consider:

– if there are sufficient details of how the research

was explained to participants for the reader to

assess whether ethical standards were

maintained

– if the researcher has discussed issues raised by

the study (e. g. issues around informed consent

or confidentiality or how they have handled the *effects of the study on the participants during*

and after the study)

– if approval has been sought from the ethics

committee

Data Analysis

8. Was the data analysis sufficiently rigorous? Write comments here

Consider:

– if there is an in-depth description of the analysis

process

– if thematic analysis is used. If so, is it clear how

the categories/themes were derived from the

data?

– whether the researcher explains how the data

presented were selected from the original

sample to demonstrate the analysis process

– if sufficient data are presented to support the

findings

– to what extent contradictory data are taken

into account

– whether the researcher critically examined their

own role, potential bias and influence during

analysis and selection of data for presentation

Findings

9. Is there a clear statement of findings? Write comments here

Consider:

– if the findings are explicit

– if there is adequate discussion of the evidence

both for and against the researcher's arguments

– if the researcher has discussed the credibility of

their findings (e.g. triangulation, respondent

validation, more than one analyst.)

– if the findings are discussed in relation to the

original research questions

Value of the research

10. How valuable is the research? Write comments here

Consider:

– if the researcher discusses the contribution the

study makes to existing knowledge or

understanding (e.g. do they consider the

findings in relation to current practice or policy,

or relevant research-based literature?)

– if they identify new areas where research is

necessary

– if the researchers have discussed whether or

how the findings can be transferred to other

populations or considered other ways the

research may be used

Appendix 3

NHS Ethics and NHS R&D permission to proceed with study

Appendix 4

Participant Information Packs

UNIVERSITY OF
BIRMINGHAM

PARTICIPANT LETTER OF INVITATION

School of Clinical Psychology
Psychology Department
Frankland Building
University of Birmingham
Edgbaston
B15 2TT
Tel: 0121 414 4932

Thank you for taking time to look at this information.

My name is Julie Singleton, I am a Trainee Clinical Psychologist at the University of Birmingham. I am interested in how people cope when they are caring for their spouse/partner who has dementia. I think that this is important as many people are affected by dementia currently and more people will be affected by it in the future, either by having dementia themselves or through caring for someone with dementia.

As part of my training course, I am conducting research to look at how carers cope with some difficult situations and how this is connected with the kind of relationship that they have with their spouse/partner. I will be meeting with the caring spouse/partner **for up to 90 minutes,** at their convenience, **to ask them some questions.** I am currently looking for people who would be interested in taking part.

You have been given this information because you might be interested in taking part. The information you have been given will hopefully answer many of the questions you might have. Please give yourself at least 24 hours to decide if you would like to take part. If you would prefer not to take part, this will not affect the care you or your spouse/partner receive.

If you would like to take part, I would be grateful if you could complete the consent form and contact details sheet in this pack and send them to me, in the stamped addressed envelope.

If you have any questions about the research, please contact me on the number above or you can e-mail me on [redacted]

Thank you for considering taking part.
Best wishes.

Yours sincerely,

Julie Singleton

Trainee Clinical Psychologist

University of Birmingham

Supervised by:

J R Oyebode, BA, M Psychol (Clinical), PhD.
Director Clinical Psychology Doctorate, University of Birmingham

Consultant Clinical Psychologist, Birmingham and Solihull Mental Health Foundation Trust

PARTICIPANT INFORMATION SHEET

Research Title: Relationships and coping in dementia.

Researcher: Julie Singleton

Thank you for taking the time to read this information. I am a student undertaking this research project as part of my Clinical Psychology Doctorate. The following information may be helpful to you in deciding whether you wish to participate.

What is the research about?

This research aims to explore people's experience of being in a relationship where one person has a form of dementia. It is looking at how carers cope with some difficult situations and how this is connected with the kind of relationship that they have.

Why is this research being conducted?

As part of my Clinical Psychology Doctorate course I need to complete a piece of research. I have chosen to explore peoples' experiences of caring for a spouse/partner with dementia as this area particularly interests me.

The UK has an ageing population and therefore many more people will experience dementia in future, either being diagnosed with it themselves or caring for someone who has dementia. As a result, services will need to provide effective support to enable people to be cared for in their own homes. This research aims to increase knowledge and understanding of the issues that carers experience in supporting their spouse/partner so as to shape services to maintain quality of life for couples.

Why have I been invited to take part?

You have been invited to take part because your spouse/partner has dementia. You do not have to take part in the study. If you do not take part, it will not affect your own, or your spouse/partner's care in any way.

What will happen if I agree to take part?

- If you would like to take part, please consider your decision for at least 24 hours before signing the consent form and returning it along with your contact details using the stamped and addressed envelope provided.
- I will then contact you by telephone and ensure that you understand the information you have been given and are still happy to take part in the study. If you are happy to proceed, I shall arrange to visit you at your home or at the service where you heard about the research. Every effort will be made for this to be at a time and place that suits you. If you need to travel to meet with me, your travel expenses will be reimbursed. Please allow ninety minutes for our appointment. In order to give us privacy for our discussion, it will be important that we meet at a time when alternative care is available for your spouse/partner. Unfortunately, we are not able to provide care for your spouse/partner during this meeting.
- When we meet I shall ask a few questions such as the length of your relationship with your spouse/partner and how long ago they were diagnosed as having a dementia. We will complete three questionnaires and a short interview together. The questions will be about what sorts of difficulties you experience in supporting your spouse/partner, about how you experience your relationship now and about how you cope in difficult situations you may experience with your spouse/partner. I would like to audio record the interview part of the appointment to make sure that your responses are noted. I will be the only person who will listen to the recording, it will be destroyed as soon it is typed up into an anonymised format. Your name will not be recorded on any of the forms I complete in the appointment so as to protect your confidentiality.

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

You are able to withdraw your consent to participate in the study at anytime, before or after your participation, and this will not affect you or your spouse/partner's care in any way. You can withdraw your consent by informing me when I make contact with you or contacting me on the number below.

What are the benefits of me participating?

There are no direct benefits of taking part. We hope that the research will contribute to the efforts to inform services as to how to better support carers and improve quality of life for both the caring and the cared-for spouse/partner. A summary of the findings will be sent to you if you wish to receive it.

What are the possible disadvantages of taking part?

There is the possibility that you may become upset during the meeting because of the sensitive nature of some of the questions. Should you become upset, you can access support from the service in which you were approached regarding the research- this may be you local NHS dementia service or carer's support service. I shall give you their contact details when I meet with you.

What will happen to the results of the research study?

The results will be reported in a thesis and will be stored at the University of Birmingham. It will be considered for publication in a journal and may be presented at a conference. All data will be kept anonymous and no identifying information will be used.

What if I feel I need support regarding some of the issues raised in the research?

If you feel you need support regarding any of the issues raised in this research, you can contact:

INFORMATION GIVEN ABOUT SERVICE THROUGH WHICH THE PARTICIPANT WAS APPROACHED

What if I have any questions about the research?

If you have any questions about the research, you can contact me on:

Julie Singleton, Trainee Clinical Psychologist, University of Birmingham

Tel: 0121 414 4932

Email:[redacted]

What if I have any concerns about the research?

If you have any concerns about the way in which the research is being conducted, you may contact my supervisor:

J R Oyebode, BA, M Psychol (Clinical), PhD.
Director Clinical Psychology Doctorate, University of Birmingham

Consultant Clinical Psychologist, Birmingham and Solihull Mental Health Foundation Trust

School of Psychology

University of Birmingham

Edgbaston

Birmingham B15 2TT

0121 414 7576

If you feel that you need to make a complaint about the research, you can contact:

PATIENT ADVICE AND LIAISON SERVICES (PALS) FOR TRUST THROUGH WHICH THE PARTICIPANT WAS APPROACHED OR IF PARTICIPANT WAS APPROACHED THROUGH A CHARITABLE ORGANISATION:

If you feel that you need to make a complaint about the research, you can contact:

Professor Glyn Humphrys, College Director of Research, University of Birmingham

0121 414 4930

Thank you for considering taking part.

UNIVERSITY OF
BIRMINGHAM

CONSENT FORM

Research site: ....

Research Project: Relationships and coping in dementia.

Participant Identification Number:...

Please initial box

1. I confirm that I have understood the information sheet dated 12.07.2010 Version 2 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 taking part 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 spouse/partner’s medical/social care or legal rights being affected. ☐

3. I understand that I can withdraw from the study at anytime up to when the analysis of the data is completed. During this time I may contact the researcher and withdraw my responses entirely or in part, without giving any reason, and without my own or my spouse/partner’s medical/social care or legal rights being affected. ☐

4. I understand that relevant sections of my research data collected during the study may be looked at by individuals from the University of Birmingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

5. I understand that parts of the data may also be made available to the professiona through which I was approached about the research. This will only occur if there are concerns about my own or my spouse/partner’s safety. ☐

6. I understand that in any write-up of the data, my name will not be linked to any responses and that I will not be identifiable in any way. ☐

7. I give my permission for some of my responses to be anonymously directly quoted in the write-up of the data. I understand that no identifiable information regarding myself or my spouse/partner will be included in these quotes. ☐

8. I agree to have responses on one questionnaire audio recorded. I understand the recording will be stored securely and only the main researcher (Julie Singleton) will ☐

listen to the audio-tape. The recording will be deleted as soon as it has been transcribed into an anonymous format.

9. I agree to take part in the above study. ☐

10. I am happy for you to contact me using the address and telephone number below. ☐

....	....	....
Name of participant	Date	Signature

Contact details:

Address:..

....

....

....

Telephone Number:...

The best time to contact me is:

(day of the week, time of day) ....

....	....	....
Name of researcher	Date	Signature

Appendix 5

Data Collection Packs

UNIVERSITY OF
BIRMINGHAM

PARTICIPANT NUMBER:

DATE COMPLETED:

‘Thank you for agreeing to meet me today. Do you have any questions before we start?’ (Clarify any information regarding data storage, confidentiality, withdrawal from the study).

‘To begin with I would like to ask you a couple of questions about you and your spouse/partner.’

How many years have you been in a relationship with (spouse/partner’s name)?:....................................

For how long has (spouse/partner’s name) been diagnosed with a dementia?:................................

What type of dementia was spouse/partner’s name diagnosed with?:..

QUESTIONNAIRE 1(adapted Caregiving Hassles Questionnaire, Kinney & Parris Stephens 1989):

This set of questions lists things that can occur in day-to-day care-giving.
Please answer ‘Yes’ or ‘No’ to indicate whether the event happened during the past week.

1. Your spouse criticising/complaining	**Yes**	**No**
2. Your spouse declining mentally	**Yes**	**No**
3. Assisting your spouse with walking	**Yes**	**No**
4. Extra expenses due to care-giving	**Yes**	**No**
5. Friends not showing understanding about care-giving	**Yes**	**No**
6. Your spouse losing things	**Yes**	**No**
7. Undesirable changes in your spouse’s personality	**Yes**	**No**
8. Assisting with your spouse’s toileting	**Yes**	**No**
9. Transporting your spouse to doctor/other places	**Yes**	**No**
10. Conflicts between your spouse and family	**Yes**	**No**

11. Your spouse not showing interest in things Yes No

12. Bathing your spouse Yes No

13. Family not showing understanding about care-giving Yes No

14. Your spouse yelling/swearing Yes No

15. Your spouse not co-operating Yes No

16. Your spouse’s forgetfulness Yes No

17. Assisting your spouse with exercises/therapy Yes No

18. Doing spouse’s laundry Yes No

19. Your spouse leaving tasks uncompleted Yes No

20. Your spouse being confused/not making sense Yes No

21. Lifting or transferring your spouse Yes No

22. Not receiving care-giving help from friends Yes No

23. Your spouse frowning/scowling Yes No

24. Your spouse living in past Yes No

25. Helping your spouse eat Yes No

26. Picking up after your spouse Yes No

27. Your spouse being verbally inconsiderate; not respecting others’ feelings Yes No

28. Being in your spouse’s presence Yes No

29. Your spouse talking about /seeing things that aren’t real Yes No

30. Dressing your spouse Yes No

31. Not receiving care-giving help from family Yes No

32. Your spouse asking repetitive questions Yes No

33. Your spouse not recognising familiar people Yes No

34. Giving medications to your spouse	**Yes**	**No**
35. Preparing meals for your spouse	**Yes**	**No**
36. Your spouse wandering off	**Yes**	**No**
37. Your spouse being agitated	**Yes**	**No**
38. Assisting your spouse with health aids (eg. Dentures, braces)	**Yes**	**No**
39. Your spouse requiring day supervision	**Yes**	**No**
40. Leaving your spouse with others at home	**Yes**	**No**
41. Your spouse hiding things	**Yes**	**No**
42. Your spouse requiring night supervision	**Yes**	**No**

PARTICIPANT NUMBER:

Questionnaire 2 (Relationship Questionnaire)- Answering questions about caring for a female spouse/partner.

‘The following questions are about how you feel about your relationship. Please listen to the following questions carefully and then give the response that best expresses your view, choosing from ‘Agree a lot’, ‘Agree a little’, ‘Neither’, ‘Disagree a little’, ‘Disagree a lot’. (Place card with the various choices in front of them). You can go back to any previous items and change your response if you wish to. Please answer ALL questions as honestly as possible.’

1	It’s like there’s a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	The dementia has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	It makes me feel uncomfortable if she is affectionate towards me.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	I care for her, but I don’t love her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

6	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	I feel like her carer now, not her husband.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
8	She’s a shadow of her former self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
9	I don’t feel about her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	I only tell her what she needs to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	Despite all the changes, she’s still her old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	The bond between us isn’t what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	Sometimes I feel it’s like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	I feel shut off from her.	Agree a lot	Agree a	Neither	Disagree a	Disagree a lot

			little		little	
16	I feel I’ve been grieving for her.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	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
18	Compared to how she used to be, she’s a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	I don’t like it if she comes too close to me.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	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
21	I don’t feel I really know her any more.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	She still has many of the same qualities that first attracted me to her.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
24	She’s in a world of her own most of the time.	Agree a lot	Agree a	Neither	Disagree a	Disagree a lot

			little		little	
25	It doesn’t feel like a partnership any more	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
26	Sometimes I feel she invades my personal space.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

PARTICIPANT NUMBER:

QUESTIONNAIRE 3 (Carer Responses Questionnaire, created by research team)

‘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 they developed dementia.’

SITUATION 1: ‘Your spouse/partner is trying to do something that you think is risky eg: trying to cook when they are unable to do it anymore, or leaving the house by themselves. You think what they are doing is risky because they might possibly injure themselves, fall over, get in trouble with other people, or be unable to find their way home.’

Have you experienced this situation since your spouse/partner developed dementia?

YES/NO

If yes, how often have you experienced this situation?

Everyday

At least once a week

At least once a month

Only occasionally

SITUATION 2: ‘You are relaxing in front of the television in the evening and your spouse/partner has been pacing in the lounge for a while. He/she suddenly changes their route and begins to pace across the TV disrupting your view.’

Have you experienced this situation since your spouse/partner developed dementia?

YES/NO

If yes, how often have you experienced this situation?

Everyday

At least once a week

At least once a month

Only occasionally

SITUATION 3: ‘Your spouse/partner has had difficulty sleeping and tends to disturb your sleep. On this occasion, your spouse/partner wakes you up and seems unable to settle him/herself.’

Have you experienced this situation since your spouse/partner developed dementia?

YES/NO

If yes, how often have you experienced this situation?

Everyday

At least once a week

At least once a month

Only occasionally

SITUATION 4: ‘Your spouse/partner asks you the same question that he/she has already asked you a number of times.’

Have you experienced this situation since your spouse/partner developed dementia?

YES/NO

If yes, how often have you experienced this situation?

Everyday

At least once a week

At least once a month

Only occasionally

IDENTIFY MOST FREQUENTLY OCCURING SITUATION. IF THE SITUATIONS OCCUR ONLY OCCASIONALLY OR NOT AT ALL:

SITUATION 5: ‘Tell me about a difficult situation that frequently occurs with your spouse.’

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 SITUATION THAT THEY HAVE THE MOST EXPERIENCE WITH (The participant will be answering questions for two situations)

INFORM THEM 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?’

PARTICIPANT NUMBER:

REREAD SITUATION AGAIN- NUMBER:-----------

Tell me about the last time a situation like this happened.

Why do you think your spouse was behaving in that way?

What do you find helps in this situation?

Why do you respond in that way?

What doesn’t help in this situation?

What are your thoughts and feelings at the time? (optional question to elicit more information).

Is there anything else that you have tried to deal with this situation?

Appendix 6

Coding the Data

Factors to be coded

Factor and definition	**Example of influence on management of the behaviour**
Neurological impairments Evidence that the choice/implementation of strategy is influenced by beliefs about disabilities in language, cognition, physical or social functioning arising from the dementia. Include here any examples where the participant refers to "dementia" generally as an influence on their choice of a specific management tactic.	"There's no point trying to explain to her why she can't do it because she just doesn't understand." This would be an example of a strategy that they are aware of, but do not currently use. Reference to her difficulties in understanding is evidence that her language and cognitive difficulties have been considered in the rejection of this strategy/tactic.
Other health conditions Evidence that the choice/implementation of strategy is influenced by consideration of other health conditions that may have an impact on the person with dementia. In some cases, it may not be clear whether a disability is due to the dementia or other health conditions. Unless the carer specifically links it to this other condition, the disability should be classified under 'neurological impairments'.	"I have to watch what he eats. He's got an ulcer and if he eats anything spicy, it causes him a lot of pain, and he can lash out if he's in pain."
Pre-morbid personal history Evidence that the choice/implementation of strategy is influenced by consideration of events or circumstances that happened to the person with dementia before the onset of the dementia. Also, jobs, activities or achievements that occurred before the onset of the dementia.	"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. I try to make it look like I'm asking for his help if I want him to do something." The implication here is that he doesn't like being given orders because of his experiences in the army, and this has influenced her in her

	choice of how she tries to get him to do things.
Current events, activities and environment Evidence that the choice/implementation of strategy is influenced by consideration of events that have taken place since the onset of the dementia; features of the current social or physical environment in which the person with dementia finds themselves; and/or current activities.	"I avoid taking her anywhere where there's crowds, because they get her worked up." The belief that crowds can trigger aggression leads the carer to avoid crowds as a way of avoiding aggression.
Personality Evidence that the choice/implementation of strategy is influenced by the carer's beliefs about the long-standing pre-morbid personality of the person with dementia. Personality refers to general patterns of behaviour, thoughts and feelings that characterize the individual (e.g. being fussy, outgoing, ambitious). The evidence needs to be clear that the carer is thinking about what the person's personality was like before the onset of the dementia.	"We stick to a routine. He was always a control freak, and wanted to know who was doing what when. If something happens 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." Beliefs about his personality lead the carer to stick to a routine as a way of avoiding aggression. This excerpt should also be encoded as an example of 'neurological impairments': Her understanding of his aggression is influenced by beliefs about his cognitive difficulties, and this understanding, in turn, influences how she tries to avoid the aggression occurring.
Likes and dislikes Evidence that the carer has considered the likes and dislikes of the person with dementia in their choice/implementation of a strategy. Note that there should be evidence that likes/dislikes have been an influence on the choice/implementation of the management strategy. The participant may refer to likes and dislikes that the carer perceives to be the	"I take him out for a walk to try to calm him down. He always liked walking. It helped him relax." Beliefs about the person's likes have influenced the decision to take him a walk to try to calm him down.

direct cause of the challenging behaviour (e.g. with reference to lack of co-operation – "She just doesn't like getting out of bed in the morning."). This example should not be included as evidence because it has not influenced the choice or implementation of a management strategy. You should code evidence as 'likes and dislikes' only if the carer actually uses the words 'likes' or 'dislikes' or something very similar (e.g. 'prefers').	
Thoughts (surface vs deep) • Evidence that the carer, in choosing or implementing a strategy, has considered what are/might be the thoughts of the person with dementia (both their thoughts relating to the situation that triggers the challenging behaviour and their possible thoughts should a particular management tactic be used). Thoughts include appraisals and interpretations of the situation/tactic, and goals and intentions. • References to cognitive states due to neurological impairment should be included under 'neurological impairments', and not as 'thoughts' (e.g. references to being 'confused' or 'forgetful') • Evidence relating to thoughts should be marked on the record form as **"surface"** or **"deep"**. Mark the evidence as **deep** when the reference is to specific thoughts that the person with dementia has and there is evidence that the carer has thought about what the other person is thinking (i.e. that the participant has engaged in theory of mind activity) (example in next column). **Surface** means that the reference is vague; does not refer to specific thoughts that the person with dementia may have; and did not require the participant to take the	"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, and I don't want her to think that I'm blaming her. Because I don't blame her – it's not her fault." The carer has thought about how the person with dementia will interpret raised voices, and this has led to him trying not to raise his voice when dealing with the challenging behaviour.

perspective of the other person and think about what they are thinking (e.g. “I suppose it’s just the way he thinks about these things.”). You should not include as ‘deep’, instances where the participant’s statements are just repeating what the person with dementia has said about what they are thinking.	
<u>Feelings (surface vs deep)</u> • Evidence that the carer, in choosing or implementing a strategy, has considered the feelings, mood or emotions of the person with dementia (both their feelings relating to the situation that triggers the challenging behaviour and their possible feelings should a particular management tactic be used). • As with ‘thoughts’, evidence relating to feelings should be marked on the record form as **“surface”** or **“deep”**. **Surface** means that the reference is vague; does not refer to specific feelings that the person with dementia may have; and did not require the participant to take the perspective of the other person and think about what they are feeling (e.g. “He has a temper tantrum.” “It’s just mood swings.”). **Deep** refers to specific feelings and/or evidence that the participant has thought about what the other person is thinking (example in next column). You should not include as ‘deep’, instances where the participant’s statements are just repeating what the person with dementia has said about their feelings.	“Sometimes when she starts asking over and over for her mother, 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.” Thinking about what the person with dementia is feeling leads the carer to respond to the repetitive questions with a hug.

	Participant identity number:
Challenging behaviour: (e.g. repetitive questioning)	
Strategies currently used:	
Description of strategy (e.g. Trying to reason with him about why he should not engage in the behaviour)	Factors influencing, plus evidence (e.g. Neurological impairment – can’t follow attempts to explain reasons for not doing it, lines 340-352)
1. 2. 3. 4.	
Other strategies mentioned:	
Description of strategy (e.g. Avoiding crowds)	Factors influencing, plus evidence (e.g. Thoughts deep – I think she thinks I’m getting at her, lines 523-540)
1. 2. 3.	
Notes:	

Coder Name: Participant Number:

Challenging behaviour: (e.g. repetitive questioning)

Repetitive Questioning

Strategies currently used:

Description of strategy	Factors influencing, plus evidence
(e.g. Trying to reason with him about why he should not engage in the behaviour)	(e.g. Neurological impairment – can't follow attempts to explain reasons for not doing it, lines 340-352)
1. Answering the question (187-188)	1. To put her at ease (197-198, 158), She's very anxious about that situation (167)- Surface feelings She's forgotten (166), because of the dementia (210-211)- Neurological Impairment Erratic heartbeat (211-212)- Other health conditions She thinks the situation is causing the sensations she has (218-220)- Deep Thoughts
2. Be quiet (171)	2. To reduce the impact of the environment on her anxiety (171-181)- Current events, activities & environment. Her experiencing an adrenaline rush (174-179)- deep feelings Her thinking that situations are worse than they are (171-174) & (184-185) – deep thoughts
3. Speaking very quietly and saying very little (202)	3. Because shouting offends her (205-206)-

	Likes & Dislikes
4. Persuade her (224)	4. No evidence
5. Going out with her (225-228, 233-235)	5. Physical exercise (231-233)- Other health conditions Implication is to reduce questions but no evidence of why he thinks that helps- ie: specific factor.
Other strategies mentioned:	
Description of strategy (e.g. Avoiding crowds)	Factors influencing, plus evidence (e.g. Thoughts deep – I think she thinks I'm getting at her, lines 523-540)
1. Getting cross/ shouting (201-206)	Shouting offends her (205-206)- Likes & Dislikes
Notes:	

Appendix 7

SPSS outputs

Tests of Normality:

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
LR	.159	20	.198	.904	20	.050
TI	.258	20	.001	.858	20	.007
BADLTOT	.177	20	.102	.890	20	.026
IADLTOT	.258	20	.001	.868	20	.011
COGTOTAL	.171	20	.128	.914	20	.077
CHSBEH	.148	20	.200[*]	.941	20	.255
CHSSOC	.208	20	.023	.920	20	.098
CHSTOTAL	.170	20	.131	.945	20	.299
TotalC	.122	20	.200[*]	.935	20	.194
NEURO	.264	20	.001	.862	20	.008
HEALTH	.527	20	.000	.351	20	.000
HISTORY	.377	20	.000	.661	20	.000
CURR	.337	20	.000	.740	20	.000
PERSON	.509	20	.000	.433	20	.000
LIKEDIS	.291	20	.000	.774	20	.000
THOSUR	.450	20	.000	.583	20	.000
THODEE	.369	20	.000	.641	20	.000
FEELSUR	.193	20	.049	.898	20	.038
FEELDEEP	.284	20	.000	.766	20	.000
Neuropercentage	.121	20	.200[*]	.936	20	.201

PerCFactorPercentage	.087	20	.200*	.974	20	.842

a. Lilliefors Significance Correction

*. This is a lower bound of the true significance.

BRCM Internal Reliability:

Reliability Statistics

Cronbach's Alpha	N of Items
.927	26

CHS Total Scale Internal Reliability:

Reliability Statistics

Cronbach's Alpha	N of Items
.645	42

CHS Behavioural Subscale Internal Reliability:

Reliability Statistics

Cronbach's Alpha	N of Items

Reliability Statistics

Cronbach's Alpha	N of Items
.736	12

CHS Cognitive Subscale Internal Reliability:

Reliability Statistics

Cronbach's Alpha	N of Items
.486	9

CHS Social Network Subscale Reliability:

Reliability Statistics

Cronbach's Alpha[a]	N of Items
-.075	5

a. The value is negative due to a negative average covariance among items. This violates reliability model assumptions. You may want to check item codings.

CHS Basic ADL subscale reliability:

Reliability Statistics

Cronbach's Alpha	N of Items
.838	9

CHS Instrumental ADL subscale reliability:

Reliability Statistics

Cronbach's Alpha	N of Items
.481	7

Inter-rater reliability for Coding:

Symmetric Measures

		Value	Asymp. Std. Error[a]	Approx. T[b]	Approx. Sig.
Measure of Agreement	Kappa	.353	.043	11.874	.000
N of Valid Cases		192			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Inter-rater reliability excluding differences due to missed codes:

Symmetric Measures

		Value	Asymp. Std. Error[a]	Approx. T[b]	Approx. Sig.
Measure of Agreement	Kappa	.722	.048	16.766	.000
N of Valid Cases		113			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Correlations:

Correlations

			LR	TI	BADLTOT	IADLTOT	CHSSOC	COGTOTAL	CHSTOTAL	CHSBEH	Total C	Neuropercentage	PerCFactorPercentage
Spearman's rho	LR	Correlation Coefficient	1.000	.231	-.054	-.239	-.368	-.424	-.492*	-.270	.392	-.078	-.281
		Sig. (2-tailed)	.	.328	.821	.310	.110	.063	.027	.250	.087	.745	.231
		N	20	20	20	20	20	20	20	20	20	20	20
	TI	Correlation Coefficient	.231	1.000	.176	-.030	-.678**	-.346	-.337	-.148	.397	-.117	.151
		Sig. (2-tailed)	.328	.	.457	.901	.001	.136	.146	.532	.083	.623	.525
		N	20	20	20	20	20	20	20	20	20	20	20

	BADLTOT	Correlation Coefficient	-.054	.176	1.000	.607**	.028	-.127	.266	-.650**	.405	-.273	.173
		Sig. (2-tailed)	.821	.457	.	.005	.907	.592	.256	.002	.077	.244	.466
		N	20	20	20	20	20	20	20	20	20	20	20
	IADLTOT	Correlation Coefficient	-.239	-.030	.607**	1.000	.095	.432	.576**	-.254	-.164	-.202	.120
		Sig. (2-tailed)	.310	.901	.005	.	.690	.057	.008	.279	.488	.393	.616
		N	20	20	20	20	20	20	20	20	20	20	20
	CHSSOC	Correlation Coefficient	-.368	-.678**	.028	.095	1.000	.374	.551*	.167	-.346	.276	-.110

	Sig. (2-tailed)	.110	.001	.907	.690	.	.104	.012	.481	.135	.238	.645
	N	20	20	20	20	20	20	20	20	20	20	20
COGTOTAL	Correlation Coefficient	-.424	-.346	-.127	.432	.374	1.000	.760**	.458*	-.647**	.239	-.056
	Sig. (2-tailed)	.063	.136	.592	.057	.104	.	.000	.042	.002	.310	.815
	N	20	20	20	20	20	20	20	20	20	20	20
CHSTOTAL	Correlation Coefficient	-.492*	-.337	.266	.576**	.551*	.760**	1.000	.416	-.584**	.174	-.050
	Sig. (2-tailed)	.027	.146	.256	.008	.012	.000	.	.068	.007	.463	.833
	N	20	20	20	20	20	20	20	20	20	20	20

	CHSBEH	Correlation Coefficient	-.270	-.148	-.650**	-.254	.167	.458*	.416	1.000	-.735**	.386	-.180
		Sig. (2-tailed)	.250	.532	.002	.279	.481	.042	.068	.	.000	.092	.447
		N	20	20	20	20	20	20	20	20	20	20	20
	TotalC	Correlation Coefficient	.392	.397	.405	-.164	-.346	-.647**	-.584**	-.735**	1.000	-.482*	.490*
		Sig. (2-tailed)	.087	.083	.077	.488	.135	.002	.007	.000	.	.031	.028
		N	20	20	20	20	20	20	20	20	20	20	20
	Neuropercentage	Correlation Coefficient	-.078	-.117	-.273	-.202	.276	.239	.174	.386	-.482*	1.000	-.626**

		Sig. (2-tailed)	.745	.623	.244	.393	.238	.310	.463	.092	.031	.	.003
		N	20	20	20	20	20	20	20	20	20	20	20
	PerCFactorPercentage	Correlation Coefficient	-.281	.151	.173	.120	-.110	-.056	-.050	-.180	.490*	-.626**	1.000
		Sig. (2-tailed)	.231	.525	.466	.616	.645	.815	.833	.447	.028	.003	.
		N	20	20	20	20	20	20	20	20	20	20	20

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Correlations with outliers (Participant 3 and 17 excluded):

			LR	TI	BADLTOT	IADLTOT	CHSSOC	COGTOTAL	CHSTOTAL	CHSBEH	TotalC	Neuropercentage	PerCFactorPercentage
Spearman's rho	LR	Correlation Coefficient	1.000	.181	-.116	-.204	-.364	-.346	-.433	-.206	.367	-.209	-.193
		Sig. (2-tailed)	.	.472	.647	.417	.137	.159	.072	.413	.134	.404	.443
		N	18	18	18	18	18	18	18	18	18	18	18
	TI	Correlation Coefficient	.181	1.000	-.032	-.151	-.728**	-.373	-.412	.015	.313	-.402	.378
		Sig. (2-tailed)	.472	.	.901	.550	.001	.127	.089	.954	.205	.098	.122
		N	18	18	18	18	18	18	18	18	18	18	18

	BADLTOT	Correlation Coefficient	-.116	-.032	1.000	.584*	.085	-.173	.282	-.630**	.374	-.481*	.286
		Sig. (2-tailed)	.647	.901	.	.011	.739	.494	.257	.005	.126	.043	.250
		N	18	18	18	18	18	18	18	18	18	18	18
	IADLTOT	Correlation Coefficient	-.204	-.151	.584*	1.000	.129	.381	.541*	-.274	-.191	-.251	.076
		Sig. (2-tailed)	.417	.550	.011	.	.610	.119	.020	.272	.449	.316	.766
		N	18	18	18	18	18	18	18	18	18	18	18
	CHSSOC	Correlation Coefficient	-.364	-.728**	.085	.129	1.000	.406	.608**	.165	-.337	.359	-.150
		Sig. (2-tailed)	.137	.001	.739	.610	.	.094	.007	.512	.171	.143	.553
		N	18	18	18	18	18	18	18	18	18	18	18

	COGTOTAL	Correlation Coefficient	-.346	-.373	-.173	.381	.406	1.000	.725**	.429	-.654**	.452	-.234
		Sig. (2-tailed)	.159	.127	.494	.119	.094	.	.001	.076	.003	.060	.351
		N	18	18	18	18	18	18	18	18	18	18	18
	CHSTOTAL	Correlation Coefficient	-.433	-.412	.282	.541*	.608**	.725**	1.000	.388	-.594**	.311	-.202
		Sig. (2-tailed)	.072	.089	.257	.020	.007	.001	.	.111	.009	.209	.422
		N	18	18	18	18	18	18	18	18	18	18	18
	CHSBEH	Correlation Coefficient	-.206	.015	-.630**	-.274	.165	.429	.388	1.000	-.726**	.625**	-.350
		Sig. (2-tailed)	.413	.954	.005	.272	.512	.076	.111	.	.001	.006	.154
		N	18	18	18	18	18	18	18	18	18	18	18

	TotalC	Correlation Coefficient	.367	.313	.374	-.191	-.337	-.654**	-.594**	-.726**	1.000	-.654**	.635**
		Sig. (2-tailed)	.134	.205	.126	.449	.171	.003	.009	.001	.	.003	.005
		N	18	18	18	18	18	18	18	18	18	18	18
	Neuropercentage	Correlation Coefficient	-.209	-.402	-.481*	-.251	.359	.452	.311	.625**	-.654**	1.000	-.565*
		Sig. (2-tailed)	.404	.098	.043	.316	.143	.060	.209	.006	.003	.	.015
		N	18	18	18	18	18	18	18	18	18	18	18
	PerCFactorPercentage	Correlation Coefficient	-.193	.378	.286	.076	-.150	-.234	-.202	-.350	.635**	-.565*	1.000
		Sig. (2-tailed)	.443	.122	.250	.766	.553	.351	.422	.154	.005	.015	.
		N	18	18	18	18	18	18	18	18	18	18	18

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Mann-Whitney U Test to compare gender and mean level of continuity:

Test Statistics(b)

	TotalC
Mann-Whitney U	8.000
Wilcoxon W	53.000
Z	-3.154
Asymp. Sig. (2-tailed)	.002
Exact Sig. [2*(1-tailed Sig.)]	.001(a)

a Not corrected for ties.

b Grouping Variable: SEX

Comparison of mean cognitive difficulties according to gender:

Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means						
								95% Confidence Interval of the Difference	
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper

COGTOTAL	Equal variances assumed	1.046	.320	-2.205	18	.041	-1.58586	.71931	-3.09707	-.07464
	Equal variances not assumed			-2.302	17.213	.034	-1.58586	.68887	-3.03788	-.13384