



# Development of a Measure of Guilt in People with Dementia

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# Background

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- Guilt in Dementia is often considered in the context of caregiving but less attention is given to guilt experienced by people with dementia.
- Fear of becoming a burden, feelings of uselessness, increased concern for loved ones and feelings of guilt are prominent in people with dementia.  
(Alzheimer's Society, 2012; Clare, 2003; Cotrell & Schulz, 1993; Ostwald et al., 2002; Pearce et al., 2002; Werezak & Stewart, 2002).
- Guilt has been identified as a feature of depression in research that examined the symptom profile of depressed people with dementia.  
(Ballard et al., 1993; Chemerinski, Petracca, Sabe, Kremer & Starkstein, 2001; Merriam et al., 1988; Starkstein, Jorge, Mizrahi & Robinson, 2005).



# Research Aim

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- Given the potential for distress to be caused by feelings of guilt, it was deemed important to develop a reliable way of assessing their presence or absence in people with dementia.
- Thus, the study aim was to develop and validate a measure of guilt in people with dementia.

# Method

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- **The study adopted a two-stage, mixed-method design:**
- **Stage one** consisted of item generation and scale construction.
- **Stage two** involved the validation of the new measure and exploration of its psychometric properties.

# Stage 1: Item Generation for the Guilt Scale

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- **Item generation:**
- An initial pool of 27 potential scale items was generated based on the following procedures:
  - Running a focus group with people with dementia to gain insight into their experience of guilt and help inform the content of items for the measure.
  - An examination of existing literature on guilt in people with dementia.
  - Examining existing measures of guilt.

# Construct Definition

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- The following operational definition of 'Guilt in People with Dementia' was used:
  - *Feelings of sadness and remorse associated with anticipated and/or perceived adverse emotional, social and practical effects their living with dementia will have on their family members and significant others*

# Scale Items

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- This initial pool of items was then reviewed by 6 professionals with substantial experience of working with people with dementia and 21 items were retained.
- **Example Items included:**
- *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 as I used to.*
- *I feel I am letting my friends and family down.*

## Stage 2: Validation of Measure

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- **Initial validation study:**
- The 21 guilt items, the Geriatric Depression Scale (GDS-15) and the Warwick Edinburgh Mental Well-Being Scale (WEMWBS) were completed by postal survey.
- Participants had received a diagnosis of either Dementia or Mild Cognitive Impairment (MCI).
- 61 people returned completed questionnaires: (21 females and 40 males, all aged 60+).
- Nine data sets were incomplete and thus the total sample size for data analysis was 52.

# Results 1: Reliability

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- **Item reliability:**
- Item-total correlations of the guilt measure were examined.
- Poorly correlated items were removed ( $r < .30$ )
- Eight items were removed resulting in a final version of the measure consisting of 13 items.
- **Internal reliability:**
- Internal consistency reliability of the 13-item scale was good ( $\alpha = .93$ )



# Results 2: Factor Analysis

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- **Exploratory analysis of factor structure:**
- The 13 items of the guilt scale were subjected to Principal Components Analysis (PCA) to examine the factor structure the scale.
- Two components had an eigenvalue  $< 1.0$ , explaining 53.1% and 10.5% of the variance, respectively and were thus retained for further inspection.

# Factor loadings for GPWDS items

	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	

# Results 3: Validity

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- **Convergent validity:**

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	WEMWBS	GDS-15
GPWD-13	-.548**	.434**

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



# Clinical Implications

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- The development of a relatively brief self-report measure of guilt in people with dementia provides a potentially useful assessment tool for clinicians.
- Psychological interventions that focus on guilt, particularly in depressed individuals with dementia, may help those people to manage feelings of guilt, expectations of self, and concerns about burdening others.



# Future research directions

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- A further validation study with a larger sample and details of current level of cognitive functioning is needed.
- Incorporation of the measure into studies of psychological interventions for depression in people with dementia could help to increase our understanding of:
  - Whether targeting guilt is helpful in those depressed individuals where guilt is a prominent feature.
  - Which interventions are effective in helping people with dementia to cope with feelings of guilt that cause them distress.



# Study limitations

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- Limitations of the study:
  - Small sample size.
  - Having limited information on current level of cognitive functioning.
  - Reliance on postal survey methodology for the validation study.



# Conclusion

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- Preliminary findings indicate that the new measure appears to have good psychometric properties.
- It has the potential to be a valuable tool in the study of guilt in people with dementia, subject to further validation studies.

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