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# **Living with dementia: The burden of guilt**

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A thesis submitted in part fulfilment of the requirements for the degree of Doctor  
of Clinical Psychology

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### **List of Abbreviations**

AA	Alzheimer's Association
AD	Alzheimer's disease
ADL	Activities of Daily Living
APA	American Psychiatric Association
BPSD	Behavioural and Psychological Symptoms of Dementia
CAMHS	Children and Adolescent Mental Health Service
CAT	Cognitive Analytic Therapy
CB	Caregiver Burden
CGQ	Caregiver Guilt Questionnaire
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DoH	Department of Health
DSM	Diagnostic and Statistical Manual
FA	Factor Analysis
GDS	Geriatric Depression Scale
GPWDS	Guilt in People With Dementia Scale
MMSE	Mini Mental State Examination

NHS	National Health Service
PCA	Principal Components Analysis
PwD	People with Dementia
SPSS	Statistical Package for Social Sciences
WEMWBS	Warwick Edinburgh Mental Well-Being Scale
ZBI	Zarit Burden Interview

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Finally, I want to dedicate this thesis to my grandparents, Harry and Pam Semple. Your commitment and devotion to each other throughout your 64 years of marriage inspires me everyday. This is for you.

### **Declaration**

This thesis was carried out under the academic supervision of Dr Tom Patterson (Academic Director at the Coventry and Warwick Clinical Psychology Doctorate) and under the clinical supervision of Jane Muers (Retired Clinical Psychologist).

Apart from these collaborations I can confirm that the intellectual content of the work is the result of my own efforts and of no other person. This work, or any part thereof, has not been submitted for a degree to the University or any other institution.

The nominated journals for publication of chapters 1 and 2 are ‘*Dementia: The International Journal of Social Research and Practice*’ (see Appendix I for Author Instructions).

The nominated journal for publication of chapter 3 is *Reflective Practice* (see Appendix XXIII for Author Instructions).

## Summary

Previous research has identified guilt as a significant emotion for both people with dementia and their caregivers. As guilt has been associated with psychopathology and depression, it is important to explore the nature, prevalence and clinical implications of this self-conscious emotion within the context of the dementia caregiving dyad.

Chapter 1 presents a critical review of the quantitative and qualitative literature exploring feelings of guilt and caregiver burden in informal caregivers of people with dementia. The paper particularly focuses on evidence regarding the relationship of guilt to the construct of caregiver burden, the conceptualisation and measurement of guilt and burden in dementia caregivers and the factors associated with caregiver guilt and burden. Methodological limitations are discussed in relation to the clarity of the results. Clinical implications and future research suggestions are identified.

Chapter 2 presents a mixed methods research paper on the development and validation of a measure of guilt for people with dementia. The results reveal strong item-total correlation in the new scale. Good reliability and convergent validity of the measure are also demonstrated. Study limitations, clinical implications and future directions are discussed.

Chapter 3 offers a reflective account of my experience of the research process as well as my reflective learning, personal and professional development during this process and clinical training my generally

*Word count of thesis (excluding tables, figures and references): 18,156*

## **Chapter 1 Literature Review**

### **Guilt and caregiver burden in informal caregivers of people with dementia: A critical review of the literature**

Prepared for submission to '*Dementia: The International Journal of Social Research  
and Practice*' (see Appendix I for Author Instructions)

Overall chapter word count (excluding tables, figures and references): 8,116



### **1.1 Abstract**

Guilt and burden are common experiences for informal caregivers of people with dementia and are associated with a range of adverse consequences. The aim of the present review was to critically evaluate the existing empirical literature investigating caregiver guilt and burden in informal caregivers of people with dementia. A systematic search of the literature revealed ten articles that met the inclusion criteria. Search terms used were related to Dementia, Alzheimer's, burden, care and guilt. Findings of the studies reviewed fell into four broad areas; conceptualisation of guilt in relation to burden; caregiver characteristics; care recipient characteristics; and the role of support. The present review highlighted the discrepancies between studies in terms of conceptualisation and measurement of caregiver guilt and its relationship to caregiver burden. Evidence indicates that caregiver and care recipient characteristics influence the experience of guilt and burden. Methodological limitations, clinical implications and future research suggestions are discussed.

**Keywords:** burden; caregiver; dementia; guilt

## **1.2 Introduction**

### **1.2.1 Dementia and caregiving**

Dementia is the term used to describe a collection of symptoms, including difficulties with memory, reasoning and communication, and a loss of skills needed to carry out daily activities. Dementia can be caused by a number of different diseases, such as Alzheimer's or vascular disease, that cause structural and chemical changes in the brain (Knapp & Prince, 2007). The Alzheimer's Society (2014) Dementia UK: Update report estimates that there will be 850,000 people with dementia (PwD) living in the United Kingdom (UK) by May 2015. There are as many as 670,000 family members and friends acting as informal caregivers. Informal caregiving refers to the act of providing help and assistance to friends or relatives who are unable to provide for themselves (Pearlin, Mullan, Semple & Skaff, 1990). A recent report from the Alzheimer's Society (Alzheimer's Society, 2014) estimated the total annual cost of dementia to society in the UK in 2013 was £26.3 billion, with an average cost of £32,250 per person. They further estimated that the total cost of unpaid care by informal caregivers for PwD was £11.6 billion (Alzheimer's Society, 2014).

The majority of care and support for PwD is provided by informal caregivers (Knapp & Prince, 2007; Tremont, 2011). Consequently, informal caregivers are increasingly being recognised as a valuable resource (Wimo, Jönsson, Bond, Prince & Winblad, 2013). The effects of caring for a spouse or parent with dementia have been widely

researched. It is well documented that caregiving can have negative consequences, including poor physical health and increased rates of emotional distress, such as caregiver burden (CB) and depression (Gonyea, Paris & De Saxe Zerden, 2008; Martin, Gilbert, McEwan & Irons, 2006; Pinquart & Sörensen, 2003; Romero-Moreno et al., 2013).

### **1.2.2 Caregiver Burden (CB)**

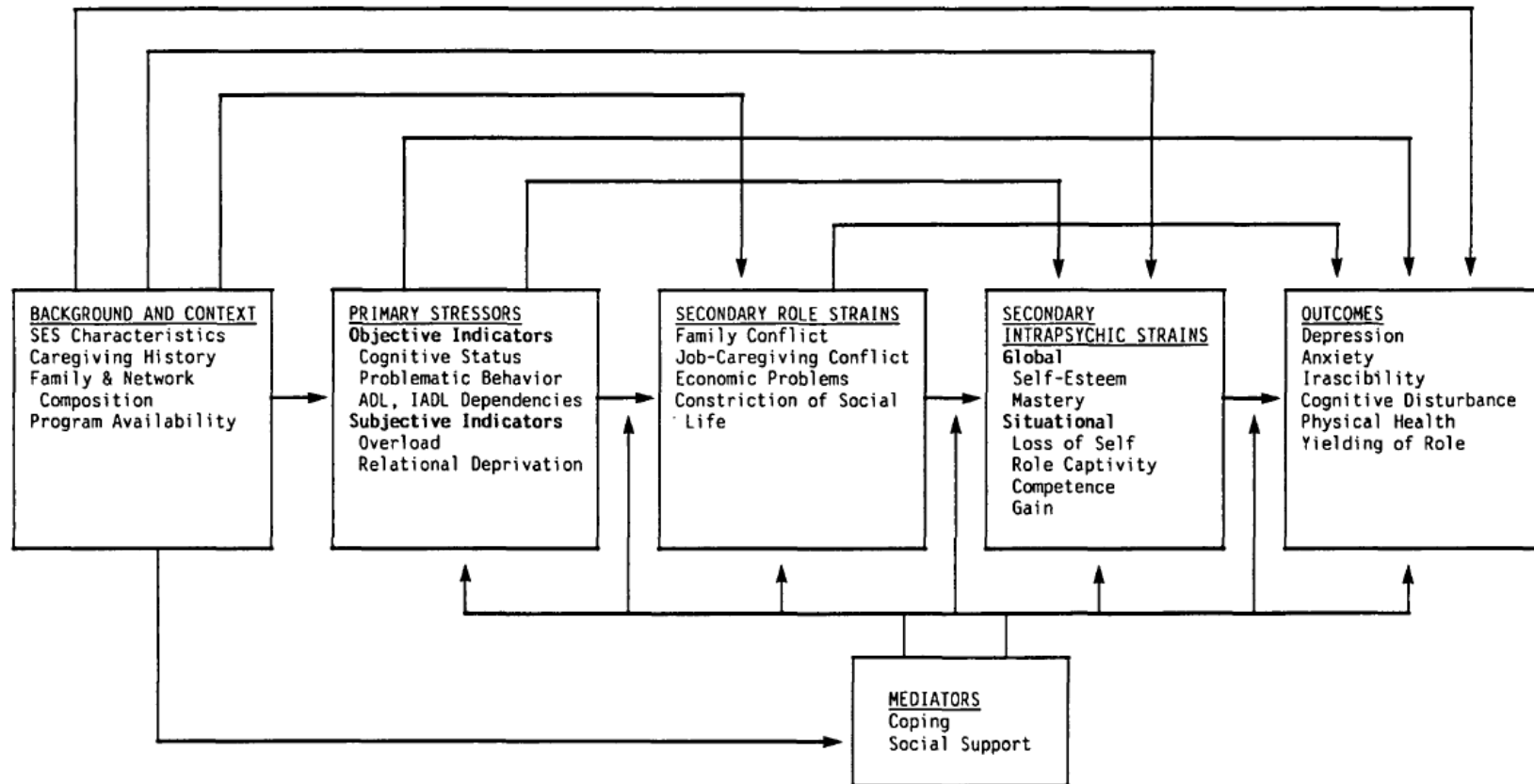
Historically, CB has been broadly defined and differentially measured. This has resulted in researchers treating the effects of caregiving as either one-dimensional or inconsistently labelling these effects as subjective or objective (Poulshock & Deimling, 1984). It has been suggested that burden refers to the more tangible and objective aspects of care, while the term stress in the context of caregiving describes the subjective appraisal of strain on caregivers (Parks & Pilisuk, 1991). However, it is arguably unhelpful to make such distinctions between two inextricably related concepts. A more holistic definition describes CB as the physical, physiological, emotional, social and financial problems that family members caring for impaired older adults may experience (George & Gwyther, 1986).

It has long been suggested that the degree of burden and the stress process experienced by caregivers is influenced by multiple factors (Pearlin et al., 1990). Pearlin and colleagues (1990) presented a conceptual framework of the “Stress

Process” in Alzheimer’s caregiving (see *Figure 1*). Within this model particular attention is paid to the relationships among the conditions that lead to personal stress and the ways these relationships change and develop over time. Similarly, the extent of burden a caregiver experiences reflects the individual’s historical, social and psychological framework, as well as the individual’s style of relating and kinship to the care recipient (Parks & Pilisuk, 1991; Pinquart & Sörensen, 2011).

Since Pearlin’s model, there has been an increase in the amount of research seeking to identify and investigate factors that contribute to CB (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch and López-Pousa, 2010; Gonyea et al., 2008; Kim, Chang, Rose & Kim, 2012). Kim and colleagues (2012) investigated the multidimensional predictors associated with CB in 302 caregivers of PwD. They concluded that caregiver socio-demographic factors, dementia-related factors and caregiving-related factors predicted CB. Dementia related factors, reflecting functional decline in care recipients, were the most significant predictors. The more impaired the care recipients were in terms of activities of daily living (ADL), the greater the burden reported by caregivers (Kim et al., 2012).

Figure 1. The stress process model (Pearlin et al., 1990)



### **1.2.3 Guilt and caregiving**

Within psychological literature, guilt has been defined in many different ways (Kugler & Jones, 1992). Guilt has been described as the dysphoric feeling associated with the recognition that one has violated a personally relevant moral or social standard (Kugler & Jones, 1992). In caregiving research this definition of guilt has been applied to the caregiver's appraisal of their behaviours and thoughts with regard to their caring role (Gonyea et al., 2008).

Guilt has been found to be a significant and common emotion for caregivers of aging relatives (Gonyea et al., 2008), patients at end-of-life stages (Andershed & Harst de, 2007; Harst de, Andershed, Roxberg & Brunt, 2013), people with mental illness (Boye, Bentsen & Malt, 2002; Wasserman, de Mamani & Suro, 2012), and in the context of cancer care (Spillers, Wellisch, Kim, Matthews & Baker, 2008). Guilt has also been associated with burden and depression in both caregiving and non-caregiving samples (Brodaty, 2007; Ghatavi, Nicolson, MacDonald, Osher & Levitt, 2002; Gonyea et al., 2008).

Gonyea et al., (2008) sought to explore the effects of the intra-psychic strain of guilt on caregivers' psychological well-being and its potential as a predictor of CB in 66 adult daughters caring for their aging mothers. They found that guilt was positively associated with burden and that it accounted for a significant amount of variance in the daughter's sense of burden, even after controlling for demographic and stressor

variables. However, this study was limited by its cross-sectional nature and by its focus on a relatively small sample drawn from a specific subset of caregivers.

#### **1.2.4 *Guilt and burden in dementia caregivers***

In the context of caring for PwD, feelings of guilt have been recognised as a common and significant experience for caregivers (Alzheimer's Society, 2013; Easton, 1997; Losada, Márquez-González, Peñacoba & Romero-Moreno, 2010; Martin et al., 2006; Romero-Moreno et al, 2013). Furthermore, a model of CB presented by Brodaty (2007) identified guilt as a key factor that exacerbates CB (Brodaty, 2007; Brodaty & Green, 2000; Poulshock & Deimling, 1984).

To explore CB in the specific context of dementia caregiving, the Zarit Burden Interview (ZBI; Zarit, Reever & Bachpeterson, 1980) was developed. The ZBI explores areas of common concern for caregivers of PwD such as health, finances, social life and relationships. The 22-item ZBI (Zarit, Orr & Zarit, 1985 as cited in Bedard et al., 2001) remains the most widely used measure of CB in dementia. The ZBI assesses factors related to the amount of burden experienced by principal caregivers of PwD such as functional and behavioural impairments, as well as the home care context of PwD. The ZBI is reported to have good internal consistency and good test-retest reliability (Hébert, Bravo & Prévile, 2000; Knight, Fox & Chou, 2000).

Whilst CB has historically been measured and conceptualised as a unitary construct (Zarit et al., 1980), it has been suggested that burden is a multidimensional construct and that a global score may not give a helpful and accurate assessment (Bedard et al., 2001; George & Gwyther, 1986; Hébert et al., 2000; Knight et al., 2000) and also that caregivers with identical total scores on measures of burden may be affected by different aspects of burden, such as feelings of guilt (Ankri, Andrieu, Beaufils, Grand & Henrard, 2005). However, the development and validation of the Caregiver Guilt Questionnaire (CGQ) suggests that guilt may be a separate, but closely related construct to burden (Losada et al., 2010). Given that solid theoretical accounts of guilt in the caregiving literature are still lacking, further research is needed to improve our understanding of the relationship between caregiver guilt and burden.

#### **1.2.5 Rationale**

Research has shown that CB and feelings of guilt are significant experiences for caregivers of PwD and other illnesses. However, there remains a lack of clarity about the relationship between these two important constructs and the implications for caregiver mental health and well-being. There is increasing evidence indicating that feelings of guilt and CB are closely linked. However, there are currently no critical reviews that explore what the existing empirical evidence can tell us about this relationship, specifically within the context of dementia caregiving.



### **1.2.6 Research aim**

To critically evaluate existing empirical literature investigating the relationship between guilt and burden in informal caregivers of PwD.

## **1.3 Method**

### **1.3.1 Search strategy**

Search terms were informed by the research questions.

Table 1. *Search terms*

Concept	1. Dementia	2. Guilt	3. Caregiver	4. Burden
Search term	Dementia	Guilt*	Care*	Burden*
	OR			
	Alzheimer*			

*Note.* \* Represents truncation in order to capture variation used in the terminology.

### **1.3.2 Data sources**

A systematic literature search was conducted in the databases, PsycINFO (ProQuest), CINAHL (EBSCO), Web of Knowledge, which included Medline, and Scopus using the search terms and truncated search terms indicated in Table 1. These databases were chosen in order to reflect the psychological and psychiatric nature of the key concepts under exploration.

### **1.3.3 Selection criteria**

While the searches were not restricted to a particular time frame, the final literature search was conducted on 5<sup>th</sup> December 2014; consequently studies published after this date were not considered. In order to assess the relevance of articles, inclusion and exclusion criteria were applied.

### **1.3.4 Inclusion criteria**

Studies were included if; they were published in a peer-reviewed journal; the paper was written in English; the sample included informal caregivers for PwD; there was a significant focus on guilt and CB. Papers were deemed to have met this final criterion if either (i) a focus on both guilt and CB was stated in the aims of the study; (ii) both variables were formally measured (in quantitative studies), or (iii) both variables appeared as themes identified within the study findings (in qualitative studies).

### **1.3.5 Exclusion criteria**

Studies were excluded if; the paper was a review paper, dissertation abstract, editorial, commentary, conference proceeding, response, letter, discussion piece or legal paper; the paper was a case study or personal account of caregiving; the sample included caregivers for people with illnesses or diagnoses other than

dementia; the aim of the study was to explore guilt and/or burden in relation to making a specific decision i.e. end of life, tube feeding, nursing home placement.

#### **1.3.6 *Manual search***

A manual search was then performed on the papers identified following application of the above criteria. The reference lists and citation lists of all papers identified within these searches were reviewed for relevant published research.

#### **1.3.7 *Search results***

The study selection process is shown as a flow diagram in Figure 2. After the study selection process was completed 10 studies remained.

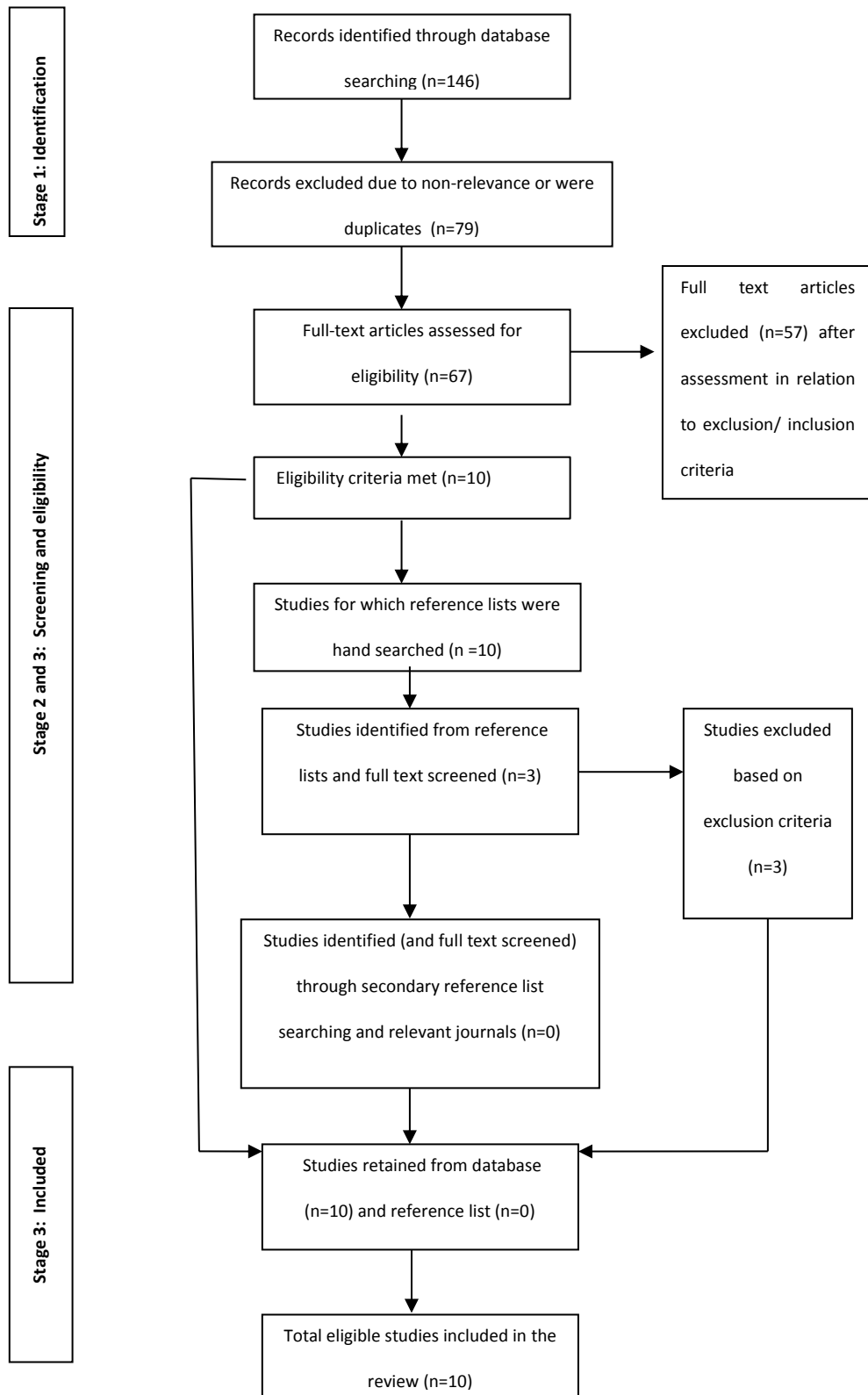


Figure 2. Flow diagram presenting the study selection process (Moher, Liberati, Tetzlaff & Atman, 2009)

### **1.3.8 Quality assessment**

The studies selected for the current review utilised both quantitative and qualitative research methods. The range of psychological and health research is wide and can be of a quantitative and/or qualitative nature. Both research approaches provide valuable information and often complement each other. Until recently, critical reviews of literature have often omitted qualitative studies (Dixon-Woods, Argarwal, Jones, Young & Sutton, 2005). However, it has become increasingly unacceptable to exclude research on the grounds of its methodology as the findings of such studies could have important implications. Therefore the current review included both qualitative and quantitative evidence to facilitate the consideration of a wider spectrum of evidence.

A quality framework that would adequately appraise both types of literature was sought. Traditionally, quality frameworks have focused on evaluating quantitative literature (Caldwell, Henshaw & Taylor, 2005). This has resulted in a tendency to evaluate qualitative research against criteria appropriate for quantitative research, which may lead to unfair criticism (Caldwell et al., 2005). Caldwell et al. (2005) noted that whilst some authors critique qualitative and quantitative research with separate frameworks, there is a move towards convergence and a need to establish a common approach between both research methods. As such, the quality assessment framework developed by Caldwell et al. (2005) was used to assess the papers comprising the current review (see Appendix II).

#### **1.3.8.1 Quality assessment results**

The studies were considered against 18-quality criteria, and rated as: 0, criterion not met; 1, criterion partially met; or 2, criterion met. The total number of ratings was then calculated and a score out of 36 given to each paper (see Appendix III). The mean for qualitative studies was 26 with a range of 22-30 while the mean for quantitative studies was 29.57 with a range of 21-34.

#### **1.3.8.2 Reliability of quality ratings**

To enhance the reliability of the quality assessment, a second researcher independently rated two articles and an inter-rater reliability analysis using the Kappa statistic was performed. The results of the inter-rater analysis were Kappa = .913 ( $p < .001$ ), 95% CI (0.746 – 1.08) indicating an almost perfect level of agreement, and Kappa = .163, ( $p = .407$ ), 95% CI (-0.213 - 0.539), indicating a slight level of agreement. As a rule of thumb values of Kappa from .40 to .59 are considered moderate, .60 to .79 substantial, and .80 outstanding (Landis & Koch, 1977). Given the low Kappa coefficient for the second study, the reviewers met to discuss the discrepancies between their ratings. The points of this discussion were used to inform the rigour of the approach to quality rating all studies. Following this discussion the study was rated again by both reviewers and the amended Kappa = .523 ( $p < .005$ ), 95% CI (0.147 – 0.899) indicating a moderate level of agreement.

#### **1.3.8.3 Summary of quality assessment**

No studies were excluded on the basis of poor quality. The quality review process was particularly helpful in assessing the methodological quality and potential biases in the reviewed studies. It is important to note that overall, quantitative studies attained higher scores on the quality assessment than qualitative research. It is possible such differences in quality ratings were a consequence of comparing both research methodologies and their differing epistemologies. It may also be indicative of limitations of quality frameworks that explore both research methodologies.

#### **1.3.9 Data synthesis**

The analysis in the present review used thematic synthesis techniques (Britten, Campbell, Pope, Donovan, Morgan & Pill, 2002; Lloyd, Patterson & Muers, 2014). Following the identification of relevant studies, each paper was reviewed closely to identify the dominant themes. Following this, similarities and differences between study findings were critically evaluated. The themes relevant to the aim of the present review are presented (Dixon-Woods et al., 2005).

#### **1.3.10 Study characteristics**

Table 2 summarises the key characteristics of the studies reviewed. Seven quantitative studies and three qualitative studies were reviewed. The results of the

current review are presented in relation to the aims of the review identified in section 1.2.6.



Table 2. *Summary of study characteristics*

Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
<p>Ankri, J., Andrieu, S., Beaufils, B., Grand, A., &amp; Henrard, J. C. (2005).</p> <p>Beyond the global score of the zarit burden interview: Useful dimensions for clinicians.</p> <p>Paris, France</p> <p>To explore the structure of the ZBI</p> <p>To examine the relations of the dimensions found within functional disabilities and other patient health indicators</p>	Cross-sectional	Purposive	152 dyads*	<p><u>Care recipients</u></p> <p>Recruited from: an outpatient memory clinic, community dwelling</p> <p>Gender: 106 female, 47 male</p> <p>Dementia severity: 42.9% CDR=1, 50.8% CDR=2, 2.4% CDR=3</p> <p>Age, mean (SD): 80.9 (7.0)</p> <p>MMSE, mean (SD): 20.2 (5.8)</p> <p>Dementia diagnosis: AD (67.6%), VaD (9.2%), Mixed dementia (10.6%), other (12.6%)</p> <p>Duration of symptoms in months mean (SD): 29.7 (21.6)</p> <p><u>Caregiver</u></p> <p>Kinship: Spouse (49.3%), adult child (44.2%), other (niece, nephew, friend (4.3%), regular home help (2.2%))</p> <p>Age: no information</p>	<p>22-item Zarit Burden Interview (ZBI) (Zarit et al., 1986 as cited in Ankri et al., 2005)</p> <p>Resident Assessment Instrument (RAI) (Morris et al., 1999a as cited in Ankri et al., 2005; Morris et al., 1999b as cited in Ankri et al. 2005)</p> <p>Clinical Dementia Rating (CDR) (Hughes et al., 1982 as cited in Ankri et al., 2005)</p> <p>Mini-Mental State Examination (MMSE; Folstein et al., 1975 as cited in Ankri et al., 2005)</p>	Measures completed	Factor analysis	<p>Factor analysis of 22 ZBI items: Five factors had an eigenvalue greater than 1; three were retained</p> <p>1) Consequences on caregivers daily social and personal life (accounted for 41.5% of the variance)</p> <p>2) Psychological burden and emotional reactions (8.6% of the variance)</p> <p><b>3) Guilt (6.2% of the variance)</b></p> <p>- Adult children scored higher on factor 3 (guilt)</p> <p>- Scores on factor 3 increased with verbal aggression, sadness, depression, lack of instrumental activities of daily living and progression of dementia (irrespective of MMSE or CDR)</p> <p>Children less involved in daily care were more</p>	32/36

prone to 'guilt' as defined by the questions on ZBI

Guilt and fear of inadequacy increased with the severity of the illness and psychological problems such as sadness and depression

Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
<p>Conde-Sala, J., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., &amp; López-Pousa, S. (2010).</p> <p>Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design.</p> <p><i>Spain</i></p> <p>To identify and compare the factors associated with caregiver burden among spouse and adult-child caregivers.</p> <p>Examined the extent to which patient and caregiver factors contribute and caregiver</p>	Cross-sectional	Purposive	251 dyads	<p>Recruited from: Memory and Dementia Assessment unit Gender: Males 34.0%. Females 66.0%</p> <p>Relationship to care recipient: 112 spouses and 139 adult-child</p> <p><u>Spouses</u> Age, mean (SD): 73.66 (7.48). (range 56-87) Living with the patient: 112 (100%)</p> <p><u>Adult-child</u> Age, mean (SD): 49.39 (7.29). (range 28-65) Living with the patient: 55 (39.6%)</p> <p>Dementia diagnoses: AD (DSM-IV criteria) Dementia severity: minimal, mild moderate and severe.</p>	<p><u>Caregiver Burden:</u> Zarit Burden Interview (ZBI; Zarit et al, 1986 as cited in Conde-Sala et al., 2010) <u>Socio-demographics</u> Cambridge Mental Disorders of the Elderly Examination Revised (CAMDEX-R; Roth et al., 1998 as cited in Conde-Sala et al., 2010) (Spanish adaptation; Vilalta-Franch et al., 1990 as cited in Conde-Sala et al., 2010)</p>	Measures completed.	Quantitative-Multivariate linear regression analysis	<p>Previous factor analysis (Turró-Garriga et al., 2008 as cited in Conde-Sala et al., 2010) was used for the internal analysis of the CBI (Zarit et al., 1986 as cited in Conde-Sala et al., 2010). Factor 1, social burden; Factor 2, psychological stress; <b>Factor 3 feelings of guilt</b>; Factor 4, emotional pressure; Factor 5, relationship of dependency.</p> <p>Greater burden among adult-child on F1, F2 and F3, but the most significant difference was in the guilt factor.</p> <p>Feelings of guilt were associated with not</p>	34/36

burden	<p><u>Cognitive Assessment</u> Cambridge Cognitive Examination – Revised (CAMCOG-R). Mini Mental State Examination (MMSE; Folstein et al., 1975 as cited in Conde-Sala et al., 2010)</p> <p><u>Functional Assessment</u> Disability assessment for dementia (DAD; Gelinas et al., 1999 as cited in Conde-Sala et al., 2010).</p> <p><u>BPSD</u> Spanish adaptation of Neuropsychiatric Inventory (NPI; Vilalta-Franch et al., 1999 as cited in Conde-Sala et al., 2010)</p> <p><u>Caregiver Physical and Mental Health</u> Health Survey (SF-12; Ware et al., 1996 as cited in Conde-Sala et al., 2010, Spanish adaptation;</p>	<p>living with the patient.</p> <p>Differences in the experience of burden between adult-child and spouse caregivers of persons with dementia</p> <p>Although sons scored higher on burden, daughters showed the strongest correlation between burden and mental health.</p>
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Alonso et al.,  
1998 as cited in  
Conde-Sala et al.,  
2010)

Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
Gruffydd, E., & Randle, J. (2006).  Alzheimer's disease and the psychosocial burden for caregivers.  <i>UK</i>  To explore the psychosocial impact of caring for someone with AD	Cross- sectional	Purposive	8 caregivers	Recruited from: Alzheimer's Association Kinship: spouses Gender: 4 male, 4 female Living situation: community (3), community hospital (4), residential home (1)	None	Semi- structured interview schedule	Descriptive Analysis (Colaizzi, 1978 as cited in Gruffydd & Randle, 2006)	Four themes emerged: 1) 'Changes' 2) 'Not knowing' 3) 'Dealing with behaviour' 4) 'Fallout'  Within the theme 'dealing with behaviour' all caregivers identified that they became physically and psychologically 'tired', as well as experiencing physical symptoms of stress including increased blood pressure and anxiety.  As part of the theme 'fallout' all participants felt some level of guilt, either due to not being patient enough or for feeling they have failed their spouse  Concluded that a number of 'negative psychosocial	30/36

								consequences' as a result of caring for someone with AD, one of which was feelings of guilt. Identified that support is considered to be the key element in reducing this.	
Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
Karlin, N. J., Bell, P. A., & Noah, J. L. (2001).  Long-term consequences of the Alzheimer's caregiver role: A qualitative analysis.  USA  To examine the long term consequences of caring for PwD	Longitudinal	Purposive	51 caregivers	Recruited from: Earlier quantitative study (Karlin, Bell & Noah, 1999 as cited in Karlin et al., 2001; Miller & Guo, 2000 as cited in Karlin et al., 2001), Gender: Males 43.1%. Females 56.9%. Age, mean: 67.3 Relationship to care recipient: Adult-child (37.2%); spouse (54.9%); sibling (3.9%); grand-child (2%); distant relative (2%) Length of time caring, mean: 8.4 years (range 1.3-22). Ethnicity: 48 Caucasian, 1 African-American, and 2 Hispanic. Dementia diagnoses: AD Dementia severity: No information	None	Semi-structured interviews	Thematic analysis	There were 7 themes identified: role issues and role reversal, problems and burden of being a caregiver, support sources and resources, support group issues, protection, nursing home placement, and guilt, research awareness and participation and additional contributions as a caregiver.  The burden of the role leads to substantial emotional toll- including feelings of guilt related to not being able to do enough for the patient and nursing home placement.	22/36

Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
<p>Losada, A., Marquez-González, M., Penacoba, C., &amp; Romero-Moreno, R. (2010).</p> <p>Development and validation of the caregiver guilt questionnaire</p> <p><i>Spain</i></p> <p>To develop a measure that will assess guilt in the context of dementia caregivers</p>	Cross-sectional	Purposive	288 caregivers	<p>Recruited from: Social and Health Care Centres.</p> <p>Gender: Males 20.8%. Females 79.2%.</p> <p>Mean age: 59.63 years</p> <p>Relationship to care recipient: Spouse- 37.2%; adult-child- 57.6%; other relative- 5.2%</p> <p>Length of time caring: No information</p> <p>Ethnicity: No information</p> <p>Dementia diagnoses: AD- 58.4%, other dementia, 41.6%</p> <p>Dementia severity: No information</p>	<p>Zarit Burden Interview (Zarit et al 1980)</p> <p>The revised memory and behavioural problems checklist, (Teri at al 1992 as cited in Losada et al., 2010)</p> <p>Barthel Index (Mahoney and Barthel, 1965 as cited in Losada et al., 2010) to explore functional status</p> <p>Leisure time satisfaction measure, (Stevens et al 2004 as cited in Losada et al., 2010)</p> <p>The Psychosocial Support Questionnaire (PSQ; Reig et al 1991 as cited in Losada et al., 2010)</p> <p>The Tension Anxiety subscale from the profile of mood states (POMS, McNair</p>	Semi-structured interviews	Principal components analysis	<p>22 items from the measure were retained. The factors were named: guilt about wrong doing by the care recipient, guilt about not rising to the occasion as caregivers, guilt about self-care, guilt about neglecting other relatives and guilt about negative feelings towards other people. Reliability was acceptable and significant associations were found to CGQ and ZBI guilt factors.</p> <p>Adult children experienced higher levels of guilt than spouses. Females were more likely to report feelings of guilt, as well as greater role conflict and role strain. Females are also found to report more burden in the caregiving literature.</p> <p>Hypothesised that caregiver guilt contributes to development and</p>	32/36

					et al 1971 as cited in Losada et al., 2010) Centre for Epidemiological Studies-Depression ale (CEDS-D; Radloff, 1977 as cited in Losada et al., 2010)			exacerbates caregiver burden.	
Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
Parks, S. H., & Pilisuk, M. (1991).  Caregiver burden - gender and the psychological costs of caregiving.  USA Examine the combined effects of control, support and coping style on the psychological costs of caregiving To present a systematic account of the psychological costs of caregiving	Snow-balling	Purposive	176 caregivers	Recruited from: A University medical centre's Alzheimer's disease clinic. Gender: 51 Males (40%). 125 Females (60%). Age: No information Relationship to care recipient: All adult children to a parent with Alzheimer's disease Length of time caring: No information Ethnicity: Almost entirely white Dementia diagnoses: AD Dementia severity: No information	Hopkins Symptoms Checklist-90 (Derogatis, 1982 as cited in Parks and Pilisuk, 1991) Measured by a 7 item locus of control measure. The Burden Interview (Zarit, Gatz & Zarit, 1981 Parks and Pilisuk, 1991 ; Zarit et al 1980) The provisions of social support scale, (Turner, Frankel & Levin, 1983 as cited in Parks and Pilisuk, 1991)	Structured interview	Principal factor analysis to explore coping styles  Multiple regression	The analysis identified four categories of burden. Two of which were psychological: guilt and resentment, and two were identified to work load and environmental factors: being overwhelmed and embarrassed.  Psychological factors associated with the caregivers' well-being were identified as anxiety, depression, feelings of guilt and resentment towards the parent.  Identified different coping styles between men and women. For women a sense of being out of control	26/36

								predicted depression, anxiety and guilt.	
Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
<p>Roach, L., Laidlaw, K., Gillanders, D., &amp; Quinn, K. (2013).</p> <p>Validation of the caregiver guilt questionnaire (CGQ) in a sample of British dementia caregivers.</p> <p>UK.</p> <p>To test the psychometric properties of the Caregiver Guilt Questionnaire in British dementia caregivers</p>	Cross-sectional	Purposive	221 Caregivers	<p>Recruited from: A larger project exploring outcome measures for dementia caregivers.</p> <p>Gender: 76 (34.4%) Males. 145 (65.6%) Females.</p> <p>Age. mean: 68.6</p> <p>Relationship to care recipient: Spouse 80.5%; adult-child 17.3%.</p> <p>Length of time caring, mean (SD): 4.4 years (3.8)</p> <p>Ethnicity: No information</p> <p>Dementia diagnoses: Alzheimer's disease- 110 (51.4%) Other dementia- 74 (33.5%)</p> <p>Dementia severity: No information</p>	<p>Caregiver Guilt Questionnaire (Losada et al., 2010)</p> <p>Zarit Burden Inventory Guilt factor, (ZBI Zarit et al., 1980)</p> <p>Center for Epidemiological Studies Depression, (CES-D, Radloff, 1977 as cited in Roach et al., 2013)</p>	Measures completed.	Principal axis factoring	<p>Discusses guilt as a separate psychological construct to burden and depression, although measures convergent validity with guilt factor from ZBI.</p> <p>The 5 factor structure of guilt found by Losada et al. (2010) was replicated in a British sample of dementia caregivers.</p> <p>Established a clinical cut-off score of 22.</p> <p>CGQ and guilt factor of ZBI correlated strongly and positively.</p> <p>Adult child caregivers experienced higher levels of guilt in comparison to spouses. Female caregivers experienced higher levels of guilt.</p>	33/36



Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
<p>Rosa, E., Lussignoli, G., Sabbatini, F., Chiappa, A., Di Cesare, S., Lamanna, L., &amp; Zanetti, O. (2010).</p> <p>Needs of caregivers of the patients with dementia.</p> <p>Italy</p> <p>The aim was to isolate the needs caregivers express within the following critical areas: medical, social, psychological and educational</p>	Cross-sectional	Purposive	112 caregivers	<p>Recruited from: Patients admitted to the Alzheimer's Dementia Research and Care Unit, Memory Clinic, Brescia</p> <p>Gender: 77 (69%) females and 35 (31%) males.</p> <p>Age, mean (SD): 55 (10)</p> <p>Relationship to care recipient: No information</p> <p>Length of time caring, No information</p> <p>Ethnicity: No information</p> <p>Dementia diagnoses: No information</p> <p>Dementia severity (mean MMSE): 9 +/- 7 No information</p>	<p>Caregiver Burden Inventory (CBI; Novak &amp; Guest, 1989), Socio-demographic variables, Objective burden indicators (e.g. daily hours dedicated to caring), Center for Epidemiological Studies Depression, (CES-D, Radloff, 1977 as cited in Rosa et al., 2010); State-Trait Anxiety Inventory (STAIY1; STAIY2, Spielberger et al., 1990 as cited in Rosa et al., 2010), "Questionnaire assessing caregivers needs" measured caregivers needs in 4 domains 1) medical 2) educational needs 3) emotional and</p>	Measures completed	<p>Statistical analysis using SPSS: Variance analysis</p>	<p>Variance analysis showed correlation between emotional needs expressed and the subjective and objective burdens reported.</p> <p>Need for emotional support with feelings of guilt (along with other things) linked to objective and subjective burden.</p> <p>Those who reported more objective burden also had problems with emotions such as rage and guilt (<math>p&lt;0.0002</math>)</p>	21/36

psychological  
needs, 4) service  
needs

Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
<p>Samuelsson, A. M., Annerstedt, L., Elmståhl, S., Samuelsson, S., &amp; Grafström, M. (2001).</p> <p>Burden of responsibility experienced by family caregivers of elderly dementia sufferers: Analyses of strain, feelings and coping strategies.</p> <p><i>Sweden</i> To gain a deeper understanding of the caregivers burden and the experience of giving care to a relative suffering from dementia</p>	Cross-sectional	Purposive	8 family caregivers of elderly dementia sufferers	<p>Recruited from: An on-going study of PwD rehoused in Malmö, Sweden.</p> <p>Gender: 4 females and 4 males</p> <p>Age, range: 38-63</p> <p>Relationship to care recipient: 5 adult children, 2 spouses, 1 adult-child in-law</p> <p>Length of time caring: No information</p> <p>Ethnicity: No information</p> <p>Dementia diagnosis: Either AD or VaD</p> <p>Dementia severity: MMSE scores 1-17</p>	None	Open-ended questions	<p>Content Analysis (Knall &amp; Webster, 1988 as cited in Samuelsson et al., 2001; Miles &amp; Huberman, 1994 as cited in Samuelsson et al., 2001)</p>	<p>The analysis identified six categories reflecting the feelings and experiences of the caregivers: 1) 'Symptoms of dementia, 2) The patient's situation, 3) Relationship before onset of dementia, 4) The caregiver's strain, 5) The caregiver's emotions, 6) The caregiver's coping strategies.</p> <p>Feelings of guilt were seen as part of the emotional burden caregivers experienced. The two husbands 'shouldered the heaviest burden' Concluded that the family caregivers of dementia sufferers experience high emotional burden, with feelings of guilt as a part of that. Feelings of guilt were conceptualised as part of the emotional</p>	26/36

								strain/burden experienced by caregivers.	
Authors, Title of study, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Data Analysis	Key Findings	Quality Score
Springate, B. A., & Tremont, G. (2014).  Dimensions of caregiver burden in dementia: Impact of demographic, mood, and care recipient variables.  USA To explore the dimensions of the ZBI in a sample of dementia caregivers experiencing high levels of distress To examine different predictors of these dimensions of caregiver burden To explore the relationships between different aspects of caregiver burden, demographic variables, caregiver depression and patients behavioural symptoms and cognitive and functional status.	Cross-sectional	Purposive	206 caregivers	Recruited from: Memory disorders centres, geriatricians and community advertising Gender: 87.7% female, 12.3% male Age, mean (SD): 62.88 (12.69) years Relationship to care recipient: 114 spouses, 92 adult children Length of time caring, mean (SD): 45.29 (35.50) months Ethnicity: No information Dementia diagnoses: AD (78.7%), FTD (3.2%), VaD (2.8%) and Lewy body dementia (1.9%) Dementia severity: mild-moderate	Zarit Burden Interview (Zarit et al 1980); Center for Epidemiological Studies Depression, (CES-D, Radloff, 1977 as cited in Springate & Tremont, 2014); Burns Relationship Satisfaction Scale (BRSS; Burns, Sayer, unpublished data, 1988 as cited in Springate & Tremont, 2014); Revised Memory and Behaviour Problem Checklist (RMBPC; Teri, Truax, Logsdon et al., 1992 as cited in Springate & Tremont, 2014); Lawton-Brody Activities of Daily Living	Measures completed	Exploratory Factor Analysis, Multiple regression	83.9% of caregivers reported clinically significant burden.  Factor analysis of ZBI found 5 factors, but only 3 were retained; 1) direct impact of caregiving upon caregivers lives, 2) feelings of guilt, 3) frustrations and embarrassment. Guilt factor scores were positively correlated with both caregiver and patients depression scores. Guilt was negatively correlated with caregiver age Guilt was <b>not</b> associated with patient's global cognition, behavioural problems of functional abilities. Caregiver age and CES-D scores emerged as significant predictors of guilt, as measured by the guilt factor on ZBI. Adult children reported	29/36

	<p>Questionnaire (Lawton &amp; Brody, 1969 as cited in Springate &amp; Tremont, 2014); Dementia Rating Scale-2 (DRS; Jurica, Leitten &amp; Mattis, 2001 as cited in Springate &amp; Tremont, 2014)</p>	<p>higher levels of burden specifically impact on lives and guilt</p>
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*\* Please note the error in sample size calculation is an error in the original article.*

## **1.4 Findings**

Empirical findings from the studies reviewed are described under the following four broad areas: the conceptualisation of guilt in relation to burden; caregiver characteristics; care-recipient characteristics and the role of support.

### **1.4.1 The conceptualisation of guilt in relation to burden**

Review of the studies raises questions about the relationship between caregiver guilt and burden. Some studies have conceptualised guilt as a component of CB, but an independent factor to psychological burden, while others have found guilt to be a specific component of the construct of psychological burden. Still other studies have conceptualised caregiver guilt and burden as two separate constructs, concluding that guilt in caregivers of PwD is a complex and multidimensional construct that warrants independent research and measurement.

#### **1.4.1.1 Guilt as a dimension of burden**

Two of the quantitative studies reviewed conducted a factor analysis (FA) of the ZBI (Zarit et al., 1980) (Ankri et al., 2005; Springate & Tremont, 2014). Ankri and colleagues (2005) used 152 dyads of French, community dwelling PwD and their primary caregivers. The sample included primarily spousal and adult-child caregivers, 56% of which lived with the person with dementia. Factor analysis led to the identification of three relevant factors; *'the social consequences for the*

*caregiver*'; *'psychological burden*'; and *'feelings of guilt*'. Ankri et al. (2005) concluded that guilt was a component of burden, but that *'feelings of guilt*' and *'psychological burden*' were two separate components of burden. *'Feelings of guilt*' was seen to refer to the caregivers' sense that they should be doing more for the care recipient and that they could do a better job of caring, whereas *'psychological burden*' comprised other emotional reactions to caregiving, including embarrassment, tenseness, strain and anger (Ankri et al., 2005).

Springate and Tremont (2014) also identified feelings of guilt as a component or factor of burden. This sample included 114 spousal, and 92 adult-child caregivers of PwD from the US. As with Ankri's study an exploratory FA of the ZBI resulted in three factors being retained. However, two of the three factors were described differently from the factors identified by Ankri, though they do seem to refer to similar and broadly comparable aspects of burden. The three factors were: *'direct impact of caregiving upon caregivers*', *'feelings of guilt*', and *'frustration and embarrassment*'.

The ZBI items that constituted the guilt factor in Ankri's and Springate's study were similar, however Ankri included the items, *'Do you feel you don't have enough money to support your relative in addition to the rest of your expenses?'* and *'Do you feel that you will be unable to take care of your relative much longer?'*

Springate and Tremont (2014) included the question '*Do you feel angry when you are around your relative?*' in the guilt factor of burden, however Ankri allocated this item to the '*psychological burden*' factor. These differences in the ZBI items comprising the factors points to some inconsistency in findings between the two studies and indicates a need for further studies to clarify these ambiguities.

Gruffydd and Randle (2006) explored the psychosocial burden for caregivers of people with AD. The sample included eight spousal caregivers, four husbands and four wives, all recruited via the Alzheimer's Association (AA) in the UK. Descriptive analysis of semi-structured interviews identified four themes; 'changes'; 'not knowing'; 'dealing with behaviour' and 'fallout'. Within the theme 'fallout', the authors identified that all caregivers experienced feelings of guilt. The guilt experienced by caregivers in this study was attributed to not being patient enough with the person with dementia, and/or feelings of failure about not being able to care for them at home. In this study, the researchers conceptualised guilt as a component of the psychosocial burden of caregiving for PwD. It is not clear how they came to this conclusion. The researchers state that their findings identified a number of negative psychosocial consequences for caregivers, but go on to conceptualise this as psychosocial burden in the title. However, no assessment measure was used to show that participants felt 'burdened', nor were they recruited according to strain or burden. The reader can only assume it was based on the researchers own conceptualisation and definition of guilt and burden, thus

creating doubt around the credibility of the findings. This was a small study conducted with only spousal caregivers, reducing the transferability of the findings. Caregivers were also recruited from the AA, which may have biased the findings as it can be argued caregivers accessing support services may not represent the wider population of dementia caregivers.

A quantitative study (Parks & Pilisuk, 1991) exploring the psychological costs of caregiving for PwD conducted a FA of the ZBI. The sample included 176 adult-child caregivers of parents with AD, 125 females and 51 males. The analysis revealed four factors of burden: *'guilt'*, *'resentment'*, *'being overwhelmed'* and *'embarrassment'*. These four factors were grouped into two categories: *'psychological costs'* (guilt and resentment) and *'workload and environmental factors'* (being overwhelmed and embarrassment). This study obtained a relatively low score in the quality assessment (28/36) and the findings should therefore be interpreted cautiously, particularly in the absence of any replication studies.

#### **1.4.1.2 Guilt as a separate construct to burden**

In contrast to the findings suggesting that guilt may be a component of burden (Ankri et al., 2005; Gruffydd & Randle, 2006; Parks & Pilisuk, 1991; Springate & Tremont, 2014), research elsewhere has conceptualised guilt as a separate construct to CB. The development and validation of the CGQ on samples of Spanish



(Losada et al., 2010) and British caregivers (Roach, Laidlaw, Gillanders & Quinn, 2013) highlighted the importance of understanding caregiver guilt and the complexity of this emotion in relation to caring for PwD, independently of CB.

Principal components analysis of the CGQ in this study identified five factors: *'guilt about doing wrong by the care recipient'*; *'guilt about failing to meet the challenges of caregiving'*; *'guilt about self-care'*; *'guilt about neglecting other relatives'*; and *'guilt about having negative feelings towards other people'* (Losada et al., 2010). The study's sample included 288 Spanish dementia caregivers, 228 females and 60 males. There were 107 spousal caregivers and 166 adult-child caregivers, with an average age of 78.97.

The first two factors showed good convergent validity with the ZBI guilt factor obtained by Ankri et al. (2005) ( $r = .401^{**}$ ;  $r = .352^{**}$ ). The moderate, positive correlation between the Ankri's ZBI guilt factor and the total CGQ score ( $r = .455^{**}$ ) suggests that guilt and burden are related constructs, however correlational analyses does not allow one to determine the precise nature of the relationship.

The weak correlations between Ankri's ZBI guilt factor and the CGQ factors of *'guilt about self-care'* ( $r = .182^{*}$ ), *'guilt about having negative feelings towards other*

*people'* ( $r = .177^*$ ) and *'guilt about neglecting other relatives'* ( $r = .136$ ) demonstrated that the CGQ measured dimensions of guilt not accounted for by the ZBI guilt factor obtained by Ankri et al. (2005), thus lending support to the conceptualisation of guilt as an independent, albeit related, construct. Therefore, given the evidence reviewed it appears caregiver guilt may be best conceptualised as an independent construct to caregiver burden, however further research is needed to clarify this.

#### **1.4.2 Caregiver characteristics**

##### **1.4.2.1 Relationship of caregiver**

A number of the studies reviewed explored differences in CB and guilt between adult-child and spousal caregivers of PwD (Ankri et al., 2005; Conde-Sala et al., 2010; Losada et al., 2010; Roach et al., 2013; Samuelsson, Annerstedt, Elmståhl, Samuelsson & Grafström, 2001; Springate & Tremont, 2014). In studies looking at caregiver guilt as a component of burden, caring for a parent with dementia was found to be associated with greater levels of burden, specifically on ZBI guilt factors, than caring for a spouse (Ankri et al., 2005; Conde-Sala et al., 2010; Springate & Tremont, 2014). Ankri et al. (2005) similarly found that adult-child caregivers scored higher on their ZBI guilt factor specifically.

A cross-sectional study exploring the differential features of burden between spousal and adult-child caregivers (Conde-Sala et al., 2010) used data collected from 112 spouse and 139 adult-child caregivers of PwD in Spain. The sample comprised of 34% males and 66% females. Not living with a parent was associated with higher levels of guilt as measured by the '*feelings of guilt*' subscale of the ZBI obtained by a previous FA study (Turro'-Garriga et al., 2008 as cited in Conde-Sala et al., 2010). Adult-child caregivers living with their parent with dementia experienced higher levels of burden when compared to spouse caregivers that lived with the person with dementia (Conde-Sala et al., 2010). Sons were found to have the highest overall burden scores, however no data was presented on comparisons between sons and daughter's scores on the guilt subscale of burden (Conde-Sala et al., 2010).

These results were replicated by Springate and Tremont (2014) who also found that spousal caregivers reported significantly less guilt-specific burden than adult-child caregivers. Scores on their ZBI guilt factor were negatively correlated with age. Caregivers living separately from the care recipient also scored significantly higher on this factor.

Two of the studies reviewed examined differences in caregiver guilt between spouse and adult-child caregivers using the CGQ (Losada et al., 2010; Roach et al.,

2013). Adult-child caregivers had higher total CGQ scores than spouses, and higher scores on all CGQ factors (Losada et al., 2010). The ZBI guilt factor obtained by Ankri et al. (2005) was used to assess convergent validity in Losada's (2010) study. Significant correlations were found between this ZBI guilt factor and CGQ total score and all factors with the exception of '*guilt about neglecting other relatives*'. This finding suggests that the ZBI guilt factor obtained by Ankri et al. (2005) may not capture all domains of caregiver guilt, as there was no significant correlation found with this fourth factor of the CGQ. Similarly, Roach et al. (2013) used the ZBI guilt factor obtained by Ankri et al. (2005) to measure convergent validity of the CGQ in a sample of 221 British caregivers of PwD. They also found that adult-child caregivers reported higher levels of guilt as measured by the CGQ and the ZBI guilt factor (Roach et al., 2013).

Finally, a qualitative study exploring the 'burden of responsibility experienced by family caregivers' of PwD concluded that husbands experienced the heaviest burden, and expressed feelings of guilt (Samuelsson et al., 2001). The sample from this Swedish study included eight family caregivers of PwD, six adult-child caregivers and two husbands. Participants were selected according to '*strain*' as measured by a CB scale developed from a measure originally used for caregivers of individuals with a chronic illness, thus limiting the generalisability of the result to a wider sample of caregivers. Qualitative content analysis of in-depth interviews resulted in six categories; '*symptoms of dementia*'; '*the patient's situation*';

*'relationship before onset of dementia'; 'the caregiver's strain'; 'the caregiver's emotions'; and the 'caregiver's coping strategies'.* Caregiver guilt was discussed within the theme *'the caregiver's emotions'*. Specifically, feelings of guilt about not doing enough were emphasised and were reported most frequently by husbands.

Of the studies reviewed that directly compared adult-child and spousal caregivers, all but one found adult-child caregivers of PwD experience higher levels of guilt and burden. The methodological differences in these studies make it difficult to draw firm conclusions. In addition to this, these studies were conducted in a number of different countries (USA, UK, Spain and Sweden). Cultural differences between studies, such as differences in expectations regarding family-led care, may influence how caregivers experience burden and guilt, making findings across studies difficult to compare. Guilt is considered a culturally sensitive emotion that is strongly influenced by cultural values, social norms and cultural conceptions of identity and the self (Bierbrauer, 1992).

#### **1.4.2.2 Gender**

The influence of gender on CB and guilt was explored in four of the studies reviewed (Conde-Sala et al., 2010; Losada et al., 2010; Parks & Pilisuk, 1991; Roach et al., 2013). Conde-Sala et al. (2010) found that among spousal caregivers, wives reported the greatest burden, but made no comment on differences reported

specifically on the guilt subscale of burden used in this study (Turro'-Garriga et al., 2008 as cited in Conde-Sala et al., 2010). In contrast, they found that sons scored higher on burden but daughters showed a stronger correlation between burden scores and mental health. However, these comparisons were only made on the total burden scores. No analysis was conducted on possible gender differences on the separate subscales of burden; therefore limited conclusions can be made with regard to gender differences and guilt.

Losada et al. (2010) and Roach et al. (2013) explored gender and caregiver guilt using the CGQ. Both these studies reported that female caregivers scored higher on the CGQ than male caregivers. Losada et al. (2010) suggested this was particularly apparent on the factors '*guilt about neglecting other relatives*' and '*guilt about having negative feelings towards other people*'. However, 79.2% of the sample was female. Women generally perceive more responsibility for caring for family members, thus female caregivers may be more susceptible to guilt about neglecting others. They also noted that higher scores on the CGQ could explain why females report higher levels of burden than other caregivers, and hypothesised that caregiver guilt contributes to the generation and exacerbation of CB. However, the cross-sectional nature of Losada's (2010) study limits what inferences can be drawn about this causal hypothesis.

Roach et al. (2013) concluded that females experienced higher levels of guilt as measured by the CGQ total score, however they did not present findings for individual factor scores in relation to gender. This would have been interesting to compare and contrast with results from the Losada et al. (2010) study because the sample in Roach's study included more male caregivers.

Parks and Pilisuk (1991) examined the psychological costs and burden of caregiving for a parent with AD, in relation to caregivers coping styles and social support. They found that men who reported high sense of embarrassment, as an aspect of burden, also experienced high guilt. Women reported significantly more '*stress*' from their caregiving situation than men. It is assumed that '*stress*' refers to participant scores on the ZBI; however, this is not made clear in the paper and serves as one example of a lack of clarity that was noted across studies in the language used to define the negative effects of caregiving.

Whilst it is difficult to draw any firm conclusions due to differences in measurement of guilt and burden and female sample bias, it appears that women generally experience higher levels of guilt and burden associated with caregiving for a relative with dementia.

#### **1.4.2.3 Coping styles**

Coping styles in relation to guilt and burden appeared as a prominent theme in some of the studies reviewed. Parks and Pilisuk (1991) assessed caregiver coping styles based on their use of 52 types of expressive and instrumental coping behaviours during a recent stressful event involving the care-recipient. They found that women were more likely to cope using fantasy, while withdrawal was more common among men. A low personal sense of mastery predicted guilt in women. No analysis was presented on the relationships between overall ZBI scores and coping styles, which represent a weakness of this study. Caregiver coping strategies were reported as a theme in just one of the studies included in the present review (Samuelsson et al., 2001). Coping strategies were categorised as either problem-focused or emotion-focused. These authors reported that coping well or poorly was associated with the experience of burden and guilt.

One of the studies reviewed looked at the needs of caregivers of PwD (Rosa et al., 2010). Their sample included 112 primary caregivers of PwD, 77 females and 35 males. The average age of caregivers was 55. Caregiver burden was assessed using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989). Five factors of burden have been identified in the CBI; *'time dependence burden'*, *'developmental burden'*, *'physical burden'*, *'social burden'* and *'emotional burden'*. 'Sense of guilt' was categorised as an emotional reaction to caregiving. It was assessed using a questionnaire designed to evaluate caregivers' needs. The results highlighted a



positive correlation between caregiver need for emotional support with guilt and difficulty employing effective coping strategies. The emotional burden that caregivers reported increased as the employment of coping strategies decreased. Caregivers that expressed the greatest social burden also expressed greater need for support with guilt (Rosa et al., 2010).

It is important to note that this study was rated poorly in the quality appraisal (21/36), particularly due to concerns regarding the assessment of guilt and clarity of results. Caregiver guilt was assessed using a self-report questionnaire on the needs of caregivers for emotional support with negative emotions. No details were given on how the conclusions drawn regarding the experience of guilt were separated out from the experience of other emotions, including rage, embarrassment and grief, therefore raising questions about the reliability of the findings.

The evidence reviewed suggests that caregiver coping styles may play an important part in managing caregiver burden and guilt, however further research is needed to clarify what 'effective' coping strategies may be and for whom.

#### **1.4.2.4 Caregiver depression**

Many of the studies reviewed explored the relationship between caregiver guilt, burden and depression (Conde-Sala et al., 2010; Losada et al., 2010; Roach et al., 2013; Rosa et al., 2010; Springate & Tremont, 2014). Findings from one study suggest that daughters show the strongest correlation between burden and depressive symptoms ( $r = -.54^{***}$ ) (Conde-Sala et al., 2010) but no analysis on the relationship between guilt factor scores and mental health was presented. Rosa et al. (2010) concluded that caregivers who expressed the greatest need for emotional support with feelings of guilt also expressed higher levels of depressive symptoms.

Scores on the ZBI guilt factor obtained by Springate and Tremont (2014) also positively correlated with caregiver depressive symptoms. Of particular note in this study, was the finding that caregiver depression was a unique predictor of guilt as indicated by high scores on their ZBI guilt factor.

Both of the studies that used the CGQ found a positive correlation between scores on the CGQ and depressive symptoms (Losada et al., 2010; Roach et al., 2013), however these studies only administered the guilt factor of the ZBI obtained by Ankri et al. (2005) alongside the CGQ. Therefore, the relationship between CGQ scores, overall burden and depressive symptoms was not explored. Nonetheless, they do indicate a link between guilt and depression in caregivers of PwD.

### **1.4.3 Role of support**

Karlin, Bell and Noah (2001) explored the long-term consequences of caring for someone with AD. They employed a qualitative analysis on interviews with 51 family caregivers, a relatively large sample size for a qualitative study. Analysis identified seven themes. The authors concluded that the reported level of CB did not differ between those caregivers that were currently attending, no longer attending or had never attended a support group. Caregiver guilt in this study was discussed under the theme '*Protection, nursing home placement, and guilt*'. The authors hypothesised that guilt may precipitate dissatisfaction in the quality of care facilities and adequate emotional support is required to help alleviate caregiver guilt. This study only scored 22/36 on the quality appraisal, particularly falling down in presenting a clear and justified method of data analysis and producing a comprehensive discussion in which the findings were compared and contrasted with previous research. Furthermore, some of the PwD referred to in the study were in residential care. This should be kept in mind when interpreting the findings of this study.

Similarly, Gruffydd and Randle (2006) concluded that support in the form of increased information about the progression of AD and coping strategies is needed to reduce the '*psychosocial burden*' for caregivers of PwD but these authors did not discuss the role of support in caregiver guilt.

Social support and caregiver guilt were negatively correlated in the Losada et al. (2010) study. Social support was measured using The Psychosocial Support Questionnaire (PSQ; Reig et al., 1999 as cited in Losada et al., 2010). Caregivers with higher scores on the PSQ reported lower guilt on the CGQ factors of *'guilt about doing wrong by the care recipient'*, *'guilt about failing to meet the challenges of caregiving'*, and total CGQ scores. However, the cross-sectional design employed in this study means it is not possible to make causal inferences about guilt and frequency of social support.

The current review highlights that increased support in various forms may reduce caregiver burden and guilt. However, further research is needed to fully understand the precise nature of this relationship.

#### **1.4.4 Care recipient characteristics**

The impact of the functional, behavioural and cognitive status of the care recipient on CB and guilt was explored in several of the reviewed studies (Ankri et al., 2005; Conde-Sala et al., 2010; Losada et al., 2010; Springate & Tremont, 2014). Caregiver scores on the ZBI guilt factor in Ankri's study were related to the care recipients' verbal aggressiveness, depression, and functional disability. Total ZBI scores also increased significantly with the severity of dementia, behavioural difficulties and functional disability (Ankri et al., 2005).

Conde-Sala et al. (2010) found that CB increased with greater functional disability and behavioural and psychological symptoms of dementia (BPSD), noting differences between spousal and adult-child caregivers. Care recipient characteristics, especially the presence of BPSD, had a greater effect on CB in spouses than in adult-child caregivers, whereas high CB in adult-child caregivers was associated with caregiver characteristics, suggesting their experience of burden is less to do with the care recipient and more to do with their own difficulties in managing their caregiving role. No information from this study was available on the relationship between care recipient characteristics and scores on the guilt subscale of the ZBI used in this study (Turro'-Garriga et al., 2008 as cited in Conde-Sala et al., 2010). However, Springate and Tremont (2014) found that caregiver guilt, as measured by the ZBI guilt factor obtained in their study, was not associated with the recipients' cognitive, behavioural or functional abilities.

One study that used the CGQ explored the relationship between care recipient characteristics and caregiver guilt found significant correlations between caregiver guilt and behavioural problems in the care recipient (Losada et al., 2010). The authors concluded that higher functional status was '*positively*' associated with scores on one factor of the CGQ; '*guilt about failing to meet the challenges of caregiving*', lending further support to the view that guilt is an independent construct with multiple facets that have different relationships to variables such as care recipient characteristics.

There were inconsistencies between the studies reviewed with regard to the measures employed to assess care recipient characteristics. Only two of the studies reviewed used the same measure to assess behavioural problems in care recipients (Losada et al., 2010; Springate & Tremont, 2014). However, these two studies found contradictory results with regards to the association between care recipients' behavioural problems and caregiver guilt.

It is possible cultural differences between the Spanish and American samples of caregivers may have influenced the appraisal of behavioural difficulties and caregiver guilt. Further studies may help to determine whether or not this was the case. Also, the different measures used to assess caregiver guilt in these two studies may have contributed to the conflicting findings on the relationship between the care recipients' behavioural problems and caregiver guilt. Furthermore, the majority of care recipients in Springate and Tremont's (2014) study had AD (78.7%), however only 58.4% of care recipients in Losada's (2010) study were diagnosed with AD. Possible differences in diagnoses and levels of distress, in addition to aforementioned cultural differences, make direct comparison of findings from the two studies difficult.

From the papers reviewed it appears that there is a relationship between care recipient' characteristics and the experience of guilt and burden in caregivers;

particularly, between functional disability and CB. However, conflicting results make it difficult to come to any firm conclusions.

## **1.5 Discussion of findings**

### **1.5.1 Conceptualisation**

With regard to the conceptualisation of guilt, the studies reviewed broadly fell into two areas; guilt conceptualised as a factor or aspect of burden and guilt viewed as a separate, independent construct. Findings from the present review point to a lack of clarity in the literature regarding the conceptualisation of guilt in informal caregivers of PwD as well as a lack of clarity about the relationship of guilt to the construct of burden. The majority of studies reviewed assume that guilt is a facet of CB and fail to consider guilt as potentially an independent construct that may merit separate study. For example, does caregiver guilt influence caregiver help seeking and the use of respite services? Consequently, there is a paucity of empirical evidence exploring caregiver guilt as an independent construct and its psychological and behavioural implications for caregivers of PwD (Losada et al., 2010). Future research should endeavour to explore this further.

### **1.5.2 Measurement**

Many of the studies reviewed assessed caregiver guilt factors obtained from FA studies of the ZBI (Ankri et al., 2005; Conde-Sala et al., 2010; Parks & Pilisuk, 1991;

Springate & Tremont, 2014). The use of ZBI guilt factors to assess caregiver guilt implies the conceptualisation of guilt as an aspect of CB, however, not all factor analyses of the ZBI have identified guilt as a factor of CB (Bédard et al., 2001; Hébert et al., 2000; Knight et al., 2000; O'Rourke & Tuokko, 2003). Similarly, differences between studies in the allocation of ZBI items to the guilt factor indicate a need for further studies to clarify these ambiguities. The present review highlights that ZBI guilt factors do not measure all facets of caregiver guilt. Consequently, reliance on guilt factors obtained from FA of the ZBI to measure caregiver guilt is problematic.

The development and validation of the CGQ highlights the importance of considering guilt as a multidimensional construct in dementia caregivers. Factor analyses of the CGQ found multiple components of caregiver guilt (Losada et al., 2010; Roach et al., 2013) and significant relationships between individual factors of the CGQ, caregiver and care recipient characteristics, depression and anxiety (Losada et al., 2010; Roach et al., 2013). The use of the CGQ alongside the ZBI in future studies would be a more appropriate and robust approach to further our understanding of the nature of guilt in informal caregivers of PwD, and the relationship between guilt and burden.



### **1.5.3 Methodological considerations**

The quality assessment raised concerns regarding methodological issues in some of the studies reviewed. There was a lack of information in the qualitative studies regarding both methodology and data analysis. More explicit description of methodological processes followed would have strengthened those papers. Quantitative research was more adept at exploring the relationship between guilt, burden and other factors. However, the differing psychometric properties of the various measures used to assess other factors makes comparing and contrasting results difficult.

#### **1.5.3.1 Sampling**

All of the studies, apart from one, used purposive sampling. This was somewhat necessary given the specific caregiving population targeted. Findings from the present review highlight the limitations of purposive sampling and recruitment methods with regards to generalisability and transferability of the study findings. Dura and Kiecolt-Glaser (1990) suggested that studies regarding dementia caregivers might unintentionally recruit a non-representative sample. For example, dementia caregivers that take part in research are generally those who care for individuals with less severe dementia and can therefore travel to participate in studies (Dura & Kiecolt-Glaser, 1990).

Two of the studies reviewed here selected caregiver participants based on high reports of burden or distress (Samuelsson et al., 2001; Springate & Tremont, 2014), reducing the transferability and generalisability of these findings to a wider sample of dementia caregivers. Female caregivers dominated the samples in almost all of the studies reviewed, which is representative of informal caregivers as a population. Sixty to 70% of all unpaid dementia caregivers are women (Alzheimer's Research UK, 2015). However, this raises questions regarding the generalisability of results to male caregivers. Further research with male caregivers, as well as analysis of gender differences in studies of guilt, is needed. Furthermore, participants were primarily recruited from health and social care services, or support services. Therefore, the experiences of caregivers that do not access support services are not captured in this review.

There was also a lack of data provided in some of the studies reviewed in relation to sample characteristics such as length of time caring, ethnicity and severity of dementia. This is important as these factors have been found to be related to CB but have not yet been considered in studies of caregiver guilt (Gallicchio, Siddiqi, Langenberg & Baumgarten, 2002).

#### **1.5.4 Limitations**

The present review has a number of limitations. Firstly, it is possible the study selection criteria may have resulted in some relevant studies being excluded, despite efforts to be inclusive. For example, studies reviewed were limited to those written in English. This may have resulted in the exclusion of potentially relevant research published in other languages. The current review also excluded studies that focussed on guilt and burden in relation to specific decisions, as well as non-peer reviewed literature.

As mentioned, the present literature review did not include studies of caregiver guilt and burden in relation to specific decisions. Some studies have investigated feelings of guilt and burden in dementia caregivers at times of critical decisions (e.g. end of life, tube feeding) (Forbes, Bern-Klug & Gessert, 2000; Hoefler, 2000). However, it was felt that studies of the experience of caregiver guilt and burden in relation to specific treatment or transition-related decisions refer to emotional responses to very particular and time-specific contexts. These were considered to be distinct from the experience of guilt and burden more generally during the day-to-day lives of caregivers. It was also felt that it would be very difficult to directly compare the findings from studies of relating to the process of specific decision making with findings from other non-decision focussed studies, and would represent a departure from the focus of the review.

Finally, both qualitative and quantitative research was reviewed. As was anticipated, qualitative studies reviewed tended to focus on descriptions of guilt or burden and were less concerned with the way in which researchers had conceptualised guilt and CB. In general, quantitative studies were more proficient at explicitly exploring the relationship between these two concepts.

### ***1.5.5 Clinical implications***

#### ***1.5.5.1 Depression***

This current review highlights the strong association between depressive symptoms and caregiver guilt in dementia caregivers (Losada et al., 2010; Roach et al., 2013; Springate & Tremont, 2014). Some evidence suggests that guilt contributes to psychopathology and depression (Ghatavi et al., 2002; O'Connor, Berry, Weiss & Gilbert, 2002), while other studies claim that guilt is a positive construct that serves an adaptive and protective function (Tangney & Dearing, 2003; Tangney, Wagner, & Gramzow, 1992). Tangney and Dearing (2003) suggest the degree to which we can determine if guilt is maladaptive is, in part, down to how we define and measure it. Thus, the lack of consistency in the measurement of caregiver guilt in the studies reviewed presents as a significant limitation.

The specific role of caregiver guilt in the relationship between guilt, burden and depression is still unclear. Given the cross-sectional nature and measurement issues of many of the studies reviewed, it is difficult to determine whether guilt plays a predictive role or is a consequence of high levels of CB. However, the current review suggests that feelings of guilt, in relation to caregiving quality and ability, play a significant role in the psychological well-being of dementia caregivers. Given the quality ratings, reliability and validity statistics, and the establishment of a clinical cut-off score for the CGQ (Roach et al., 2013), there is evidence to suggest that it would be beneficial to clinically assess caregiver guilt using the CGQ.

#### ***1.5.5.2 Vulnerable groups***

The current review highlighted that caregiver and care recipient characteristics are related to caregiver guilt and burden and that not all caregivers of PwD who report high levels of burden will experience high levels of guilt. Conde-Sala et al. (2010) found a stronger association between burden and mental ill-health in daughters, however no analysis was presented on the relationship between guilt and mental health status. More in-depth analysis of the relationship between caregiver guilt and mental health difficulties is indicated. Of relevance here, Romero-Moreno et al. (2013) found that daughters of PwD who report higher levels of guilt have higher levels of depressive symptoms. This appears to suggest that caregiver guilt may be of clinical significance, at least for daughters of PwD. However, further investigation is needed to build on these preliminary findings.

The differences observed between adult-child and spousal caregivers in relation to guilt, burden and mental health difficulties highlights that caregivers should not be considered a homogenous group. It appears from the findings of the current review that clinical interventions should be tailored differently for adult-child and spousal caregivers to target the particular problematic factors of burden and guilt for each group identified in the literature. Here again, further research is needed to clarify the relationship between caregiver kinship, guilt, burden and depression.

#### ***1.5.5.3 Clinical assessment, formulation and intervention***

The findings of the current review highlight that it is important for clinicians to adopt a holistic and person-centred approach when delivering and developing interventions and services for dementia caregivers. Assessment and formulation of caregiver needs should take into account all factors that may contribute to caregiver distress (e.g. feelings of guilt, burden, care recipient characteristics, coping style, support, relationship to care recipient). Findings from the present review also highlight the importance of careful consideration when using assessment measures of caregiver guilt and burden.

Finally, clinical interventions that focus on self-conscious emotions, such as compassion focussed therapy (Gilbert, 2010), may be helpful in reducing feelings of

guilt and depressive symptoms. It is likely the most successful interventions for caregivers are those that are informed by comprehensive assessment and are tailored to address the facets of guilt and burden that are significant for that individual.

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## **Chapter 2 Empirical Paper**

### **Developing and validating a measure of guilt for people with dementia**

In preparation for submission to '*Dementia: The International Journal of Social  
Research and Practice*' (see Appendix I for Author Instructions)

Overall chapter word count (excluding tables, figures and references): 6,233

## **2.1 Abstract**

Previous research has identified guilt is a significant emotion for people with dementia. The aim of the present study was to develop and validate a new measure of guilt for people with dementia. The study employed a two-stage, mixed-methods approach. Firstly, an initial item pool was generated. Secondly, survey data was collected from a sample of 61 participants with a diagnosis of either mild cognitive impairment or dementia. Reliability analysis of the developed scale resulted in a 13-item scale with good internal consistency reliability ( $\alpha=0.93$ ). Significant associations between the developed scale and a measure of depression ( $r = .54, p < .001$ ) and well-being ( $r = -.65, p < .001$ ) were found. Exploratory principal components analysis identified a single underlying component, accounting for 53.1% of variance in the new scale. This new measure of guilt provides a clinically relevant tool for the assessment of guilt in people with dementia.

**Keywords:** *Guilt, dementia, questionnaire, development*

## **2.2 Introduction**

Dementia is the term used to describe a collection of symptoms, including difficulties with memory, reasoning and communication, and a loss of skills needed to carry out daily activities. Dementia can be caused by a number of different diseases, such as Alzheimer's or vascular disease, that cause structural and chemical changes in the brain (Knapp & Prince, 2007). Current estimates indicate that there will be 850,000 people living with dementia in the UK by May 2015, and statistical projections suggest that this figure is set to rise to over 1,000,000 by 2025 and 2,000,000 by 2051 (Alzheimer's Society, 2014). The Department of Health (DoH) publication 'Living Well with Dementia: A National Dementia Strategy' (DoH, 2009) emphasises the importance of early diagnosis and treatment for People with Dementia (PwD) to ensure good quality care and intervention before individuals reach crisis point. Currently, less than half of PwD receive a formal diagnosis (Alzheimer's Society, 2015a). If dementia is not diagnosed, then the PwD and their caregivers are denied the possibility of making choices regarding options for help, support and treatments (social and psychological, as well as pharmacological) which may be of benefit. (DoH, 2009). However, when dementia is diagnosed in a timely way, PwD and their caregivers can receive the treatment, care and support following diagnosis that will enable them to live as well as possible with dementia (DoH, 2009).

A diagnosis of dementia has profound effects on both PwD and their family. There has been substantial research investigating the emotional impact of caring for PwD and the effects of caregiver burden on the caregiver's mental health and well-being (Gonyea, Paris & de Saxe Zerden, 2008; Martin, Gilbert, McEwan & Irons, 2006; Romero-Moreno et al., 2013). However, caregiving by its very nature is a process involving both the caregiver and the patient, suggesting that research should examine the experiences of both individuals in the dementia caregiving dyad (Cahill, Lewis, Barg & Bognor, 2009).

The majority of dementia research has neglected the perspective of PwD, as historically they were considered unable to meaningfully contribute as research participants (Cotrell & Schulz, 1993; Ostwald, Duggleby & Hepburn, 2002). However, in recent years there has been increased interest in the perspective of PwD and qualitative studies documenting the experiences of PwD report they fear becoming a burden to others, which results in feelings of guilt and concern for their caregivers (Aminzadeh, Byszewski, Molnar & Eisner, 2007; Cotrell & Schulz, 1993; De Boer et al., 2007; Gillies, 2000; Holst & Hallberg, 2003; Ostwald et al., 2002; Pearce, Clare & Pistrang, 2002; Robinson, Giorgi & Ekman, 2012; Steeman, Casterlé, Godderis & Grypdonck, 2006; Werezak & Stewart, 2002; Woods, 2001).

### ***2.2.1 The experience of people with dementia***

There is increasing recognition that PwD are able to express their views and communicate their emotional experiences (De Boer et al., 2007). The Alzheimer's Society (2012) conducted a survey in the UK with PwD in the 'early stages' of dementia and living in their own homes. Alzheimer's Society dementia support workers and dementia advisers working in England, Wales and Northern Ireland distributed the survey to PwD. The survey found that 48% of respondents reported that they felt like a burden to their family and 19% of people felt they were a burden to friends (Alzheimer's Society, 2012). Studies have found that fear of becoming a burden; feelings of uselessness, increased concern for their loved ones and feelings of guilt are prominent features of early stage dementia (Clare, 2003; Cotrell & Schulz, 1993; Ostwald et al., 2002; Pearce et al., 2002; Werezak & Stewart, 2002). For example, Pearce et al. (2002) conducted a qualitative study to examine the appraisals and coping of 20 men diagnosed with early stage Alzheimer's Disease (AD). 'Concern for wife' was identified as a theme. Men reported they worried about how their AD affected their wives' lifestyle and health. They expressed concern about their wives' losses and about the increase in their wives' workloads as a result of their memory problems.

A review of qualitative studies documenting experiences of people with early stage dementia concluded the fear of becoming a burden creates much guilt in PwD since they feel responsible for the suffering and disappointment of their caregivers

(Steeman et al., 2006). A study investigating PwD awareness of carer distress hypothesised that PwD who are aware of distress in their caregivers may attribute this to the caring role. Consequently, the person with dementia may feel responsible but at the same time powerless to change the situation and thus be distressed as well (Ablitt, Jones & Muers, 2009). Von Kutzleben and colleagues (2012) conducted a systematic literature review of the review publications on subjective experiences of PwD, revealing a number of important themes regarding the experiences of PwD. One of these themes was '*Emotions*', which included the sub-themes of '*sense of guilt*' and '*becoming a burden*' (von Kutzleben, Schmid, Halek, Holle & Bartholomeyczik, 2012).

Similarly, a previous study examining the perspectives of women with dementia receiving care from their adult daughters discussed the concept of 'grateful guilt' (Ward-Griffin, Bol, & Oudshoorn, 2006). This study was part of a larger qualitative investigation of mother-daughter dyads within the care process of dementia. A sample of eight community dwelling women, with mild to moderate cognitive impairment, were interviewed separately from their daughters, who were all providing care to participants. All the mothers in this Canadian study reported feeling grateful for the care they received, however, at the same time guilty for being a burden; "*I'm happy when she helps me, but at the same time I feel guilt.*" (Ward-Griffin et al., 2006, p. 138).

### **2.2.2 Defining and measuring guilt**

In the psychological literature, guilt has been defined in many different ways (Kugler & Jones, 1992). It has been operationally defined as a transient emotional state according to current circumstances (state guilt) and also as an enduring personality trait reflective of an individual's psychological make-up (trait guilt) (Kugler & Jones, 1992). Guilt has also been defined as a self-conscious emotion associated with feelings of sadness, remorse and empathy following harm to another (Gilbert, 2010). In the qualitative literature documenting the experiences of PwD, guilt is defined as feelings of sadness and remorse associated with the *anticipation* of harm the burden of their dementia may cause to their loved ones (Clare, 2003; Ostwald et al., 2002; Pearce et al., 2002; Werezak & Stewart, 2002).

Guilt is an internal affective state, which makes it very difficult to explicitly quantify; nonetheless researchers need a way to measure guilt. Existing measures of guilt can be divided into two categories; those that measure guilt as an emotional state and those that assess guilt as a personality trait (Tangney & Dearing, 2003). A recent review of definitions and measurements of guilt found that measures of guilt do not correspond well to the definitions from which they derive, potentially leading to inconsistent research findings (Tilghman-Osborne, Cole & Felton, 2010) but for the purposes of the present study, we are concerned with state-guilt (i.e. guilt as an internal affective state in PwD) as opposed to trait-guilt.

### **2.2.3 *Guilt and depression***

Given that PwD report feelings of guilt in relation to fears of becoming a burden to their friends and family, it is important to understand the clinical implications of such experiences. Research into the relationship of guilt to depression is fraught with contradictory findings (Tilghman-Osborne et al., 2010). Some studies suggest that guilt contributes to psychopathology and depression (Ghatavi, Nicolson, MacDonald, Osher & Levitt, 2002; O'Connor, Berry, Weiss & Gilbert, 2002), while others assert that guilt is a positive construct, which serves a protective role (Tangney, Wagner, & Gramzow, 1992).

Excessive or inappropriate guilt occurring nearly every day is one of the diagnostic symptoms of the syndrome of major depression (Jarrett & Weissenburger, 1990). Not only does the symptom 'feelings of guilt' appear in the diagnostic criteria for major depression in DSM V (American Psychiatric Association, 2013), it also appears in depression rating scales (Beck, Ward & Mendelson, 1961; Hamilton, 1960). One study that examined the specificity and nature of guilt in participants with major depression, compared to patients with another chronic medical illness and healthy controls, concluded that guilt represented both an enduring and fluctuating feature of depressive illness over its longitudinal course (Ghatavi et al., 2002).



#### **2.2.4 *Guilt and depression in people with dementia***

Depression is one of the most common behavioural and psychological symptoms in dementia (Zubenko et al., 2003). Some studies have suggested that guilt and other psychological symptoms of depression are less prevalent in PwD (Merriam, Aronson, Gaston & Wey, 1988; Zubenko et al., 2003); however Gallagher et al. (2010) found that elderly patients with functional depression under-report psychological symptoms in comparison to younger patients. Thus any age-related decreased prevalence of guilt could potentially be attributable to reporting bias rather than being an effect of dementia (Ballard, Cassidy, Bannister & Mohan, 1993).

A number of quantitative studies looking at the symptom profile of depression in PwD have found guilt to be a feature of depression in a significant proportion of PwD ranging from 25%-50.9% (Ballard et al., 1993; Chemerinski, Petracca, Sabe, Kremer & Starkstein, 2001; Merriam et al., 1988; Starkstein, Jorge, Mizrahi & Robinson, 2005). Merriam et al. (1988) administered semi-structured interviews to family caregivers of PwD to assess the psychiatric symptoms of AD in 175 community dwelling AD patients. These authors found that 50.9% of AD patients experienced feelings of guilt as a symptom of depression, as reported by the caregiver, though proxy reporting of guilt was a limitation of this study. In a larger study of 670 AD patients, Starkstein et al. (2005) examined major and minor depression in participants more directly. They found that participants with AD and

“sad mood” experienced more guilt than those “without sad mood”. Interestingly, “guilty ideation” was the depressive symptom that most strongly discriminated between those AD patients with and without sad mood. These results indicate that guilt is a construct that has relevance to depression in PwD.

The majority of studies investigating the experiences of PwD have looked at patients in the ‘early stages’ of dementia. Previous research has shown that PwD who have awareness of their deficits experience increased emotional difficulties (Aalten, Van Valen, Clare, Kenny & Verhey, 2005; Harwood, Sultzer & Wheatley, 2000). It is certainly conceivable that individuals, who are aware of their cognitive deficits and the impact of the dementia on those around them, may experience more feelings of guilt and more psychological symptoms of depression as an emotional response to their difficulties (Aalten et al., 2005).

### **2.3 The present study**

The present study endeavoured to develop and validate a measure of guilt in PwD. To ensure face validity, it was important that the developed measure closely corresponded to the definition of guilt from which it derived. The present study was concerned with feelings of guilt in a specific clinical population and within the unique context of having dementia. As such, a specific definition and measure was developed.

In line with this, the current study adopted an operational definition of guilt in PwD as *'feelings of sadness and remorse associated with anticipated and/or perceived adverse emotional, social and practical effects that their living with dementia may have on their family members or significant others.'*

#### **2.4 Rationale and research aim**

A number of recent studies have identified guilt as being an important factor in the experiences of PwD (De Boer et al., 2007; Gillies, 2000; Pearce et al., 2002; Steeman et al., 2006; Ward-Griffin et al., 2006), while other studies point to the presence of feelings of guilt in PwD with depression (Ballard et al., 1993; Chemerinski et al., 2001; Merriam et al., 1988; Starkstein et al., 2005). Improving our knowledge about the nature of guilt in PwD may increase our ability to understand the experience of PwD and could help to inform post-diagnostic support. Currently, there is not a specific measure available to measure guilt in PwD. Thus, the aim of the present study was to develop and validate a measure of guilt in PwD.

#### **2.5 Method**

The present study adopted a two-stage, mixed-methods design. Stage one consisted of item generation and scale construction. Stage two involved the validation of the developed scale and exploration of its factor structure.

### **2.5.1 Stage one: Item generation and scale construction**

In line with traditional approaches to scale construction (DeVellis, 2003; Oppenheim, 1992) the lead researcher familiarised herself with the existing literature regarding the conceptualisation and measurement of guilt more generally, as well as particularly in relation to PwD. Given that there was no existing definition of guilt that related specifically to the clinical population of interest, an operational definition of guilt in PwD was developed in line with the research literature: *'Feelings of sadness and remorse associated with anticipated and/or perceived adverse emotional, social and practical effects that their living with dementia may have on their family members or significant others.'*

#### **2.5.1.1 Item generation**

An initial pool of potential scale items was generated based on the following procedure:

1. Reviewing definitions of guilt found in the literature (Gilbert, 2010; Tangney & Dearing, 2003; Tangney et al., 1992; Tilghman-Osborne et al., 2010).
2. Reviewing the qualitative literature detailing the experiences of PwD (Clare, 2003; Ostwald et al., 2002; Pearce et al., 2002; Werezak & Stewart, 2002).
3. Reviewing existing measures of guilt, such as The Guilt Inventory (Jones, Schratte & Kugler, 2000; Kugler & Jones, 1992), The Interpersonal Guilt Questionnaire (O'Connor et al., 1997) and The State Shame and Guilt Scale

(Marschall, Sanftner, & Tangney, 1994), as well as drawing upon items targeting the construct of guilt within depression measures (Hamilton, 1960).

4. Transcribing and analysing the audio data from a focus group that was held with PwD about the feelings they experienced since being diagnosed with dementia (see Appendix IV). In line with the thematic analysis method outlined by Braun and Clarke (2006), themes extracted from the focus group data were used to inform item generation (see Appendix V and VI for thematic map and focus group participant documents respectively).

The researcher developed an initial pool of 27 items (see Appendix VII). All of the items were either derived from the sources described above or generated on the basis of one of the four procedures (see Appendix VIII for details of the sources on which each item were based) in order to provide a broad and representative reflection of the target construct. Items were worded both positively and negatively to avoid acquiescence bias (DeVellis, 2003; Oppenheim, 1992). In line with Oppenheim's guidelines on scale construction, and with consideration of the target population, particular attention was paid to question wording and length (Oppenheim, 1992). Items were kept relatively short, hypothetical questions and double negatives were avoided and simple terminology was employed.

The initial item pool was then subjected to independent rating by six healthcare professionals with specialist knowledge of dementia in order to further determine content and face validity of the items (DeVellis, 2003) (see Appendix IX). Items judged as reflective of the reviewers' experiences with PwD were retained, as well as items that were rated as relevant to the construct of guilt in PwD. Six of the initial items were discarded, resulting in 21 items and the wording of some items was changed in line with feedback from the expert reviewers. Although the resulting item pool was quite large, it was anticipated that further items would be eliminated at later stages. Furthermore, over-inclusivity and redundancy is considered better than rejecting items too early in the scale development process, as reliability of the scale varies as a function of the number of items (DeVellis, 2003).

#### **2.5.1.2 Scale construction**

The remaining 21 items were used to construct the initial Guilt in People With Dementia Scale (GPWDS) (Appendix X). The scale consisted of five positive, reverse scored statements, for example "I feel good about myself", "I do not feel guilty about my memory problems" and 16 negatively worded items, for example "I feel guilty about my memory problems" and "I feel guilty about not being able to do as much as I used to". Responses to items were scored on a four-point Likert scale ranging from 'all of the time' to 'never', so that higher scores reflected more frequent feelings of guilt. Positively worded items were interspersed throughout

the scale in an attempt to reduce acquiescence response bias. Given the target population, the language used in the instructions to participants was kept as straightforward as possible, as were the responses to each item. Response options were also kept consistent throughout the GPWDS (Oppenheim, 1992).

## **2.5.2 Stage two: Validation of measure**

### **2.5.2.1 Participants**

Participants were recruited through clinician's caseloads, research-interested databases and a third-sector dementia support group giving. Questionnaire packs were either sent in the post or distributed to participants by a clinician involved in their care. A total of 193 questionnaire packs were posted to PwD registered on research-interested databases and 58 were returned, a response rate of 30%. One participant was recruited from a clinician's caseload and two were recruited from the support group giving a total of 61 responses. There were 21 female and 40 male participants. All participants had a diagnosis of either dementia (any type) or Mild Cognitive Impairment (MCI), and had also self-reported having memory problems on the demographic questionnaire (see Appendix XIX). Participant's age ranges were 60-69 ( $n=6$ ), 70-79 ( $n=22$ ), 80-89 ( $n=32$ ) and 90+ ( $n=1$ ). Nine participants lived alone, 46 lived with a spouse, three participants lived with a spouse and a child, and three participants reported they lived 'with others'.

### **2.5.2.2 Measures**

According to previous literature, PwD and recipients' of informal care experience guilt about the burden they pose to their loved ones (De Boer et al., 2007; Ward-Griffin et al., 2006). In addition, studies have shown guilt to be a prevalent symptom of depression in a significant proportion of patients with dementia (Ballard et al., 1993; Merriam et al., 1988; Starkstein et al., 2005). Based on these findings reported in existing empirical literature, it was hypothesised that the scores on the GPWDS would be positively correlated with scores on a measure of depression and negatively correlated with scores on a measure of well-being. The following measures were therefore administered alongside the new scale to test for convergent validity (DeVellis, 2003).

#### **2.5.2.2.1 Geriatric Depression Scale-15 (GDS-15)**

The Geriatric Depression Scale (GDS) (see Appendix XI) was developed to specifically detect depression in the elderly, following consideration of unique characteristics of depression in this sample population (Yesavage & Sheikh, 1986). The development of the 15-item, shorter version of the GDS (GDS-15) (Yesavage & Sheikh, 1986) takes into consideration issues such as fatigue and ability to concentrate for substantial lengths of time, which are relevant to an elderly population. Studies have shown the GDS-15 to be a valid and reliable measure for assessing depression in people with cognitive impairment (Conradsson et al., 2013). The GDS-15 has been reported to have high internal consistency and good



concurrent criterion validity in a sample of 834 participants, aged 85 and over, with and without cognitive impairment. Cronbach's alpha ( $\alpha$ ) ranged from .64 to .82 for participants with Mini-Mental State Examination (MMSE) scores ranging from 5-30 (Conradsson et al., 2013).

#### **2.5.2.2.2 *Warwick Edinburgh Mental Well-Being Scale (WEMWBS)***

The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) (see Appendix XII) is a 14-item scale designed to measure positive mental health or mental well-being. It was developed to capture the wide concept of well-being, including affective-emotional aspects, cognitive-evaluative dimensions and psychological functioning and has been validated on a representative general population sample of British, Chinese and Pakistani adults (Taggart, Friede, Weich, Clarke, Johnson & Stewart-Brown, 2013; Tennant et al., 2007). It is a relatively short measure, which combined with its simple language and instructions, makes it feasible to use with PwD in the early stages of the disease. The WEMWBS has been reported to have good content validity, a Cronbach's  $\alpha$  score of .91 in a population sample and a one week test re-test reliability of .83. It also showed high correlations with other mental health and well-being scales (Tennant et al., 2007).

### **2.5.3 Procedure**

Ethical approval was granted for the present study by Coventry University (see Appendix XIII), the NHS Health Research Authority (see Appendix XIV) and the local Research and Development departments of each NHS trust (see Appendix XV). Potential participants were identified from research-interested databases, clinicians' caseloads and a third-sector support group. Given the difficulties inherent in recruiting participants with a diagnosis of dementia, a broad diagnostic spectrum was adopted to allow recruitment of participants who had been clinically assessed as having either a dementia (any type) or MCI. Moreover, people diagnosed with MCI have an increased risk of developing dementia (Alzheimer's Society, 2015b; Maioli et al., 2007) and it is unclear whether feelings of guilt begin at the point of dementia diagnosis or at an earlier stage. Therefore, it was deemed appropriate to include data from participants diagnosed with either MCI or Dementia. Questionnaire packs were distributed to participants if they met any of the following criteria: 1) had been diagnosed with either Dementia or MCI; 2) where MMSE scores available, had MMSE score of >18 (Tombaugh & McIntyre, 1992) at last point of assessment 3) where recruited from clinical services, had been assessed as able to complete self-report measures by a clinician; 4) where recruited from research databases, had been assessed as able to complete self-report measures by a clinician.

Informed consent was gained through completion and return of a signed consent form (see Appendix XVI) and a completed questionnaire pack. The questionnaire pack included a participant invitation letter (see Appendix XVII), a participant information sheet (PIS; see Appendix XVIII), a participant consent form, a demographic information questionnaire (see Appendix XIX) and three self-report measures, the GPWDS, the WEMWBS and the GDS-15. Within the PIS, participants were assured that they were able to decline participation or withdraw at any time without it impacting upon any healthcare services they may or may not have been receiving. Upon completion and return of the questionnaire packs, each participant was given a participant number to aid data organisation and preserve anonymity. A small number of completed questionnaires were returned with partially completed consent forms (e.g. without a signature and printed name). In those cases, the participants could not be identified or contacted. After much deliberation and discussion with the research supervision team, it was decided that it appeared that those individuals had intended to participate by virtue of completing and returning questionnaires. They were therefore included in the study.

## **2.6 Results**

### **2.6.1 Item selection**

Internal consistency reliability of questionnaire measures is seen as a precondition to validity (Nunally, 1978; Oppenheim, 1992), and Cronbach's  $\alpha$  is considered the best index of internal consistency reliability (Kline, 1994). Calculation of Cronbach's

$\alpha$  for the initial 21-item GPWDS indicated an acceptable internal consistency reliability ( $\alpha = .87$ ). However, if a developed scale measures a single underlying continuum, then the scale items should be highly inter-correlated and each item should correlate substantially with the total scale, and the underlying continuum (DeVellis, 2003; Oppenheim, 1992). As such, the item-total correlations were then examined in order to evaluate the performance of individual items and decide which items from the 21-item GPWDS should be retained in the final scale (see Appendix XX for item-total statistics).

Items with an item-total correlation of less than .30 were discarded from the scale (Field, 2005). A total of eight items (3, 8, 11, 12, 13, 15, 20, 21) were removed. Inspection of these items revealed that the majority of them were positively worded, reverse scored items, which endorsed the absence of guilt. The fact that all positively worded items had low item-total correlations may just be a coincidence. However, it may also be that these items presented an unanticipated challenge to cognitive flexibility, as the majority of items in the measure (indeed all of the retained items) were negatively worded.

### **2.6.2 *Internal consistency reliability***

The final GPWDS consisted of 13 items (see Table 3 for item-total correlations & Appendix XXI). Nine data sets were excluded from the analysis due to missing data.

The remaining 52 complete data sets were used for the internal consistency reliability analysis. Calculation of  $\alpha$  for the final 13-item scale indicated good internal consistency reliability ( $\alpha = .93$ )

### **2.6.3 Convergent validity**

This was assessed using Pearson's correlation coefficient to explore the relationships between the 13-item GPWDS and two constructs that were hypothesised to be related, depression and well-being. Depression, which was hypothesised, to be positively related to guilt in PwD was measured using the GDS-15. As can be seen in Table 4, a moderate positive correlation was found between the GPWDS and the GDS-15. A moderate inverse correlation was found between the GPWDS and the WEMWBS. Both of these findings were in line with the study hypotheses and support the validity of the new measure.

Table 3.

*Item-total correlations, means and standard deviations of final scale items*

	Item	Item-Total Correlation	Item Mean	Item SD
1.	I feel guilty about my memory problems	.581	1.83	.83
2.	I think my memory problems cause my family and friends difficulties	.679	2.13	.77
4.	I worry about the impact of my memory problems on my family and friends	.791	2.15	.89
5.	I feel I am becoming a burden on my family and friends	.755	2.00	1.03
6.	I feel guilty about not being able to do as much as I used to	.651	2.27	1.01
7.	I feel bad about not being able to remember people's names	.376	2.44	.96
9.	I think I cause my family and friends extra trouble	.627	2.13	.86
10.	I worry about how my memory problems affect my family and friends' lives	.701	2.23	.96
14.	I feel responsible for the disappointment in my family and friends	.764	1.69	.94
16.	I feel guilty that others have to do more now I have memory problems	.728	2.35	.99
17.	I feel guilty leaving things to others to do	.802	2.21	1.05
18.	I feel like I need to say sorry to my family and friends because of my memory problems	.662	2.00	1.01
19.	I feel I am letting my friends and family down	.658	1.65	.76
Final Scale		-	27.10	8.83

Table 4.

*Correlations of GPWDS, GDS-15 and WEMWBS*

	WEMWBS	GDS-15
GPWDS	-.548**	.434**

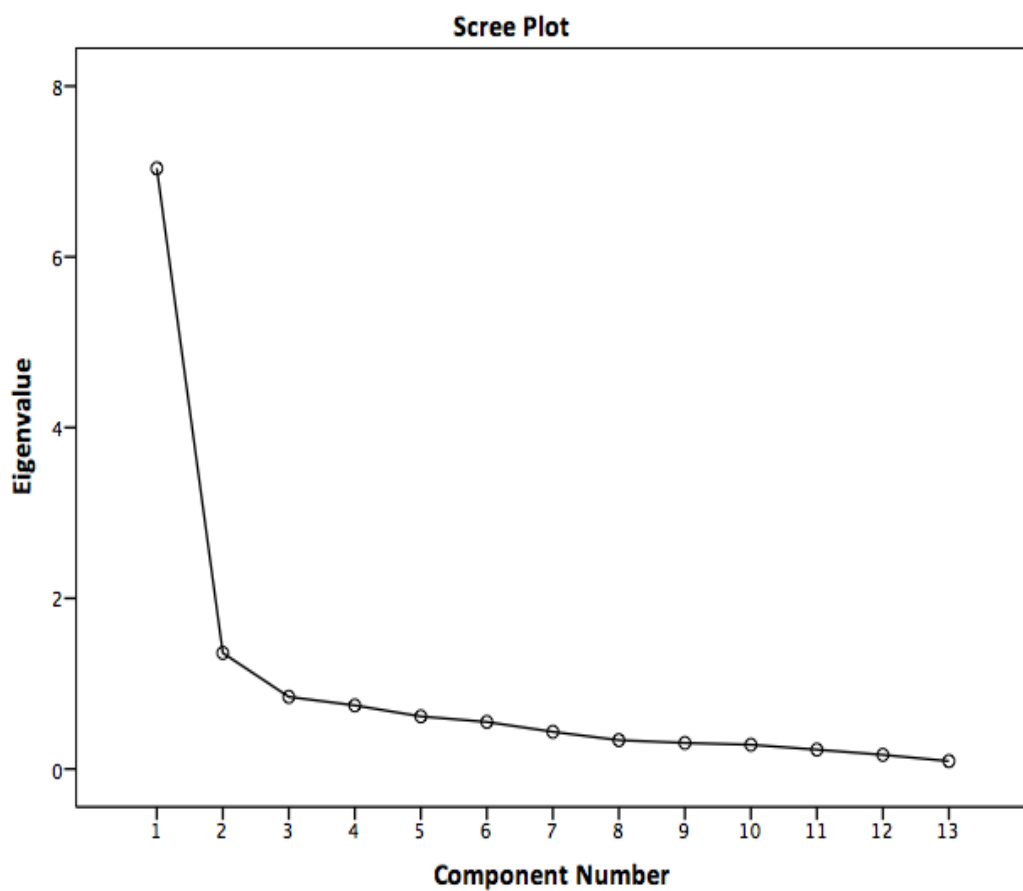
\*\* Pearson's correlation is significant at the 0.01 level (2-tailed).

#### **2.6.4 Exploratory analysis of factor structure**

The 13 items of the final GPWDS were subjected to a preliminary Principal Components Analysis (PCA) to identify the component structure underlying the scale items. Although the participant to item ratio was lower than the recommendation of 10:1 (Nunnally, 1978) for FA, initial inspection of the correlation matrix revealed the presence of a large number of coefficients of .30 and above. In addition, a Kaiser-Meyer-Olkin value of .86 exceeded the recommended value of .60 (Kaiser, 1974) and the Bartlett's Test of Sphericity (Bartlett, 1954) reached statistical significance at  $p < .001$ , supporting the factorability of the correlation matrix (see Appendix XXII).

Two components with eigenvalues greater than one were identified, explaining 53.1% and 10.5% of the variance, respectively. However, examination of the scree plot is agreed by many factor analysts to be the preferred solution to selecting the

correct number of components (Kline, 1994). Inspection of the scree plot revealed a clear break after the first component (see *Figure 3*). In addition, inspection of the item loadings showed that, with the exception of item 7, all items loaded more strongly onto the first component than the second (see Table 5), supporting the presence of a single factor.



*Figure 3.* Scree plot showing principal component analysis with Direct Oblimin rotation of the 13-item GPWDS



Table 5.

*Component loadings*

	Item	Factor 1	Factor 2
1.	I feel guilty about my memory problems	.629	.547
2.	I think my memory problems cause my family and friends difficulties	.737	
4.	I worry about the impact of my memory problems on my family and friends	.835	
5.	I feel I am becoming a burden on my family and friends	.801	
6.	I feel guilty about not being able to do as much as I used to	.698	.331
7.	I feel bad about not being able to remember people's names	.427	.630
9.	I think I cause my family and friends extra trouble	.699	-.535
10.	I worry about how my memory problems affect my family and friends' lives	.761	
14.	I feel responsible for the disappointment in my family and friends	.819	
16.	I feel guilty that others have to do more now I have memory problems	.783	
17.	I feel guilty leaving things to others to do	.847	
18.	I feel like I need to say sorry to my family and friends because of my memory problems	.719	
19.	I feel I am letting my friends and family down	.708	.311

\* Values below .30 are not shown.

## **2.7 Discussion**

### **2.7.1 Summary of findings**

The main aim of the current study was to develop and validate a new measure of guilt for PwD. Item generation and development of the measure was informed by review of the qualitative literature detailing the experiences of PwD, current definitions and measures of guilt, the clinical experience of the researchers and six clinical professionals consulted. Item generation was also informed by themes derived from a thematic analysis of the transcript of a focus group held with PwD about the feelings they have experienced since the diagnosis of dementia. The development of the measure was informed by drawing upon relevant empirical sources, conceptual and theoretical accounts of the construct of guilt, clinical expertise, and the experience and views of PwD and in doing so support both the content validity and the face validity of the 13-item GPWDS

As hypothesised, following examination of item-total correlations of the initial scale items, several items were removed as they were only weakly correlated with the total scale score, suggesting that they either did not tap into the same overarching construct as the other items or that they were not producing reliable responses from participants. The final 13-item scale comprised all items with an item-total correlation greater than .30 and showed excellent internal consistency reliability.

The items removed appeared to fall into two categories; items that may have been structured in a more complex way and reverse scored items that endorsed the absence of guilt. It is possible that some of the items may not have been clearly written, despite having been rated as appropriate items by expert raters. However, it is also possible that these items were answered less reliably either due to the demands they placed on understanding phrases that were too complex for participants or due to the cognitive flexibility required to respond accurately. Given the presence of cognitive impairment of the sample used, it would not be surprising if certain items placed greater cognitive demand on participants than others and were less reliably answered. It would be appropriate to remove any such items from a measure that was designed for use with people with cognitive difficulties.

Most of the items removed endorsed the absence of guilt, some of which were positively worded. Research has shown that many individuals respond more favorably to questions worded positively and that this bias may be more pronounced in individuals who have a greater degree of cognitive impairment (Guyatt et al., 1999). Indeed, Bedard and colleagues (2003) found an increase in the affirmative answers to positively worded questions in the GDS-15 as participant MMSE scores decreased and concluded the reliability of the GDS-15 was variable for participants with MMSE scores less than 20. This suggests the greater the degree of cognitive impairment, the more likely that the respondent's answers will

be positively biased. Removal of the positively worded items that endorsed the absence of guilt, in the GPWDS following correlational analysis corrects for this bias.

The convergent validity of the GPWDS was supported by the moderate positive correlation found between the GPWDS and the GDS-15, and the moderate inverse correlation found between the GPWDS and the WEMWBS. These findings are consistent with the author's theoretical understanding of guilt in PwD, which informed the operational definition of guilt in PwD adopted in the present study. These findings are also consistent with evidence from other sources indicating that guilt could be considered maladaptive (Tangney & Dearing, 2003) and has negative consequences for PwD.

The results of a preliminary PCA demonstrated that the final 13-item scale comprises a single underlying factor. However, these findings are valid only for the participants of the present study and future investigation of the psychometric properties of the scale will be required to provide additional support for this conclusion.

The response rate in the present study was 30%. This is one and a half standard deviation below the average response rate for questionnaire-based research

(Baruch, 1999). It is important to recognise the challenges associated with conducting research with PwD. Hubbard, Downs and Tester (2003) highlight the impact that verbal communication impairment, memory loss and reduced decision making capacity has on the inclusion of PwD in research. Given the cognitive decline associated with the sample population, it may have been advantageous to administer the questionnaires during face-to-face interviews. However, issues such as cost and time were important factors in the feasibility of the present study. It is also not possible to know to what extent the participants completed the questionnaire independently or with assistance from a caregiver. It is possible that participants who lived with a spouse or caregiver may have been supported to complete the questionnaires. It is also possible that completing a sensitive questionnaire such as the GPWDS in the presence of a caregiver may yield biased answers.

### ***2.7.2 Limitations and future research***

In the present paper, the development of the GPWDS and results of initial efforts to validate the new measure are presented. Initial findings are encouraging and support the internal consistency reliability and convergent validity of the 13-item GPWDS. Moreover, the incorporation of the views and perceptions of PwD about guilt (in addition to other conceptual and psychometric sources) in the development of scale items supports the face validity of the measure. However, future research is necessary to further demonstrate the psychometric properties of

the GPWDS in a larger sample of PwD. A replication study with a larger sample of PwD would allow for further statistical analysis, such as confirmatory FA to build on the preliminary findings presented here. Nonetheless, these initial findings suggest the GPWDS has promising potential for use in both clinical and research settings.

Questionnaire packs were distributed either by a clinician involved in the care of the participant or via post. There are several advantages and disadvantages associated with postal surveys. The main advantages of postal questionnaires include, low cost of data collection, low cost of processing, avoidance of interviewer bias and the ability to reach respondents who live at widely dispersed addresses. However, postal questionnaires can result in low response rates, missed opportunities to correct misunderstandings and offer help or explanations, no control over the order in which questions are answered or incomplete questions, and no opportunity to collect qualitative data that may be relevant to the research question (Oppenheim, 1992). Future research could consider administering the GPWDS in face-to-face interviews to address these limitations and investigate the research clinical application of the GPWDS further.

The conceptualisation of guilt in PwD used in the present study infers that PwD have insight and awareness of the consequences of dementia, and make appraisals about the present or future impact that their cognitive and functional deterioration

may have on those around them. Therefore, the generalizability of the findings from this study is limited to those PwD that have such awareness and insight. Future research could usefully collect data on a range of sample characteristics, such as cognitive and functional status of participants, age at diagnosis and type of dementia, to determine whether these characteristics are differentially associated with feelings of guilt in PwD. Findings from such studies might inform more targeted therapeutic interventions for particularly vulnerable individuals following a diagnosis of dementia.

Further information regarding participants' cognitive and functional status may have been helpful in exploring the relationship between these factors and feelings of guilt in PwD in the present study. Given the evidence that guilt in PwD is associated with the perceived burden the dementia poses on family and friends, it would be particularly interesting for future research to explore the relationship between functional impairment and guilt in PwD.

The current study did not pilot the developed measure on a small sample of PwD prior to the main validation stage. The absence of a pilot study is a limitation. Pilot studies can be used to check out the 'nuts-and-bolts' of the scale, such as how easily the scale instructions are followed, how well the scale format functions, how long the scale takes to complete and how appropriate the scale items are for the

target respondent population (Dawis, 1987). However, the expert review process served some of the functions described. With regard to random error, although internal consistency of the scale has been found to be good, no test-retest assessment of guilt was possible. Therefore future studies could endeavour to assess the test-retest reliability of the GPWDS.

Guilt is considered to be a culturally sensitive emotion, strongly influenced by cultural perspectives and social norms (Bierbrauer, 1992). Therefore, there may be substantial differences in the experience of guilt in PwD across cultures. No information was available on the ethnicity or cultural background of participants in the current study. In order to test the cross-cultural content validity of the GPWDS future studies could use this instrument to study guilt in PwD from a range of cultures, to explore similarities and differences.

### **2.7.3 Clinical implications**

The findings of the current study indicate the importance of addressing feelings of guilt when working clinically with PwD. The development of a relatively brief and accessible measure of guilt for PwD provides a quick and easy assessment tool for clinical services. The use of the GPWDS along with other psychometric assessment tools, particularly measures of mood, may serve to further clinicians' understanding



of the relationship of guilt to psychopathology and may inform the focus of therapeutic interventions.

Interventions that focus on helping PwD review and adjust their expectations of themselves in relation to their role and 'duties' in the dementia-caregiver dyad, accept their limitations, and acknowledge their additional needs post-diagnosis, may facilitate a reduction in their feelings of guilt that may contribute to depression. Consequently, clinicians can support PwD to acknowledge and manage feelings of guilt, as a way of reducing their distress and promoting helpful adjustment to the diagnosis of dementia. Finally, protective factors against guilt and depression were not explored in the present study. However, interventions that promote more adaptive behaviours, such as increased social support, maintaining leisure activities and accessing post-diagnostic support may help alleviate some of the negative feelings associated with the impact of receiving a diagnosis of dementia.

#### **2.7.4 Conclusion**

In conclusion, the 13-item GPWDS presents acceptable psychometric properties, and has the potential to be a valuable tool in the assessment of guilt in PwD subject to further validation studies. Future studies using the GPWDS with a larger sample

and in other countries could usefully build on the preliminary findings presented here and permit further analysis of its utility.

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## **Chapter 3 Reflective Paper**

### **Reflections on the '*flight path*' to becoming a Clinical Psychologist: Clinical training and the research process**

Prepared for submission to *Reflective Practice* (See Appendix XXIII for Author  
Instructions)

Overall chapter word count (excluding references): 3,817

### **3.1 Abstract**

This paper provides a reflective account of my journey through the research process and my journey through clinical psychology training more generally. Following a discussion of the turbulence and uncertainty I experienced during clinical training, this paper explores issues and challenges that stimulated reflection throughout the research process. Within the context of these reflections on my personal and professional journey, points of both personal and professional development are illustrated throughout the paper.

### **3.2 Introduction**

The present paper provides a reflective account of both my experiences and learning during training as well as my experience of, and learning from the research process. I reflect on my views at the beginning of clinical training, discuss the shift that occurred in these perspectives and outline the experiences that facilitated this transition throughout the duration of the course. Particular attention will also be paid to my reflections throughout the research process, including the reasons behind my embarking on a research project with people with dementia (PwD), the development of this thesis, and the links between my own experiences and the experiences of PwD and their families highlighted in the thesis.

### **3.3 Take off**

Although the concept of the 'reflective-practitioner' was not new to me when I embarked on a career in clinical psychology, I felt more comfortable and familiar with the 'scientist-practitioner' model. Prior to pursuing clinical psychology as a career I had wanted to study medicine, and the majority of my experience as an assistant psychologist was in neuropsychology, working in settings dominated by the medical model, standardised assessments and crunching numbers to determine the needs of an individual. Consequently, at the beginning of training my understanding of clients fitted much more clearly within a medical model. I thought I was going to "learn how to do therapy". I was enthusiastic about learning how to



deliver the latest evidence-based interventions, and filling up my clinical ‘tool box’ with therapy techniques and tools that would make people ‘better’.

With this in mind, I felt overwhelmed by the reflective ethos of the Coventry and Warwick course, and I was drawn towards Cognitive Behavioural Therapy (CBT) because of its structured and manualised approach. The presence of paper and worksheets, boxes and step-by-step guides reassured me. It gave me a sense of direction and control in sessions, which otherwise left me feeling incompetent. Despite this, the majority of the time, I felt completely out of my depth working in a therapeutic capacity and I quickly decided I was not “good” at therapy, and began to question my decision to pursue a career in clinical psychology.

### **3.4 Turbulence**

My second year of training saw a shift in my perspectives. Whilst on my CAMHS placement I became increasingly ambivalent towards clinical psychology. My love affair with structured and manualised approaches became tainted by a loss of belief in both the ability of therapy to facilitate change in clients and my competence at delivering it. I felt disillusioned and struggled to engage in the therapeutic work with clients. I did not believe what I was doing was going to make a difference to the clients and my ‘*mojo*’ disappeared completely. My uncertainty about clinical psychology as the right career for me reached its peak and I started to flounder.

The focus on family systems, parenting styles and attachment (Gerhardt, 2004) when working in CAMHS opened my eyes to the impact of a family system's thoughts, beliefs and view of the world on the development and presentation of those in it. This facilitated my own personal reflection on my family system whilst growing up and the role it played in the difficulties I experience being a traditional therapist. Prior to clinical training I was naïve with regards to the influence of my own early experiences, attachment relationships and the beliefs of my primary attachment figures on my professional development. On reflection, my difficulty making sense of more subjective and reflective approaches to psychological therapy were hugely influenced by the beliefs held within my early family system. Ironically, it is my opinion that it is the reflective ethos of the Coventry and Warwick course that enabled me to express and process the feelings I was experiencing at this time in a helpful way, and with support. It left me wondering whether, if I had been on a different clinical doctorate, the outcome would have been the same and if I would have reached the point of completing my thesis.

### **3.5 *Landing***

When I reflect on the views I held at the beginning of the clinical doctorate, it is shockingly apparent the extent to which it has been an agent of change for me. Clinical training has taught me that the human experience, and indeed mental health problems, cannot be reduced to boxes, symptoms, diagnosis and treatment,

right or wrong, 'mad or bad' or black or white, and it cannot be 'fixed'. With all this in mind it is safe to say I *feel* like a different person to what I was three years ago.

I have learnt that we all form our own version of reality according to our past and present experiences and that our relationships are a central component of those experiences. Relationships serve as the building blocks to our psychological development and consequently, mental health. Therefore, it makes sense that the evidence suggests it is the therapeutic relationship that is the most important factor in the efficacy of psychological ways of working (Lambert & Barley, 2001). At the beginning of training I found this a somewhat abstract, subjective and unquantifiable notion, which was difficult to digest; I now find it comforting. In therapeutic contexts I am less focussed on 'getting it right' and following a pre-set agenda. I feel more engaged with the client in the here and now, and am able to focus on building helpful therapeutic relationships. Consequently, I am now less frightened of my role as a therapist and would like to further my therapeutic skills by training in a specific therapeutic framework, such as Cognitive Analytical Therapy (CAT), that emphasises relationships, reciprocal roles and relational patterns.

### **3.6 Research process**

#### **3.6.1 Research proposal**

Towards the end of the first year, while I was on my older adult placement, we were required to write our research proposal. My grandfather was diagnosed with dementia the year before I started the doctorate whilst I was working as a research assistant for a dementia research network. It was this job, the experience of watching my grandfather deteriorate, with little support or a diagnosis and the familiarity of working with PwD, which cemented my decision to complete a research project with PwD.

I felt passionate about completing a project that would focus on and reflect the feelings and experiences of PwD, not their caregivers. This was not because I had less empathy for caregivers, or felt they were not deserving of help and support. I fully appreciate the burden that many caregivers of PwD bear. However, whilst on my older adult placement I felt strongly that the support offered by the team was focused on the caregivers needs, while the experience of PwD was neglected somewhat. Furthermore, on a personal level, it was watching my grandfather slowly become more dependent and cognitively disabled and the impact that had on his confidence and his sense of self that caused me the most distress. I was convinced that, despite his cognitive impairments, my grandfather was aware of the implications of his diagnosis and the impact this would have on my grandmother. Although he never verbally expressed his feelings, I had a sense that

he felt bad about the burden of dementia and his increasing dependency on my grandmother.

Consequently, I researched the experiences of PwD and discovered that within the qualitative literature feelings of guilt were well documented (Pearce, Clare & Pistrang, 2002; Ward-Griffin, Bol, & Oudshoorn, 2006; Werezak & Stewart, 2002). However, I was also confident that I wanted to complete a quantitative research project. I was more familiar and confident with quantitative research methods, using SPSS, statistics and the reporting of the 'significance' of results. The security and certainty that quantitative methods provide appealed to me. There are rules to follow, the analysis is either right or wrong, results are either significant or not. I recall sitting in teaching on qualitative methodologies and feeling a strong aversion to what I thought at the time was the subjectivity of qualitative analysis. I remember feeling perplexed at how conclusions and implications could be drawn from a researcher's interpretations and 'subjective' analysis of participants' experiences.

Given the rest of my cohort's preference for qualitative methodologies I was in the minority of just two trainees who were pursuing a quantitative project. This made me wonder if by choosing a quantitative approach I would be neglecting the needs of PwD, potentially reducing their experiences down to a set list of statements and

answers, and black and white statistics. Together with my decision that I was not good at therapy, I was left wondering if I was really a 'proper' psychologist. I began to question the motives behind my determination to complete a quantitative project. At the same time, I was advised that the research question should determine the methodology and personal methodological preference was not a good enough reason to choose a particular research project.

However, following a discussion with my supervisors I was reassured that a big part of making this course manageable was knowing and playing to your strengths. Different people are drawn to different areas and methodological confidence is an important aspect of completing a thesis when juggling the various demands of the doctorate. As such, with the support and guidance of my supervisors the idea to develop and validate a new measure of guilt for PwD was conceived.

Reflecting on this now, I am aware that my preference for quantitative methods stems from previous experience and my tendency towards objectivity, certainty and clear answers to questions. I am happy I chose the project I did, and ironically it evolved to be a mixed-methods project! The qualitative analysis involved in the development of the guilt measure did not turn out to be as bewildering as I had anticipated! Consequently, I am now more open to qualitative research methods

and appreciate the importance of these in helping clinical psychologists to understand and interpret the experiences of clients.

### **3.6.2 Ethics**

One of the major challenges throughout the research process was gaining ethical approval. My supervision team and I anticipated that given the participant sample involved, the Research Ethics Committee would focus on the issue of gaining informed consent from participants. Consequently, I spent a great deal of time ensuring my ethics application clearly stated The Mental Capacity Act 2005 Code of Practice (2007) and the assumption of capacity, not the lack of. I recall feeling angry and irritated by this. On reflection, it is likely my anger stemmed from my experience of working with PwD and the assumption that is often made about PwD lacking capacity. To this end, in my clinical experience with PwD, people with Learning Disabilities and people with Acquired Brain Injury, I often find myself acting as an advocate for clients, with regards to their right to make their own decisions.

Overall, the process of applying for ethical approval left me feeling out of control and anxious. I was frustrated by the extensive paperwork and form filling involved. I felt the level of detail required in the application forms was more relevant for medical research, such as clinical drug trials. I recall feeling that I was jumping

through hoops that were not necessary for a postal questionnaire based research study. At times I felt like giving up and wondered if completing a research project with PwD was really worth all the bureaucracy involved in going through NHS ethics. It is thanks to my research supervision team and husband's patience and reassurance, that I was able stay focused enough to reach the light at the end of the ethics tunnel! On reflection, I think it was the unfamiliarity of the process that caused the most anxiety. Nonetheless, despite the personal challenge it presented, I do understand the value of this process. I appreciate the importance of ensuring the quality and ethical appropriateness of all clinically relevant research that is conducted and the hugely important role that ethics committees play in protecting potentially vulnerable participants.

### **3.6.3 Guilt**

Guilt is such a complex emotion, both to experience and to research. Throughout the research process my roles as a wife, daughter, granddaughter and friend all felt compromised as the thesis took over more and more of my emotional and practical capacity. As my ability to fulfil my roles elsewhere dwindled, the guilt I felt over completing the doctorate and the consequences it has had on my personal relationships became more apparent.



To add to my increasing sense of inadequacy during the research process, I broke my foot and my grandfather died. My Granddad's death was both expected and devastating. He was a large part of my inspiration to complete a research project with PwD, and it was completing the thesis and the doctorate overall, that meant I could not spend more time with him in the last stages of his life. My feelings of guilt about not being there for my Grandparents during this time made me think specifically about some of the findings from my literature review. In particular, I thought about the fact that women caregivers tend to score more highly on the Caregiver Guilt Questionnaire factor '*guilt about neglecting other relatives*' (Losada, Márquez-González, Peñacoba & Romero-Moreno, 2010).

On reflection, my own feelings of guilt about neglecting *all* areas and people in my life, other than the doctorate and completing my thesis, reflected the experiences that caregivers of PwD reported in my literature review. This was particularly apparent for adult-child caregivers of PwD, which ignited thoughts about how I would cope in the future should I be placed in that position.

On another note, breaking my foot effectively immobilized me for six weeks following Christmas 2014. As a consequence, my leg was plastered to below the knee and I could not drive. This experience of feeling completely reliant on others for help made me very uncomfortable. I felt guilty about the burden I was placing

on my family and friends, and for asking for help with what were normally such everyday, menial tasks. I felt vulnerable and as though I was of less value to those around me. The similarities between my own experience in relation to feeling guilty about being a burden, and my empirical paper, re-engaged me in my thesis and gave me a much needed injection of enthusiasm.

Not being able to go to placement or workshops also forced me to reflect on the value I placed on my independence; why was I so uncomfortable being reliant on others? Why did I feel so guilty about asking for help? And why did I feel I was 'worth' less with a broken foot? I found 'The Helper's Dance List' a helpful tool in facilitating reflection on the feelings I was experiencing about being a 'care recipient' rather than the more familiar and comfortable position of 'caregiver'. 'The Helper's Dance List' refers to a framework utilized by CAT to help individuals notice when, how and why we might join or create unhelpful dances with those we help (Potter, 2014). Whilst I appreciate that my relationships with my friends and family may not be categorized as helping relationships as such, I felt that the descriptions of different dances helped me to reflect on my relational style and how that influenced my reactions to being incapacitated. In particular, the concept of a shared responsibility and not blaming myself, the other or the system was helpful in encouraging a balanced view of my responsibility.

The sense of dependency and the feelings evoked about myself during this time made me think about how it might feel for a person with dementia to be a 'care recipient'. I reflected on the psychological adjustment required of PwD to accept a diagnosis that has such life changing implications for both the person with dementia and their families, and go on to 'live well with dementia'.

#### **3.6.4 Participants**

At the start of the research project I felt most anxious about recruitment. I had experience of working with PwD in a research capacity and was aware of how difficult recruitment can be. I believe that dementia research is vital and it is fundamentally important to involve the actual person with dementia in research studies. Research has shown that being involved in research gives PwD a sense of purpose and agency (Higgins, 2012). Despite these beliefs and despite having identified recruitment sources and having an ethically approved recruitment strategy, I felt anxious that some participants and/or their families would be cross or upset when they received the questionnaire. When I received messages from the office that relatives of PwD wanted me to contact them, I felt worried they were calling to say how inappropriate they thought it was that I had sent somebody with dementia a questionnaire about guilt. On reflection, I think this was due to my experience of relatives and clinicians 'gate-keeping' PwD, denying them the opportunity to participate in research because they believe they are protecting

them and refraining from the use of the word 'dementia' for fear of upsetting them.

In reality the correspondence I received from participants throughout the research process was both humbling and inspiring. I was touched by the time and effort participants took in completing the questionnaires. I had letters and phone calls wishing me luck with the research, as well as blank questionnaires returned with apologies and explanations as to why they had declined to take part. The motivation and sense of satisfaction these letters and calls gave me reinforced my decision to conduct a thesis I had a genuine interest in.

### **3.6.5 Relationships**

#### **3.6.5.1 Dementia caregiving dyad**

Prior to and throughout the research process, particularly when I was completing the literature review, I was struck by the vast amount of research on the negative consequences for the caregiver of caring for a person with dementia. On reflection, I think I have underestimated the impact that caring for my grandfather had on my grandmother. I think this was in part due to the stoic nature of my grandmother but also due to my preoccupation with empathising with and understanding the perspective of the person with dementia. Consequently, I have found myself becoming increasingly curious about the dynamics of the dementia caregiving dyad,

and the relationship, rather than either of the individuals separately. For example, research has shown aspects of the prior relationship impact both on the way the caring relationship functions and on how the caregiver and care recipient roles are experienced (Daire, 2002; Steadman, Tremont, & Davis, 2007) With this in mind, I have wondered how the spousal and/or parent-child relationship prior to a diagnosis might influence the experience of guilt in a person with dementia. This is an area I would be keen to research further in the future. On a more personal note, I have wondered if my grandmother would have coped the way she did caring for my grandfather if their relationship had not been as strong and reciprocal prior to the diagnosis.

As mentioned previously, the results that adult-child caregivers experience greater guilt and daughters in particular show a stronger correlation between burden and mental health, often left me thinking about my own parents and the impact a diagnosis of dementia would have on our relationship. Throughout the research process I was also working in an Early Intervention Dementia Service. In this role I worked with a client that was the same age as my father. During this time I would often find myself feeling anxious about how I would cope, being an only child and living over 100 miles away from my parents, if I had to care for one of them. At this time, I found clinical supervision and my husband's support invaluable. I also found adopting a more mindful approach to managing my thoughts about the future helpful.

### **3.6.5.2 Supervisory relationship**

Pistole and Watkins (1995) suggest that elements of an attachment relationship can be seen in the supervisory relationship. Reflecting on the elements of the research process that have facilitated and supported the completion of this thesis, the 'research' supervisory relationship is the one that stands out the most. The concept of supervisors serving as a secure base (Bowlby, 1988) particularly resonates with me. On a number of occasions when I felt overwhelmed, my research team were able to contain me in a safe and grounding manner. This served both a protective and a freeing function. Following research supervision meetings I have felt listened to, supported and reassured, but also more confident in my own abilities (Pistole & Watkins, 1995). On reflection, my supervisory relationship with my research team has been instrumental in completing this thesis

### **3.7 Conclusion: The end in sight**

I chose to take on a project with personal relevance as I anticipated it would make staying engaged and writing up easier. However, having now completed my thesis, I am struck by the feelings and reflections the research process evoked in me. This research process has furthered my understanding of the complimenting roles, but also the competing demands of being a clinician and a researcher. I have learnt that the research process can be a bumpy road with unexpected turns and potholes that will slow you down. Challenges such as the ethical approval process, time and

competing demands of one's personal and professional life all impact on the feasibility of being a scientist-practitioner (David, 2006).

Additionally, both my journey through clinical training and the research process have reinforced the importance of relationships when working as a clinical psychologist and in the human experience more generally. Relationships have transpired as a dominant theme within my reflections, including the instrumental role of the therapeutic relationship in therapy, the significance of the relationship at the heart of the dementia caregiving dyad and the importance of my own personal relationships in my personal and professional development.

When I embarked on the clinical psychology doctorate programme, I had an understanding of the value of research and its importance in clinical practice. I was familiar with the concept of a scientist-practitioner but my ambition was never to be a researcher and in my mind I had polarised the two roles; clinician versus researcher. Furthermore, I had no burning desire to get my research published. However, undertaking this project has ignited an unexpected excitement about getting involved in research in a clinical context upon qualifying, as well as about pursuing the publication of my work as a means of contributing to the knowledge base that enables us to support PwD in the most appropriate way.

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## Appendices

### **Appendix I:** *Author instructions for Dementia: The International Journal of Social Research and Practice*

#### **Manuscript Submission Guidelines**

##### *Dementia: The International Journal of Social Research and Practice*



1. [Peer review policy](#)
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*Dementia* publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

#### **1. Peer review policy**

*Dementia* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

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## **2. Article types**

*Dementia* welcomes original research or original contributions to the existing literature on social research and dementia.

*Dementia* also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

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## **3. How to submit your manuscript**


Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

*Dementia* is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne<sup>®</sup> Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

**IMPORTANT:** If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the '[Online Help](#)' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

**Innovative Practice** papers must be submitted by email to Jo Moriarty [jo.moriarty@kcl.ac.uk](mailto:jo.moriarty@kcl.ac.uk).

**Books for review** should be sent to: Book Review Editor  *Dementia*, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: [hwilkins@staffmail.ed.ac.uk](mailto:hwilkins@staffmail.ed.ac.uk)

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Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

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## **6. Other conventions**

### **6.1 Informed consent**

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at <http://icmje.org>. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (<http://www.wma.net>) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (<http://www.cioms.ch>). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

### **6.2 Ethics**

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or

hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

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## **7. Acknowledgements**

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

### **7.1 Funding Acknowledgement**

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit [Funding Acknowledgement](#) on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

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## **9. Manuscript style**

### **9.1 File types**

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

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*Dementia* conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

*Language and terminology.* Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

*Abbreviations.* As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

## 9.3 Reference Style

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## 9.4 Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

### 9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

### 9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

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For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

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## **11. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at [dem.pra@sagepub.com](mailto:dem.pra@sagepub.com)

## Appendix II: Quality appraisal framework (Caldwell et al., 2005)



### Appendix III: Quality assessment results

Met criterion = 2, partially met criterion =1, not met criterion =0

Quality Framework	Ankri et al., (2005)	Conde-Sala et al., (2010)	Gruffydd, E., & Randle, J. (2006).	Karlin et al., (2001)	Losada et al., (2010)	Parks & Pilisuk, (1991)	Roach et al., (2013)	Rosa et al., (2010)	Samuelsson et al., (2001)	Springate & Tremont (2014)
1. Does the title reflect the content?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Are the authors credible?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Does the abstract summarise the key components?	Yes	Yes	Yes	Partially	Partially	Partially	Yes	Partially	Partially	Yes
4. Is the rationale for undertaking the research clearly outlined?	Yes	Yes	Partially	Partially	Yes	Yes	Yes	Partially	No	Yes
5. Is the literature review comprehensive and up to date?	Yes	Yes	Partially	No	Yes	No	Yes	Partially	Partially	Yes
6. Is the aim of the research clearly stated?	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
7. Are all ethical issues identified and addressed?	No	Partially	Partially	No	Yes	No	No	No	Partially	Partially
8. Is the Methodology identified and justified?	Yes	Yes	Yes	Partially	Partially	Partially	Yes	Yes	Partially	Yes

9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?	Partially	Yes	Yes	Partially	Partially	Yes	Yes	No	No	Partially
<b>Quality Framework</b>		<b>Ankri et al., (2005)</b>	<b>Conde-Sala et al., (2010)</b>	<b>Gruffydd, E., &amp; Randle, J. (2006).</b>	<b>Karlin et al., (2001)</b>	<b>Losada et al., (2010)</b>	<b>Parks &amp; Pilisuk, (1991)</b>	<b>Roach et al., (2013)</b>	<b>Rosa et al., (2010)</b>	<b>Samuelsson et al., (2001)</b>	<b>Springate &amp; Tremont (2014)</b>
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes	No
11. Is the population identified?	11. Is the context of the study outlined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Quality Framework		Ankri et al., (2005)	Conde-Sala et al., (2010)	Gruffydd, E., & Randle, J. (2006).	Karlin et al., (2001)	Losada et al., (2010)	Parks & Pilisuk, (1991)	Roach et al., (2013)	Rosa et al., (2010)	Samuelsson et al., (2001)	Springate & Tremont (2014)
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes	No
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	Yes	Yes	Yes	Partially	Yes	Yes	Yes	Partially	Yes	Yes
15. Are the results presented in a way that is appropriate and clear?		Yes	Yes	Yes	Yes	Yes	Partially	Yes	No	Yes	Yes
16. Is the discussion comprehensive?		Yes	Yes	Partially	Partially	Yes	Yes	Yes	Yes	Yes	Yes
17. Are the results generalizable?	17. Are the results transferable?	Partially	Partially	Partially	Yes	Partially	Partially	Partially	Partially	Partially	Partially
18. Is the conclusion comprehensive?		Yes	Yes	Partially	No	Yes	Yes	Yes	No	Partially	Yes
<b>Score</b>		<b>32/36</b>	<b>34/36</b>	<b>30/36</b>	<b>22/36</b>	<b>32/36</b>	<b>28/36</b>	<b>33/36</b>	<b>21/36</b>	<b>26/36</b>	<b>29/36</b>

#### Appendix IV: Example transcript and coding

arguing wife

30 F: you argue with Joan (and it...what does] it do to you... That  
31 (P1: yeah yeah)

32 P1: well, I wonder who's right and who's wrong and i'll always know who's right (P2: laughs) Denial about getting it wrong

33 F: do you? uncertainty about own ability - not trusting their memory

34 R: you?

35 P2: are you finished?

36 P1: if you've got summit, yeah go on

37 P2: ummm, i've had a not very nice life. My father was, umm, got, [ummm,tha]- that's it, in St talk about past

38 F: {blinded}

39 (cont.) Dunston's when he went to St. Dunston's and urgh and urgh people came along and well talk about the past

40 how's you dad getting along, you know, and all and it used to worry me and he, of course he got got

41 baskets, dog baskets, of course he couldn't see 'em but he just made them in his thoughts I s'pose

42 but he got quite good and I, I used to play football...Errm with bla- erm Nuneaton borough

43 R: yeah talking about deceased family

44 P2: and I saw, err, we went to Blackpool...

45 R: mm

46 P2: for a holiday and it was a err, St. Dunston's home so we saw my dad all day, not, you know, he

47 went to bed and that's it and he got up and looked... and erm cos what I liked about my holidays was

48 they had, erm, (pause) a sort of chap like him a jock and funny you know talking about the past

49 F: yap

50 P2: and he used to take about 115 (inaudible) on the beech at 6 or 7 o'clock in the morning, you talk about

51 know, and took, let them, let them let them go out 5 yards or whh-whatever cos they couldn't go far the past

52 cos they were all blind they were and err (stutter) and come back and take them back

53 R: so more recently then when you've had a few more problems with your memory since you've got

54 older and er, have there been things that you need more help with? Either of you?

55 P2: [sigh] mmmm, no not, no I dunna know uncertainty Denial

56 R: [P1] you said that...

57 P1: yes, I do admitting you need more help / accepting more help. help

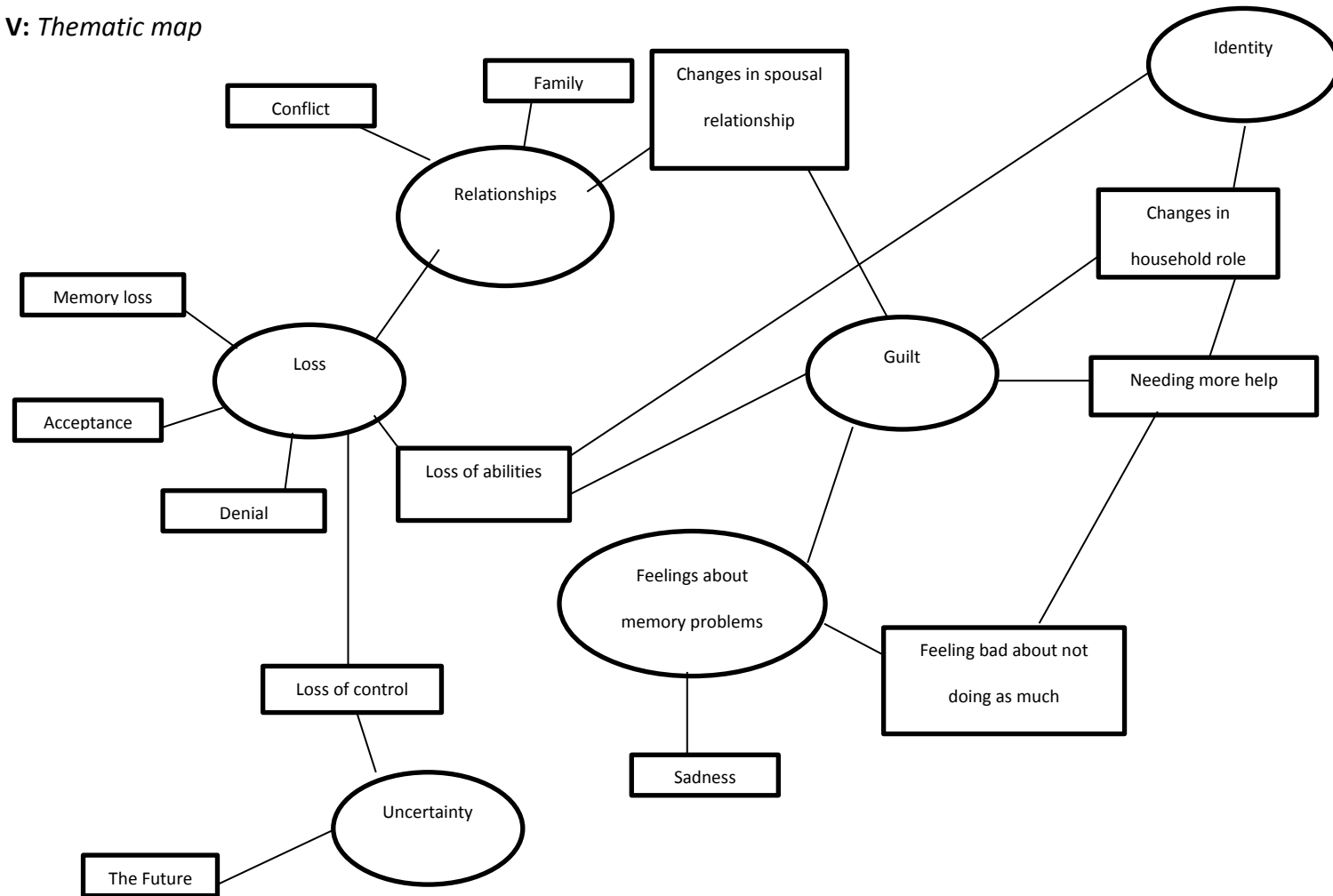
58 R: you need more, a little more help

59 P1: well no I don't need more help, but erm, driving. denying needing more help.

60 R: ah ok.

Line No	Data Extract	Code	sub-theme	Theme
4	"I know i've lost a little bit of my memory"	Talking about loss of memory	memory loss	loss
		knowing he has memory loss	memory loss	
		accepting he has memory loss	acceptance of memory loss	
4,5	"i've lost a lot of other things as well"	loss of other aspects of life not just memory	loss	
10	"I used to play international football"	talking about what he used to be able to do	loss of abilities	
12,13	"it's a few national ones for me so it wasn't too bad, but I used to play with them... what else?"	thinking about the past	the past	the past
16	"shout at his missus"	shouting at his wife	spousal relationships	relationships
20	"well I can't remember some things"	Talking about loss of memory	memory loss	loss
		knowing he has memory loss	memory loss	
		accepting he has memory loss	acceptance of memory loss	acceptance and loss
22	"when I can't remember some things I argue with [wife]"	arguing with his wife	conflict in spousal relationships	conflict and relationships
		memory problems causing difficulties in realtionships	conflict in spousal relationships	
32	"I wonder who's right and who's wrong "	uncertainty about accuracy of memory	uncertainty	uncertainty
		being unsure	uncertainty	

**Appendix V: Thematic map**





## Appendix VI: Focus group participant documents

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Fax 024 7666 5702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eric Knight  
BSc (Hons) Psychol, CPsychol

THE UNIVERSITY OF  
WARWICK

Coventry  
University

### Focus Group Invitation Letter

You are being invited to take part in a group discussion about the feelings people with memory problems may experience. The group will be run by Jane Muers, the chair of your local support group, and Leanne Semple, a trainee clinical psychologist from Coventry and Warwick universities.

If you are interested in taking part in this group discussion please read the enclosed information.

If, after reading the information sheet, you are happy to take part in the study please read and sign the consent form enclosed.

Thank you for taking the time to read this information.

Yours Sincerely,

Jane Muers  
(Chair RDSG, Honorary Research Fellow Coventry University)

Leanne Semple  
(Trainee Clinical Psychologist)

Stage one invitation letter. Version 1. 18.2.14

Dean of Faculty of Health and Life Sciences  
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Head of Department of Psychology  
Professor James Bevilacqua BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7667 3000

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**WARWICK**



**Focus Group Information Sheet**

You are being invited to take part in a group discussion about the feelings people with memory problems may experience.

**What is the purpose of the group discussion?**

The aim of the group discussion is to gain a better understanding of the feelings people with memory problems may experience.

**Why have I been chosen?**

The discussion requires people with memory problems to talk about their experiences. Your local support group has suggested that you may want to take part in the discussion.

**Do I have to take part?**

No. It is your choice whether to take part or not.

If you do choose to participate you can leave the discussion at any time.

Your contribution to the discussion will still be used for the study unless you withdraw your consent before the 1<sup>st</sup> September 2014.

Any healthcare services and support you receive will not be affected in any way if you choose to take part or not.

*Stage one information sheet. Version 1.1 20.2.14*

**Dean of Faculty of Health and Life Sciences**

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priority Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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**What if I want to stop?**

You can leave the group discussion at any time.

**Will my information be kept confidential?**

Your involvement in the discussion will remain confidential to the Trainee Clinical Psychologist and her supervisors. The information from the discussion will be written in a report and be used for a research study about the experiences of people with memory problems. You will not be named in the written report.

**What are the risks or benefits of taking part?**

The discussion will involve talking about feelings you may have experienced since experiencing memory problems. If you feel distressed in any way during the discussion you are free to leave at any time.

**What if there is a problem?**

If you are concerned about any aspects of the discussion please contact the researcher or one of her supervisors (see contact details below).

**What will happen to the results of the discussion?**

We would like to record the discussion and transcribe it so that what is said can be analysed and the themes explored.

The information from the discussion would then be written in a report and used for the research study. All participants will be anonymised in the writing of the report.

The overall study may be put forward for publication in a psychology and/or mental health journal.

The results will also be shared with the local NHS and voluntary organisations which have provided assistance with the study. No information that can identify you will be published and your involvement in the discussion will remain confidential to the research team.

If you would like to receive a summary of the overall findings please contact the researcher (see contact details below). Your information will remain anonymous and feedback will not be provided on individual responses.

**Thank you for taking time to read this information.**

#### **Contact Details**

Leanne Semple	Clinical Psychology Doctorate
Main researcher	Faculty of Health and Life Sciences
	Coventry University
(Trainee Clinical	James Starley Building
Psychologist)	Priory Street
	Coventry
	CV1 5FB
	Tel: 07984006932

*Stage one information sheet. Version 1.1 20.2.14*

### Contact Details

Dr Tom Patterson	Clinical Psychology Doctorate
Research supervisor	Faculty of Health and Life Sciences
	Coventry University
(Clinical Psychologist)	James Starley Building
	Priory Street
	Coventry
	CV1 5FB
	Tel: 024 7688 8328
Jane Muers	Clinical Psychology Doctorate
Research supervisor	Faculty of Health and Life Sciences
	Coventry University
(Clinical Psychologist)	James Starley Building
	Priory Street
	Coventry
	CV1 5FB
	Tel: 024 7688 8328

Coventry University  
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Programme Director  
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Dr Eva Knight  
BSc Clin Psych, CPsychol

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WARWICK



### Focus Group Consent Form

Please initial box

1. I confirm that I have read and understood the participant information sheet and I have been given the opportunity to ask any questions. ☐
2. I understand participation in the group discussion is completely voluntary and I can withdraw at any time without giving a reason. ☐
3. I am happy for the information from the discussion to be recorded and transcribed ☐
4. I am happy for the information to be analysed and written up as part of a research study about the experiences of people with memory problems and that my information will remain anonymous. ☐
5. I agree to take part in the group discussion ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

Stage one consent form, Version 1, 16.2.14

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### Focus Group Debrief Sheet

Thank you for taking part in the group discussion about your feelings since being diagnosed with memory problems.

The focus group was designed to gather information about the experiences of people with memory problems. The information gathered will be used to help develop a questionnaire designed to assess feelings of guilt in persons with memory problems.

Once developed the questionnaire will be trialled with a group of participants in stage two of this study.

We hope taking part in this discussion was a comfortable experience for you all. We appreciate that some of the topics discussed may have caused some emotional distress. If this is the case we encourage you to let us know so we can help you and direct you to appropriate support services.

Many thanks again for your support with this study.

*Stage one debrief sheet, Version 1, 18.2.14*  
Dean of Faculty of Health and Life Sciences

Dr Linda Meriman: Mphil, PhD, DpodM, CertEd, Coventry University, Priory Street, Coventry, CV1 5FB, Tel 024 7679 5805

Head of Department of Psychology



**Appendix VII: 27-item Guilt in People with Dementia Scale (GPWDS) sent for expert review**

**Developing and Validating a Measure of Guilt for Persons with Dementia**  
Draft for Expert Review

		All of the time	Most of the time	Some of the time	Never
1	I think my memory problems cause my family and friends harm				
2	I worry about the impact of my memory problems on my family and friends				
3	I worry about becoming a burden on my family and friends				
4	I feel guilty about not being able to do as much I used to				
5	I feel bad about not being able to remember people's names				
6	I feel I am a burden to my friends and family				
7	I think I am a nuisance to my family and friends				
8	I feel bad my family and friends have to help me more now				
9	I cause my family and friends extra trouble				
10	I worry about how my memory problems affect my family and friends' lives				
11	I think my memory problems cause arguments with my family and friends				
12	I feel guilty about arguing with my family and friends				
13	I feel responsible for disappointment in my family and friends				
14	I feel guilty that others have to do more now I have memory problems				
15	I feel guilty leaving things to others to do				
16	I feel like apologizing to my family and friends for my memory problems				
17	I feel I have let my friends and family down				
18	I think my memory problems are a punishment				
19	I feel good about myself *				
20	I feel alright about what I can do *				
21	I feel fine about my family and friends having to do more for me now *				
22	I feel guilty about my changes in my relationships since having memory problems				
23	I think it is my fault things are more difficult now				



		All of the time	Most of the time	Some of the time	Never
24	I am worry free *				
25	I am guilt free *				
26	I think my memory problems cause my family and friends harm				
27	I think I am to blame for my memory problems				

(\* indicates reverse scored item)

### Appendix VIII: Development of questionnaire

Item	Source
I think my memory problems cause my family and friends harm	(O'Connor et al., 1997 Interpersonal guilt: the development of a new measure)
I worry about the impact of my memory problems on my family and friends	Ostwald et al., 2002
I worry about becoming a burden on my family and friends ( <i>anticipated</i> )	Cahill et al., 2009; Werezak & Stewart, 2002
I feel guilty about not being able to do as much I used to	Focus Group
I feel bad about not being able to remember people's names	Gillies, 2000
I feel I am a burden to my friends and family ( <i>current</i> )	Cahill et al., 2009
I think I am a nuisance to my family and friends	Gillies, 2000
I feel bad my family and friends have to help me more now	Ward-Griffin, Bol & Oudshoorn, 2006/ Focus Group
I cause my family and friends extra trouble	(Pearce, Clare & Pistrang, 2002)
I worry about how my memory problems effect my family and friends' lives	(Pearce, Clare & Pistrang, 2002)
I think my memory problems cause arguments with my family and friends	Focus Group
I feel guilty about arguing with my family and friends	Focus group
I feel responsible for disappointment in my family and friends	(Steeman et al., 2006)
I feel guilty that others have to do more now I have memory problems	Focus Group

I feel guilty leaving things to others to do	Focus Group
I feel like apologising to my family and friends for my memory problems	Tangney & Dearing, 2003 (SSGS)
I feel I have let my friends and family down	Hamilton Depression Rating Scale (HAMD)/Cornell Scale for Depression in Dementia/Gillies, 2000
I think my memory problems are a punishment	HAMD/Cornell Scale for Depression in Dementia
I feel good about myself	Positive/reverse statement State Shame and Guilt Scale (SSGS) and The Guilt Inventory (Kugler & Jones, 1992)
I feel alright about my family and friends having to do more more for me now	Positive/reverse statement
I feel fine about what I can do	Positive/reverse statement
I feel guilty about my changes in my relationships since having memory problems	Focus Group
I think it is my fault things are more difficult now	Focus Group
I am worry free	Guilt Inventory/reverse statement (Jones, Schratter & Kugler, 2000)
I am guilt free	Guilt Inventory/reverse statement (Jones, Schratter & Kugler, 2000)
I think I am to blame for my memory problems	(Tilghman-Osborne et al.2010) definition of guilt, behavioural self blame

## Appendix IX: Expert review email

From: Leanne Semple <sempel@uni.coventry.ac.uk>  
To: "Merritt Claire (RNU) Oxford Health" <Claire.Merritt@oxfordhealth.nhs.uk>,  
"Pavlou Claire (RYG) C&W PARTNERSHIP TRUST"  
<Claire.Pavlou@covwarkpt.nhs.uk>, "Buckell, Anna (Early Intervention Team)01"  
<Anna.Buckell@hacw.nhs.uk>, "Borley Gayle (NORTHAMPTONSHIRE  
HEALTHCARE NHS FOUNDATION TRUST)" <gayle.borley@nhs.net>  
Cc: JANE MUERS <jane.muers@btinternet.com>, "Tom Patterson (Senior  
Lecturer/Practitioner - Clinical Psychology)" <aa5654@coventry.ac.uk>  
Subject: Expert Review: Developing and Validating a Measure of Guilt for Persons  
with Dementia  
Date: 15 August 2014 07:59:23 BST

Dear All,

As you are aware for my Clinical Doctorate research project I am developing and validating a measure of guilt for persons with Dementia.

As part of the development process I would like to seek an expert review of the (draft) measure from people who are knowledgeable in the content area and have experience of working in dementia services. This process serves to maximize the measure's face and content validity. Following this process, items will be selected for inclusion in line with feedback received from you and a number of other expert reviewers, prior to recruitment for the validation study. The items on the (draft) measure have been generated by drawing on qualitative literature reporting the experiences of people with dementia and also the results of a thematic analysis of a focus group held with people with dementia.

As such I would be extremely grateful if you could review the attached measure by:

1. Identifying and listing any items you do not feel represent the construct of guilt in people with dementia (in accordance with your clinical experience)
2. Providing feedback on any concerns you may have regarding the wording of items and accessibility of the measure for people with dementia.

Please be aware that the (draft) measure also contains reverse worded/positive statements.

We are aware that this measure is likely to only be suitable for persons with early stage dementia and MCI. Please bear this in mind when reviewing the items and considering the appropriateness of the measure.

Please do not hesitate to contact me with any questions or concerns.

Many Thanks.

Kind Regards,  
Leanne Semple

Leanne Semple  
Trainee Clinical Psychologist  
Coventry and Warwick Course  
Tel. 07984006932

## Appendix X: 21-item GPWDS (post expert review)

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Worcestershire Health and Care NHS  
NHS Trust

### GPWD

Below are some statements about feelings and thoughts.

Please read each statement and tick the box that best describes how you feel.

		All of the time	Most of the time	Some of the time	Never
1	I feel guilty about my memory problems				
2	I think my memory problems cause my family and friends difficulties				
3	I feel good about myself				
4	I worry about the impact of my memory problems on my family and friends				
5	I feel I am becoming a burden on my family and friends				
6	I feel guilty about not being able to do as much I used to				
7	I feel bad about not being able to remember people's names				
8	I feel fine when my family and friends do things which I used to				
9	I think I cause my family and friends extra trouble				
10	I worry about how my memory problems affect my family and friends' lives				
11	I think my memory problems cause arguments with my family and friends				
12	I do not feel guilty about my memory problems				

Dean of Faculty of Health and Life Sciences  
Dr Linda Merriam, MSc, PhD, DipEd, CerdEd, Coventry University, Priory Street, Coventry, CV1 5PB, Tel 024 7665 6805

Head of Department of Psychology  
Professor James Trevelan BSc PhD, University of Warwick, Coventry, CV4 7AL, Tel 024 7667 3008

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		All of the time	Most of the time	Some of the time	Never
13	I feel guilty if, as a result of my memory problems, I argue with others.				
14	I feel responsible for disappointment in my family and friends				
15	I feel alright about what I can do				
16	I feel guilty that others have to do more now I have memory problems				
17	I feel guilty leaving things to others to do				
18	I feel like I need to say sorry to my family and friends because of my memory problems				
19	I feel I am letting my friends and family down				
20	I do not worry about my memory problems				
21	I think I am to blame for my memory problems				

**Appendix XI: 15-item Geriatric Depression Scale (GDS-15; Yesavage & Sheikh, 1986)**

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Worcestershire Health and Care NHS Trust

### Geriatric Depression Scale

Below are some questions about your feelings.

Please circle the answer that best describes how you have felt recently.

1.	Are you basically satisfied with your life?	YES/NO
2.	Have you dropped many of your activities and interests?	YES/NO
3.	Do you feel that your life is empty?	YES/NO
4.	Do you often get bored?	YES/NO
5.	Are you in good spirits most of the time?	YES/NO
6.	Are you afraid that something bad is going to happen to you?	YES/NO
7.	Do you feel happy most of the time?	YES/NO
8.	Do you often feel helpless?	YES/NO
9.	Do you feel you have more problems with memory than most people?	YES/NO
10.	Do you prefer to stay at home, rather than going out and doing new things?	YES/NO
11.	Do you think it is wonderful to be alive?	YES/NO
12.	Do you feel pretty worthless the way you are now?	YES/NO
13.	Do you feel full of energy?	YES/NO
14.	Do you feel that your situation is hopeless?	YES/NO
15.	Do you think that most people are better off than you are?	YES/NO

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Head of Department of Psychology  
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**Appendix XII: Warwick Edinburgh Mental Well-Being Scale (WEMWBS; Tennant et al., 2007)**

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**The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)**

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been feeling interested in other people					
I've had energy to spare					
I've been dealing with problems well					
I've been thinking clearly					
I've been feeling good about myself					
I've been feeling close to other people					
I've been feeling confident					
I've been able to make up my own mind about things					
I've been feeling loved					
I've been interested in new things					
I've been feeling cheerful					

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)  
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Dr Linda Merriam MPhil PhD DEdEd CertEd Coventry University, Priory Street, Coventry CV1 5FB Tel 024 7655 5905

Head of Department of Psychology  
Professor James Trostian BSc PhD University of Warwick, Coventry CV4 7AL Tel 024 7657 3000



**Appendix XIII: Confirmation of Coventry University ethical approval**

**TO WHOM IT MAY CONCERN**

QRS/Ethics/Sponsorlet

Wednesday, 26 February  
2014

Dear Sir/Madam

**Researcher's name:** Leanne Semple  
**Project Reference:** P19226  
**Project Title:** Developing and validating a measure of guilt for people with dementia

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully



**Professor Ian Marshall**

**Deputy Vice-Chancellor, Academic**

## Appendix XIV: Local NHS Research Ethics Committee correspondence and approval

  
**Health Research Authority**  
**NRES Committee West Midlands - Coventry & Warwickshire**  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS  
Telephone: 0115 883 9440

25 April 2014

Miss Leanne J Semple  
34 Bishopsgate  
Bishops Itchington  
Southam  
CV47 2UT

Dear Miss Semple,

<b>Study title:</b>	<b>Developing and validating a questionnaire measure of guilt for people with dementia.</b>
<b>REC reference:</b>	<b>14/WM/0095</b>
<b>IRAS project ID:</b>	<b>145789</b>

Thank you for your letter of 21 April 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Rebecca Morledge, [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net).

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

#### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		20 February 2014
Evidence of insurance or indemnity	Allianz	
Investigator CV		21 February 2014
Letter from Sponsor	Coventry University	26 February 2014
Letter of invitation to participant	1.1 Stage two	28 February 2014
Letter of invitation to participant	1 Focus Group	18 February 2014
Other: CV - Dr Tom Patterson		20 February 2014
Other: Letter from insurance brokers	AON	01 July 2013
Other: Letter from insurance brokers	AON	01 July 2013
Other: Focus Group Debrief Sheet	1	18 February 2014
Participant Consent Form: Stage two	1.1	20 February 2014
Participant Consent Form: Focus Group	1	18 February 2014
Participant Information Sheet: Focus Group	1.1	20 February 2014
Participant Information Sheet: Stage 2	1.4	08 April 2014
Protocol	1.1	
REC application	145789/569244/1/505	20 February 2014
Response to Request for Further Information		21 April 2014

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**14/WM/0095**

**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely,



**Dr Helen Brittain**  
**Chair**

Email: NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Miss Natassia Embury, West Midlands South Comprehensive Local Research Network



## Health Research Authority

### NRES Committee West Midlands - Coventry & Warwickshire

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6PS

Tel: 0115 8839 440

07 October 2014

Miss Leanne J Semple  
34 Bishopsgate  
Bishops Itchington  
Southam  
CV47 2UT

Dear Miss Semple,

Study title:	Developing and validating a questionnaire measure of guilt for people with dementia.
REC reference:	14/WM/0095
Amendment number:	1
Amendment date:	23 September 2014
IRAS project ID:	145789

The above amendment was reviewed on 03 October 2014 by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

There were no Ethical issues

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	1	23 September 2014
Other [Demographics Questionnaire]	1	16 September 2014
Other [Geriatric Depression Scale - reproduced for study]	1	19 September 2014
Other [WEMWBS - reproduced for study]	1	19 September 2014
Other [GPWD]	1.2	19 September 2014

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

#### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/WM/0095: Please quote this number on all correspondence
--

Yours sincerely,



**Dr Helen Brittain**  
Chair

E-mail: [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Miss Natassia Embury, West Midlands South Comprehensive Local Research Network*

**Appendix XV: Local Research and Development department ethical approval and correspondence**

*Coventry and Warwickshire Partnership Trust R&D Approval*



Clinical Research Network: West Midlands  
Fourth Floor, West Wing (ACF40002)  
University Hospitals Coventry & Warwickshire NHS Trust  
University Hospital  
Clifford Bridge Road  
Coventry  
CV2 2DX

5<sup>th</sup> June 2014

Miss Leanne Semple  
Trainee Clinical Psychologist  
Coventry and Warwickshire Partnership NHS Trust  
St Michaels Hospital  
St Michaels Road  
Warwick  
CV34 5QW

Dear Miss Semple

**Project Title: Developing and validating a measure of guilt for persons with dementia**  
**R&D Ref: PAR240314**  
**REC Ref: 14/WM/0095**

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at Coventry and Warwickshire Partnership NHS Trust. The details of your study have now been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
REC Favourable Opinion Letter	14/WM/0095	25/04/2014
Protocol	1.1	
Letter of Invitation to Participant	1.1 Stage Two	28/02/2014
Participant Consent Form: Stage Two	1.1	20/02/2014
Participants Information Sheet: Stage Two	1.4	08/04/2014
SSI Form	145789/568249/6/125/230367/29217	19/02/2014
R&D Form	145789/569270/14/278	20/02/2014

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.



All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

You will be sent an annual progress report which must be completed in order to ensure that the information we hold on our database remains up to date, in line with RGF requirements.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.


Yours sincerely



**Natassia Embury**  
**RM&G Facilitator**

**Cc:** Tom Patterson, Clinical Psychologist, CWPT.  
Ian Marshall, Sponsor Representative,  
Dr Judith Bond, Coventry and Warwickshire Partnership NHS Trust  
Mrs Jane Muers, Academic Supervisor,

*Worcestershire Health and Care Trust R&D Approval*

Worcestershire Health and Care   
NHS Trust

Research & Development  
Worcestershire Health and Care NHS Trust  
Isaac Maddox House  
Shrub Hill Road  
Worcester  
WR4 9RW

Tel: 01905 681514

Samantha.Whitby@hacw.nhs.uk  
www.hacw.nhs.uk

Our Ref: **14\_127\_NP**

23 May 2014

Dear Leanne,

Thank you for your research application entitled '**Developing and validating a measure of guilt for persons with dementia.**'

I take great pleasure in informing you that your application has been granted approval by the Research and Development Group, on behalf of Worcestershire Health and Care NHS Trust on 19 May 2014.

Please accept this letter as official confirmation of local Trust Approval.

I should like to take this opportunity to wish you well with your research, and look forward to seeing your final report and recommendations.

If I can be of further assistance please do not hesitate to contact me.

Yours sincerely,



Yours sincerely

**Sam Whitby**  
Audit, Research & Clinical Effectiveness Manager

*Oxford Health Foundation Trust R&D Approval*

Oxford Health   
NHS Foundation Trust

Caring, Safe and Excellent

Professor John Geddes  
Director of R&D  
Dept of Psychiatry, University of Oxford  
Warneford Hospital  
Oxford OX3 7JX  
Tel: 01865 226451 Fax: 01865 204198  
e-mail: john.geddes@psych.ox.ac.uk

Our Ref: OHFT PID 1018

3 December 2014

Mrs Claire Merritt  
Lead Research Nurse Manager  
NIHR Clinical Research Network: Thames Valley and South Midlands  
John Radcliffe Main Hospital  
Room 4401D, Level 4  
Oxford  
OX3 9DU

Dear Mrs Merritt

**Study Title: Developing and validating a questionnaire measure of guilt for people with dementia**  
**REC No.: 14/WM/0095**

I am pleased to confirm that Oxford Health NHS Foundation Trust will grant NHS Permission (Trust management approval) for the above named research study, as described in your application. NHS Permission is granted as of the date of this letter. This confirmation is dependent on formal approval by a National Research Ethics Service Committee and any other relevant regulatory body authorisation being in place.

NHS Trusts are required to meet and report on performance standards set against national recruitment targets, one of which is first participant recruited to a study within 70 calendar days of a valid research application being received by the Trust. I can confirm that your first participant target recruitment date is **06/02/2015**.

In addition to this, a study is expected to recruit its target sample size within its recruitment period. In your NHS Site-Specific Information Form (SSI Form) it is stated that Trust involvement will end on **30/04/2015** and that a target recruitment of **30** participants is required. If you feel that you may not meet these targets please notify the R&D department immediately.

It is noted that **Coventry University** has agreed to sponsor this study.

I must remind you of the declaration that was signed in the SSI Form. This explains your responsibilities as a researcher including adherence to the principles of the Research Governance Framework (RGF), Good Clinical Practice (GCP) and the Data Protection Act. Please note that the Trust is required to monitor research to ensure compliance with the RGF and other legal and regulatory requirements. This is achieved by random audit of research.

NHS Permission is dependent upon submission to the R&D Department of the following and may be revoked if these conditions are not met:

- date of first participant recruited
- quarterly response to request for recruitment figures
- annual reports and evidence of submission to REC and any other regulatory body

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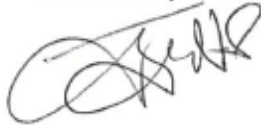
Oxford Health NHS Foundation Trust  
Chancellor Court, 4000 John Smith Drive, Oxford Business Park South, Oxford OX4 2GX  
Telephone: (01865) 778911 [www.oxfordhealth.nhs.uk](http://www.oxfordhealth.nhs.uk)  
Caring, Safe and Excellent  
Delivering high quality research to improve health care for all

OHFT NHS Permission\_Guilt in people with dementia\_OHFT PID 1018  
1 of 2

- any substantial or non-substantial amendment to the conduct of the study
- final report on completion of the study
- immediate notification to R&D of changes in involvement of key site personnel: Chief Investigator or Principal Investigator

I wish you every success with the study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'J. Geddes', written over a horizontal line.

**Professor John Geddes**  
**Director of R&D**

**Cc:**

Sponsor – I. Marshall, Coventry University (i.marshall@coventry.ac.uk)

Leanne Semple, Trainee Clinical Psychologist, Coventry and Warwickshire Partnership NHS Trust

## Appendix XVI: Participant consent form for validation stage of study

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7666 8328  
Fax 024 7666 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eva Knight  
BSc Clin.Psy.D. CPsychol.

THE UNIVERSITY OF  
WARWICK

Coventry  
University

Worcestershire Health and Care NHS Trust

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**CONSENT FORM**

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**Title of Project:** Developing and validating a measure of guilt for persons with dementia

**Name of Researcher:** Leanne Semple (Trainee Clinical Psychologist)

Please initial box

1. I confirm that I have read and understood the information sheet and I have been given the opportunity to ask any questions.
2. I understand participation in the study is completely voluntary and I can withdraw at any time without giving a reason why.
3. I understand I can stop at any time.
4. I understand that any support, medical care and health services that I receive will not be affected by my participation in the study.
5. I understand I will be asked to complete some questionnaires about my feelings.
6. I understand that the findings from this research may be written up for publication in journals and that my information will remain anonymous.

Dean of Faculty of Health and Life Sciences  
Dr Linda Morrison MPhil PhD DipEd CertEd Coventry University Priory Street, Coventry CV1 5FB Tel 024 7674 5200

Head of Department of Psychology  
Professor James Trevelan BSc PhD University of Warwick, Coventry CV4 7AL Tel 024 7667 3009

[www.coventry.ac.uk](http://www.coventry.ac.uk)

7. I agree to take part in this study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person	Date	Signature taking consent.

## Appendix XVII: Participant invitation letter for validation stage of study

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7668 8328  
Fax 024 7668 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eve Knight  
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF  
WARWICK

Coventry  
University

Worcestershire Health and Care NHS Trust

Invitation Letter

**Title of Project:** Developing and validating a measure of guilt for persons with dementia

You are being invited to take part in a research study for people with memory problems. A local support group or NHS service has suggested that you may want to take part in this study.

Before you decide if you want to take part it is important for you to understand the purpose of the research and what it will involve. Please read the enclosed participant information sheet.

If, after reading the participant information sheet you are happy to take part in the study all you have to do is complete the enclosed consent form, questionnaires and return in the stamped addressed envelope.

Thank you for taking the time to read this information.

Yours Sincerely,



Leanne Semple  
(Trainee Clinical Psychologist)

Dean of Faculty of Health and Life Sciences  
Dr Linda Mearman: Mphil PhD DoodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology  
Professor James Trevelyan BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk



## Appendix XVIII: Participant information sheet for validation stage of study

**Coventry University**  
Priory Street, Coventry CV1 5FB  
Telephone 024 7688 8328  
Fax 024 7688 8702

**Programme Director**  
**Doctorate Course in Clinical Psychology**  
Dr Eve Knight  
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF  
**WARWICK**

**Coventry University**

**Worcestershire Health and Care NHS Trust**

**Information Sheet**

**Title of Project:** Developing and validating a measure of guilt for persons with dementia

You are being invited to take part in a research study conducted by a Trainee Clinical Psychologist from the Universities of Coventry and Warwick as part of her Clinical Psychology Doctorate.

The research study is being supervised by two qualified clinical psychologists.

Before you decide if you want to take part it is important for you to understand the purpose of the research and what it will involve.

We encourage you to talk to your friends and family about your decision to participate. Please contact the researcher if you have concerns or if you would like her to go through the information with you.

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

The aim of the study is to develop a questionnaire measure of the feelings people with memory problems may experience. It is hoped that this will lead to greater understanding of the feelings of people with memory problems and improve the support offered to both you and your friends and family.

**Why have I been chosen?**

The study requires people with memory problems to complete the questionnaire. A local support group or NHS service has suggested that you may want to take part in the study.

**Dean of Faculty of Health and Life Sciences**  
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**  
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

[www.coventry.ac.uk](http://www.coventry.ac.uk)



**Do I have to take part?**

No. It is entirely your choice whether to take part or not. If you do choose to participate you can withdraw from the study at any time.

Any healthcare services and support you receive will not be affected in any way if you choose to take part or not.

If you choose to take part, please sign the consent form included in this pack.

You can withdraw your data from the study at any point prior to 1<sup>st</sup> March 2015.

**What would taking part involve?**

Taking part involves completing a number of questionnaires about feelings you may experience.

These should take approximately 15-30 minutes to complete.

You can complete them on your own or with the researcher. If you would like the researcher to support you please contact her (see contact details below). Once you have done this you will not be asked to contribute further.

**What if I want to stop?**

You can stop at any time

**Will my information be kept confidential?**

All of the information that you provide will remain confidential. It will be stored in a locked cabinet and will only be seen by the researcher and her supervisors.

**What are the risks or benefits of taking part?**

The questionnaire asks about feelings of guilt you may experience since having memory problems.

If you feel that completing the questionnaires is distressing in any way you are free to stop at any time. Please contact your GP or call The National Dementia Helpline for further support.

**The National Dementia Helpline Telephone: 0300 222 1122**

**What if there is a problem?**

If you are concerned about any aspects of the study please contact the researcher or one of her supervisors (see contact details below). If you would like to make a complaint about the study please contact The Patient Liaison Advice Service (PALS).

**How to contact PALS:**

**Telephone:** 0800 212 445 (Freephone)

**Write to:** PALS, Coventry and Warwickshire Partnership NHS Trust, Wayside House, Wilsons Lane, Coventry, CV6 6NY

**What will happen to the results of this study?**

The results of this study may be put forward for publication in a psychology and/or mental health journal. The results will also be shared with the local NHS and voluntary organisations which have provided assistance with the study.

if you would like to receive a copy of the findings please contact the researcher (see contact details below). Your information will remain anonymous and feedback will not be provided on individual responses.

Thank you for taking time to read this information.

#### Contact details

Leanne Semple  
Main researcher

(Trainee Clinical Psychologist)

Clinical Psychology Doctorate  
Faculty of Health and Life Sciences  
Coventry University  
James Starley Building  
Priory Street  
Coventry  
CV1 5FB

Dr Tom Patterson  
Research supervisor

(Clinical Psychologist)

Tel: 024 7688 8328  
Clinical Psychology Doctorate  
Faculty of Health and Life Sciences  
Coventry University  
James Starley Building  
Priory Street  
Coventry  
CV1 5FB

Jane Muers  
Research supervisor

(Clinical Psychologist)

Tel: 024 7688 8328  
Clinical Psychology Doctorate  
Faculty of Health and Life Sciences  
Coventry University  
James Starley Building  
Priory Street  
Coventry CV1 5FB Tel: 024 7688 8328

**Appendix XIX: Participant demographic sheet for validation stage of study**

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7655 8328  
Fax 024 7655 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eve Knight  
BSc Clin.Psy.D., CPsychol

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Coventry  
University

Worcestershire Health and Care NHS Trust

### Demographic questionnaire

Please answer the questions below by ticking the box that applies to you

What is your gender? Male ☐ Female ☐

How old are you?

Younger than 50	<input type="checkbox"/>
50-60	<input type="checkbox"/>
60-69	<input type="checkbox"/>
70-79	<input type="checkbox"/>
80-89	<input type="checkbox"/>
90 +	<input type="checkbox"/>

Do you live:

alone	<input type="checkbox"/>
With a Spouse	<input type="checkbox"/>
With a Child	<input type="checkbox"/>
With another/others	<input type="checkbox"/>

Do you have memory problems? Yes ☐ No ☐

Stage Two: Demographic Questionnaire Version 7.18.9.14

Dean of Faculty of Health and Life Sciences:  
Dr Linda Martinian MPhil PhD DipEd CertEd Coventry University Priory Street, Coventry CV1 5FB Tel 024 7659 8806

Head of Department of Psychology:  
Professor James Trevelyan BSc PhD University of Warwick, Coventry CV4 7AL Tel 024 7657 3009

**Appendix XX: Item-total statistics (SPSS output)**

Table 6. *Item-total statistics for 21 items of GPWD*

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
G1	41.60	87.855	.568	.665	.860
G2	41.26	87.020	.604	.769	.859
G3	41.06	91.800	.264	.651	.869
G4	41.21	83.736	.697	.766	.854
G5	41.40	82.290	.710	.841	.853
G6	41.09	82.167	.704	.768	.853
G7	40.94	88.235	.381	.558	.866
G8	41.04	94.129	.056	.550	.878
G9	41.21	86.823	.536	.829	.860
G10	41.11	83.184	.665	.779	.855
G11	42.13	92.592	.329	.656	.867
G12	40.38	94.633	.017	.524	.881
G13	41.87	92.114	.287	.841	.868
G14	41.64	82.801	.702	.856	.853
G15	41.32	91.048	.289	.608	.868
G16	41.04	82.129	.735	.824	.852
G17	41.11	81.010	.758	.896	.851
G18	41.45	83.209	.657	.668	.855
G19	41.77	86.661	.647	.737	.858
G20	40.55	94.687	.031	.679	.878
G21	42.06	95.322	.018	.471	.875

## Appendix XXI: Final Scale 13-item GPWDS

Name: \_\_\_\_\_

Date: \_\_\_\_\_

### Guilt in People With Dementia Scale (GPWDS)

Below are some statements about feelings and thoughts.

Please read each statement and tick the box that best describes how you feel.

	All of the time	Most of the time	Some of the time	Never
I feel guilty about my memory problems				
I think my memory problems cause my family and friends difficulties				
I worry about the impact of my memory problems on my family and friends				
I feel I am becoming a burden on my family and friends				
I feel guilty about not being able to do as much I used to				
I feel bad about not being able to remember people's names				
I think I cause my family and friends extra trouble				
I worry about how my memory problems affect my family and friends' lives				
I feel responsible for disappointment in my family and friends				
I feel guilty that others have to do more now I have memory problems				
I feel guilty leaving things to others to do				
I feel like I need to say sorry to my family and friends because of my memory problems				
I feel I am letting my friends and family down				

GPWDS (Semple, Patterson & Muers, 2015)

**Appendix XXII: Principal Components Analysis (SPSS output)**

Table 7. *Correlation matrix of final GPWD scale*

		Correlation Matrix <sup>a</sup>												
		G1	G2	G4	G5	G6	G7	G9	G10	G14	G16	G17	G18	G19
Correlation	G1	1.000	.435	.536	.480	.591	.441	.196	.295	.356	.455	.466	.373	.520
	G2	.435	1.000	.626	.546	.306	.344	.534	.568	.629	.480	.546	.430	.549
	G4	.536	.626	1.000	.682	.495	.354	.557	.596	.664	.649	.631	.543	.539
	G5	.480	.546	.682	1.000	.471	.338	.618	.554	.547	.540	.741	.604	.424
	G6	.591	.306	.495	.471	1.000	.360	.317	.438	.460	.631	.626	.480	.529
	G7	.441	.344	.354	.338	.360	1.000	.045	.249	.241	.208	.236	.284	.347
	G9	.196	.534	.557	.618	.317	.045	1.000	.575	.656	.565	.593	.539	.280
	G10	.295	.568	.596	.554	.438	.249	.575	1.000	.644	.533	.705	.484	.484
	G14	.356	.629	.664	.547	.460	.241	.656	.644	1.000	.645	.740	.537	.531
	G16	.455	.480	.649	.540	.631	.208	.565	.533	.645	1.000	.700	.452	.474
	G17	.466	.546	.631	.741	.626	.236	.593	.705	.740	.700	1.000	.461	.458
	G18	.373	.430	.543	.604	.480	.284	.539	.484	.537	.452	.461	1.000	.661
	G19	.520	.549	.539	.424	.529	.347	.280	.484	.531	.474	.458	.661	1.000
Sig. (1-tailed)	G1		.001	.000	.000	.000	.001	.081	.017	.005	.000	.000	.003	.000
	G2			.000	.000	.014	.006	.000	.000	.000	.000	.000	.001	.000
	G4				.000	.000	.005	.000	.000	.000	.000	.000	.000	.000
	G5					.000	.007	.000	.000	.000	.000	.000	.000	.001
	G6						.004	.011	.001	.000	.000	.000	.000	.000

G7	.001	.006	.005	.007	.004		.375	.038	.043	.070	.046	.021	.006
G9	.081	.000	.000	.000	.011	.375		.000	.000	.000	.000	.000	.022
G10	.017	.000	.000	.000	.001	.038	.000		.000	.000	.000	.000	.000
G14	.005	.000	.000	.000	.000	.043	.000	.000		.000	.000	.000	.000
G16	.000	.000	.000	.000	.000	.070	.000	.000	.000		.000	.000	.000
G17	.000	.000	.000	.000	.000	.046	.000	.000	.000	.000		.000	.000
G18	.003	.001	.000	.000	.000	.021	.000	.000	.000	.000	.000		.000
G19	.000	.000	.000	.001	.000	.006	.022	.000	.000	.000	.000	.000	

---

a. Determinant = 9.03E-005



Table 8. *Kaiser Meyer-Olkin value and Bartlett's Test of Sphericity*

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.	Bartlett's Test of Sphericity		
	Approx. Chi-Square	df	Sig.
.859	426.830	78	.000

Table 9. *Communalities of final GPWDS*

Item	Initial	Extraction
G1	1.000	.694
G2	1.000	.547
G4	1.000	.698
G5	1.000	.648
G6	1.000	.597
G7	1.000	.580
G9	1.000	.775
G10	1.000	.637
G14	1.000	.735
G16	1.000	.622
G17	1.000	.747
G18	1.000	.519
G19	1.000	.597

*\*Extraction Method: Principal Component Analysis.*

Table 10. *Eigenvalues and total variances explained by each component*

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings <sup>a</sup>
	% of			% of			
	Total	Variance	Cumulative %	Total	Variance	Cumulative %	Total
1	7.037	54.130	54.130	7.037	54.130	54.130	6.657
2	1.359	10.455	64.585	1.359	10.455	64.585	3.746
3	.845	6.501	71.086				
4	.745	5.730	76.816				
5	.616	4.739	81.555				
6	.551	4.237	85.792				
7	.436	3.350	89.142				
8	.338	2.598	91.740				
9	.305	2.347	94.087				
10	.284	2.184	96.272				
11	.227	1.744	98.015				
12	.166	1.275	99.290				
13	.092	.710	100.000				

Extraction Method: Principal Component Analysis.

a. When components are correlated, sums of squared loadings cannot be added to obtain a total variance.

**Appendix XXIII: Author instructions for *Reflective Practice: International and Multidisciplinary Perspectives***



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