

**VOLUME I: RESEARCH COMPONENT**

**OBSERVATIONAL CODING SYSTEMS APPLIED TO  
STUDY INTERACTIONS BETWEEN COUPLES  
WHERE ONE SPOUSE HAS A CHRONIC CONDITION**

**by**

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A thesis submitted in partial fulfilment to the University of Birmingham for the degree of

Doctorate in Clinical Psychology

School of Psychology

University of Birmingham

May 2013

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## **Overview of Thesis**

This thesis was completed as part of a three-year Doctorate in Clinical Psychology at the University of Birmingham. It comprises two volumes: a research component, and a clinical component.

Volume I includes three research papers. Paper one is a critical literature review of observational coding systems applied to measure interactions between couples when one spouse has a chronic condition. Paper two presents an empirical study concerning the development and psychometric evaluation of a person-centred coding system in spousal dementia care. The final paper is an executive summary of the empirical paper.

Volume II includes five clinical practice reports. The first report presents the assessment, cognitive-behavioural and psychodynamic formulations of a 48-year-old man experiencing anxiety and depression. The second report is a qualitative evaluation of staff experiences of a Cognitive Behavioural Approaches supervision group. The third report is a single-case experimental design investigating the effectiveness of a behavioural intervention implemented with a six-year-old girl with sleeping difficulties and a learning disability. The fourth report presents a case study describing a behavioural intervention implemented with inpatient staff working with a 74-year-old man experiencing memory difficulties, anxiety and depression. The fifth report is an abstract describing assessment, formulation, intervention, and evaluation of work completed with a 13-year-old girl with anxiety.

## **Acknowledgements**

Firstly, thank you to the couples who participated in the study and who welcomed me into their home.

Secondly, I would like to thank my research supervisors, Drs Jan Oyebode and Gerry Riley, for their guidance, support and inspiration. This work would not have been possible without them.

Thirdly, I would also like to thank Dr Sue Adams, Dr Jon Williamson, Dr Peter Bentham, Dr Reema Swarna, Mary Brown, and Jeremy Smith from a local NHS Trust. They have offered advice, encouragement and help with recruitment of participants. I am also appreciative of David Prytherch for his help understanding coding system software. Thank you to Lauren Albrecht and Bradley Crook who volunteered to help with the coding.

Finally, a big thank you to my parents and my husband who have seen me through the high and lows of my journey to becoming a Clinical Psychologist.

## TABLE OF CONTENTS

### VOLUME I: RESEARCH COMPONENT

<b>Contents</b>	<b>Page</b>
<b>I      CHAPTER ONE: LITERATURE REVIEW</b>	<b>1</b>
Abstract	2
Introduction	3
1.1 Aims of the Current Review	7
Method	7
2.1 Validity	7
2.2 Reliability	8
2.3 Generalizability	10
2.4 Utility	10
2.5 Theory	10
2.5 Search Terms	11
2.6 Inclusion and Exclusion Criteria	13
Overview of Papers	23
3.1 Marital Interaction Coding System (MICS)	23
3.2 Rapid Marital Interaction Coding System (RMICS)	26
3.3 Specific Affect Coding System (SPAFF)	29
3.4 Validation and Invalidation Behavioural Coding System (VIBCS)	31
3.5 Living in Family Environments (LIFE)	33

3.6 Communication Skills Test (CST)	36
3.7 Kategoriensystem für Partnerschaftliche Interaktion (KPI)	38
3.8 Interactional Dimensions Coding System (IDCS)	41
3.9 Observational Coding System for Emotional Overinvolvement	43
Synthesis of Findings	45
Discussion and Recommendations	47
References	49
<b>II CHAPTER TWO: EMPIRICAL PAPER</b>	<b>57</b>
Abstract	58
Introduction	59
1.1 Aims of the Current Study	64
Method	64
2.1 Ethics	64
2.2 Participants and Recruitment	64
2.3 Measures	67
2.4 Procedure	72
2.5 Data Analysis	73
Results	74
3.1 Descriptive Data	74
3.2 Internal Consistency	75
3.3 Inter-rater Reliability	76
3.4 Correlations	79
Discussion	81

4.1 Strengths and Limitations of the Coding System	83
4.2 Strengths and Limitations of the Evaluation	85
4.3 Implications for Clinical Practice	88
4.4 Conclusion	88
References	89
<b>III CHAPTER THREE: EXECUTIVE SUMMARY</b>	<b>94</b>
<b>IV APPENDICES TO VOLUME I</b>	<b>97</b>
A: Evaluation pro forma	98
B: NHS ethical and Research and Development approval	100
C: Information Packs and Consent Forms for Participants	105
D: Observational Coding System of Person-Centred Care (Final Version)	113
E: Birmingham Relationship Continuity Measure (BRCM)	124
F: Raw SPSS Data and Calculations	127
G: Instructions for authors	134

## TABLE OF CONTENTS

### VOLUME II: CLINICAL COMPONENT

<b>Contents</b>	<b>Page</b>
<b>I      CLINICAL PRACTICE REPORT ONE</b>	<b>1</b>
Case formulation of a client experiencing obsessive-compulsive disorder from a cognitive-behavioural and psychodynamic perspective	
1.1    Abstract	2
1.2    Case information	3
1.2.1   Presenting difficulties	3
1.2.2   Background information	4
1.2.3   Assessment	5
1.3    Cognitive-behavioural formulation	7
1.3.1   Overview	7
1.3.2   Rationale	8
1.3.3   Beck's (1976) longitudinal formulation	8
1.3.4   Salkovskis et al's (1998) OCD-specific maintenance formulation	12
1.4    Psychodynamic formulation	15
1.4.1   Overview	15
1.4.2   Rationale	15
1.4.3   Malan's (1995) Triangle of Conflict	15
1.3.4   Malan's (1995) Triangle of Person	18



1.4	Reflections	24
1.5	References	28
<b>II</b>	<b>CLINICAL PRACTICE REPORT TWO</b>	<b>33</b>
	Evaluation of a supervision service to non-psychologists who implement cognitive behavioural approaches as part of their clinical practice	
2.1	Abstract	34
2.2	Introduction	35
2.2.1	General planning context	35
2.2.2	The service context	36
2.2.3	The need for evaluation	37
2.2.4	Aims	40
2.3	Method	41
2.3.2	Design	41
2.3.3	Recruitment and Participants	41
2.3.4	Procedure	42
2.3.5	Interview and questionnaire development	43
2.3.6	Data analysis	43
2.4	Results	44
2.4.1	Qualitative responses	44
2.4.2	Quantitative responses	52
2.5	Discussion	54
2.5.1	Aim one: Effectiveness of supervision	54
2.5.2	Aim two: Improvements	56

2.5.3	Aim three: Factors blocking attendance	57
2.5.4	Strengths and limitations	57
2.5.5	Recommendations	59
2.5.6	Conclusion	60
2.6	References	61
<b>III</b>	<b>CLINICAL PRACTICE REPORT THREE</b>	<b>64</b>
	A single-case experimental design to increase appropriate sleep behaviour in a six-year-old girl with physical and learning disabilities	
3.1	Abstract	65
3.2	Introduction	66
3.2.1	Referral information	66
3.2.2	Presenting difficulties	66
3.2.3	Assessment	66
3.3	Formulation	69
3.4	Intervention	73
3.5	Experimental design	76
3.6	Results	77
3.6.1	Visual analysis	77
3.6.2	Statistical analysis	79
3.6.3	Additional visual analysis	81
3.6.4	Kate's report	83
3.6.5	Sleep Disturbance Index	84
3.7	Discussion	84

3.7.1	Limitations	85
3.7.2	Personal reflections	87
3.8	References	89
<b>IV</b>	<b>CLINICAL PRACTICE REPORT FOUR</b>	<b>93</b>
	A case study detailing a behavioural intervention implemented with nursing staff to manage challenging behaviour in a 74-year-old man with a diagnosis of vascular dementia	
4.1	Abstract	94
4.2	Context of case study	95
4.3	Referral	95
4.4	Assessment	95
4.4.1	Interview with Diane	96
4.4.2	Interview with staff	97
4.4.3	Interview with Alan	99
4.4.4	Descriptive functional behaviour assessment	99
4.4.5	Outcome measures	100
4.4.6	Goals	100
4.5	Formulation	101
4.5.1	Biological factors	101
4.5.2	Psychological factors	102
4.5.3	Social factors	103
4.5.4	Alan's needs	106
4.6	Further assessment	106

4.7	Intervention	107
4.8	Evaluation	111
4.8.1	Quantitative outcomes	111
4.8.2	Qualitative outcomes	113
4.9	Reflections	114
4.10	References	117
<b>V</b>	<b>CLINICAL PRACTICE REPORT FIVE</b>	<b>121</b>
	A case study of a 13-year-old girl referred to CAMHS for night-time anxiety	
5.1	Abstract	122
<b>VI</b>	<b>APPENDICES TO VOLUME II</b>	<b>123</b>
	A: DSM-IV-TR diagnostic criteria for OCD	124
	B: Information sheet for service evaluation participants	127
	C: Consent form for service evaluation participants	129
	D: Interview schedule for service evaluation participants	131
	E: Questionnaire given to service evaluation participants	133
	F: Description of Lucy's sleep disorders	135
	G: Lucy's sleep diary	137
	H: The inpatient service	139
	I: Behavioural chart completed by ward staff	141
	J: List of Alan's medication	143

## **LIST OF TABLES OF FIGURES FOR VOLUME I**

Table 1. Types of validity used to evaluate coding systems	8
Table 2. Types of reliability used to evaluate coding systems	9
Table 3. Generalizability, utility and theoretical factors used to evaluate coding systems	11
Table 4. Breakdown of relevant articles found according to database and search terms	12
Table 5. Inclusion and exclusion criteria applied to research papers	13
Table 6. Summary of reviewed papers	14
Table 7. Inclusion and exclusion criteria for participants	66
Table 8. Codes created from analysing video transcripts	70
Table 9. Descriptive data for participants	74
Table 10. Descriptive data for the codes used by the raters	76
Table 11. Cross tabulations of the frequencies of use of coding categories by the two independent raters	78
Table 12. Cross tabulations of the frequency of person-centred and non-person-centred codes by the two independent raters	79
Figure 1. Graph plotting BRCM scores against the ratio between person-centred and non-person-centred behaviours	80

## **LIST OF TABLES OF FIGURES FOR VOLUME II**

Table 1. The Trust's supervision standards	39
Table 2. Themes from qualitative analysis	44
Table 3. Number of participants responding to questionnaire items	53
Table 4. Breakdown of sessions in terms of content covered	74
Table 5. Lag-1 autocorrelations for dependent variables	79
Table 6. Double bootstrap analysis of the dependent variables	81
Table 7. Physical health events leading up to Alan's admission	98
Figure 1. Longitudinal formulation of Edward's OCD	10
Figure 2. OCD-specific maintenance formulation	14
Figure 3. Edward's Triangle of Conflict	17
Figure 4. Malan's Triangle of Conflict mapped into Triangle of Person	19
Figure 5. Edward's Triangle of Person	23
Figure 6. Formulation of Lucy's sleep disorders using the '5 Ps' model	71
Figure 7. Number of minutes Lucy slept	77
Figure 8. Number of minutes Lucy took to settle	78
Figure 9. Number of night-waking incidences	78
Figure 10. Number of minutes Lucy slept, revised	82
Figure 11. Number of minutes Lucy took to settle, revised	82
Figure 12. Number of night-waking incidences, revised	83
Figure 13. Alan's biopsychosocial formulation	105
Figure 14. Alan's pre- and post-intervention scores on the CBS	112
Figure 15. Number of challenging behaviour incidents reported and PRN	113

Lorazepam administered with Alan

**CHAPTER ONE:**  
**A SYSTEMATIC REVIEW OF**  
**OBSERVATIONAL CODING SYSTEMS**  
**APPLIED TO SPOUSAL INTERACTIONS**  
**IN CHRONIC CONDITIONS**

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### **Abstract**

This literature review critically evaluates observational coding systems that have been used to measure marital interactions when one spouse has a diagnosis of a chronic condition. A systematic search using three databases identified nine coding systems that have been used to assess the nature and quality of interaction between couples with a range of chronic conditions on a variety of tasks. A description of each coding system is provided, as well as its theoretical development, evaluation of its application, reliability, validity, generalizability, and utility with a chronic condition population. From the nine coding systems reviewed, the conclusions are that these measures used to assess marital interaction in chronic conditions are lacking in information regarding validity, and the use of many coding systems are not justified in relation to theory. Finally, the review highlights the lack of research utilising a coding system within this population. The implications are that coding systems need to be developed that specifically focus on helpful and unhelpful behaviours when caring for someone with a chronic condition.

*Keywords:* chronic condition, spouses, interaction, coding system, observation



## **Introduction**

Chronic physical and mental health conditions refer to illnesses or diseases of progressive or long duration (World Health Organisation, 2012), which may require long-term management (Department of Health, 2004). Chronic conditions may affect a person's physical, cognitive, emotional and social functioning, and may impact upon activities of daily living (Leventhal, Halm, Horowitz, Levanthal, & Ozakinci, 2005). Examples of chronic health conditions include arthritis, cancer, dementia, depression, diabetes, obsessive-compulsive disorder, psychosis, and respiratory diseases.

### **Impact of Chronic Conditions**

Whilst many people manage their chronic condition well, it may be accompanied by chronic disability requiring regular medical treatment (Bartolo et al., 2010) in addition to care and support (Leventhal et al., 2005). As the majority of people with chronic conditions live at home, provision of care and support is typically provided by family members (Ablitt, Jones, & Muers, 2009; Pinquart & Sörensen, 2003). For adults with chronic conditions, care-givers are mostly spouses (Lewis, 1998; Yorgason et al., 2010).

It is not within the scope of this review to discuss literature concerning the impact of caring for someone with a chronic condition on the health and well-being of care-givers, nor is it to further review caregiver-based interventions, as these areas have been extensively reviewed (Glajchen, 2004; Pierce, Steiner, Hicks, & Holzaepfel, 2006; Sanders & Power, 2009). In brief, a meta-analysis found that carers of frail older people reported higher levels of stress and depression, and lower levels of subjective well-being and physical health when compared to non-caregivers (Pinquart & Sörensen, 2003). Some research has found that caring for a spouse with a chronic condition is stressful and burdensome, and a physical,

psychological, emotional and social strain, (Lieberman & Fisher, 1995; Murray & Livingstone, 1998; Poulin et al., 2010).

However, not all care-giving experiences are burdensome. Netto, Jenny, and Philip (2009) found that family care-givers of people with dementia reported 'personal growth', incorporating greater understanding and resilience. These carers further reported increasing closeness within the relationship.

### **Importance of Relationships**

Research has suggested that the quality of relationships between care-giving spouses and care-recipients impacts upon mental health, quality of care and quality of life. Pinquart and Sörensen (2003) found that carers' ability to adjust to the care-giving role was influenced by their perceived quality of the relationship prior to the onset of their relatives' condition, as well as continuity of this relationship. Ablitt et al's (2009) review highlighted that the quality of both the pre-morbid and current relationship was associated with better mental health for the spousal carer and better functional outcomes for the person with dementia. Reports of higher marital satisfaction were identified as a protective factor against the impact on carers' mental health when caring for a spouse with cancer (Fang, Manne, & Pape, 2001). Sebern and Riegel (2009) found that supportive relationships were important for patients with heart failure and contributed to their ability to self-care. Poulin et al. (2010) reported greater amounts of helping behaviours provided by spousal carers predicted higher levels of positive affect, and overall well-being for carers and care-recipients. This suggests that a good relationship can reduce perceived burden, stress and strain in care-givers, and is associated with better emotional and general well-being for both spouses.

## **Methods for Investigating Spousal Interaction**

Given this evidence about the role of relationships in outcomes, an important research aim would be to better understand the aspects of relationships associated with better and poorer outcomes. This may help couples maintain or develop a positive relationship. To address this aim, various methods have been used, including qualitative methods, questionnaires and observations.

Qualitative studies provide ways of assessing how care-givers perceive their interactions with their spouse with a chronic condition. Phinney (2006) discovered that carers of spouses with dementia believed that they reduced demands, and assisted their spouse to keep involved in activities of daily living. However, whilst qualitative interview-based research provides interesting insights into subjective perceptions, these may not tell us what we would see if we were to observe behaviour (Romano et al., 1991). Indeed, Small, Gutman, Makela, and Hillhouse (2003) found that care-givers perceived themselves using simpler language when communicating with their spouse with Alzheimer's disease in everyday tasks, but observations of their interactions showed that they overestimated their use.

Questionnaires have widely been used to assess relationship quality (Ablitt et al., 2009). However, questionnaires are similarly susceptible to influences of social desirability and other response biases. Riley et al. (2013) assert that questionnaires have typically been developed for use with the general population; it is therefore questionable whether they are sensitive to aspects of the relationship that are relevant for considering the impact of the relationship on outcomes in the context of chronic conditions.

Observational methods have been used less often to study marital interaction in this context (Chambless et al., 2002; Manne et al., 2004), yet have the advantage of being less subjective than the other two approaches. Like qualitative methods, but unlike questionnaires,

they have the potential to provide information about specific ways in which aspects of the relationship may impact upon outcomes.

### **Observational Coding Systems for Spousal Interactions**

As with questionnaire studies, observational studies have applied coding systems developed for use in the general population, rather than developing a system specifically for studying spousal interaction in the context of chronic conditions. These coding systems have predominantly arisen from behavioural marital theory and therapy (Baucom & Kerig, 2004), and utilised to capture verbal and non-verbal behaviours of distressed and non-distressed couples during discussion. We, therefore, do not know if these coding systems capture behaviours associated with helpful and unhelpful interactions in couples where one has a chronic condition.

Microanalytical, or fine-detailed, coding systems have been developed for the purpose of observing couples interacting on conflict-resolution discussion tasks; for example, as cited by Baucom and Kerig (2004), the Marital Interaction Coding System (Hops, Wills, Weiss, & Patterson, 1972), and the Kategoriensystem für Partnerschaftliche Interaktion (Hahlweg et al., 1984). More recently, global or macroanalytical coding systems have emerged for similar purposes, including the Interactional Dimensions Coding System (Julien, Markman, & Lindahl, 1989; cited in Kline et al., 2004), and the Communication Skills Test (Floyd & Markman, 1984). These coding systems predominantly focus on frequencies of behaviour, although other coding systems, such as the Couples Interaction Rating System (Heavey, Gill, & Christensen, 1998; cited in Baucom & Kerig, 2004) focus on behavioural sequences. Coding systems, such as the Specific Affect Coding System (Gottman, McCoy, Coan, & Collier, 1996; cited in Shapiro & Gottman, 2004), have been developed to assess verbal and non-verbal emotion observed within interactions.

## **Aims of the Current Review**

Given the potential value of observational methods for understanding how aspects of the relationship promote better (or worse) outcomes, this review offers a systematic, critical analysis of coding systems that have been used in research for observing couples' interactions where one person has a chronic physical or mental health condition. It will evaluate the evidence of their psychometric properties and usefulness for this population, so that conclusions may be drawn about which, if any, are most appropriate. Recommendations about how such measures need to be developed for future research will be made.

## **Method**

Kerig and Baucom's (2004) book was used to provide an overview of existing coding systems. They describe and discuss each coding system in terms of its theoretical development, reliability, validity and utility. Using these constructs, a pro forma (Appendix A) was developed for evaluation purposes. This includes how well the coding system is described, its theoretical justification, and its reliability, validity, generalizability and practical utility with chronic conditions.

## **Validity**

Heyman (2001), and Floyd and Rogers (2004), provide information regarding how types of validity have been used to evaluate coding systems. Validity concerns the extent to which each coding system clearly defines the construct that it intends to measure, and measures what it purports to measure. Table 1 describes the types of validity used to evaluate coding systems for the purpose of this review.

**Table 1.** Types of validity used to evaluate observational coding systems (Floyd & Rogers, 2004; Heyman, 2001).

<b>Type of validity</b>	<b>Description</b>
Concurrent	The extent to which the coding system correlates with a test, such as a questionnaire, that purports to measure the same behaviours or concepts as the coding system. A high correlation would imply that a coding system has good concurrent validity.
Predictive	The extent to which a coding system can successfully predict a future outcome.
Content	The extent to which the task used is likely to evoke the range of behaviours required to measure the construct, and whether the coding system captures all behaviours related to the construct it aims to measure.
Construct	The extent to which hypotheses, based on theories about the construct the system purports to measure, are confirmed when the coding system is used to measure the construct. A measure would have good construct validity if there is a sound theoretical base, and hypotheses are confirmed when the system is used to measure the construct.
Discriminative	The extent to which a coding system can differentiate between two different groups where it is expected there will be definite a priori differences, e.g. distressed and non-distressed married couples. To have discriminative validity there should be clear differentiation between the groups as shown by correlations.

## **Reliability**

Table 2 describes the types of reliability used to evaluate coding systems. Reliability refers to the extent to which the coding system is applied in a consistent and accurate way, and produces consistent results (Floyd & Rogers, 2004). There are three ways of assessing reliability: internal consistency, inter-rater reliability, and test-retest reliability.

**Table 2.** Types of reliability used to evaluate coding systems (Floyd & Rogers, 2004).

<b>Type of reliability</b>	<b>Description</b>
Internal consistency	The extent to which items within the coding system measure the same underlying construct. Internal consistency can be calculated using Cronbach's coefficient alpha (Cronbach & Shavelston, 2004). For the purpose of evaluation, a Cronbach's alpha of 0.7 and above will be judged an acceptable level of reliability (Goddard & Villanova, 2006).
Inter-rater reliability	The extent to which two raters agree that behaviour is given a specific code (Floyd & Rogers, 2004). Reliability will be assessed on a number of levels. Firstly, the statistical test used. Cohen's kappa (Cohen, 1960) is a stringent measure of inter-rater agreement; it analyses two sets of codes on a point-by-point basis and accounts for chance agreement between raters. Some papers included in this review have reported intraclass correlation coefficients as a measure of inter-rater reliability. This refers to correlations calculated on the basis of two sets of data relating to the same measure (Floyd & Rogers, 2004). For evaluation purposes, kappas and intraclass correlations of 0.6 and above will be considered an acceptable level of reliability (Landis & Koch, 1977). Statistical methods, such as point-by-point agreement, are weak for such evaluations because they do not take into account chance agreement (Floyd & Rogers, 2004). Therefore, kappa and intraclass correlation coefficients will be rated highly. Secondly, studies obtaining inter-rater reliability on at least 20% of video-recordings will be evaluated highly. Finally, studies reporting reliability values for individual codes will be rated higher than studies reporting these values as a range; this is because it is difficult to distinguish codes with a low kappa value when presented as a range (Heyman, 2001).
Test-retest reliability	The extent to which the coding system yields the same scores when used on more than one occasion. This determines how reliable the coding system is over time. If a system does not produce stable results (or if conditions are not stable) then the coding system is not very meaningful. Note: none of the studies included in this review report test-retest reliability. It is presented here for reference only.

## **Generalizability**

Applications of coding systems will be evaluated in terms of the sample used. This includes sample size, whether the sample is clearly defined, and how representative it is likely to be of that specific chronic condition population that the sample was drawn from.

Table 3 portrays how generalizability, practical and theoretical utility factors will be used to evaluate coding systems.

## **Utility**

Coding systems will also be evaluated in terms of how much time and resources are required for their application.

## **Theory**

Authors providing adequate theoretical justification for the decision to use a specific coding system will be rated highly. Coding systems will be evaluated according to how well they have been applied to study the construct under investigation. This includes whether the constructs themselves are relevant to chronic conditions and whether theoretical justification is given for the exclusion or reclassification of codes.



**Table 3.** Generalizability, practical and theoretical utility factors used to evaluate coding systems (Floyd & Rogers, 2004).

<b>Factors under consideration</b>	<b>Description</b>
Sample	<p>Papers will be evaluated on how representative a sample is. Those utilising a reasonable sample size will be deemed highly representative. If only one chronic condition sample is used, this impedes generalizability, but indicates the usefulness of the coding system with that population. If the coding system has been applied with more than one sample, this would suggest good generalizability but only if there is an equal number of participants in each sample. A too small, ill-defined or unrepresentative sample might indicate that estimates of the coding system’s reliability and validity for that population are unreliable.</p> <p>Papers will also be evaluated on how well the sample is described (i.e. stages of disease or illness, type of relative). Papers using other family members in addition to spouses will need to include separate data analysis for spouses to ensure clarity.</p>
Training	<p>The duration of training will be considered as it provides evidence for the practical utility of the coding system. If raters are required to have excessive training, then this will be evaluated as too time-consuming and might suggest that the coding system is too complex (undermining practical utility).</p>
Theory	<p>Papers will be evaluated on their application of the coding system, encompassing the relevance to theory, and the inclusion and exclusion of codes for the purpose of analysis. When codes are excluded, it might imply that the coding system may need to be adapted for that chronic condition population.</p>

**Search Terms**

Initial literature searches were conducted in the following databases: Medline, PsycINFO, and CINAHL. A systematic search using keywords/phrases was conducted using each database in turn. Keywords were expanded using the database’s subject headings. Table 4 provides a breakdown of search strategies and outcomes.

**Table 4.** Breakdown of relevant articles found according to database and search term used.

<b>Database</b>	<b>Search term</b>	<b>Number of articles</b>	<b>Relevant articles</b>
Medline	“chronic disease” OR “chronic condition” AND “caregivers” AND “spouses” OR “marriage”	41	None
	“chronic disease” OR “chronic condition” AND “coding system”	14	None
	“observation” AND “coding system”	14	Fredman, Chambless, & Steketee (2004)
	“spouses” OR “marriage” AND “coding system”	37	Gallagher-Thompson, Dal Canto, Jacob, & Thompson (2001); Jacob & Leonard (1992); Van den Broucke, Vandereycken, & Vertommen (1995)
	“caregivers” AND “coding system”	16	Gallagher-Thompson et al. (2001)
PsycINFO	“chronic illness” OR “chronic condition” AND “caregivers” AND “spouses” OR “couples” OR “partners” OR “husbands” OR “wives”	38	None
	“chronic illness” OR “chronic condition” AND “coding system”	20	Issner, Cano, Leonard, & Williams (2012); Johansen & Cano (2007); Leong, Cano, & Johansen (2011)
	“spouses” OR “couples” OR “partners” OR “husbands” OR “wives” AND “coding system”	189	Cano, Barterian, & Heller (2008); Gallagher-Thompson et al. (2001); Issner et al. (2012); Johansen & Cano (2007); Leong et al. (2011); Manne et al. (2004); Perusse, Boucher, & Fernet (2012); Romano, Jensen, Schmaling, Hops, & Buchwald (2009); Van den Broucke et al. (1995)
	“caregivers” AND “coding system”	23	Gallagher-Thompson et al. (2001)
CINAHL	“chronic disease” OR “chronic condition” AND “spouses” OR “significant others” AND “caregivers” AND “coding systems”	6	None

## **Inclusion and Exclusion Criteria**

The goal was to identify coding systems used in research on spousal couples' interactions where at least one person had a chronic condition. The initial search resulted in 411 research papers. Inclusion and exclusion criteria were then applied (Table 5).

The literature search was limited to papers published between 1967-2012. The abstracts were visually inspected to ensure that they met inclusion criteria and were excluded if they did not. Following this, 11 papers remained. The references of these papers were examined, yielding a further three papers (Chambless et al., 2002; Cranford, Floyd, Schulenberg, & Zucker, 2011; Romano et al., 1991). In total, 14 papers, and nine coding systems, were identified and included in the review (Table 6). Each coding system is described and evaluated in more detail below, with reference to its use in the studies identified above, i.e. with couples where one has a chronic condition.

**Table 5.** Inclusion and exclusion criteria applied to research papers for this review.

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
<ul style="list-style-type: none"><li>- peer-reviewed articles</li><li>- English language</li><li>- utilised a coding system</li><li>- sample included couples or partners who were married or co-habited or in a 'romantic relationship'</li><li>- at least one spouse had a chronic condition (disease, disability or illness)</li><li>- age restricted to couples aged 18+</li><li>- research had a primary focus on the nature of couple interactions</li></ul>	<ul style="list-style-type: none"><li>- dissertations, editorials, book chapters and case studies</li><li>- research with 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</li><li>- sample investigated are parent-child, sibling, or any other non-spousal dyad</li></ul>

**Table 6.** Summary of papers reviewed.

<b>Coding system</b>	<b>Description of coding system</b>	<b>Original psychometric data</b>	<b>Application in chronic conditions</b>	<b>Codes</b>	<b>Psychometric data</b>	<b>Coder training</b>
Marital Interaction Coding System (MICS-IV)	A microanalytical coding system developed to measure couple interaction in conflict discussion.	Reported kappas >0.60.	Gallagher-Thompson, Dal Canto, Jacob & Thompson (2001).	Factor analysis on 17 codes produced:	Inter-rater reliability 0.70-0.83 (statistical test unclear)	Not stated
Hops, Wills, Weiss, & Patterson (1972)	37 verbal and non-verbal codes.  Unit of analysis: entire utterance of speech by each spouse.	Discriminative validity: can distinguish between distressed and non-distressed couples.  Construct validity: sound theoretical base.	Comparison of interactions on everyday tasks between couples with ( $n=27$ ) or without ( $n=27$ ) Alzheimer's disease.  Lack of theoretical explanation.	1. Supportive 2. Facilitative 3. Rapport	No validity data	
			Jacob & Leonard (1992).  Coded interactions of wives discussing a topic of disagreement with their husbands who either had an alcohol problem ( $n=49$ ), depression ( $n=40$ ), or control ( $n=42$ ).  Lack of theoretical explanation.	Only 16 codes used. 1. Positive 2. Negative 3. Problem-solving	Point-by-point average agreement index: all codes 72%, three categories 71%  No validity data	Not stated

<b>Coding system</b>	<b>Description of coding system</b>	<b>Original psychometric data</b>	<b>Application in chronic conditions</b>	<b>Codes</b>	<b>Psychometric data</b>	<b>Coder training</b>
Rapid Marital Interaction Coding System (RMICS)	Refined version of the MICS-IV based on factor analysis, and review of literature.	Inter-rater agreement on 17 studies (average overall kappa 0.59, range 0.55-0.82 on individual codes).	Manne et al. (2004). Observed 148 women with breast cancer having two discussions with their spouse: cancer-related, and a relationship problem.	1. Emotionally supportive 2. Emotionally unsupportive	Cohen's kappa 0.71 for cancer task, 0.88 for general task	Eight hours of training. Practise until 80% agreement achieved.
Heyman, Eddy, Weiss, & Vivian (1995a)	10 codes.  Unit of analysis: each speaker turn.	Internal consistency: >0.90 using Spearman-Brown coefficients.  Good concurrent, predictive, discriminative, and construct validity in the general population.	Lack of theoretical explanation.		No validity data	

Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
Specific Affect Coding System (SPAFF)	A coding system that observes the level of emotional interaction in couples discussing a marital problem. It considers context, tone of voice, and facial movements.	Kappas ranged 0.75-0.95	Leong, Cano, & Johansen (2011). 78 people with chronic pain and their spouses discussed a topic of disagreement to examine whether sequences of affective interaction were related to reported pain.	16 codes grouped into: 1. Validation 2. Invalidation 3. Neutral	Inter-rater agreement: Yule's Y: 0.69 invalidation 0.89 validation	2-3 months training (average 60 hours).
Gottman, McCoy, Coan, & Collier, (1996)	20 codes, which are divided into negative, positive, and neutral.  Unit of analysis: each speaker turn.	Excellent construct and discriminative validity in general population.	Lack of theoretical explanation.		No validity data	Kappa value of 0.60 required.
			Johansen & Cano (2007). 79 people with chronic pain and their spouses discussed a topic of disagreement. This was to examine whether affective marital interaction predicted levels of reported depression and pain.  Lack of theoretical explanation.	16 codes created four factors: 1. Anger/contempt 2. Sadness 3. Humour 4. Fear	Kappa coefficients: contempt (0.58), anger (0.65), sadness (0.60), humour (0.70), fear (0.33)  No validity data	2-3 months training (average 60 hours).  Kappa value of 0.60 required

Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
Validation and Invalidation Behavioural Coding System (VIBCS)  Fruzzetti (2001)	<p>Developed to examine emotional regulation in couple interactions. It considers context, tone of voice, and physical features.</p> <p>Two codes, rated on 7-point Likert scales:</p> <p>Invalidation (1 = no invalidation, 7 = only invalidation)</p> <p>Validation (1= no validation, 7 = only validation).</p> <p>Unit of analysis: coders calculate final scores by averaging the frequencies for each code.</p>	Unknown due to paper inaccessibility.	<p>Cano, Barterian, &amp; Heller (2008).</p> <p>Investigated whether spousal validation and invalidation observed in discussion task related to reports of marital quality and satisfaction in 92 chronic pain couples</p> <p>Lack of theoretical explanation.</p> <p>Issner, Cano, Leonard &amp; Williams (2012).</p> <p>Studied empathy within 57 chronic pain couples, with a focus on spousal responses to pain behaviour in a discussion task.</p> <p>Lack of theoretical explanation.</p>	See description.	<p>Inter-rater agreement: assessed using <i>r<sub>wg</sub></i> statistic.</p> <p>Validation in persons with pain (<i>mean</i> = 0.92), spouses (<i>mean</i> = 0.88); invalidation in persons with pain (<i>mean</i> = 0.91). spouses (<i>mean</i> = 0.88)</p> <p>No validity data</p> <p>Inter-rater agreement: assessed using <i>r<sub>wg</sub></i> statistic.</p> <p>Spousal invalidation (<i>mean</i> = 0.90), spousal validation (<i>mean</i> = 0.85)</p> <p>No validity data</p>	<p>5-week training programme</p> <p>5-week training programme</p>

Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
Living in Family Environments (LIFE)  Hops et al. (1990)	Originally developed to assess problem-solving interactions between depressed women and their spouses.  No full description of codes available.  Continually codes behaviours, so overall sequences of behaviours are captured as well as individual frequencies.	Unknown due to paper inaccessibility.	Romano et al. (1991). Observed 50 couples where one spouse had a diagnosis of chronic pain and 33 control couples performing four routine household activities.  Lack of theoretical explanation.	22 verbal content and 8 non-verbal affect, in 6 codes:  1. Non-verbal pain 2. Verbal pain 3. Solicitous 4. Facilitative 5. Aggressive 6. Distressed	Kappa values: non-verbal pain 0.59, verbal pain 0.66, solicitous 0.58, facilitative 0.61, aggressive 0.57, distressed 0.53  Good discriminative validity between spouse with and without pain.  Good concurrent validity: strong correlations between observed behaviours and self-report	Two-week period.  Kappa value of 0.60 required.
			Romano, Jensen, Schmaling, Hops, & Buchwald (2009). Investigated if pain behaviours exhibited by 37 people with chronic fatigue syndrome related to their relatives' behaviours when completing household activities.  Lack of theoretical explanation.	22 original codes collapsed into 4 broad categories:  1. Illness / pain behaviour 2. Solicitous 3. Facilitative 4. Aversive	Kappa values averaged 0.73 for content codes, and 0.80 for affect codes  No validity data	Two-week period.  Kappa value of 0.60 required.



Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
Communication Skills Test (CST)  Floyd & Markman, (1984)	<p>A macroanalytical coding system designed to assess relationship conflict discussions between spouses.</p> <p>40 verbal and non-verbal codes, grouped into five categories:</p> <ol style="list-style-type: none"> <li>1. Very negative</li> <li>2. Negative</li> <li>3. Neutral</li> <li>4. Positive</li> <li>5. Very positive</li> </ol> <p>Unit of analysis: entire utterance of speech by each spouse is assigned a category rating 1 – 5.</p>	<p>Kappas ranged 0.71-0.95, <i>mean</i>=0.82</p> <p>Concurrent validity: high correlation between mean CST scores and spouse's self-report of the impact of their communication on the other</p>	<p>Cranford, Floyd, Schulenberg, &amp; Zucker (2011).</p> <p>Compared communication and problem-solving behaviours in 105 couples with or without a lifetime alcohol use disorder.</p> <p>Lack of theoretical explanation.</p>	See description.	No reliability or validity data	Not stated

Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
Kategoriensystem für Partnerschaftliche Interaktion (KPI)	A microanalytical coding system that describes verbal and non-verbal behaviours in discussion of relationship problems.	Cronbach's alpha: verbal codes ranged 0.85-0.99; non-verbal codes ranged 0.52-0.89	Van den Broucke, Vandereycken, & Vertommen (1995).  Assessed levels of conflict interactions between 21 couples where the woman had an eating disorder, and two control-matched groups.	1. Positive verbal 2. Negative verbal 3. Neutral verbal 4. Positive non-verbal 5. Negative non-verbal 6. Neutral non-verbal	Inter-rater reliability 0.83 verbal, 0.80 non-verbal  Intra-rater reliability 0.86 verbal, 0.85 non-verbal  No validity data	Not stated
Hahlweg et al. (1984)	26 verbal codes, grouped into 12 categories, then reduced into 3 broader categories: positive, neutral, and negative.  Unit of analysis: each speaker turn is assigned a verbal code, and is supplemented by non-verbal code (positive or negative)	Cohen's kappa: range 0.70-0.98.  Good discriminative validity between distressed and non-distressed married couples during behavioural marital therapy.	Lack of theoretical explanation.  Chambless et al. (2002).  Investigated levels of emotional support in 22 husbands of women with panic disorder with agoraphobia, and 21 control husbands discussing a relationship problem.  Some adequate theoretical justification.		Intraclass correlation coefficient to assess inter-rater reliability: positive verbal (0.81) negative verbal (0.92) positive non-verbal (0.81) negative non-verbal (0.89)  No validity data	Not stated

Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
<p>Interactional Dimensions Coding System (IDCS)</p> <p>Julien, Markman, &amp; Lindahl (1989)</p>	<p>A macroanalytical coding system designed to capture an entire interaction between couples discussing a problem.</p> <p>9 individual and 5 dyadic codes.</p> <p>Unit of analysis: Each individual code is assigned a rating on a 9-point Likert scale (1 = <i>very low</i>, 9 = <i>very high</i>). Entire interaction is given a dyadic code.</p>	<p>Intraclass correlation coefficients assessed inter-rater reliability for individual (range 0.20-0.89) and dyadic codes (range 0.60-0.89).</p> <p>Good concurrent validity (correlating results with self-report measures). Two dyadic codes had good predictive validity for marital satisfaction over time.</p>	<p>Perusse et al. (2012).</p> <p>Used the French version to evaluate the quality of problem-solving behaviour between 75 couples where one spouse has alexithymia.</p> <p>Lack of theoretical explanation.</p>	<ol style="list-style-type: none"> <li>1. Hostility</li> <li>2. Withdrawal</li> <li>3. Communication skills</li> <li>4. Support and validation</li> </ol>	<p>Intraclass correlation coefficient for inter-rater reliability: range 0.83-0.94 for 25 couples</p> <p>No validity data</p>	<p>Raters trained for 60 hours. Practised until 0.80 level of agreement achieved.</p>

Coding system	Description of coding system	Original psychometric data	Application in chronic conditions	Codes	Psychometric data	Coder training
Observational Coding System for Emotional Overinvolvement  Fredman, Chambless, & Steketee (2004)	The theoretical underpinning was that emotional overinvolvement was thought to be higher in relatives of people with chronic mental health conditions than the general population.  Coded on a 5-point Likert scale (1 = <i>absent</i> , 5 = <i>extreme</i> )	Inter-rater reliability assessed using Spearman-Brown correction: intrusiveness 0.92, excessive self-sacrifice 0.91, exaggerated emotional response 0.73.  Construct validity: results consistent with hypotheses.  Content validity: hypothetical behaviours that might be exhibited by relatives were incorporated into code descriptions.  Concurrent and discriminative validity: determined by correlating scores with other measures of similar constructs	Fredman et al. (2004)  55 people with obsessive-compulsive disorder and 40 with panic disorder with agoraphobia discussed a topic of disagreement with a relative (71% spouses).  Comprehensive theoretical justification.	1. Intrusiveness 2. Excessive self-sacrificing 3. Exaggerated emotional response	See original	35 hours of training. Reliability value of 0.75 was required on a pilot sample.

## Overview of Papers

Fourteen papers employed nine observational coding systems to investigate interactions between couples where one spouse has a chronic physical or mental health condition. One paper presented information about the development and preliminary validation of a coding system. Most studies asked couples to discuss an area of disagreement for at least 10 minutes, with the purpose of coding the content and affect displayed. The majority of papers aimed to further understanding of relationships between methods of communication and spousal well-being (largely measured on self-reports of depression, marital satisfaction etc.). All papers related their aims to previous research, although the justification for the use of specific coding systems is less apparent. An American sample was used in all studies, except one. Overall, there was good, consistent reporting of reliability assessment.

### **Marital Interaction Coding System (MICS)**

#### Description

The MICS (Hops et al., 1972) was developed to provide descriptions of marital interaction in the context of social learning theory, which postulates that marital distress arises from negative interaction (Filsinger, 1983). Since its conception, there have been a further three refined versions of the MICS (the most recent being the MICS-IV). Couples typically have a 10-15 minute discussion on a topic of disagreement (Heyman, Weiss, & Eddy, 1995b). The MICS-IV comprises 37 codes<sup>1</sup>. *Put down* is described as “a comment intended to hurt, demean or embarrass the spouse” (Heyman et al., 1995b, p.740). Each spouse’s verbal or non-verbal behaviour is considered a ‘turn’ and assigned a code.

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<sup>1</sup> Agree, approve, accept responsibility, assent, attend, command, comply, criticise, compromise, show dysphoric affect, disengage, disagree, disapprove, deny responsibility, excuse other, excuse, humour, interrupt, mindread, mindread positive, noncompliance, offer negative solution, not tracking, off topic, problem external, problem internal, positive physical contact, paraphrase, positive solution, put down, question, smile, laugh, talk, turn off, threaten, and hostile tone of voice.

### Applications in chronic conditions

Gallagher-Thompson et al. (2001) videotaped 27 husbands with Alzheimer's disease (AD) and their wives interacting during mealtime and planning a future event; their behaviours were compared to 27 control-matched couples. They explored the relationship between interaction style and wives' depression, resilience, hope, and mutuality. Twenty MICS-IV codes were scarcely used; a factor analysis on the remaining 17 codes produced three categories: *supportive*, *facilitative*, and *rapport*. AD wives were less supportive, but more facilitative, and although they reported higher levels of depression, this was not correlated with any factors in interaction. Higher resilience in AD wives was associated with more facilitative interactions.

Jacob and Leonard (1992) compared sequential interactions between distressed marital couples, where the husband was an 'alcoholic' ( $n=49$ ) or 'depressed' ( $n=40$ ), and non-distressed couples ( $n=42$ ) on a discussion about an area in their lives they would like to change. They used an abbreviated version of the MICS which comprised 16 individual and "several combination" codes. The authors condensed these into *positive*, *negative*, and *problem-solving*; each sequence was assigned a code. Depressed husbands were more likely to respond positively to their wives' problem-solving behaviours than alcoholic or control husbands.

### Theory

Gallagher-Thompson et al. offered some insight into types of interactions that produce positive outcomes for care-giving spouses. They did not use 20 codes in their study, although they compensated for this by conducting a factor analysis on 17 codes. In contrast, full description or justification for the use of an abbreviated MICS is not provided by Jacob and

Leonard. The reclassification of codes into categories is subjective and, potentially, codes could be 'forced' into categories that do not reflect their original purpose. Infrequent use of some codes, and grouping of codes into categories, raises issues about the usefulness of the system with these populations.

### Validity

Neither study aimed to evaluate the validity of the MICS. However, Filsinger (1983) claimed that the MICS has demonstrated good construct validity and discriminative validity in the general population, distinguishing between distressed and non-distressed couples (distressed couples elicited more negative behaviours).

### Reliability

At least 20% of videotapes were coded by two raters in both papers. Jacob and Leonard assessed inter-rater agreement using point-by-point average agreement index for all 16 codes (72%) and for each of the three categories (71%). However, this method does not allow for chance agreement (Floyd & Rogers, 2004), therefore these results could be considered weak. Gallagher-Thompson et al. reported inter-rater reliability ranged between 0.70-0.83. Whilst these appear good, it is difficult to determine which codes these figures refer to or the statistical test used. These findings compare well with reliability figures with the general population (Heyman et al., 1995b).

### Generalizability

The MICS has been applied to a variety of chronic conditions, including Alzheimer's disease, alcohol abuse, and depression. Both studies use clearly defined, equally-matched groups, although the numbers are quite small. This might suggest that the MICS can be adapted for use with a range of chronic conditions.

## Utility

Neither paper explains the training process, although Heyman (2004) reports it is costly.

## Conclusion

The MICS was developed in close relation to theory. However, inconsistency in which codes have been re-classified, and lack of information concerning training, undermines the utility of the MICS with chronic condition populations, although it has potential be a reliable tool with a range of chronic conditions.

## **Rapid Marital Interaction Coding System (RMICS)**

### Description

The RMICS (Heyman, Eddy, Weiss, & Vivian, 1995a) was developed following a factor analysis of 1,086 distressed and non-distressed couples coded using the MICS-IV, with the purpose of providing researchers with a more practical coding system to code couple interactions within the general population. This yielded four factors: *hostility*, *problem discussion*, *humour*, and *responsibility discussion*. The first three became RMICS codes, whereas the fourth - an 'attribution construct' - was divided into *distress-maintaining* and *relationship-enhancing* attribution codes (Heyman, 2001). *Hostility* - statements conveying anger or irritation, extremely negative in content - was not sensitive enough to capture negative behaviour, so *psychological abuse* was created for this purpose (Heyman, 2004). Two codes from the MICS-IV were incorporated, post-factor analysis (*withdrawal*, *dysphoric affect*), to make the RMICS more exhaustive (Heyman et al., 1995b). Finally, two positive codes (*self-disclosure*, *acceptance*) from the KPI were added due to lack of positive codes from factor analysis. Couples discuss a topic of conflict for 10 minutes. Each speaker turn is



the unit of analysis. If a turn exceeds 30 seconds, then each 30-second interval is coded (Heyman, 2001).

#### Applications in chronic conditions

Manne et al. (2004) examined whether spousal responses to self-disclosure from 148 women with breast cancer related to levels of patient psychological distress and relationship satisfaction. They further investigated whether spousal responses differed between two discussion tasks (cancer-related and general), hypothesising that spouses would be more sensitive and supportive in the cancer-related discussion. Spouses engaged in more positive behaviours (e.g. *self-disclosure*, *humour*) and less *hostility* in the cancer-related discussion; these were associated with lower levels of patient psychological distress and higher relationship satisfaction.

#### Theory

Although the construction of the RMICS is well described, the non-theoretical factor analysis renders it difficult to determine whether these factors would be pertinent when applying the coding system to people with chronic conditions. Indeed, Manne et al. excluded two codes from analysis due to low base rates (*psychological abuse*, *withdrawal*). However, the RMICS has potential to be theoretically useful, as results indicate that more positive responses to patient self-disclosure are related to better outcomes for patients.

#### Validity

Manne et al. did not aim to evaluate validity of the RMICS, and they may have assumed it a valid measure for use with a cancer population. Previous studies have shown the RMICS has good concurrent, predictive, discriminative, and construct validity in the general population (Heyman, 2004; Heyman, Brown, Feldbau, & O'Leary, 1999).

### Reliability

Two coders rated 25% of the video-taped interactions. Cohen's kappa for the entire system during the cancer discussion was 0.71, and 0.88 for the general discussion. Kappa was also calculated for each code, and for each spouse; individual values ranged between 0.50-1.0. These findings are comparable with statistics from 17 studies using a general population (average overall kappa 0.59, range 0.55-0.82 on individual codes; Heyman, 2004). Heyman et al. (2001) reported good internal consistency, with Spearman-Brown split-half correlation coefficients above 0.90; however the use of this older measure of internal consistency renders these statistics less credible.

### Generalizability

This paper reported findings for women with different stages of breast cancer diagnoses. The large sample size might suggest that the RMICS is a reliable tool for women with breast cancer. Applications with other chronic conditions would determine whether these findings are generalizable.

### Utility

Manne et al. stated that raters received eight hours of training, and practised until an 80% level of agreement was achieved. This suggests that the RMICS is a practically useful tool.

### Conclusion

The RMICS has been shown to be a reliable and practical tool for measuring interactions between couples where the woman has breast cancer. Limitations include the inadequate theoretical development of the system and that Manne et al's findings are specific to one study and population group. Further research with a variety of chronic conditions may determine the generalizability of these findings.

## **Specific Affect Coding System (SPAFF)**

### Description

The SPAFF (Gottman et al., 1996) was designed to observe affect in interaction, considering concepts such as context, tone of voice, and facial movements (Shapiro & Gottman, 2004). It has mostly been applied to study emotional expression between couples discussing a topic of disagreement for 15 minutes. Shapiro and Gottman (2004) described the 20 codes, divided into *negative* (disgust, contempt, belligerence, high/low domineering, criticism, anger, tension, tense humour, defensiveness, whining, sadness, stonewalling), *positive* (interest, high/low validation, affection, humour, surprise/joy) and *neutral* (neither clearly positive nor negative). *Contempt* can be communicated by a stony facial expression or through the verbal use of mockery. The unit of analysis is each speaker turn.

### Applications in chronic conditions

Leong et al. (2011) assessed the extent to which affective behavioural interaction sequences and base rates related to self-reports of pain and marital adjustment. Seventy-eight adults with chronic pain and their spouses discussed a topic of disagreement. The authors rearranged 16 codes to assess *validation* (interest, affection, validation) and *invalidation* (disgust, contempt, belligerence, domineering, anger, defensiveness, stonewalling). Five codes did not meet definitions and were excluded. Each speaker turn was labelled validation or invalidation. Results suggested that base rates were not a predictor of pain behaviour or marital adjustment. However, male patients' invalidation response to their wives' invalidation resulted in higher reports of pain.

Johansen and Cano (2007) examined the extent to which affect, elicited in a topic of disagreement, related to depressive symptoms and pain severity in 79 couples, where one spouse had chronic pain. An abbreviated, four-factor version of the SPAFF previously used

by Johnson (2002) was applied. Codes comprised *anger/contempt*, *sadness*, *humour*, and *fear*. Expressions of sadness negatively correlated with depression in both spouses, although no affect codes related to pain severity in the spouse with pain.

### Theory

It is not clear why these papers chose the SPAFF as a measure to study interactions in a chronic pain population. Some codes were excluded from analysis, and others rearranged into categories to suit the study's aims; this questions the theoretical utility of the coding system, and may also reduce its validity. This limits the theoretical implications of the findings.

### Validity

Neither paper evaluated validity; they may have assumed it a valid measure for use with a chronic pain sample. Heyman (2001) explained that the SPAFF demonstrated excellent construct and discriminative validity in the general population.

### Reliability

Leong et al. assessed inter-rater reliability using 36% of couples. As rates of behaviour were low, kappa coefficients could not be conducted as they would be inaccurate. Therefore Yule's Y (Spitznagel & Helzer, 1985, cited in Leong et al.) assessed inter-rater agreement: 0.69 for invalidation, and 0.89 for validation, which were acceptable. Johansen and Cano assessed inter-rater reliability using 54% of videos. Kappa coefficients were moderate: contempt 0.58, anger 0.65<sup>2</sup>, sadness 0.60, humour 0.70. Fear was excluded from analysis due to poor kappa value (0.33). These results were poorer in comparison to original kappa values with the general population, which ranged 0.75-0.95 (Shapiro & Gottman, 2004), suggesting that the SPAFF may not be a reliable tool for chronic pain samples.

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<sup>2</sup> Johansen and Cano do not explain why they have separated the *anger/contempt* code for the purpose of reliability assessment.

### Generalizability

Both papers use an adequately sized, clearly defined chronic pain sample; whilst the results are promising for this population, these findings are not necessarily transferable to other chronic conditions.

### Utility

Both studies report raters received 2-3 months of training (each coder averaged 60 hours), and practised until adequate reliability was achieved (kappa 0.60). This seems time-consuming, and may suggest the SPAFF is too complex.

### Conclusions

Neither study used the SPAFF in its entirety; both abbreviated and re-organised codes without sufficient, theoretical justification. The SPAFF demonstrated moderate reliability in one study with a chronic pain sample. Studies evaluating its validity with a wider range of chronic conditions are needed.

## **Validation and Invalidation Behavioural Coding System (VIBCS)**

### Description

The VIBCS (Fruzzetti, 2001; cited in Cano, Barterian, & Heller, 2008) was developed to observe couples' interactions from an emotion regulation perspective. It utilises context, voice tone, and facial features. Codes are measured on a 7-point Likert scale. *Validation* (empathic and accepting responses promoting intimacy) ranges from 1 (*no validation*) to 7 (*only validation*), and *invalidation* (non-empathic and disrespectful responses that increase emotional distance) ranges from 1 (*no invalidation*) to 7 (*only invalidation*). The unit of analysis is each spouse's speech turn.

### Applications in chronic conditions

Cano et al. used the VIBCS to observe whether spousal validation and invalidation

related to reports of marital quality and satisfaction. Ninety-two people with chronic pain and their spouse discussed the impact of pain on their lives for 10 minutes. Observed validation was positively related to higher levels of marital satisfaction in both spouses and to perceived spousal support by the person with pain. Invalidation was negatively correlated with marital quality as reported by both spouses.

Issner, Cano, Leonard, and Williams (2012) observed 57 couples, where one spouse had chronic pain, having a 10-minute discussion about how pain affected their lives. They aimed to investigate whether spouse's perceived responses to their partner's pain behaviours were related to how empathic they were observed to be. Spouses demonstrating more empathic responses viewed themselves as solicitous or helpful. Conversely, spouses who were less satisfied in their marriage exhibited higher punishing and hostile responses.

### Theory

The original paper could not be located for the purpose of this review, therefore it is difficult to establish the VIBCS' theoretical development. The results from both studies may offer some theoretical link, in that validating responses may be associated with marital satisfaction.

### Validity

Neither study aimed to evaluate the validity of VIBCS. The original paper was not accessible so it was difficult to determine validity.

### Reliability

Both papers assess inter-rater agreement using the  $r_{wg}$  statistic, which "accounts for random measurement-error variance and systematic variance that reflects response bias" (Issner et al., p.170). Agreement was excellent in Cano et al's study for validation in persons with pain ( $mean=0.92$ ) and their spouses ( $mean=0.88$ ), and for invalidation in persons with

pain (*mean*=0.91) and their spouses (*mean*=0.88). Similar levels were achieved for spouses' validation (*mean*=0.85) and invalidation (*mean*=0.90) in Issner et al.'s study. Both studies deleted poor agreement scores ( $r_{wg} < 0.60$ ) from analysis. They do not report what these referred to, or the values, indicating that agreement scores are biased. As the original paper was not accessible, reliability statistics for the development of the coding system are unknown.

### Generalizability

Both studies utilised an adequately sized, clearly defined sample. Reliability statistics are excellent, although it would be useful to determine whether these positive findings are generalizable to other chronic conditions.

### Utility

Coder training in both studies seemed comprehensive, with a five-week training programme followed by coding practise until a good level of agreement was achieved. However the exact duration is unclear, so practical utility cannot be adequately assessed.

### Conclusion

Cano et al. assert that the VIBCS was not developed for use with couples with chronic pain. However, both papers provide promising results in terms of reliability. Studies applying the VIBCS with a broader sample of chronic conditions, with the aim of evaluating validity, would inform whether it is a useful tool for spousal interactions in this context. Information regarding its theoretical development, and justification for its use, would strengthen its potential.

## **Living in Family Environments (LIFE)**

### Description

The LIFE (Hops et al., 1990; cited in Romano et al., 1991) was adapted from other

coding systems and developed to study problem-solving interactions between depressed women and their spouses (Romano et al., 1991). There are 22 verbal and eight non-verbal codes, and the unit of analysis can be both the frequency and sequence of behaviours (Romano et al., 2009).

### Applications in chronic conditions

Romano et al. (1991) presented the development and preliminary validation of an adapted version of the LIFE. This version collapsed the original codes into categories relating to the study's hypotheses, which were derived from theories of pain in existing literature and extensive pilot testing. Categories included *non-verbal pain*, *verbal pain*, *solicitous*, *facilitative*, *aggressive*, and *distressed*. Fifty people with chronic pain and their spouses, and 33 control couples completed routine household activities. Verbal and non-verbal pain behaviours, and spouse solicitous behaviour, were higher in pain groups.

Romano et al. (2009) observed 37 individuals with chronic fatigue syndrome (CFS) and a relative (31 of whom were spouses) completing seven household activities. They examined associations between relative responses and well-being of the person with CFS. The LIFE was adapted to incorporate codes of CFS *illness/pain* behaviours, and relatives' *solicitous*, *facilitative*, and *aversive* behavioural responses. They found associations between solicitous relative behaviours and illness/pain behaviours, and aversive behaviours and higher levels of reported depression in CFS.

*Solicitous* referred to "statements inquiring about or exhibiting concern for the other's physical condition or comfort; offers of assistance; behaviour discouraging the other from activity; physical assistance or taking over a task" (Romano et al., 1991, p.556).

### Theory

As the original paper cannot be accessed, the full description of codes, and theoretical



development of the coding system, is unknown. Both papers described each code in good detail. However, it is unclear how the original 30 codes were collapsed into categories.

Romano et al. (1991) provides excellent theoretical justification for the reclassification of codes, whereas Romano et al. (2009) lacks this detail, which undermines the explanatory value of research findings using the LIFE.

### Validity

Discriminative validity was evidenced in Romano et al. (1991); rates of verbal and non-verbal pain behaviours were higher for people with chronic pain than their spouses. Strong, significant correlations were found between non-verbal pain behaviour and scores on patient self-report measures of pain severity, supporting good concurrent validity. Romano et al. (2009) did not evaluate validity.

### Reliability

Both studies calculated inter-rater agreement using 20% videos coded by two raters. Romano et al. (1991) reported moderate kappa values (non-verbal pain 0.59, verbal pain 0.66, solicitous 0.58, facilitative 0.61, aggressive 0.57, and distressed 0.53). Romano et al. (2009) reported good kappas for illness/pain (0.73), and affect codes (0.80; although a mean value is reported, making it difficult to determine reliability for each sub-construct).

### Generalizability

Initial findings might imply that the LIFE is a useful tool for different chronic conditions, although the original system was adapted to suit research aims. Romano et al's (2009) study included relatives other than spouses. Whilst this is not inherently a problem, it would have been useful to have results separated according to relative status to ascertain whether responses differed according to family member.

## Utility

Little information was provided about training, although both papers stated a kappa of 0.60 needed to be achieved over a two-week period.

## Conclusion

An adapted version of the LIFE seems a reliable tool with a CFS population, although this is undermined due to inadequate theoretical basis for reclassification. Evidence for validity is promising, although research utilising larger samples with a variety of chronic conditions is needed to determine whether Romano et al's (1991) results are generalizable. However, adaptation of the LIFE for these populations raises the issue of its usefulness with chronic conditions.

## **Communication Skills Test (CST)**

### Description

The CST (Floyd & Markman, 1984) was designed to assess relationship conflict discussions between spouses on a macroanalytical level. It was developed on the knowledge that existing research had collapsed fine-grained codes into broader positive and negative codes. There are 40 specific verbal and non-verbal codes (derived from existing coding systems), which are condensed into five broad categories: 1=*very negative* (e.g. blaming), 2=*negative* (e.g. negative non-verbal), 3=*neutral* (e.g. informative communication), 4=*positive* (e.g. empathy), and 5=*very positive* (e.g. solution proposal). *Solution proposal* is defined as the spouse suggesting a reasonable solution at an appropriate time (Floyd, 2004). The unit of analysis is an entire speech turn produced by each spouse; each turn is assigned a categorical rating.

### Applications in chronic conditions

Cranford et al. (2011) utilised the CST as part of a larger, on-going longitudinal study

comparing communication and problem-solving behaviours in couples ( $n=105$ ) with or without a lifetime alcohol use disorder (AUD). Couples had a 10-minute discussion about a marital problem and how they would work to resolve it. Wives were found to respond less positively to their husbands with AUD. Conversely, wives' AUD had negative impact on their own and their husband's marital satisfaction over time.

### Theory

The CST's theoretical foundations lie in research and clinical practice concerning communication for good relationship functioning, including effective problem-solving, empathic and warm responses, and non-verbal behaviours such as tone of voice (Floyd & Rogers, 2004). Cranford et al. do not present a comprehensive description of the codes or how they relate to alcohol behaviours. Furthermore, the neutral code was not included in analysis, questioning the purpose of its inclusion in the coding system.

### Validity

Cranford et al. did not aim to test the validity of the CST. Floyd and Markman provide initial evidence for the CST's concurrent validity (correlation between mean CST scores and a spouse's self-report of the impact of their communication on the other).

### Reliability

No reliability data is reported by Cranford et al. Floyd and Markman report good inter-rater agreement (kappa range 0.71-0.95,  $mean=0.82$ ).

### Generalizability

Despite the large sample size, lack of psychometric data provided by Cranford et al. restricts the conclusions that can be drawn about its usefulness with an AUD population. This also affects the ability to determine whether the CST would be a useful measure for a wider range of chronic conditions.

## Utility

Detail of training is not provided so the practicality of the coding system cannot be determined.

## Conclusion

Lack of psychometric data makes it difficult to determine whether the CST is a rigorous tool for investigating interactions in couples with or without AUD. However, its theoretical foundations are strong; future studies applying the CST for studying spousal interactions in chronic conditions need to make connections between their hypotheses and the CST more explicit.

## **Kategoriensystem für Partnerschaftliche Interaktion (KPI)**

### Description

The KPI (Hahlweg et al., 1984) is a microanalytical coding system that aims to capture and describe verbal and non-verbal behaviours elicited by couples when discussing a relationship problem (Hahlweg, 2004). It has been largely used in behavioural marital therapy and can discriminate between distressed and non-distressed married couples, supporting discriminative validity (Hahlweg, 2004).

The KPI comprises 26 verbal codes<sup>3</sup>, grouped into 12 categories, further grouped into three broader categories: *positive* (self-disclosure, positive solution, acceptance of the other, agreement); *neutral* (problem description, meta-communication, rest category, listening); *negative* (criticise, negative solution, justification, disagreement). Each unit of speech is

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<sup>3</sup> Self-disclosure (expression of feelings, expression of wishes and needs, expression of attitudes and behaviour); positive solution (specific constructive proposal, compromise suggestions); acceptance of the other (paraphrase, open question, positive feedback, understanding for the other, direct agreement); agreement (acceptance of responsibility, assent); problem description (neutral description of the problem, neutral questions), meta-communication (clarifying requests, related to topic), rest category, listening, criticise (devaluation of partner, specific), negative solution (destructive solution, demand for omission), justification (excuse of own behaviours, denying own responsibility), disagreement (direct disagreement, yes-but, short disagreement, blocking off) (described by Hahlweg, 2004)

assigned a verbal code, and is accompanied by a *positive* or *negative* non-verbal code (Hahlweg, 2004).

#### Applications in chronic conditions

Van den Broucke et al. (1995) used the KPI to assess neutral and conflict interactions between three groups: couples where the woman had an eating disorder ( $n=21$ ), and two control-matched groups of distressed ( $n=21$ ) and non-distressed married couples ( $n=21$ ). Rates of negative communication elicited by eating-disordered women were comparable to those elicited from both control groups, suggesting that a chronic condition is not a predictor for negative or ineffective communication.

Chambless et al. (2002) explored whether husbands of women who had a diagnosis of panic disorder with agoraphobia ( $n=22$ ) provided less emotional support during a 10-minute discussion of a relationship problem than control husbands ( $n=21$ ). Types of support included acceptance, empathy, and problem-solving solutions. The KPI seemed an appropriate tool because it covers these concepts. Husbands of agoraphobic women were more critical, less supportive and empathic, and generated fewer solutions.

#### Theory

The KPI was developed considering behavioural marital theories of communication (Chambless et al.), and was supplemented by codes from other established coding systems. Chambless et al. only used five verbal codes for analysis, and no justification is given for the exclusion of the remaining seven. However, adequate justification is provided for the use of the KPI, in that it includes relevant theoretical constructs. In contrast, it can be argued that the KPI was an inadequate measure for Van den Broucke et al.'s study, considering the lack of support for their hypotheses.

### Validity

Neither study aimed to evaluate validity. The KPI has been found to have good discriminative validity between distressed and non-distressed married couples during behavioural marital therapy (Hahlweg, 2004), and in studies between families of schizophrenic and depressed people (as reported by Chambless et al.).

### Reliability

Chambless et al. used intraclass correlation coefficients (Shrout & Fleiss, 1979) to assess inter-rater reliability for 25% of couples. They reported good levels of agreement for positive (0.81) and negative verbal codes (0.92), and positive (0.81) and negative non-verbal codes (0.89). Van den Broucke et al. used kappas to measure inter-rater reliability for verbal (0.83), and non-verbal codes (0.80). Intra-rater reliability (across the two discussion tasks) for verbal and non-verbal codes was 0.86 and 0.85 respectively. These findings are comparable to reliability statistics in the general population: Cronbach's alpha values ranging 0.85-0.99 for verbal and 0.52-0.89 for non-verbal codes, and Cohen's kappas ranging 0.70-0.98 (Hahlweg, 2004).

### Generalizability

Both studies used small samples, which undermines representativeness of these populations. However, different samples of chronic conditions were used which, in the context of good reliability statistics, may provide support for the generalizability of the KPI.

### Utility

Neither study provided details of training so practical utility cannot be assessed.

### Conclusion

The KPI has been shown to be a reliable observational tool in chronic mental health samples, although studies evaluating validity are warranted. Whilst results are promising, the

KPI needs to be applied to a wider range of chronic conditions, perhaps those with physical disability.

### **Interactional Dimensions Coding System (IDCS)**

#### Description

The IDCS (Julien et al., 1989) was created to provide an efficient, macroanalytical way of coding, and assessing the quality of an entire interaction between couples discussing a problem. Kline et al. (2004) described 14 codes, each with its own theoretical justification for inclusion. Nine individual codes are divided into positive (*communication skills, problem-solving skills, support/validation, positive affect*) and negative behaviours (*conflict, withdrawal, dominance, denial, negative affect*), and five dyadic codes include *negative escalation, positive escalation, commitment, future satisfaction* and *future stability*.

Coders break the entire interaction into three parts<sup>4</sup>, rating each of the nine individual codes within each segment on a nine-point scale: 1 (*very low*) to 5 (*moderate*) to 9 (*very high*). Each partner is then assigned an overall rating for each individual code. Finally, using the entire interaction as the coding unit, the couple is given a rating on each of the five dyadic codes using the same nine-point scale.

#### Applications in chronic conditions

Perusse et al. (2012) used the French version of the IDCS (Julien, Chartrand, Markman, & Lindahl, 1991; cited in Perusse et al.) to study spousal communication in a 20-minute conflict-resolution task. The sample comprised 75 couples, where one spouse had a diagnosis of alexithymia<sup>5</sup>. To evaluate the quality of problem-solving behaviour between couples, they focused on four communication behaviours: *hostility, withdrawal,*

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<sup>4</sup> Kline et al. explains that this is done to ease the reliability calculations for each code, because it provides a shorter time frame for raters to consider each of the codes and assign the most appropriate rating.

<sup>5</sup> Perusse et al. (2012) define alexithymia as a deficiency in identifying feelings, and describing them to other people. Individuals with a high level of alexithymia tend to develop dysfunctional ways to regulate their emotions (e.g. avoidance, hostility), and ignore the impact of their actions on others (e.g. lack of empathy)

*communication skills that focus on expression, and support and validation in regards to positive listening.* Men with alexithymia elicited more hostile behaviours than women, and their partners were more likely to show hostility, withdrawal, and lower communication skills.

### Theory

The IDCS was developed considering theories that family distress is related to negative communication patterns (Kline et al.). Perusse et al. provide clear descriptions of the codes used. However, it is not clear how, or why, these codes were categorised in this way as no theoretical framework was provided.

### Validity

Perusse et al. reported that the French version of the IDCS was validated by Julien et al. (1991), although this is not detailed. Kline et al. stated that the IDCS has good concurrent validity, assessed by correlating results with self-report measures, and good predictive validity for two dyadic codes (*negative escalation, positive escalation*) in that they both predicted marital satisfaction over time.

### Reliability

Perusse et al. explained that intraclass correlation coefficients for inter-rater reliability were assessed using 25 interactions. Coefficients ranged between 0.83-0.94, although specific coefficients are not reported for specific codes. Despite this limitation, this compares favourably with intraclass correlation coefficients in the general population, which ranged 0.20-0.89 for individual codes, and 0.60-0.89 for dyadic codes (Chartrand & Julien, 1994).

### Generalizability

As the study uses a French population and version of the coding system, it is questionable whether the same results would be achieved with a UK population.



Generalizability is impeded by the use of one chronic condition, although it would appear the IDCS is a reliable tool for this population.

### Utility

Perusse et al. ensured good reliability was achieved by training coders for 60 hours, and instructing them to practise coding until they achieved an inter-rater agreement of 0.80. Whilst robust, this is a long training procedure, questioning the practical utility of the IDCS.

### Conclusion

The IDCS was constructed on a sound theoretical base; however, its application to a sample of people with alexithymia lacks theoretical justification. No studies beyond Perusse et al. have used the IDCS with a chronic condition population, so it is difficult to determine its usefulness. Further studies evaluating validity of the IDCS with different chronic conditions would be useful.

## **Observational Coding System for Emotional Overinvolvement**

### Description and Theory

This observational coding system was developed by Fredman et al. (2004), who also aimed to provide initial support for construct validity. The theoretical underpinning is that emotional overinvolvement (EOI) - defined as intrusive behaviour, excessive self-sacrificing, and exaggerated emotional responses – is higher in relatives of people with chronic mental health conditions than the general population (Leff & Vaughn, 1985; cited in Fredman et al.). Fredman et al. provide the following definitions: *intrusiveness* refers to “the relative’s attempt to exert psychological or physiological control over the patient’s well-being”; *excessive self-sacrificing* refers to “relatives’ consistently and unreasonably placing the patient’s needs ahead of their own”; and *exaggerated emotional response* refers to “excessive anxiety directly

related to the patient's welfare or overidentification with the patient." These three constructs are coded on a 5-point Likert scale (1=*absent*, 5=*extreme*).

#### Applications in chronic conditions

Fifty-five people with obsessive-compulsive disorder (OCD) and 40 with panic disorder with agoraphobia (PDA) discussed a topic of disagreement with a relative (71% spouses) for 10 minutes. Fredman et al. hypothesised that the codes would demonstrate good concurrent validity with EOI scores and good discriminative validity with criticism scores on other measures. The results were consistent with the study's hypotheses, supporting construct validity.

#### Validity

Content validity was assessed by constructing a list of hypothetical EOI behaviours that might be exhibited by relatives during interaction and incorporating these into the three behavioural descriptions. EOI and criticism scores from the Camberwell Family Interview (Vaughn & Leff, 1976; cited in Fredman et al.) were used to evaluate concurrent and discriminant validity, respectively. The KPI's criticism score was also used to test discriminant validity. Three factors from the Relative's Reactions Questionnaire (Steketee, 1987, cited in Fredman et al.) – facilitation, guilt, responsibility – were additional measures of concurrent validity. Finally, construct validity was assessed by averaging each rater's scores for each of the three codes across all videos.

#### Reliability

Two raters coded each video. Inter-rater reliability was assessed using Spearman-Brown correction (Shout & Fleiss, 1979). Reliability was reported to be excellent (intrusiveness 0.92, excessive self-sacrifice 0.91, exaggerated emotional response 0.73).

### Generalizability

To date, no other studies have used this coding system. Considering the promising psychometric data, more research applying this coding system with a wider range of chronic mental health conditions is needed to strengthen these findings.

### Utility

Coders received 35 hours of training, and a reliability value of 0.75 needed to be achieved in a pilot sample before proceeding to the clinical sample.

### Conclusion

Fredman et al. provide a thorough evaluation of a new observational coding system for EOI. There is good theoretical basis, and reliability and validity assessments have been conducted to a good degree. This coding system has yet to be used by other researchers, although the lengthy training process may be a deterrent at this early stage.

## **Synthesis of Findings**

This review has summarised and evaluated a range of observational coding systems that have been used to study marital interaction in the context of chronic physical and mental health conditions.

Most studies included in this review asked couples to discuss a topic of conflict, with the broad aim of better understanding the impact of positive and negative interactions on well-being; the exceptions were Gallagher-Thompson et al. (2001), Romano et al. (1991) and Romano et al. (2009) who asked couples to complete everyday activities. Considering that the coding systems included in the review have typically been developed to assess conflict resolution between distressed and non-distressed couples, it is understandable that most papers reviewed have chosen these tasks.

Whilst most coding systems were described reasonably well, there is inadequate

theoretical justification for the modification of some coding systems, namely the MICS, SPAFF, LIFE, and IDCS, to meet the study's aims. This not only brings into question validity, but also the usefulness of such coding systems with chronic conditions.

There is a need for more rigorous reliability and, particularly, validity testing when applying coding systems to these populations. With the exception of Cranford et al. (2011), there is good reporting of reliability data by the papers included in this review. Whilst a variety of statistical analyses were used for this purpose, Cohen's kappa was preferred. Furthermore, at least two raters were utilised for every coding system to assess inter-rater reliability, on at least 20% of videotapes. This is necessary when investigating complexities of spouse interactions (Baucom & Kerig, 2004). Lack of validity data presented and/or verified in these studies is highly concerning. Some authors assume that ways of interacting in the general population also apply to chronic conditions. Romano et al. (1991) and Fredman et al. (2004) aimed to validate coding systems when applied to chronic conditions, with some success, although this needs expanding.

As Heyman (2001) highlighted, observational coding systems are time- and labour-intensive. Most papers commented on the amount of training required, and some specified a kappa coefficient to be achieved before proceeding to the clinical data. The SPAFF and IDCS require the longest training, which reduces their practical utility. A broad range of chronic physical and mental health populations were studied. Whilst this suggests that coding systems included in this review are potentially useful research tools for these populations, more research is needed to strengthen this argument.

Common themes may be drawn from the coding systems in terms of the types of behaviours coded. Broadly speaking, positive behaviours such as empathy and facilitativeness, and negative behaviours such as hostility and intrusiveness, are part of many

coding systems. However, some papers (e.g. Gallagher-Thompson et al., 2001) identified commonalities as a drawback of specific coding systems, suggesting that they are not tailored to certain populations.

### **Discussion and Recommendations**

This review has highlighted a need for researchers to provide good psychometric data when describing observational coding systems, and to be clearer about theoretical bases of codes used. This information will help determine whether a coding system is the most appropriate tool for specific populations.

A strength of this review is the attempt to bring together an overview of coding systems used with a broad range of chronic physical and mental health conditions, ranging from dementia (Gallagher-Thompson et al., 2001), cancer (Manne et al., 2004) to panic disorder with agoraphobia (Chambless et al., 2002; Fredman et al., 2004). However, this review illuminated a substantial gap in research literature. There is a paucity of studies utilising observational coding systems to investigate how couples interact in the context of chronic conditions. More research is needed, covering a broader range of chronic conditions, with the aim of studying interactions between spouses. This may illustrate the types of communications that are helpful and unhelpful, and which may impact upon well-being. The lack of research may be, as several authors have acknowledged (Gallagher-Thompson et al., 2001; Leong et al., 2011), due to a lack of tailored coding systems focusing on specific behaviours.

Using coding systems that have been developed in the general population to predominantly measure discussions about problems is acceptable if the focus of the study concerns problem discussions within a chronic condition population. However, as a significant proportion of care-giving provision to someone with a chronic condition concerns

physical assistance with activities of daily living (Levanthal et al., 2005), conflict resolution discussions may not be sensitive to other aspects of the relationship that are important when thinking about outcomes for both spouses. Research utilising and comparing interactions in a range of tasks would be insightful for this purpose. Observing couples completing an everyday task together may elicit other aspects of the interactions within this population that are important for understanding relationships, such as the way in which care and support is provided. Therefore, coding systems developed with the general population are not adequate for this purpose, and tailor-made systems that focus on these other aspects of relationships are required.

Informal carers have long been relied upon by health care systems to provide support to their relatives with chronic conditions, although care-giving may be stressful and burdensome for many (Poulin et al., 2010). Therefore there is a need to better understand the kinds of behaviours and interactions that protect these carers' well-being in the long-term, in order for them to provide the best care to their spouse with a chronic condition.

In summary, existing coding systems are fairly reliable tools for observing spousal interactions in the context of chronic conditions. Rather than adapting existing coding systems, it would appear that a more reliable and valid way of observing this population is to develop coding systems with a well-described theoretical base, and that specifically focus on behaviours that are helpful and unhelpful in sustaining good relationships.

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Older couples' management of multiple-chronic illnesses: Individual and shared perceptions and coping in type 2 diabetes and osteoarthritis. *Families, Systems & Health*, 28(1), 30-47. doi:10.1037/a0019396

**CHAPTER TWO:**

**DEVELOPMENT AND PSYCHOMETRIC  
EVALUATION OF AN OBSERVATIONAL CODING  
SYSTEM MEASURING PERSON-CENTRED CARE IN  
SPOUSES OF PEOPLE WITH DEMENTIA**

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May 2013

## Abstract

The notion of person-centred care has been important in investigating relationships between people with dementia and paid carers, and measures are available to assess this. It has been suggested that person-centred care may be a useful idea to apply to family-care relationships. Family members who perceive continuity in their relationship with a person with dementia may be more likely to adopt a person-centred approach to the care they provide. However, no measures of person-centred care in the context of family relationships exist. The aim of the present study was to develop an observational measure of person-centred care for this purpose. Eleven couples, where one spouse had a diagnosis of dementia, were video-taped performing an everyday task together. The care-giving spouse completed a measure of perceived continuity in the relationship. The video data were then coded using the newly developed coding system. Examples included a code relating to whether the care-giving spouse involved the person with dementia in planning the task, and a code relating to how the spouse responded to confusion or distress. The coding system was found to be a reliable observational tool (Cohen's kappa coefficients 0.652 for whether a behaviour should be coded, 0.796 for whether a behaviour was person-centred), although the small sample size limited the results. The hypothesis, that spouses scoring high on relationship continuity would relate using a more person-centred approach, was not supported. Further limitations and recommendations for future research are presented.

*Keywords:* dementia, spouses, observation, coding system, relationship continuity, person-centred care



## **Introduction**

The National Institute for Health and Clinical Excellence (NICE; 2007) defines dementia as “a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function” (p.4). There are many challenges associated with dementia. Alzheimer’s disease, for example, causes progressive loss of cognitive and social functioning, which impacts upon the individual’s ability to complete activities of daily living (Small, Gutman, & Hilhouse, 2003). As the disease progresses, familial carers become relied upon to provide emotional support, reassurance and help with activities of daily living, such as bathing and dressing (Alzheimer’s Society, 2012).

The Alzheimer’s Society (2012) defines a carer as “someone who gives a substantial amount of unpaid care and support regularly to a relative, partner or friend” (p.2). It is estimated that there are six million unpaid carers in the United Kingdom (Office for National Statistics, 2012), with two million of these over the age of 65 (The Carer’s Trust, 2012). The Alzheimer’s Society (2012) reported that there are an estimated 670,000 people caring for someone with a diagnosis of dementia, the majority of whom are spouses (Schulz & Martire, 2004). The prevalence of dementia is set to increase; the Department of Health (2009) predicts that the number of people in the UK with dementia in 2031 will be 1.4 million, and the cost of care will be over £50 billion. Services may be insufficient to meet the increased need. It is therefore increasingly important to support the delivery of care to people with dementia particularly within the home environment.

### **Burden of Care**

Research has shown that paid and unpaid carers of people with dementia describe greater stress, burden and distress than carers of other older people (Moise, Schwarzinger, & Um, 2004), particularly spousal carers (Alzheimer’s Society, 2012; Murray & Livingston,

1998). Many spouses report communication impairments as highly challenging and stressful (Chesla, Martinson, & Muwaswes, 1994). Caring for a spouse with dementia is also accompanied by emotional impact (e.g. resulting from witnessing deterioration of a loved one), and restriction of social activities (Vitaliano, Zhang, & Scanlan, 2003). Stress within the marital relationship can lead to carer burnout, which may result in the person with dementia going into residential care (Kaplan, 2001).

### **Positive Factors**

Whilst negative aspects of care-giving have been widely researched, there has been a recent shift to examine factors that drive carers to continue caring for their spouse with dementia. Improvements in communication have been found to reduce stress within the relationship (Clare & Shakespeare, 2004). Other findings suggest that carers adopt a positive approach to the care-giving role if they see it as meaningful and rewarding (Blieszner & Shifflett, 1990). Chesla et al. (1994) found that reciprocity in the relationship helped carers perceive the caring experience as loving and rewarding, rather than a burden. Siriopoulos, Brown, and Wright's (1999) findings suggested that relationship quality prior to the onset of dementia contributed to carers' positive experiences of caring. Murray and Livingston (1998) found that carers' ability to adjust to the care-giving role was influenced by the quality of the relationship prior to the onset of their relatives' illness, and their perceived continuity of this relationship. These findings have encouraged researchers to further explore the impact of relationship quality and perceptions of relationship continuity upon the nature and quality of care spouses provide.

### **Person-Centred Care**

The notion of person-centred care has been important when investigating relationships between people with dementia and paid carers. A person-centred approach to dementia care

has been strongly advocated to improve outcomes for people with dementia within a professional, care service context (Brooker, 2007), and is set as a good care standard in the National Dementia Strategy (Department of Health, 2009). Tom Kitwood's (1990) seminal work examining person-centred care in care services concluded that well-being was associated with human interactions that enhance or retain a person's sense of identity and abilities. Measures have been created to assess person-centred care within a care service context (e.g. PIECE-dem; Brooker, La Fontaine, De Vries, Porter, & Surr, 2011).

Person-centred care is a multifaceted concept, some of which are described as follows. One of the central components of person-centred care is the idea of enhancing the person with dementia's sense of agency. This refers to enabling a person to carry out activities, making a meaningful contribution, and allowing them to make choices and decisions (Brooker, 2007). Empathy is another component of person-centred care; being able to see the person with dementia's point of view, and valuing their opinion or contribution. Brooker (2007) further advocated the provision of individualised care that accommodates the person's wishes.

Research into person-centred care has predominantly focused on care service settings. However, as Schulz and Martire (2004) suggested, most care is delivered to people with dementia at home by spouses. Therefore, it seems necessary to explore how person-centred care is delivered by spouses in this setting.

### **Person-Centred Care in the Family Context**

It has been suggested that spouses who perceive continuity in their relationship with their partner with dementia are more likely to be person-centred in the care they provide (Chesla et al., 1994). Relationship continuity refers to whether a spouse perceives their relationship as a continuation of a valued relationship that they had with their spouse prior to dementia; conversely, discontinuity refers to whether a spouse perceives a changed or

different relationship, which is associated with a loss of the sense of continued identity of the person with dementia (Riley et al., 2013). This means that the spouse no longer sees the person with dementia as the same person and, to some extent, has lost the sense of them as an individual. Instead, their identity may be reconstructed in more generic terms using the spouse's understanding of dementia. The failure to appreciate the individuality of the person is at the heart of the notion of non-person-centred care (Riley et al., 2013). Couples who have a greater sense of relationship continuity are more likely to work through difficult times together (Clare & Shakespeare, 2004). Furthermore, Hellström, Nolan, and Lundh (2007) found that both spouses contributed to sustaining their positive relationship by expressing reciprocity, affection and appreciation.

Relationship continuity has been linked to differences in the general quality of care provided by the spouse, and in the quality of the relationship between the couple. Walters, Oyebode, and Riley (2010) suggested that continuity may be associated with a more empathic and person-centred approach to care. O'Shaughnessy, Lee, and Lintern (2010) implied that a good sense of relationship continuity can help carers empathise with their spouse, and they are more willing to adapt their roles to meet their spouse's needs. Both Lewis (1998) and Walters et al. (2010) noted that carers who perceived discontinuity were more likely to refer to their spouse in objectifying and depersonalised terms, and suggested they were more likely to be controlling and restrictive in their approach to care. Chesla et al. (1994) implied that the provision of care by spouse carers who perceived discontinuity was generally less tailored to the needs of the individual, thus less person-centred.

In light of the above, an association may exist between relationship continuity and person-centred care. Spousal carers may feel more able to deliver a person-centred approach to care when they perceive continuity in their relationship. This may be because they still feel

emotionally close to their spouse with dementia and see them, and their relationship, as unchanged. Person-centred care might be demonstrated by carers seeking the person with dementia's opinion, empathising with them, and inviting them to contribute to an activity. In contrast, spousal carers who perceive discontinuity of their relationship may find it difficult to relate to their spouse, or they may perceive their spouse in terms of the 'dementia' rather than 'my loved one who has a diagnosis of dementia' (Chesla et al., 1994; Riley et al., 2013). When considering how discontinuity might translate into person-centred care, care-giving spouses may show more frustration, for example, snapping at their spouse, or taking control in an activity. They may also lack empathy, say if the person with dementia appears confused, blaming the person rather than the cognitive impairments associated with dementia.

### **Quantitative Tools**

Through the use of qualitative studies, we have a good sense of how couples perceive their everyday interactions. However, Small et al. (2003) found that carers perceived themselves using simpler language when communicating with their spouse with dementia in everyday tasks, but observations of their interactions showed that they overestimated their use. Therefore, it would be useful to have quantitative measures of these interactions that could support qualitative findings.

Riley et al. (2013) developed a valid and reliable tool to quantitatively measure relationship continuity. The Birmingham Relationship Continuity Measure (BRCM) is completed by care-giving partners of people with dementia, and measures how continuous they view their relationship to be. However, no quantitative measure of person-centred care in the context of family relationships exists. Such a tool could be used, amongst other measures, in future studies to determine whether a relationship exists between relationship continuity (as measured on the BRCM) and how couples interact.

## **Aims of the Current Study**

The aim of the present study was to develop and evaluate the psychometric properties of a quantitative observational measure that could be used to measure person-centred care in domestic settings whilst couples completed an everyday task together. Three major steps were followed to achieve this aim. The first step involved constructing a coding system which incorporated a range of behaviours that could be considered person-centred or non-person-centred. The second step involved recruiting and video-taping couples carrying out an everyday task together. The coding system was then applied to the behaviours of the care-giving spouse, labelling examples of behaviour person-centred or non-person-centred. The final step involved assessing the reliability of the coding system.

A secondary aim was to collect some pilot data to test the hypothesis that person-centred care (as measured by the coding system) and relationship continuity (as reported on the BRCM) are linked. Considering existing literature, we would anticipate that spousal carers using a more empathic and person-centred approach would report a greater sense of relationship continuity.

## **Method**

### **Ethics**

Ethical approval for the study was obtained from an NHS Research Ethics Committee in April 2012 (see Appendix B for the approval letter).

### **Participants and Recruitment**

Participants were initially sought through Occupational Therapists (OTs) in inpatient and community mental health services for older people within an NHS Trust serving a large urban area as it was felt that they would be in a good position to identify couples who met the inclusion criteria. They were asked to identify potentially suitable couples from their caseload

and, at their next routine appointment, to give these couples the information sheet and the consent form (Appendix C).

The initial aim was to recruit at least 10 couples to address the aim of developing the coding system, and at least 26 couples to address the second aim of establishing whether there was a link between person-centred care and perceived relationship continuity. According to G\*POWER (Erdfelder, Faul, & Buchner, 1996), a sample size of 26 was required to achieve the desired statistical power of 0.80 for detecting a large correlation coefficient ( $r = 0.5$ ), with the alpha set at 0.05 (two-tailed).

There were considerable difficulties with recruitment throughout the duration of the study; this was particularly noticeable during the first few months of recruitment. It was believed that this may have been due to staff not being aware of the study, or not having the time to approach couples on their caseload in addition to their regular duties. Moreover, it was thought that the initial inclusion criteria were too restrictive. Due to recruitment difficulties, an amendment was submitted to the ethics committee to relax the inclusion criteria to include, for example, couples who had been together two years or more rather than the original time of 10 years (Table 7). Furthermore, information about this study was presented to *all* staff working within dementia care teams in the local NHS Trust. This was done face-to-face, where possible, to build relationships between staff and the primary researcher, provide staff with information about the study, and give them the opportunity to ask questions. Fortnightly emails were sent to staff as a reminder, and to inform them of progress, and informative posters were pinned in waiting areas within the Trust's older people's services. The researcher also attended support groups organised by voluntary and charitable agencies to promote the study. Additionally, couples who had participated in previous research conducted by a national voluntary agency were emailed and asked if they would like to participate.

**Table 7.** Inclusion and exclusion criteria for participants.

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
One person must have a diagnosis of dementia.	Other impairments are present and require a significant amount of care. This hoped to ensure that dementia was the primary concern, so other aspects did not impact upon the way couples interact.
The person with dementia and their spouse must have the capacity to understand and consent to the study.	Non-English speaking participants, as recruiting participants who require a translator could mean that some verbal data would be lost in translation.
The person with dementia is being cared for by their spouse.	
The couple have been together for at least two years and are currently living together. Recruiting couples who live together would hopefully make the study's task as routine and familiar as possible.	
No age restrictions imposed on either spouse.	

Twenty-five couples were identified and agreed for their information to be passed on to the research team. Twelve were eligible and consented to take part. Of the 13 who did not take part, six were not eligible because the person with dementia lacked capacity to consent or they were not living at home, three did not have the time, three withdrew their interest upon hearing more information, and one believed it to be another study.

Eight Caucasian couples were recruited through the local NHS trust, and four from charitable organisations. Of the people with dementia, eight were men and four were women, with a mean age of 74 ( $SD = 10.90$ , range 52-87). With regards to dementia diagnosis, this was Alzheimer's disease ( $n = 6$ ), frontotemporal dementia ( $n = 2$ ), mixed dementia ( $n = 2$ ), vascular dementia ( $n = 1$ ), and dementia not otherwise specified ( $n = 1$ ). The average length of time since diagnosis was 47 months ( $SD = 29.39$ , range four months to eight years).



Spousal carers comprised eight women and four men, with a mean age of 72 ( $SD = 7.67$ , range 62-83). The average length of relationship was 46 years ( $SD = 14.56$ , range 16-64).

## Measures

**Observational Coding System.** The coding system measuring person-centred behaviours exhibited by the care-giving spouse was developed and refined over several stages.

Firstly, findings from existing literature investigating person-centred spousal care within dementia (Clare & Shakespeare, 2004; Hellström, Nolan, & Lundh, 2005, 2007; Perry & O'Connor, 2002; Phinney, 2006; Sanders & Power, 2009; Small et al., 2006; Vikström, Borell, Stigsdotter-Neely, & Josephsson, 2005; Vikström, Josephsson, Stigsdotter-Neely, & Nygard, 2008) were consulted to generate a list of person-centred behaviours that might be observed during everyday interaction.

Secondly, other observational measures that have been applied with people with dementia were consulted, including PIECE-dem (Brooker et al., 2011), which was developed to observe the levels of person-centred care delivered by residential care-home staff to people with dementia; and the Marital Interaction Coding System (Hops, Wills, Weiss, & Patterson, 1972; cited in Heyman, 2004) which was used by Gallagher-Thompson, Dal Canto, Jacob, and Thompson (2001) to assess spousal interactions during mealtime and future event-planning tasks, where one spouse had a diagnosis of Alzheimer's disease. As the latter coding system was developed using couples from the general population, and was not developed primarily to assess person-centred care, it was not a feasible measure to use for the current study.

During the search of literature utilising observational coding systems, it was apparent that a task whereby the couple discussed a topic of disagreement for 10-15 minutes was the

preferred task for observing dyadic interaction. The aim therefore was to develop a system for coding person-centred behaviours during an everyday task; this type of task was chosen because difficulties completing activities of daily living are common in dementia and reportedly a source of frustration for some spousal carers. Therefore, it was felt that co-operating on an everyday task would better elicit person-centred and non-person-centred behaviours. Using the sources from the literature above, preliminary thoughts on person-centred themes emerged. The spouse's behaviour could be considered person-centred if they involved their partner with dementia in making choices and decisions, discussed task completion, or enabled them to make meaningful contributions (Perry & O'Connor, 2002; Vikström et al., 2005). Conversely, if the spouse was focused on simply getting the task done - either by telling the person with dementia what to do or taking over and completing the task alone (Hellström et al., 2005; Vikström et al., 2008) – then this would be considered non-person-centred. Person-centred behaviours would also involve whether the spouse considers their partner with dementia's feelings (Hellström et al., 2005), or attempt to promote positive feelings by highlighting positive aspects of their partner's performance whilst avoiding being patronising (Perry & O'Connor, 2002). Similarly, it would be considered person-centred if the spouse avoided or minimised negative feelings by not highlighting inadequacies or failures in relation to task completion, and by avoiding negative criticism of task performance (Perry & O'Connor, 2002; Sanders & Power, 2009). If a spouse takes into account the cognitive impairments of their partner with dementia, then this too would be considered person-centred (Phinney, 2006; Small et al., 2003). This would include whether the spouse tries to manage situations in a way that maximises the chances of their partner with dementia making a successful contribution, thereby promoting a positive experience of the task (Clare & Shakespeare, 2004; Vikström, et al., 2005).

Thirdly, three couples within the general population were asked to complete an everyday task together. Their interactions were filmed, and an initial pilot coding system, based on the themes outlined above, was applied to analyse the videos. These pilot data were collected to refine the coding system.

Fourthly, the verbal and non-verbal content of the 11 couples' video-tapes was transcribed. Whilst holding a clear definition of person-centred care in mind, each transcript was read and spousal statements or behaviours were annotated with a description of how each related to person-centred care. Similar descriptions were grouped together to form a total of nine broad categories. A description of what each broad category entailed was created. These categories aimed to reflect aspects of behaviours that could be considered person-centred, such as involving the person with dementia in making decisions, and being empathic in response to confusion or distress. In order to counterbalance each category, the researcher thought of opposite behaviours that could be considered non-person-centred. Categories were therefore divided into 'person-centred' and 'non person-centred' codes, with clear examples of the types of behaviours that might be seen within each code. There were a total of 18 codes - nine person-centred, nine non-person-centred (Table 8). Instructions for the application of the coding system were created. The final coding system is shown in Appendix D.

**Birmingham Relationship Continuity Measure.** The BRCM (Riley et al., 2013; Appendix E) was constructed using relationship continuity domains reported by Walters et al. (2010). It comprises 23 items rated on a 5-point Likert scale, and covers five concepts: 'relationship redefined', 'same/different person', 'same/different feelings', 'couplehood', and 'loss'. Riley et al. (2013) reported that the BRCM had good concurrent validity, internal reliability (Cronbach's  $\alpha = 0.947$ ) and test-retest reliability (intraclass correlation coefficient = 0.932), with some evidence to support construct validity.

**Table 8.** Codes created from analysing video transcripts (the coding system).

<b>Category</b>	<b>Code</b>	<b>Description</b>	<b>Example</b>
Planning	Facilitating (PC)	The person with dementia (PWD) is asked to contribute to planning the task, and is given a choice of what they would like to do	“Would you like to do X or Y?”
	Controlling (Non-PC)	The spouse allocates tasks and does not give the PWD the opportunity to say no, or does not invite them to discuss the plan	“If you get X then I will get Y”
Contribution	Enabling (PC)	The spouse verbally or non-verbally supports the PWD to continue or re-engage with the task independently	“Well done, you carry on doing that”
	Controlling (Non-PC)	The spouse interrupts the PWD without offering prior assistance or being asked to help; they prevent the PWD from getting on with the task	The spouse physically takes something from the PWD
Provision of support	Being available (PC)	The spouse lets the PWD know that they are ready to help if needed	“Let me know if you need any help”
	Hovering (Non-PC)	The spouse hovers nearby, or watches the PWD completing the task	
Asking/ordering	Polite request (PC)	The PWD is asked to do something by the spouse, but it is done so in a kind way	“Could you open that for me please?”
	Command/order (Non-PC)	The spouse snaps or otherwise demonstrates their irritation when asking the PWD to do something	“Just get on with it!”
Feedback	Praise (PC)	The spouse provides positive feedback for something the PWD has done or suggested	“Good idea!”

	Fault find (Non-PC)	The PWD's efforts are criticised or undermined in some other way	"I thought you could do this!"
Responding to communication	Active-listening (PC)	The spouse provides their full attention to what the PWD is saying, and demonstrates that they have heard and understood this	
	Ignore (Non-PC)	The PWD says something that is completely ignored by the spouse, as if it has not been heard	
Communicating with	Tailored (PC)	The spouse is sensitive to the PWD's cognitive abilities, and tailors communication so that the PWD has the chance to understand	
	Overwhelm (Non-PC)	The spouse gives too many instructions, or uses too complex language that appears to confuse the PWD	
Responding to distress	Sensitive (PC)	The PWD has shown obvious signs of distress, which the spouse picks up on and responds in a caring way	"Let me help you get started"
	Insensitive (Non-PC)	The PWD has shown obvious signs of distress, which the spouse either does not pick up on, or they respond insensitively	"What are you getting worried about?!"
Humour	Laugh with (PC)	Both the spouse and the PWD laugh or smile at someone's attempts at the task; it is clear that both have found it funny	"See I can't do it either!"
	Laugh at (Non-PC)	The spouse laughs or comments humorously at the PWD's attempts; the PWD does not demonstrate any sign that they find it funny	

PC = person-centred. Non-PC = non-person-centred

## **Procedure**

All participants were screened prior to obtaining consent by a professional involved in their care, in accordance with guidelines outlined in the Mental Capacity Act (2005). Once a couple had expressed interest in taking part and had consented for their information to be passed onto the researcher, they were contacted by telephone to confirm that they were eligible, to provide more information about the study, and to answer questions. If they verbally consented to take part, then a time and date were agreed for a meeting. Couples were informed that their involvement would be kept confidential, and that they could withdraw from the study at any point without repercussion.

Within a few weeks, the researcher visited the couple at their home where capacity was assessed again (e.g. the couple were asked to describe what they needed to do, and weigh up the pros and cons of taking part). Once written consent had been gained, demographic information was obtained. The couples were then asked to think of an everyday task that they were comfortable doing whilst being observed. The tasks chosen included preparing a meal, raking leaves, getting ready to go out, and preparing medication. Couples were asked to consent to being video-taped; this was to ensure that the data could be viewed more than once, and could be carefully coded without interruption. Eleven couples consented to be video-taped. When the couple stated that they were ready, the researcher started recording and remained in the room. The video-recorder was turned off at the end of the task. For the couple who did not consent to be recorded, the researcher remained in the room to observe the couple, making detailed notes on verbal and non-verbal behaviours. It was agreed that the data from this couple be omitted as it could not be reliably coded.

Following the observational task, carers were asked to complete the BRCM. To conclude their participation, couples were debriefed about the nature of the study.

## **Data Analysis**

Each video was transcribed by the researcher; transcriptions included verbal content as well as non-verbal aspects such as facial expression and tone of voice. Each video was then watched by the researcher, with the transcript present. When the researcher believed a spousal behaviour to be person-centred or non-person-centred, the video was paused, and the relevant part of the transcript was highlighted and assigned one of the 18 codes.

Two volunteers – a second year psychology undergraduate and a first year trainee clinical psychologist – were enlisted to help code the videos, and to establish inter-rater agreement with the researcher. They were given a two-hour tutorial about person-centred care and the coding system, and practised coding using the three pilot videos. The intent was to establish whether the volunteers fully understood the coding system, and whether it needed further refinement due to uncertainty or ambiguity. When they were deemed ready, the volunteers were asked to code each instance of spouse behaviour in the participants' videos using the same procedure as the researcher. One volunteer coded six videos, whereas the other coded five. Each rater was blind to the other's responses.

Cohen's kappa (Cohen, 1960) was used to assess each level of inter-rater agreement (see Results). This provided information about whether the codes were clear enough to be identified and distinguished from each other.

For the second aim of the study, it was hypothesised that spouses who scored high on relationship continuity would demonstrate high amounts of person-centred behaviour in the task (i.e. a positive correlation). For the purpose of analysis, the ratio between instances of person-centred and non-person-centred codes was calculated for each spouse (i.e. the total number of person-centred instances was divided by the total number of non-person-centred instances). A higher ratio indicated a greater proportion of person-centred behaviour. Ratios

were chosen because there was considerable variation in the amount of data each couple generated. This would have meant that raw totals for each couple would not have been a useful indication of how person-centred the spouse was. Ratios were correlated with the total BRCM score. As the data did not meet parametric assumptions, Spearman's rho was used to statistically analyse the correlation.

## Results

### Descriptive Data

SPSS version 20 was used to perform statistical analysis (output tables for all statistical analyses are shown in Appendix F). Table 9 summarises the continuous variable data gathered from the 11 couples.

**Table 9.** Descriptive data for participants.

Variable	Mean	Standard Deviation	Range
Duration of video-tapes (minutes)	9.40	9.03	3.44-34.53
Number of instances of behaviour coded	32.81	22.99	10-72
Person-Centred Behaviour (n)	19.36	16.49	4.50-54.50
Non-Person-Centred Behaviour (n)	8.50	6.39	1.50-24.50
Person-Centred Behaviour (%)	65.09	17.48	37.50-90
Ratio person-centred/non-person-centred	2.93	2.68	0.60-8.38
BRCM Total Score	77.18	26.58	39-113

There was considerable variation in the number of instances of behaviour coded, therefore ratios of person-centred/non-person-centred instances were calculated for the purpose of the correlational analysis. There was a higher percentage of person-centred behaviour compared to non-person-centred behaviour. This raises the question of how common non-person-centred behaviour is within spousal couples. Moreover, the descriptive



statistics for the BRCM score ( $mean = 77.18, SD = 26.58$ ) are considerably higher than those reported by Riley et al. (2013;  $mean = 57.90, SD = 23.47$ ), suggesting the present sample had a higher level of relationship continuity. A possible explanation for this, and the higher percentage of person-centred behaviour, could be that the couples who volunteered in this study were quite close, which enabled them to be more person-centred in their approach. These results are explored further in the Discussion.

Descriptive statistics were also calculated for the frequency of use of each of the 18 codes, and the percentage level of agreement between raters (Table 10). This includes codes that were applied to an instance of spouse behaviour by one rater, but this same instance was not assigned a code by the other rater. As seen in Table 10, the *enabling* code was most commonly assigned by raters; this referred to whether a spouse's contribution enabled their partner with dementia to complete the task. Although this was the most used category, raters only agreed 52% of the time. This might suggest that the description of this category needs refinement; it may be that raters used this category as a 'default' when they were unsure how to rate a specific behaviour. It is evident that refinement needs to occur for all codes; however it must be noted that a high proportion of disagreement between raters was a consequence of one rater failing to code behaviour that the other rater had assigned a code to (see Appendix F). This might suggest that the general instructions require clarification for when an instance of behaviour should be coded. Only one code (*laughing with*) had a high level of agreement between raters, which may indicate that this behaviour is easily distinguishable from other behaviours.

### **Internal Consistency**

Riley et al. (2013) reported the BRCM to have good internal consistency, as indicated by a high Cronbach's alpha for the full scale ( $\alpha = 0.947$ ). In this study, the BRCM was also

found to have good internal consistency ( $\alpha = 0.965$ ).

**Table 10.** Descriptive data for the codes used by the raters.

<b>Code</b>	<b>Total Number of Times Used</b>	<b>Agreement Between Raters</b>	<b>Disagreement Between Raters</b>	<b>% Agree</b>
1a Facilitating	44	26	18	59
1b Controlling	24	6	18	25
2a Enabling	56	29	45	52
2b Controlling	29	15	14	51
3a Being available	14	6	8	43
3b Hovering	9	5	4	56
4a Polite request	53	31	22	58
4b Command/order	19	10	9	53
5a Praise	18	9	9	50
5b Fault-find	6	2	4	33
6a Active-listening	41	23	18	56
6b Ignore	22	10	12	45
7a Tailored	11	2	9	18
7b Overwhelm	10	5	5	50
8a Sensitive	11	5	6	45
8b Insensitive	4	2	2	50
9a Laughing with	13	10	3	77
9b Laughing at	5	2	3	40

### **Inter-rater Reliability**

Kerig and Baucom (2004) assert that the purpose of examining the levels of agreement between observational raters is to check that a coding system has been applied accurately, and

that any variance is due to differences between participants rather than differences between raters. Cohen's kappa (Cohen, 1960) was used to assess inter-rater reliability. This statistic considers base rates for behaviour, and adjusts for chance agreements that randomly occur. Two types of agreement were considered.

The first considered the level of agreement between raters that an instance of spousal behaviour should be placed into one of the categories. Here, an 'instance' was defined as each unit of behaviour, or speech turn, emitted by the spouse. A 'category' referred to the nine categories within the coding system. The procedure for calculating this kappa involved going through the transcripts and counting the number of instances of spousal behaviour that both raters agreed *should* be placed in a specific category, and behaviours that both raters agreed *should not* be placed in a specific category. Agreement entailed whether both raters placed the same instance within the same category, and did not take into account agreement about whether the behaviour was person-centred or not. If, for example, both raters placed a behaviour in category four (*asking/ordering*), then this was considered an agreement, even if one rater coded the behaviour as person-centred and the other as non-person-centred. This level of agreement related to the 'what are you looking for?' component of the coding system, and was an important assessment of inter-rater reliability to illuminate whether or not the coding system could be used to clearly and reliably identify and determine the types of behaviour. According to Landis and Koch (1977), the kappa coefficient was good (0.652) with a 95% confidence interval of 0.603 to 0.701. Table 11 portrays the cross tabulations comparing raters' responses. As can be seen, there was a good level of agreement between raters for placing the same behaviours in the same category. It is interesting that the highest number of disagreements occurred when one rater did not code an instance of behaviour, but the other labelled the behaviour as either *contribution* or *responding to communication*.

**Table 11.** Cross tabulations of the frequencies of use of coding categories by the two independent raters.

		Volunteers									Total	
		.00	1.00	2.00	3.00	4.00	5.00	6.00	7.00	8.00		9.00
Primary Rater	.00	199	9	14	9	5	5	15	1	2	2	261
	1.00	6	32	6	0	4	0	0	0	0	0	48
	2.00	12	4	46	0	9	1	1	2	2	0	77
	3.00	2	0	0	11	0	0	0	0	0	0	13
	4.00	2	1	1	1	44	0	0	0	0	0	49
	5.00	5	0	2	0	0	11	0	0	0	0	18
	6.00	10	0	0	0	2	0	34	0	0	0	46
	7.00	4	0	1	0	1	0	0	9	0	0	15
	8.00	1	0	0	0	0	0	0	1	8	0	10
	9.00	0	0	0	0	0	0	0	0	0	14	14
Total		241	46	70	21	65	17	50	13	12	16	551

Values 1-9 represent the nine broad categories, whereas '0' represents an instance that a rater did not think should be placed into a category.

The main aim of the coding system was to obtain an overall measure of how person-centred a spouse's behaviours were when interacting with their partners with dementia on an everyday task. Hence, the second reliability assessment was for the level of agreement between raters on whether an instance of spousal behaviour was person-centred or non-person-centred. This referred to those instances that both raters agreed should be coded; it was not important for the purpose of analysis in which category the behaviour was placed. The level of agreement between person-centred and non-person-centred codes was good ( $kappa = 0.796$ ) with a 95% confidence interval of 0.713 to 0.878. Table 12 presents the cross tabulations for agreements on whether behaviours were person-centred or non-person-centred, and shows that there were higher levels of agreement for when behaviour was person-centred. There was little disagreement between raters, although it was noted that the main source of disagreement was a slight tendency for the two volunteers to rate behaviour as person-centred whereas the primary rater felt the behaviour was non-person-centred.

**Table 12.** Cross tabulations of the frequency of person-centred and non-person-centred codes by the two independent raters.

		Volunteers		Total
		.00	1.00	
Primary Rater	.00	62	12	74
	1.00	9	168	177
Total		71	180	251

0 = non-person-centred. 1 = person-centred

### Correlations

Bivariate correlations using Spearman's rho were conducted between the total BRCM score and the ratio of person-centred to non-person-centred behaviours. There was a very

small, non-significant negative correlation ( $\rho = -0.073, p = 0.832$ ). This does not support the hypothesis that spouses perceiving high relationship continuity would also show high levels of person-centred behaviours (i.e. a positive correlation).

Figure 1 shows the scatterplot of the person-centred/non-person-centred ratio against the BRCM scores. Two outliers were evident. These couples obtained ratios in favour of person-centred interaction that were much higher than the other nine couples, but relatively low BRCM scores. When these outliers were removed, the correlation was in the predicted direction ( $\rho = 0.283, p = 0.460$ ) although not significant. There was no evidence to support the hypothesis of a link between relationship continuity and person-centred care.

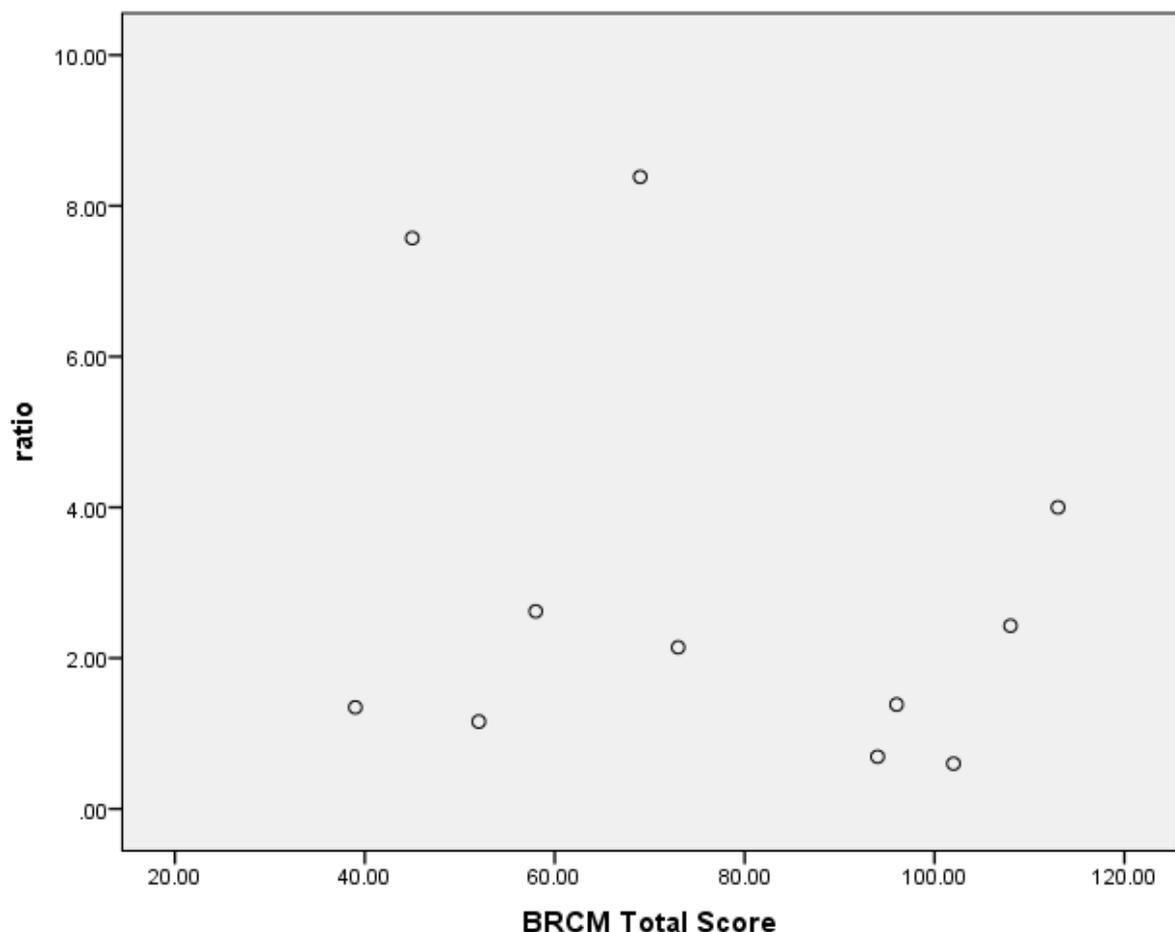


Figure 1. Graph plotting BRCM scores against the ratio between person-centred and non-person-centred behaviours.

## Discussion

An 18-code observational coding system was developed as a quantitative measure of person-centred behaviours shown by spouses of people with dementia whilst completing an everyday task. The coding system covered nine broad categories: *planning*, *contribution*, *provision of support*, *asking/ordering*, *feedback*, *responding to the person with dementia*, *communicating with the person with dementia*, *responding to distress*, and *humour*. These categories were created following inspection of 11 videos of couples interacting on an everyday task, whilst keeping previous research findings on person-centred behaviour in mind. The results suggested that the coding system has good inter-rater reliability. Reliability was assessed at two levels. Firstly, agreement between two raters was good for whether a particular instance should or should not be placed in one of the nine categories. Secondly, agreement between raters was near excellent for whether behaviour was person-centred or not. The latter reliability check was particularly important, given that the coding system was designed to measure this construct.

Enabling the person with dementia to contribute and be involved in decision-making with regards to everyday activities has been found to maintain the sense of being a couple (Hellström et al., 2005, 2007). Furthermore, doing meaningful activities together which both partners in a dyad enjoy may help sustain this sense of ‘couplehood’ (Hellström et al., 2005, 2007). The findings of the present study indicate that most ( $n = 9$ ) participating spouses tended to be more person-centred than non-person-centred in their verbal and non-verbal communication for their spouse with dementia, when working together to complete an everyday task. The most frequently observed behaviours related to enabling the person with dementia to continue being involved with the task independently, and asking the person with dementia to do something in a polite and sensitive manner.

This study further examined whether a spouse's perception of relationship continuity (as reflected by their score on the BRCM) was related to their use of person-centred approaches when working with their partner with dementia on an everyday task. The sense of being in a partnership and working together as a team has been found to contribute to a sense of relationship continuity (Davies, 2011). The results did not support the hypothesis that care-giving spouses who perceived a good sense of relationship continuity would adopt a person-centred approach. However a small, non-significant positive correlation was found when two participants with anomalous results were removed. The results may have been a consequence of an inadequate sample size. The original power calculation was for a sample of at least 26, thus a sample size of 11 would indicate that the correlational test did not have sufficient power. Ultimately, no firm conclusions can be drawn from this data about any possible links between relationship continuity and person-centred care.

We might speculate that care-giving spouses participating in this study who reported high relationship continuity but who had a lower tendency to be person-centred may have always interacted this way, meaning their relationship was a continuation of how it has always been. Furthermore, spouses reporting low relationship continuity, but who demonstrated high levels of person-centred behaviours, may have developed a person-centred approach to caring within the context of becoming emotionally detached from their relationship (Riley et al., 2013).

When examining the frequency of use for each of the 18 codes (see Table 10), it is interesting that two of the least used person-centred codes were *tailored communication* and *sensitive response*. This is surprising when considering previous research findings; for example that a person-centred approach may involve the spouse demonstrating support in a sensitive way, and taking into account their partner's cognitive impairments when



communicating with them (Phinney, 2006; Small et al., 2003). However, the high frequency of *facilitating* and *enabling* codes may support theories of person-centred care; for example, attempting to enhance the person with dementia's sense of agency by involving them in decision-making and enabling them to make meaningful contributions (Perry & O'Connor, 2002; Vikström et al., 2005). Again, we might speculate that involving the person with dementia in tasks and facilitating meaningful contributions is a more pertinent care-giving approach within domestic care-giving relationships.

### **Strengths and Limitations of the Coding System**

A good level of inter-rater reliability was achieved on the novel instrument developed for this study, supporting the notion that the coding system is a reliable tool for the purpose of observing and identifying person-centred spousal behaviours within an everyday task.

Another strength of the system is the fact that it has a clear theoretical basis. The description of the codes was developed according to the theory of person-centred care (e.g. Kitwood, 1990; Brooker, 2007). Therefore there was a clear, theoretical basis for the person-centred and non-person-centred codes. The descriptions given to the raters were thought to be detailed and the provision of examples aimed to enhance understanding of the codes; the high level of agreement between raters supports that this was effective.

Although reliability was good, there is room for further improvement. After obtaining feedback from the volunteer raters, it was clear that some codes need further refinement in the form of clearer, more distinct descriptions. The identified codes were *praise*, *confirming availability*, *hovering*, and *controlling* (within the *planning* category). Using *praise* as an example, the volunteers felt the definition could be clearer by incorporating spousal statements that demonstrate encouragement or reassurance to the person with dementia that

they are going the right way about completing a task. It is interesting that the volunteers did not comment on the description of the *contribution* category (which has the highest level of disagreement with the primary rater).

Although validity has not been formally evaluated in the present study, it can be argued that the coding system has good ecological validity as it was applied in a naturalistic setting, in that couples were in their own home and performed an everyday activity that they would have normally done. Furthermore, couples were instructed to interact and work through a task together. This was to elicit person-centred behaviours, which was the issue of interest. However, it must be acknowledged that participants' behaviour might have been influenced by the presence of the researcher, in that they may have behaved in a way that they thought the researcher wanted to see. By explaining the full purpose of the study to couples at the end, it was hoped that interactions were minimally influenced by demand characteristics.

An additional strength of the coding system was that coder training was not a time-consuming process; raters received a two-hour tutorial and the researcher deemed them competent to proceed with the coding. The application of the coding system was also relatively quick. Coding software was originally intended to be used to analyse the video-tapes as this would have reduced the time of analysis. However, this study has demonstrated that no specialist equipment or resources are required to produce good, reliable results. In light of the above, the coding system could be deemed to have good practical utility, although further studies would be needed to support this statement.

Some limitations of the coding system should be acknowledged. It was not clear what the best measure of person-centred care should be. There was considerable variation in the number of instances of behaviour coded between couples, meaning that the raw totals of person-centred and non-person-centred behaviours could not reliably be used to determine

how person-centred a spouse was. To address this issue, ratios were thought the most appropriate. However, as indicated by the two outliers, these may not be the best measures as there was wide variation within these too. It may be useful for future studies applying the coding system to ask participants to complete an everyday task within the same time frame (discussed further below).

### **Strengths and Limitations of the Evaluation**

Strengths of the evaluation included the fact that all raters were blinded to the scores of the other raters. This would suggest that responses were not influenced by any biases. Additionally, all 11 videos were included in the reliability assessment, which strengthens the results. The sample consisted of couples where one spouse had a diagnosis of dementia. There was a fairly wide range in terms of length since diagnosis, spouses' ages, and length of relationship. This might suggest that the coding system is practical for a wide variety of dementia populations.

Some limitations of the evaluation should be highlighted. The main limitation was the small sample size. Recruitment was an extremely difficult process. Barriers encountered were: relying upon other health professionals to identify potential couples, and relying on those identified to participate. Recruiting through a large NHS Trust was thought to be a good strategy as this would maximise the 'exposure' of the study, as well as the number of potential participants. However, professionals were under a lot of time pressure and often the researcher's emails went unanswered. Expanding recruitment to include voluntary agencies also proved difficult because these organisations were inundated with research demands, and they expressed concern about overwhelming their service-users. A larger sample would have provided a higher statistical power for the correlational analysis, which would provide a stronger indication of whether there were links between the spouse's perceptions of

relationship continuity and their ability to deliver person-centred care, as suggested by previous research (Chesla et al., 1994; O'Shaughnessy et al., 1999; Walters et al., 2010). It is recommended that studies utilising a larger sample also assess psychometric properties, to strengthen the reliability of the coding system and evaluate its validity. Furthermore, a larger, more diverse sample may reduce the sample biases that have possibly occurred in this study (e.g. those who volunteered were happy to be observed because they adopted a more person-centred approach to interacting with their spouse).

The codes were derived, in large part, from the videos that the codes were then applied to in assessing the reliability of the system. Whilst care was taken to not include examples directly from the videos, this is a circular process. Future applications of the coding system would determine whether the same range of codes is observed in task-focused interactions within a new sample.

Other coding systems have implemented strict guidelines in terms of the nature and duration of the task; this provides consistency for participants, and assesses the evidence for content validity. The methodology of this study was flawed by the inconsistency between the nature and duration of tasks. The results may have been skewed as some tasks required more time, therefore there were more opportunities for interaction. However, the researcher felt that giving couples the freedom to choose the task would enhance participation; this also demonstrated that the coding system was not limited to one type of task. Heyman et al. (2001) reported that a 10-minute task is sufficient enough to elicit a good number of behaviours to produce reliable results; perhaps a better approach for future research applying this coding system would be to adhere to time-limited tasks. This would hopefully ensure that a similar number of instances would be captured within a restricted time-frame. Additionally, asking couples to complete several *different* everyday tasks would give an indication of the stability

of the coding system (stability in the sense of whether a couple would have similar scores across tasks). The wide variance in the amount of data generated by each couple led to difficulties deciding upon the best measure of person-centred care (as aforementioned).

This study presents good information regarding the reliability of the system, however validity was not evaluated. This was because the initial focus of the study was to investigate whether relationship continuity and person-centred care were linked. However due to recruitment difficulties and time constraints, the focus shifted to the development of a coding system, which impeded a thorough evaluation of validity. Construct validity could be evaluated by future studies using the coding system to test hypotheses and correlating these with other measures investigating the same construct (e.g. asking spousal carers to complete a questionnaire about empathy, which is a component of person-centred care). Content validity could be assessed by having a panel of experts - independent from the research team and who are knowledgeable about person-centred care – judge whether the coding system reflects all components of person-centred care.

Agreement between raters for whether an instance should or should not be placed in a category was lower than anticipated. When the disagreements were broken down, it appeared that the primary rater ‘missed’ more instances than the volunteers. When the primary rater’s misses were reviewed in comparison to the volunteers’ ratings, some potential errors were highlighted. Some misses were due to a behaviour that was not related to the task, i.e. a question directed towards the researcher. In addition to feedback for specific codes, both volunteers were asked for feedback regarding the coding system in general, in terms of its practicality and transparency. They commented that the instructions for the application of the coding system needed to be clearer, for example making it more explicit that behaviour

should only be coded when it is obviously task-oriented, and when the spouse is obviously directing speech at the person with dementia.

### **Implications for Clinical Practice**

The coding system could be an effective tool for informing care-givers about the types of communication strategies that they use, and whether these are helpful or unhelpful in the context of person-centred care. This knowledge may help promote and maintain a good relationship. This information could be provided on an individual level, or in a psycho-educational group format.

Development of this coding system would provide a means of quantifying the person-centred aspect of relationships, and thereby provide a method of studying quantitatively how this aspect might relate to other aspects of the relationship and other outcomes. This may allow researchers and clinicians to test some of the suggestions about relationships derived from qualitative research, for example, the importance of the relationship for how well the family and the person with dementia deal with the challenges of dementia. Understanding more about specific qualities that promote specific outcomes will eventually help clinicians provide more effective support for families and people with dementia.

### **Conclusion**

Despite its limitations, the coding system developed in this study is a promising measure of spousal person-centred care. Previous research investigating this area has been qualitative, although this coding system now provides a quantitative approach, even if it is in its infancy. The psychometric properties found in this study were good, although due to the small sample size the results need to be interpreted with caution. Further work would be helpful to assess the reliability and validity of the coding system with a larger sample.

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doi:10.1177/1471301209354027

**CHAPTER THREE:**  
**EXECUTIVE SUMMARY**

# **Development and Psychometric Evaluation of an Observational Coding System Measuring Person-Centred Care in Spouses of People with Dementia**

## **Background**

A literature review of observational coding systems applied to study marital interactions where one person has a chronic condition highlighted that these systems have been developed in the general population, and that there is a need for tailored coding systems. The main purpose of the current study was to develop and evaluate the psychometric properties of an observational coding system measuring person-centred care in spouses of people with dementia. A person-centred approach may include facilitating the person with dementia to make decisions, and responding to distress in an empathic way (Brooker, 2007). Person-centred care is advocated as good practice in dementia care-service settings (Department of Health, 2009), and has been found to increase patient well-being.

Relationship continuity refers to a spouse's perception of the relationship, and whether it is a continuation of the pre-morbid relationship (Walters, Riley, & Oyebode, 2010). A secondary aim of this study was to explore whether relationship continuity was linked to how person-centred spouses were when interacting with their partner with dementia. It was hypothesised that those reporting higher continuity would be more person-centred.

## **Method**

The coding system comprised 18 codes (nine person-centred, nine non-person-centred), which were divided into nine broad categories. Eleven couples consented to complete an everyday task together whilst being video-taped. Spouses also completed the Birmingham Relationship Continuity Measure (Riley et al., 2013). Two raters coded the videos using the coding system. Inter-rater reliability was assessed by examining the level of agreement for whether an instance of spousal behaviour was placed in the same category, and

whether both raters agreed that a behaviour was person-centred. Ratios of person-centred/non-person-centred behaviours were correlated with the BRCM scores to test the hypothesis.

## **Results and Discussion**

The findings assert that the coding system is a reliable measure of person-centred care within spousal interactions on a variety of tasks. Inter-rater agreement between coders was good for whether a specific behaviour should be placed in a specific category ( $kappa = 0.652$ ), and near excellent for whether a behaviour was person-centred ( $kappa = 0.796$ ). The hypothesis, that spouses scoring high on relationship continuity would adopt a more person-centred approach to their care, was not supported.

A major limitation of the study was the small sample size; this was due to significant recruitment difficulties. Research using a larger sample should aim to evaluate the validity of the coding system. Implications for clinical practice include educating spouses about the benefits of a person-centred approach, namely the positive impact upon well-being.

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## **APPENDICES**

**APPENDIX A**

**Evaluation Pro Forma**



Coding system	
Author	Year
Sample, <i>e.g. size, diagnosis clearly defined, type of spouse, control group</i>	
How is behaviour sampled, <i>nature of task, duration</i>	
Aims and findings of the study	
How can the findings be useful for furthering our understanding of how effective communication leads to better outcomes for couples?	
The system, <i>e.g. how well is it described? Justification for its use? Theoretical background to its development? What is it measuring?</i>	
Codes used in paper, <i>e.g. how well are they described? Theoretical justification for revisions? Are any omitted, if so why?</i>	
Unit of analysis in paper	
Reliability, <i>type, what checks have been done? Individual vs range? Individual vs entirety?</i>	
Validity, <i>how is this tested and described? Are scores correlated with outcome measures?</i>	
How long does it take to train coders? To what level?	

**APPENDIX B**

**NHS Ethical and Research and Development Approval**

## **APPENDIX C**

### **Information Packs and Consent Forms for Participants**

**PARTICIPANT INFORMATION SHEET – CARER (Version 4, 12/11/2012)**

*Title of Project:* How do couples communicate with each other in everyday tasks when one person is caring for the other with dementia?

*Researchers:* Stephanie Ellis-Gray, Dr Jan Oyeboode, Dr Gerry Riley

My name is Stephanie and I am a Trainee Clinical Psychologist from the University of Birmingham. I would like to invite you to take part in a research study. Please read this information carefully before deciding if you would like to take part. Taking part is completely voluntary, so please do not think you **have** to take part. Please contact me if you have any questions.

**What is the reason for the study?**

We want to look at whether there is any link between what the carer feels about his/her relationship with the person with dementia and how the couple communicate with one another. We hope that this research will lead to couples receiving better advice and support about how they can keep a good relationship with one another.

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

You are currently caring for your spouse, who has been diagnosed with dementia.

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

1. After you have been given this information sheet to read, Stephanie will telephone you within 2 weeks to ask if you are interested in taking part. If you are, Stephanie will arrange to meet with you and your spouse to see if this study will suit you both, and that you understand what you will be asked to do. This should take no more than 30 minutes.
2. If the study is suitable, you will need to complete and sign a consent form. This will mean that you agree to do all parts of the study, and the information you provide will be used as part of the study's results. Stephanie will then arrange a time and date for you to complete the study at a venue of your choice.
3. On the day of the study, Stephanie will meet with you at the venue and check that you still know what you will be asked to do, and that you are happy to continue.
4. If so, you and your spouse will be asked to complete an everyday task together. This will be a task of your choice. You will be video-taped whilst completing the task. The video-camera will be placed in the room but it will not be in your way. We think completing the task could take up to 30 minutes. The video will be used by the research team to look at how you communicate with your spouse.
5. After you have completed the task, Stephanie will turn off the video-camera, and ask you to complete a questionnaire about the relationship you have with your spouse. This will take about 10 minutes to complete.
6. After you have completed the questionnaire, the study will be finished. Stephanie will then ask you if you have any questions or concerns, and will give you a full explanation of the study. Stephanie will also ask if you would consent to take part in a future interview about how you interact with your spouse on an everyday task, as a follow-on to the observational study. Only you will be interviewed. If you consent, the interview will likely take place in January-March 2013.

We will ask if we may let your GP know that you will be taking part in the study. We will not write to your GP unless you give us your permission.

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

Your taking part will remain completely confidential. You will not be discussed with anyone outside the research team. The video-tape and completed questionnaire will not be seen by anyone outside the research team, and it will not be possible to identify you in publications of this research. Your spouse will not see the questionnaire, or the responses you make. Your name, or any other identifiable information, will not be written on the questionnaire or the video-tape. These will only be labelled with a number assigned to you by the research team.

A copy of the video-tape, the information gathered from the recording and the questionnaire will be stored on a password-protected computer at the University of Birmingham. No record of your name will be stored on computer. The video-tape will be wiped as soon as this copy has been made. The paper copy of the questionnaire and your consent form will be stored in separate locked filing cabinets at the University. The University requires such data be kept for 10 years. Please be assured that your information will be securely stored during this time.

At the end of the study, a report of the findings will be sent to you if you are interested. This research will also be submitted by Stephanie as part of her doctoral studies at the University of Birmingham. It is possible that a research paper will be published in a scientific journal and that the results will be presented to professionals, carers or people with dementia.

#### **What are the possible risks of taking part?**

Stephanie will telephone you in the first instance to discuss whether it is suitable for you as a couple to take part. As part of this discussion, Stephanie will ask you whether you have any concerns about safety in the agreed venue for you and your spouse. If you do have any safety concerns that cannot be resolved, you will not be asked to take part in the study. Also, the questionnaire asks some questions about sensitive issues, and you may find this upsetting. Stephanie will check with you whether it has been upsetting, and will direct you to sources of support if you wish.

#### **What will happen if I want to withdraw from the study?**

You are free to withdraw at any point and you do not need to say why. Your video-tape and questionnaire will be destroyed. The standard of care you and/or your spouse receive will not be affected.

#### **Expenses and payments**

If you have had to buy anything extra for the study, please keep your receipt and we will reimburse you for the cost.

#### **What happens if I have any concerns, questions or complaints?**

This study has been reviewed and approved by a local NHS research ethics committee. If you would like to discuss any aspect of this study please contact Stephanie on:

Telephone:



Email:



Post: Stephanie Ellis-Gray  
School of Psychology,  
The University of Birmingham,  
Edgbaston,  
Birmingham B15 2TT

If you would like to make a complaint about this study, you can contact the **Patient Advice and Liaison Service (PALS)** within [REDACTED] NHS Foundation Trust on:

Telephone: 0800 953 0045 (Monday-Friday, 8am-8pm) Text: 07985 883509

PALS Freepost RLXJ-XLRU-GGY, [REDACTED]

**CONSENT FORM - CARER (Version 4, 12/11/2012)**

Research site: The University of Birmingham

Study Number: RG\_11-210

Title: How do couples communicate with each other in everyday tasks when one person is caring for the other with dementia?

Participant Identification Number:.....

**CONSENT FORM**

*Title of Project:* How do couples communicate with each other in everyday tasks when one person is caring for the other with dementia?

*Researchers:* Stephanie Ellis-Gray, Dr Jan Oyebode, Dr Gerry Riley

Please tick box

1. I confirm that I have understood the 'participant information sheet – carer version 4' dated 12/11/2012. I have had time to consider the information, ask questions and have had these answered reasonably.
2. I understand that taking part in the study is voluntary and that I can stop taking part at any time, without giving any reason, and without my own or my spouse's care or legal rights being affected.
3. I understand that the data collected is confidential and will only be looked at by the research team conducting the study at the University of Birmingham. Parts of my data may also be made available to the NHS team responsible for me or my spouse's care, but only if any previously undisclosed issues of risk to me or my spouse's safety are disclosed.
4. Are you happy to be video-taped completing the task? YES/NO (please circle)
5. I understand that the information I provide for the study (observation data and the questionnaire) may be published in any write-up of the data, but that this will be anonymous and I will not be identifiable.
6. I give my permission for you to inform my GP that I am taking part in the study.
7. Are you happy to be approached at a later date to take part in an interview about completing an everyday task with your spouse? If yes, you will be asked to give consent again nearer the time. YES/NO (please circle)
8. I agree to take part in the study.

.....  
Print name

.....  
Date

.....  
Signature

**PARTICIPANT INFORMATION SHEET – PATIENT (Version 3, 09/10/2012)**

*Title of Project:* How do couples communicate with each other in everyday tasks when one person is caring for the other with dementia?

*Researchers:* Stephanie Ellis-Gray, Dr Jan Oyebode, Dr Gerry Riley

My name is Stephanie and I am a Trainee Clinical Psychologist from the University of Birmingham. I would like to invite you to take part in a research study. Please read this information carefully before deciding if you would like to take part. Taking part is completely voluntary, so please do not think you **have** to take part. Please contact me if you have any questions.

**What is the reason for the study?**

We want to look at whether there is any link between how couples communicate with one another and the kind of relationship they have. We hope that this research will lead to couples receiving better advice and support about how they can continue to get on well with one another.

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

You have been asked if you would like to take part because you have a diagnosis of dementia.

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

7. After you have read this information sheet, Stephanie will telephone you within 2 weeks to arrange to meet with you and your spouse at your home. This is to see if this study will suit you both. Stephanie will answer any questions you have and make sure you know what you will be asked to do. This should take no more than 30 minutes.



8. If you would like to take part, then you will need to complete and sign a consent form.



9. You and your spouse will be asked to complete an everyday task together (like making a sandwich). This will be recorded on a video-camera.



10. Your spouse will be asked to fill in a questionnaire.



We will ask if we may let your GP know that you will be taking part in the study. We will not write to your GP unless you say we can.



**What will happen to the information I provide for the study?**

Your taking part will remain completely confidential. Only the research team will see the video-tape of you completing the task.

All of your information will be securely stored at the University of Birmingham. The study will be written up as part of Stephanie's studies. It may also be sent to a scientific journal. A summary of the findings will be sent to you if you would like one.

**What are the possible risks of taking part?**

Stephanie will discuss with you and your spouse whether there are any safety concerns about completing the task. You will not be asked to take part if there are any concerns that cannot be sorted out.

**What will happen if I want to withdraw from the study?**

You are free to withdraw at any point and you do not need to say why. Your video-tape will be erased. The care you receive will not be affected.

**Expenses and payments**

If you have had to buy anything extra for the study, please keep your receipt and we will give you a refund.

**What happens if I have any concerns, questions or complaints?**

This study has been reviewed and approved by a local NHS research ethics committee. If you would like to discuss any aspect of this study please contact Stephanie on:

Telephone: [REDACTED]

Email: [REDACTED]

Post: Stephanie Ellis-Gray  
School of Psychology  
The University of Birmingham  
Edgbaston  
Birmingham B15 2TT

If you would like to make a complaint about any part of the study, you can contact the **Patient Advice and Liaison Service (PALS)** within [REDACTED] NHS Foundation Trust on:

Telephone: 0800 953 0045 (Monday-Friday, 8am-8pm)

Text: 07985 883509

PALS Freepost RLXJ-XLRU-GGY, [REDACTED]

**CONSENT FORM – PATIENT (Version 4, 12/11/2012)**

Research site: The University of Birmingham

Study Number: RG\_11-210

Title: How do couples communicate with each other in everyday tasks when one person is caring for the other with dementia?

Participant Identification Number:.....

**CONSENT FORM**

*Title of Project:* How do couples communicate with each other in everyday tasks when one person is caring for the other with dementia?

*Researcher:* Stephanie Ellis-Gray, Dr Jan Oyebode, Dr Gerry Riley

Please tick box

9. I confirm that I have understood the ‘participant information sheet – patient version 3’ dated 09/10/2012. I have had time to read and think about the information, ask questions and have had these answered in a way that makes sense to me.
10. I understand that taking part in the study is voluntary and that I can stop taking part at any time, without giving any reason. I know that I can do this without my own or my spouse’s care or legal rights being affected.
11. I understand that the information collected from me is confidential and will only be looked at by the research team running the study at the University of Birmingham. Some of this information may also be made available to the NHS team responsible for my care, but only if any risk to me or my spouse is identified.
12. Are you happy to be video-taped completing the task? YES/NO (please circle)
13. I understand that the information I provide for the study (observation data) may be published in any write-up of the study, but that this will be anonymous and people will not be able to identify me.
14. I give my permission for you to inform my GP that I am taking part in the study.
15. I agree to take part in the study.

.....  
Print name

.....  
Date

.....  
Signature

**APPENDIX D**

**Observational Coding System of Person-Centred Care (Final Version)**

# **CODING SYSTEM FOR PERSON-CENTRED CARE**

## **Definition of person-centred care**

Promoting a continuation of the person in the context of their normality. Supporting the person to continue their life as they usually would. Allowing the person to be involved in discussion of the best strategies. Providing the person with choices and opportunities to make decisions about how they can meaningfully contribute to getting the task done. Enabling the person to carry out meaningful activities. Kitwood (1997) advocated the notion of couples 'being present' with each other, and being able to be creative, flexible, compassionate, empathic, and responsive. He defined personhood as 'standing or status that is bestowed upon one human being, by others, in the context of the relationship and social being. It implies recognition, respect, and trust'.

## **General instructions**

You will be asked to view a video of a couple completing an everyday task together. When watching this video, you will need to observe what the spouse does (their non-verbal behaviour) as well as listen to what they say and how they say it (verbal behaviour).

You then need to decide whether a spouse's behaviour requires a code below. However you need to be *certain* that a code is appropriate; if there is any doubt, then do not code the behaviour at all. You may find that two (or more) codes are applicable to one piece of spousal behaviour. However this should only occur when it is really difficult to distinguish between the two codes. Finally, not all statements or behaviours necessitate a code, e.g. if the spouse asks a factual question "do we have this in the house?"

Codes are arranged in opposing pairs.

- |                               |                                     |
|-------------------------------|-------------------------------------|
| 1. Planning                   | 6. Responding to communication      |
| a. facilitating               | a. active listening                 |
| b. controlling                | b. ignoring                         |
| 2. What support is provided?  | 7. Communicating back               |
| a. enabling                   | a. tailored                         |
| b. controlling                | b. overwhelming                     |
| 3. How is support provided?   | 8. Responding to confusion/distress |
| a. being available            | a. sensitive                        |
| b. hovering                   | b. insensitive                      |
| 4. Asking                     | 9. Humour                           |
| a. polite request             | a. laughing with                    |
| b. orders                     | b. laughing at                      |
| 5. Positive/negative feedback |                                     |
| a. praise                     |                                     |
| b. fault find                 |                                     |

## **1. Planning**

What are you looking for? Any statements from the spouse relating to the planning of the task – i.e. who is doing what, when or how. Much of this planning may take place at the beginning, but you should also look out for planning statements throughout the task. Sometimes the task may not go according to plan and problem-solving or a new plan is needed. You should include these statements under this category as well.

### **1a Facilitating Planning (person-centred)**

The spouse verbally invites and involves the person with dementia (PWD) to discuss and make decisions about how the task will be completed. This means that the PWD is being asked their opinion about who will do what, when this will be completed, and how it will be completed. It is clear that the spouse is proposing a plan, and the PWD is being asked to think of and choose possibilities about how the task can be completed:

- 1) The spouse asks the PWD an open-ended question about how to get the task started, “how would you like to do this?”

The spouse proposes that the tasks are allocated, and gives the PWD a choice of tasks, asking which they would prefer to do. It is left open so that the PWD can decide whether or not they choose to take part:

- 2) The spouse provides the PWD with a choice and asks which they would like to do, “would you like to do X or Y?”

The spouse may also ask a question in such a way that positions the PWD as ‘the expert’, perhaps because the PWD has had experience of doing the task before, and the spouse is therefore consulting the PWD for their expert opinion:

- 3) The spouse asks the PWD for their opinion, or how they would go about completing the task, “what do you think?”, “what did you used to do here?”

Ultimately, the spouse facilitates the PWD’s involvement in the planning of the task.

### **1b Controlling (non-person-centred)**

The spouse takes charge of allocation tasks, and does not give the PWD the opportunity to share their opinion. The PWD is not given a choice of tasks, but is told which one to do. It is as if this is the final decision, and the PWD is not invited to contribute to the planning process:

- 1) The spouse might say “if you get X then I will get Y.”

## **2. Support provided to get on with the task**

What are you looking for? You are looking at what the spouse does in relation to steps in the task that the person with dementia is trying to carry out. You are coding whether the spouse supports the PWD to carry the step out by themselves (enabling) or takes over (control). The PWD should be in the process of carrying out the step, or is about to do so. Do not use this code for instructions or other guidance that the spouse provides in relation to planning the task.

### **2a Enabling (person-centred)**

The spouse provides verbal instructions, visual prompts or other cues to enable the PWD to complete the task alone. The spouse may gesticulate or mime what the PWD needs to do, point to an object, or remove obstacles so that it is clear to the PWD what they need to do. However, the spouse does not do the actions for the PWD. Even though the spouse might provide a significant amount of support, behaviours are coded as Enabling if the spouse lets the PWD get on with the task following their help.

You should also encode motivational support as Enabling. If the PWD shows signs of disengaging from the task, either due to lack of interest, confusion or uncertainty, the spouse encourages or reassures them that they can do it, enabling them to continue completing the task.

- 1) The spouse encourages and supports the PWD to continue with activity, “well done, you carry on doing that”
- 2) The spouse reassures the PWD that they can do the task, perhaps reminding them that they have done it well before, “you make lovely cups of tea”

Motivational support is to be distinguished from ‘Praise’ because it is said to re-engage the PWD in the task. If some positive or praising comments are said whilst the PWD is completing the task, then it is coded as ‘Praise’.

The spouse might also position the PWD as ‘the expert’. When a difficulty is encountered, the spouse might help or assist the PWD in problem-solving, enabling the PWD to think of ways to get the task going again in relation to a specific difficulty.

- 3) The spouse asks whether the task is moving along the right path at the right pace, “is this going well?”
- 4) If the PWD cannot find something, the spouse might ask “when did you last see it?”

## **2b Controlling (non-person-centred)**

The spouse gives assistance, or interrupts, without being asked for help by the PWD and without giving the PWD a choice in the matter. The spouse takes control without making an initial respectful offer of assistance. Essentially the spouse disrespectfully takes over the task from the PWD, ignoring the PWD's efforts or the fact that they might be doing well, and perhaps showing signs of impatience.

- 1) The spouse huffs or pushes the PWD out of the way.
- 2) The spouse physically takes something from the PWD or otherwise deliberately prevents the PWD being involved.

## **3. How support is provided**

What are you looking for? You are looking for statements from the spouse that offer support to the PWD, and you are looking at how the spouse monitors what the PWD is doing.

### **3a Confirming Availability (person-centred)**

The spouse makes a statement to the effect that they are available to help if required – e.g. “Let me know if you need any help” or “I’ll just be in the kitchen if you need me”. The spouse makes a statement to check whether the PWD is in need of help – e.g. “Are you okay?”

### **3b Hovering (non-person-centred)**

This is a non-verbal code where the spouse monitors the PWD completing the task when the PWD has not requested they do so. It might be that the spouse hovers nearby, perhaps ready to take over if the PWD struggles.

#### **4. Asking/ordering**

What are you looking for? You are looking for statements from the spouse that are intended to get the PWD to do something.

##### **4a Polite Request (person-centred)**

The spouse asks the PWD to do something in a polite and respectful manner. It provides the PWD the opportunity to say no, and to not be involved in taking part. The spouse is asking for the PWD's assent. In order to be coded 'Polite Request', the statement must be made in a friendly and respectful tone of voice. Think of 'Polite Request' as a softened command as opposed to an order. When a 'Polite Request' takes place, it is clear that the PWD is being requested to help.

- 1) The spouse asks PWD for assistance, "could you open that for me please?"
- 2) The spouse might ask the PWD to do something for them in a specific way, "would you mind getting *that* from *there* please?"

Similarly, the spouse allocates tasks, but it is done so in a respectful way that is providing the PWD the option of saying no.

- 3) The spouse asks the PWD "do you want to do X and I'll do Y?"

NOTE: Any trace of irritation or hostility will be coded 'Command/Order'.

##### **4b Command/Order (non-person-centred)**

The spouse is disrespectful towards the PWD when giving instructions. They may be barking an order or command at the PWD. The tone of voice the spouse uses might be whiny or fierce, suggesting that the spouse is becoming irritated, impatient or annoyed.

- 1) The spouse snaps at the PWD in a frustrated way, or in a manner that would suggest the PWD should know what to do, "just get on with it!"



## **5. Positive/negative feedback**

What are you looking for? You are looking for statements from the spouse that evaluate the person's contribution to the task in a positive (praise) or negative (fault find) way.

### **5a Praise (person-centred)**

A statement from the spouse that expresses appreciation, approval, admiration, or praise of the PWD. The message conveyed is a complimentary one, communicating the PWD to be competent, capable, likable, or possessing other positive characteristics. In general, praise serves to bolster the PWD sense of agency by providing them with recognition that they have done a good job and are appreciated.

- 1) A statement or question containing positive, evaluative descriptors, "good idea! Great plan! You did well there"
- 2) The spouse might thank the PWD for doing something, perhaps what was considered the spouse's job, "oh thank you very much, you did a better job than I could have done"

### **5b Fault Find (non-person-centred)**

A statement whereby the spouse puts down, blames, criticises or invalidates the PWD's efforts. This could be indicated by their tone of voice, which is disrespectful, "I thought you could do this!"

## **6. Responding to communication from the person with dementia**

What are you looking for? You are looking for instances where the PWD says something, and you are rating how the spouse responds to this.

### **6a Active-listening (person-centred)**

Code as Active Listening if the spouse stops what they are doing and gives the PWD full attention when they have said something; and if the spouse's verbal or non-verbal response is relevant to what the PWD has said. This is person-centred because the spouse is showing that they value the PWD's suggestions.

The PWD might ask the spouse to keep an eye on them completing a task. If the spouse stays as requested, then this is coded as Active-Listening because it is adhering to the PWD's wishes. However, the spouse's presence is almost 'benign'.

The PWD may ask the spouse to complete the task for them. Again, this is person-centred because it aims to reduce distress for the PWD. The distinction is that the PWD has made an attempt to complete the task on their own, and has invited the spouse to watch or physically assist them.

### **6b Ignore (non-person-centred)**

A lack of verbal or non-verbal response by the spouse to what the PWD has just said. It is an absence of feedback. When this occurs, it is as if nothing was said. It is as if the PWD's words had no impact. When this occurs non-verbally, there are no head nods, no facial movements, and no sign that the PWD's words have registered with the spouse. The spouse might even proceed with their own line of discussion, dismissing what the PWD has said. The spouse might do the opposite of what the PWD has recommended or instructed. The spouse might interrupt what the person with dementia has said or make some remark that is unrelated to what the person with dementia has said.

## **7. Communicating with the person with dementia**

What are you looking for? You are looking at the spouse's communications directed to the PWD, and you are looking for evidence about whether these are sensitive or insensitive to the cognitive difficulties of the PWD.

### **7a Tailored communications (person-centred)**

This code should be used when the spouse is talking the PWD through the plan for the task, or providing support to enable their completion of the task; and they break down a larger amount of information or instructions and provide the information or instructions gradually – in such a way that they are easier to digest and follow.

Also use this code if the spouse checks whether the PWD has understood what the spouse has said to them.

### **7b Overwhelming communications (non-person-centred)**

A series of questions or instructions that seem to use too complicated language for the PWD to understand, are delivered too quickly, too quietly, or are too lengthy. The evidence for this will be in the PWD's response to the question or instruction. If they appear confused, puzzled, anxious or otherwise distressed then it is possible they are overwhelmed.

The spouse does not provide the PWD a chance to think about the question or instruction in order to give an informed response. The PWD might feel overwhelmed because they are not being given sufficient time to respond, or what they are saying is cut short by the spouse talking over them.

- 1) The spouse asks the PWD a question, but acts without receiving a response. They may also repeat a question without giving the PWD a chance to process it.
- 2) The spouse asks the PWD a question, but predicts and voices the response before the PWD has the chance to give the answer.
- 3) The spouse cuts across the PWD when they are talking.

## **8. Responding to confusion or distress**

What are you looking for? You are looking for signs that the PWD is confused or upset, and you are rating whether and how the spouse responds to these signs.

### **8a Sensitive Response (person-centred)**

If the PWD shows signs of distress, or that they are struggling with the task, and the spouse picks up on it and responds sensitively, then this is coded 'Sensitive Response'. The spouse is showing the PWD that they are in tune with how they might be feeling, and offers reassurance.

For example, the PWD might say in a fretful voice "oh I don't know what to do" and the spouse might respond with "ok, let me help you get started / continue" or "shall I help you with X?"

### **8b Insensitive Response (non-person-centred)**

In contrast, if the PWD shows signs of distress that spouse does not pick up on, then this is coded 'Insensitive Response'. The spouse allows the PWD to struggle on. Furthermore, if the spouse does acknowledge the PWD's distress, and responds in an insensitive way, then this too comes under this code, "what are you getting worried about, it's not that hard."

## **9. Humour**

What are you looking for? You are looking for any instances where the spouse says something intentionally humorous.

### **9a Laughing with (person-centred)**

A statement made by the spouse that encourages the PWD to laugh at the activity, or how they are completing the activity, “come on, chop-chop!” The spouse may also draw the PWD’s attention to a mistake they themselves have made, “see I can’t do it either!” It is clear by the tone of voice and expression through laughter or smile that **both** are finding the situation humorous. Do not code as *laughing with* if there is no evidence that the PWD finds the remark humorous.

### **9b Laughing at (non-person-centred)**

A humorous remark about the PWD that is directed to the PWD or to others, and there is no evidence that the PWD has found the remark humorous. The PWD might look upset or confused. Do not code as *laughing at* if it is possible that the person with dementia has simply not heard the remark.

An example of this code might be, “I think snails could do the task quicker!”

**APPENDIX E**

**Birmingham Relationship Continuity Measure (Male Care-Recipient)**

## **Birmingham Relationship Continuity Measure**

This questionnaire is about your husband (partner) and your relationship with him.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example).

If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

### Example

	Caring for my partner can be difficult	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
--	--	-------------	----------------	---------	-------------------	----------------

1	He's in a world of his own most of the time.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The dementia has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for him, but I don't love him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like his carer now, not his wife (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	He's a shadow of his former self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
8	I don't feel about him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
9	Our relationship has changed beyond recognition since the dementia started.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, he's still his old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn't what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it's like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how he used to be, he's a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I've lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It's like there's a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don't feel I really know him any more.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	He still has many of the same qualities that first attracted me to him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn't feel like a partnership any more	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE



## **APPENDIX F**

### **Raw SPSS Data and Calculations**

Descriptive Statistics

**Descriptive Statistics**

	N	Minimum	Maximum	Mean	Std. Deviation
PWDAge	11	52.00	87.00	73.7273	10.90955
LengthSinceDiagnosis	11	4.00	96.00	47.4545	29.39171
CarerAge	11	62.00	83.00	72.1818	7.67868
LengthOfRelationship	11	16.00	64.00	45.7273	14.56084
BRCMScore	11	39.00	113.00	77.1818	26.58126
PCPercentage	11	37.50	90.00	65.0909	17.48259
PC	11	4.50	54.50	19.3636	16.49408
NONPC	11	1.50	24.50	8.5000	6.39140
Ratio	11	.60	8.38	2.9391	2.68099
TotalInstances	11	10.00	72.00	32.8182	22.99051
VideoLength	11	224	2093	564.0000	541.80550
Valid N (listwise)	9				

**Primary Rater \* Volunteers Crosstabulation**

	Volunteers																			Total
	.00	1.10	1.20	2.10	2.20	3.10	3.20	4.10	4.20	5.10	5.20	6.10	6.20	7.10	7.20	8.10	8.20	9.10	9.20	
.00	199	4	5	11	3	7	2	3	2	5	0	11	4	0	1	1	1	1	1	261
1.10	2	26	0	6	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	37
1.20	4	0	6	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	11
2.10	7	3	0	29	0	0	0	5	1	1	0	0	1	2	0	2	0	0	0	51
2.20	5	0	1	2	15	0	0	2	1	0	0	0	0	0	0	0	0	0	0	26
3.10	0	0	0	0	0	6	0	0	0	0	0	0	0	0	0	0	0	0	0	6
3.20	2	0	0	0	0	0	5	0	0	0	0	0	0	0	0	0	0	0	0	7
4.10	2	0	0	1	0	1	0	31	3	0	0	0	0	0	0	0	0	0	0	38
4.20	0	0	1	0	0	0	0	0	10	0	0	0	0	0	0	0	0	0	0	11
5.10	3	0	0	0	0	0	0	0	0	9	0	0	0	0	0	0	0	0	0	12
5.20	2	0	0	2	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	6
6.10	5	0	0	0	0	0	0	0	1	0	0	23	1	0	0	0	0	0	0	30
6.20	5	0	0	0	0	0	0	1	0	0	0	0	10	0	0	0	0	0	0	16
7.10	3	0	0	0	0	0	0	1	0	0	0	0	0	2	1	0	0	0	0	7
7.20	1	0	0	1	0	0	0	0	0	0	0	0	0	1	5	0	0	0	0	8
8.10	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	5	1	0	0	8
8.20	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	2
9.10	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	10
9.20	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2	4
Total	241	33	13	52	18	14	7	46	19	15	2	34	16	6	7	8	4	13	3	551

Cronbach's alpha for BRCM internal consistency

**Reliability Statistics**

Cronbach's Alpha	N of Items
.965	23

**Item-Total Statistics**

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
VAR00001	74.4545	659.673	.584	.964
VAR00002	73.8182	699.564	.079	.968
VAR00003	74.7273	656.018	.738	.963
VAR00004	73.4545	648.273	.676	.963
VAR00005	72.9091	656.891	.790	.963
VAR00006	74.2727	632.818	.799	.962
VAR00007	74.4545	646.473	.646	.964
VAR00008	74.0909	640.091	.838	.962
VAR00009	73.6364	630.855	.855	.962
VAR00010	74.0909	642.091	.689	.963
VAR00011	74.0909	631.091	.850	.962
VAR00012	74.2727	630.618	.772	.963
VAR00013	73.6364	641.055	.730	.963
VAR00014	73.5455	656.273	.738	.963
VAR00015	73.7273	643.818	.696	.963
VAR00016	73.8182	650.164	.647	.964
VAR00017	74.4545	631.473	.825	.962
VAR00018	74.3636	622.055	.950	.961
VAR00019	73.2727	651.218	.864	.962
VAR00020	72.9091	664.091	.669	.964
VAR00021	73.1818	650.564	.792	.962
VAR00022	72.8182	687.964	.513	.965
VAR00023	74.0000	619.400	.949	.960

Inter-rater Reliability: Kappa coefficient for whether an instance of spousal behaviour should be placed in a specific category

**Primary Rater \* Volunteers Crosstabulation**

		Volunteers										Total
		.00	1.00	2.00	3.00	4.00	5.00	6.00	7.00	8.00	9.00	
Primary Rater	.00	199	9	14	9	5	5	15	1	2	2	261
	1.00	6	32	6	0	4	0	0	0	0	0	48
	2.00	12	4	46	0	9	1	1	2	2	0	77
	3.00	2	0	0	11	0	0	0	0	0	0	13
	4.00	2	1	1	1	44	0	0	0	0	0	49
	5.00	5	0	2	0	0	11	0	0	0	0	18
	6.00	10	0	0	0	2	0	34	0	0	0	46
	7.00	4	0	1	0	1	0	0	9	0	0	15
	8.00	1	0	0	0	0	0	0	1	8	0	10
	9.00	0	0	0	0	0	0	0	0	0	14	14
Total		241	46	70	21	65	17	50	13	12	16	551

**Symmetric Measures**

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Measure of Agreement	Kappa	.652	.025	32.964	.000
N of Valid Cases		251			

a. Not assuming the null hypothesis.

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

Calculation for confidence interval

$$k = 0.652 \pm 1.96 \times 0.025 = 0.603 \text{ to } 0.701$$

Inter-rater Reliability: Kappa coefficients for person-centred and non-person-centred behaviours

**Primary Rater \* Volunteers Crosstabulation**

		Volunteers		Total
		.00	1.00	
Primary	.00	62	12	74
Rater	1.00	9	168	177
Total		71	180	251

**Symmetric Measures**

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Measure of Agreement	Kappa	.796	.042	12.622	.000
N of Valid Cases		251			

a. Not assuming the null hypothesis.

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

Calculation for confidence interval

$$P = (62+168)/251 = 0.916$$

$$Pe = \frac{(74 \times 71) + (177 \times 80)}{251} = 0.308$$

$$SE(k) = \sqrt{\frac{0.916(1-0.916)}{251(1-0.308)^2}} = 0.042$$

$$k = 0.796 \pm 1.96 \times 0.042 = 0.713 - 0.878$$

Spearman's rho correlation

With all participants

Correlations			
		BRCM	ratio
Spearman's rho	Correlation Coefficient	1.000	-.073
	BRCM Sig. (2-tailed)	.	.832
	N	11	11
	Correlation Coefficient	-.073	1.000
	ratio Sig. (2-tailed)	.832	.
	N	11	11

With participants split

Outliers removed ( $n = 9$ )

Correlations <sup>a</sup>			
		BRCM	ratio
Spearman's rho	Correlation Coefficient	1.000	.283
	BRCM Sig. (2-tailed)	.	.460
	N	9	9
	Correlation Coefficient	.283	1.000
	ratio Sig. (2-tailed)	.460	.
	N	9	9

Outliers only ( $n = 2$ )

Correlations <sup>a</sup>			
		BRCM	ratio
Spearman's rho	Correlation Coefficient	1.000	1.000
	BRCM Sig. (2-tailed)	.	.
	N	2	2
	Correlation Coefficient	1.000**	1.000
	ratio Sig. (2-tailed)	.	.
	N	2	2

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

**APPENDIX G**

***Ageing & Society* Instructions for Authors**