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# The contribution of caregiver psychosocial factors to distress associated with Behavioural and Psychological **Symptoms in Dementia [BPSD]**

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The contribution of caregiver psychosocial factors to distress associated with Behavioural and Psychological Symptoms in Dementia [BPSD]

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Key words

Caregiver; BPSD; dementia; distress; psychosocial; path analysis

Key points

Caregiver psychosocial factors explained 56% of the variance in BPSD-related distress.

When psychosocial factors were controlled for frequency of BPSD was no longer a

significant predictor of BPSD-related distress.

Relationship quality, guilt, perceived sense of competence, reactivity to BPSD, and burden

mediated the relationship between BPSD frequency and BPSD-related distress. None of

the psychosocial factors were moderators.

The path model explained 41% of the variance in BPSD-related distress and provided a

good fit to the data.

Psychosocial factors contribute to BPSD-related distress and must be taken into account

when planning intervention programs aiming to reduce BPSD-related distress.

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# **Objective:**

To identify which caregiver factors predict BPSD-related distress and to outline their potential mechanisms.

### **Method:**

Informal caregivers of people with dementia (n = 157) recruited from 33 community mental health teams in seven NHS Trusts across England completed questionnaires regarding psychosocial factors (relationship quality, competence, guilt, health-related quality of life in the caregiver and person with dementia, reactivity to BPSD, and burden) and frequency of BPSD. Analyses included hierarchical multiple regression, mediation, moderation, and path analysis.

### **Results:**

Caregiver psychosocial factors explained 56% of the variance in BPSD-related distress. Once caregiver psychosocial factors were controlled for, frequency of BPSD was not a significant predictor of BPSD-related distress. Caregiver reactivity to BPSD, burden, competence, and relationship quality directly influenced BPSD-related distress. Guilt influenced distress indirectly via competence, burden, and reactivity to BPSD. The final model accounted for 41% of the variance in BPSD-related distress and provided a good fit ( $X^2 = 0.089$ , df = 1, p = 0.765).

# **Conclusions:**

Caregiver psychosocial factors such as their sense of competence, guilt, burden, and reactivity to BPSD contribute to BPSD-related distress. Multi-tailored interventions for the management of behaviour problems in family settings could provide support to address these psychosocial factors which are associated with BPSD-related distress.

#### Introduction

BPSD can occur in up to 90% of people with dementia and has been associated with the breakdown of home care, increased psychiatric referral, misuse of medication, and increased health care costs (Cerejeira et al., 2012). BPSD are described as a major source of distress for the caregiver (Tan et al., 2005; Craig et al., 2005; Bandeira et al., 2007) and it is the 'BPSD-related distress', rather than the presence of BPSD *per se* (Chan et al., 2003) that is an important predictor of breakdown of care at home (Gaugler et al., 2011). In understanding caregiver burden Campbell et al. (2008) note that neither cognitive function, level of dependence nor the presence of BPSD are significant predictors of caregiver burden. Instead, caregiver psychosocial factors, such as level of their sense of competence, quality of relationship with their relative, and personality (neuroticism) are important considerations (Campbell et al., 2008).

'Behaviour that challenges' (NICE-SCIE, 2006) has been defined as 'a manifestation of distress or suffering for the person with dementia, or of distress in the caregiver (Bird & Moniz-Cook, 2008). A conceptualisation of this nature suggests that factors other than the person with dementia can influence reports of BPSD (Moniz-Cook et al., 2000).

Psychological paradigms frame BPSD within an interpersonal context involving the experiences of people with dementia and also their caregivers (Bird & Moniz-Cook, 2008). Thus the context of the caregiver's psychosocial factors such as how they accept their situation, their sense of competence, and/or burden could influence the strategies they feel able to utilise and potentially the course of BPSD in the home setting (de Vugt et al., 2004). Furthermore, personality characteristics of the caregiver were found to indirectly influence BPSD-related distress (Melo et al., 2011). The current study builds upon the work by Melo et al. (2011) by identifying how

psychosocial factors other than personality characteristics influence BPSD-related distress, and by conducting multiple analyses with a larger sample size.

Caregiver psychosocial factors such as their sense of competence, guilt, and quality of life have received little attention but the sparse literature suggests some of these factors might be potential mechanisms by which 'BPSD-related distress' occurs. For example, caregivers with higher self-efficacy in controlling upsetting thoughts were shown to have more positive gains and less burden when confronted with more BPSD (Cheng et al., 2012) or to perceive their caregiving role more optimistically (Semiatin & O'Connor, 2012), and guilt made a significant contribution to caregiver burden, even when other important variables such as activities of daily living were controlled for (Gonyea et al., 2008). Moreover, psychosocial factors such as the caregiving relationship, rather than the characteristics of the person with dementia (Iecovich, 2011), are associated with caregiver stress and burden (Steadman et al., 2007).

According to the stress-process model Pearlin et al. (1990) used over successive decades, we hypothesised that caregiver psychosocial factors (rather than the presence of BPSD alone) would be stronger predictors of BPSD-related distress. By identifying caregiver factors which may act as a barrier to their effective responses to BPSD, this information could be used to focus and tailor intervention programmes to reduce BPSD-related distress, and improve the management of behaviour problems in family settings.

#### Method

## **Participants**

The sample comprised one hundred and fifty-seven family caregivers and their relatives with dementia residing in their own homes. Two cases were deleted following missing value analysis. Participants were recruited through Challenge FamCare, a national NIHR-funded study on the management of challenging behaviour in people with dementia living at home (www.challenge.demcare.com) which was reviewed and approved by the York Research Ethical Committee (Reference number REC 09/H1311/28). Participants were recruited through 33 community mental health teams (CMHTs) across 7 NHS community mental health organisations throughout England. The majority of interviews were conducted in the caregiver's home, or at their local CMHT.

Inclusion criteria for the family caregiver were: a) must not receive remuneration for providing care; b) aged 18 or over; c) reporting at least 5 problems on the 24-item Revised Memory Behaviour Problem Checklist (Teri et al., 1992); d) able to understand and speak English. Inclusion criteria for the person with dementia were: a) fulfil diagnostic criteria for dementia using DSM-IV (American Psychiatric Association, 1994); b) not in receipt of respite care; c) not in the palliative stage of the disease.

#### Measures

Frequency of behavioural problems was measured using The Revised Memory and Behaviour Problems Checklist (RMBPC) (Teri et al., 1992). This is a 24-item caregiver report of observable behavioural problems in the person with dementia, rate of occurrence scored on a 4-point score. Good levels of validity and reliability noted by Teri et al. (1992).

Distress was assessed using the Neuropsychiatric Inventory with Caregiver Distress Scale (NPI-D; Cummings et al., 1994). The NPI assesses 12 behavioural disturbances occurring in people with dementia and the distress the symptom causes on a 5-point scale (Cummings, 1997). The instrument is both valid and reliable (Cummings et al., 1994).

Quality of Caregiver Patient Relationship (QCPR; Spruyette et al., 2002) is a 14-item scale. Responses are scored on a 5-point scale. QCPR has good internal consistency and concurrent validity (Spruyette et al., 2002).

The Guilt Scale (Woods et al., 1996) measures the amount of guilt the caregiver might feel. The answers are scored on a 4-point scale. Woods et al. (1996) report good internal consistency and concurrent validity.

The RMBPC (Teri et al., 1992) measures the caregiver's reaction to the reported behaviour, i.e. how 'bothered or upset', rated on a 4-point scale, with lower scores indicating reduced reactivity to behaviour.

The Relative Stress Scale (RSS; Greene et al., 1982) was used to measure burden of care. The RSS consists of 15 items, rated on a 4-point scale. This scale has good reliability and validity (Greene et al., 1982).

The Short Sense of Competence Questionnaire (SSCQ; Vernooij-Dassen et al., 1999) consists of 7 items rated on a 5-point scale. Psychometric properties are reported by Vernooij-Dassen et al. (1999), and good internal consistency was reported by Vernooij-Dassen et al. (2004).

Quality of life was measured by the EQ-5D (EuroQol group, 1990). This scale has good reliability and validity (Hurst et al., 1997). The caregiver completed the questionnaire to record their own health-related quality of life and they also completed the EQ-5D rating the person with dementia's quality of life.

#### Data analyses

A hierarchical multiple regression analysis was performed. Only variables which significantly predicted caregiver distress remained in the final regression model and were entered into moderator and mediator analyses. Procedures described by Baron and Kenny (1986) and elaborated by Holmbeck (2002) were followed for the mediation and moderation analyses. The significance of the mediating effect was calculated using the Sobel test (Sobel, 1982) using the bootstrapping procedure outlined by Preacher and Hayes (2004).

To test the theoretical model (Figure 1) an exploratory path analysis was conducted using AMOS (Analysis of Moment Structures; Arbuckle, 2003; Version 23). The model was developed in line with existing empirical and theoretical evidence, as well as the correlation, mediation and moderation analysis conducted in this current study. Only variables which had a strong ( $r \ge 0.5$ , Cohen, 1988) significant correlation with other variables and/or supported by existing theory were entered into the theoretical model. Maximum likelihood method was used to estimate the model. The model fit was examined using goodness of fit indices: Chi-square goodness of fit statistic; ratio of Chi square to degrees of freedom; Bentler Comparative Fit Index (CFI; Bentler, 1990); Normed Fit Index (NFI; Bentler & Bonett, 1980) and Steiger-Lind root mean square of approximation (RMSEA; Steiger, 1990). A non-significant Chi-square with a ratio of Chi-square to degrees of freedom of less than 2 or 3 (Schreiber et al. 2006), NFI and CFI values greater than

0.90 (Bentler & Bonett, 1980) and an RMSEA value greater than 0.05 indicate a good fitting model (Kline, 2005). Global fit indices, modification indices (MI), correlation of residuals, standardised residuals, existing theory and empirical research, guided the re-specification of the model (Kline, 2011). All relevant statistical assumptions inherent to the application of SEM (e.g. multivariate normalcy) were examined and affirmed in preliminary analyses.

### **Results**

The majority of caregivers were female (n = 110), and most were married to the person with dementia (n = 83). The caregivers' mean age was 66.34 (range: 36-94). The majority of people with dementia were also female (n = 91) with a mean age of 80.35 (range: 60-97). Large significant correlations (r > 0.5) were seen between BPSD-related distress, reactivity to BPSD, frequency of BPSD, and burden. Moderate significant correlations (r > 0.3) were identified between BPSD-related distress and competence, relationship quality, and guilt (Table 1). Caregiver perception of person with dementia quality of life had a small significant association (r > 0.1) with BPSD-related distress, and caregiver quality of life had a non-significant association (Table 1).

## Insert Table 1

Predictors of caregiver BPSD-related distress

Variables were entered in 5 steps based on different themes. Step1 included the caregiver's perception of their relationship and their perception of caregiving: relationship quality; sense of competence; and guilt, 2) perception of the quality of life of the person with dementia, 3) reaction to BPSD, 4) perception of burden, and 5) the caregiver's reported frequency of BPSD.

Relationship quality did not significantly predict caregiver distress (Table 2). After controlling for all other caregiver variables, frequency of BPSD only contributed 1% to the overall model, and did not significantly predict caregiver distress (Table 2). Variables which significantly predicted distress remained in the final model; these were competence, guilt, quality of life of the person with dementia, reactivity to BPSD, and burden (Table 3).

# Insert Table 2 and 3

Mediators and moderators of the relationship between BPSD frequency and BPSD-related distress Relationship quality, guilt, competence, reactivity to BPSD, and burden all met the criteria of a mediator variable with significant indirect effects, whereas quality of life of the person with dementia did not (Table 4). None of the psychosocial factors were found to moderate the association between BPSD frequency and BPSD-related distress (data not shown).

### Insert Table 4

Path analysis

The overall goodness of fit of the theoretical model was evaluated, resulting in a significant Chisquare ( $X^2 = 59.723$ , df = 5, p < 0.001) showing that the model was a poor fit. Alternative goodness of fit indices were examined (CFI = 0.857, NFI = 0.850, RMSEA = 0.267) and similarly these indices indicated the model to be a poor representation of the data.

### Insert Figure 1

Following this, an exploratory approach was adopted in order to construct a model which better reflected the data. Consequently, a pathway was added between competence and reactivity to BPSD. The fit of the model after step 1 was  $X^2 = 32.788$ , df = 20, p = 0.036, CFI = 0.967, NFI =

0.918, and RMSEA = 0.064, indicating that the model still did not fit the data. In step 2 a pathway was added between guilt and reactivity to BPSD. The fit of the model after step 2 was  $X^2 = 23.920$ . df = 19, p = 0.199, CFI = 0.987, NFI = 0.940, and RMSEA = 0.041, indicating that the model did fit the data, however, modification indices, correlation of residuals and standardised residuals remained problematic.

In step 3 a pathway between guilt and competence was added. The fit of the model after step 3 was  $X^2 = 3.534$ , df = 2, p = 0.171, CFI = 0.996, NFI = 0.991, and RMSEA = 0.076. The majority of global fit indices indicated that the model did fit the data, however, RMSEA value was greater than 0.06 and correlation of residuals and standardised residuals remained problematic. In step 4 a pathway was added between quality of relationship and reactivity to BPSD as this had the most problematic residuals and made the most theoretical sense. The fit of the model after step 4 was df = 1, p = 0.765, NFI = 1.000, CFI = 1.000, and RMSEA = 0.000 indicating a very good model fit,  $X^2$  to degrees of freedom ratio was calculated to be less than two ( $X^2 = 0.089$ ) indicating an excellent fit (Schreiber et al. 2006), and 40.93% of the variance in BPSD-related distress was represented within the model (Figure 2). 

Insert Figure 2

#### **Discussion**

This study is the first to examine the mechanisms through which caregiver psychosocial factors could influence BPSD-related distress. Consistent with the hypothesis, caregiver perceptions of competence, guilt, quality of life of the person with dementia, reactivity to BPSD, and burden significantly predicted distress, and explained more variance than BPSD frequency (which was not a significant predictor of BPSD-related distress). Relationship quality, competence, guilt, burden, and reactivity to BPSD were mediators in the relationship between BPSD frequency and BPSD-related distress. The unique conclusions of the path analysis were that burden and increased reactivity to BPSD together both directly exacerbated BPSD-related distress. In contrast, relationship quality and competence decreased BPSD-related distress. Guilt indirectly influenced BPSD-related distress through competence, burden, and reactivity to BPSD. A further advantage of this study is the use of a specific distress measure associated with BPSD rather than the use of a generic distress measure which has often been used to measure different psychological constructs (e.g. Black et al., 2004). The specificity of the distress measure provides researchers and clinicians with greater confidence when applying the above findings.

This study compliments the findings from Melo et al. (2011) by accounting for a further 41% of the variance in BPSD-related distress by including different psychosocial factors other than personality characteristics. In accordance with Campbell et al. (2008), frequency of BPSD was not a significant predictor of BPSD-related distress once caregiver psychosocial factors were controlled. In line with previous work on burden (de Vugt et al. 2004; Campbell et al., 2008) it was found that all variables measuring caregiver psychosocial factors included in the analysis (other than caregiver-rated quality of life), were significantly associated with BPSD-related distress. The person with dementia's quality of life was found to be associated with BPSD-related

distress in the caregiver. Ornstein et al. (2013) posited that perceived poor quality of life in the person with dementia could increase caregiver depression by evoking empathy; in our case empathy for the person with dementia could influence BPSD-related distress. Relationship quality and frequency of BPSD were omitted from the final regression model since they no longer significantly predicted BPSD-related distress. The absence of BPSD frequency from the model was in line with previous research (Fauth & Gibbons, 2014; Campbell et al., 2008). However, the removal of relationship quality was unexpected, but this might be because this variable was grouped with both competence and guilt, which were both strong predictors of BPSD-related distress.

Previous research has focused on the link between relationship quality and depression (Ablitt et al., 2009), stress, and burden (Lyonette & Yardley, 2003; Steadman et al., 2007; Iecovich, 2011) rather than specifically with BPSD-related distress. Although burden and BPSD-related distress are different psychological constructs, explanations for why those with poorer relationships experience greater burden may also partly explain why those with poorer relationships experience greater BPSD-related distress. Those with greater relationship quality also have more intrinsic motivation to care, along with greater admiration for the person they are caring for (Lyonette & Yardley, 2003), which may be a protective factor against BPSD-related distress. Those who reported a better past relationship also reported having a greater sense of reward and satisfaction (Kramer, 1993; Williamson & Schaffer, 2001), in addition to better problem-solving and communication (Steadman et al., 2007). These qualities may be protective factors against BPSD-related distress.

Increased reactivity to BPSD resulted in greater levels of BPSD-related distress. This was

consistent with de Vugt et al. (2004), who noted that caregivers who use non-adaptive strategies reported more depressive symptoms, and caregivers who demonstrated emotionally reactive or avoidant ways of responding to problematic situations were associated with more subjective stress (Powers et al., 2002).

Those with greater levels of competence may be less likely to experience BPSD-related distress for reasons similar to those explaining why those with greater competence experience less burden. Cheng et al. (2012) suggested that competence was a buffer against burden, since these caregivers with greater levels of competence had more positive gains and experienced less burden when confronted with more BPSD. In addition, Quinn et al. (2012) found that greater competence significantly predicted caregivers' ability to find meaning in caregiving and find something positive from the experience. The association between relationship quality and competence was a substantial link in the path analysis, and also in the correlation analysis. This association was also seen from Quinn et al. (2012) and Townsend and Franks (1997). Caregivers who feel trapped in their role as a caregiver have been associated with lower caregiving competence (Aneshensel et al., 1995), therefore it may be possible that those caregivers who feel trapped subsequently have a poorer relationship, and in turn lose competence in caregiving, since they may no longer be intrinsically motivated.

Caregivers who had better quality relationships with the person with dementia experienced less guilt. This association could be explained by the suggestion that caregivers experience guilt because they no longer feel so close to the person with dementia, in addition the caregiver may also feel concerned about their provision of care (Jarrett, 1985). Caregivers who experienced greater levels of guilt also felt less competence in their caregiving role. The direct association between guilt and competence, and between guilt and relationship quality has not been explored

previously in the literature. Research is needed to understand why there is an association between these two constructs. It may be possible that caregivers feel guilty about the poor relationship between themselves and the person with dementia, which in turn leads to feelings of incompetence.

Burden was the most common mediator in the final model, mediating the relationship between BPSD-related distress and relationship quality, BPSD-related distress and competence, between BPSD-related distress and guilt, and BPSD-related distress and reactivity to BPSD. Previous research has not examined the association between guilt and reactivity to BPSD. Studies have focused on guilt in relation to overall burden but not on the caregivers' reaction to BPSD. The association between relationship quality and reaction to BPSD is consistent with findings by Steadman et al. (2007), who found that caregivers with high pre-morbid relationship satisfaction demonstrated significantly less reactivity to BPSD. In addition, these findings are congruous with Cheng et al. (2012), who found that self-efficacy for controlling upsetting thoughts moderated the relationship between problematic behaviours and caring gains. Burden was also seen to be a major mediator in a path model examining the relationships between personality dimensions, depression, and BPSD-related distress (Melo et al., 2011). It is likely that burden would be a mediator for both competence and reactivity to BPSD, since burden has been associated with the caregiver's ability to deal with the symptoms and their perception of what the illness means (de Vugt et al., 2004). Since burden is a multidimensional construct it is probable that it would act as a mediator between the other psychosocial factors and BPSD-related distress.

Cross-sectional data were collected, therefore a recommendation would be to assess caregiver factors longitudinally to test for causality. Some of the re-specifications of the path model were directly motivated by the data (in conjunction with theory), and thus must be viewed as

exploratory in nature, and might say little about the true model underlying the data, therefore this model should be cross-validated with data from independent samples (Mueller & Hancock, 2008). Nevertheless, the authors have employed recommended statistical methods (Kline, 2011), recommended goodness of fit indices and an exploratory method which has been utilised in previous research (Franche et al., 2006; Lenior et al., 2005; Miranda-Castillo et al., 2010; Ngai et al., 2011). There is individual item overlap between the NPI (Cummings et al., 1994) and the RMPBC (Teri et al., 1992), however, these measures are distinct since the NPI omits an explicit domain related to memory problems. In addition, there are many other items which do not overlap between both measures as described by Jackson et al. (2014).

#### Conclusion

Listening to and responding to caregivers' perceptions of caregiving and perceptions of BPSD will assist healthcare workers to develop strategies to reduce BPSD-related distress and promote positive aspects of caregiving. Multi-tailored interventions for the management of behavioural problems should include support for addressing caregiver psychosocial factors which are associated with BPSD-related distress. Specifically, more support is needed to improve the quality of the caregiving relationship (perhaps through promoting shared valued activities), reduce feelings of guilt, and improve caregiving competence since reducing burden has taken precedence in previous psychosocial interventions. Studying the effectiveness of an intervention managing challenging behaviour in family settings which targets these caregiver factors would provide the opportunity to test the model generated in this study. The findings indicate that caregiver psychosocial factors such as burden, reactivity to BPSD, quality of relationship, competence, and guilt may put caregivers at risk of experiencing BPSD-related distress. Thus these factors are important mechanisms to target when aiming to lower the level of distress associated with BPSD.

Table 1. Pearson Product-moment correlations between BPSD-related distress and caregiver psychosocial factors and means and standard deviations n=155.

	1	2	3	4	5	6	7	8	9	M(SD)
Variables										
1. BPSD-related distress	70									13.37 (9.63)
2.Frequency of BPSD	.61**	/- <i>,</i>								31.62 (12.00)
3. Relationship quality	39**	34**								53.02 (8.74)
4. Caregiver competence	43**	42**	.71**	-						24.72 (5.96)
5. Caregiver guilt	.37**	.34**	33**	44**	-					6.08 (4.97)
6. PwD HRQOL (FC rated)	27**	26**	.07	.07	06	-				0.47 (0.32)
7. Caregiver HRQOL	15	11	.21*	.09	16*	15	-			0.88 (0.20)
8. Caregiver burden	.60**	.48**	46**	50**	.52**	35**	18*	-		20.45 (10.00)
9. Reactivity to BPSD	.70**	.68**	38**	41**	.40**	26**	16	.52**	-	19.85 (11.99)

<sup>\*</sup> p<.05 (2-tailed)\*\*p<.01 (2-tailed). BPSD= behavioural and psychological symptoms in dementia, HRQOL= health-related quality of life, PwD= person with dementia, FC= family caregiver.

Table 2. Initial regression model of predictors of BPSD-related distress

R	$R^{2}$	$R^2$	В	SE	β	t
		Change				
.49	.24**	.24**				
			.18	.11	16	-1.64
			36	.17	22*	-2.09
			.43	.15	.22**	2.78
.54	.29**	.05**				
			-10.21	3.13	23**	-3.26
.72	.52**	.23**				
			.46	.05	.57**	8.44
.75	.56**	.04**				
			.25	.07	.27**	3.54
.75	.57**	.01				
			.12	.06	.14	1.78
	.49	.49 .24**  .54 .29**  .72 .52**  .75 .56**	Change  .49 .24** .24**  .54 .29** .05**  .72 .52** .23**  .75 .56** .04**	Change  .49	Change  .49	.49 .24** .24**  .18 .1116  .36 .1722*  .43 .15 .22**  .54 .29** .05**  -10.21 3.1323**  .72 .52** .23**  .46 .05 .57**  .75 .56** .04**  .25 .07 .27**

 $<sup>\</sup>beta$  weights and significance levels of predictors of caregiver distress as measured by the NPI \* p < .05 (2-tailed), \*\* p < .01 (2-tailed).

Table 3. Significant predictors of BPSD-related distress

	R	$R^{2}$	$R^{2}$	В	SE	β	t
			Change				
Step I	.48	.23**	.23**				
Competence				54	.13	33**	-4.14
Guilt				.44	.15	.23**	2.86
Step 2	.53	.28**	.05**				
PwD health-related quality of life				-6.94	2.14	23**	-3.24
Step 3	.72	.52**	.24**				
Reactivity to BPSD				.46	.05	.58**	8.67
Step 4	.75	.56**	.04**				
Burden				.25	.07	.28**	3.67

<sup>\*</sup> p < .05 (2-tailed), \*\* p < .01 (2-tailed). PwD= person with dementia.

Table 4. Mediation analysis between BPSD frequency and BPSD-related distress

Mediator	Indirect effect	Significance of effect
Relationship quality	0.06	0.012
Guilt	0.05	0.019
Competence	0.07	0.008
PwD health-related quality of life	0.02	0.135
Reactivity to BPSD	0.28	0.000
Burden	0.16	0.000
PwD= Person with dementia.		

Figure 1. Theoretical relationship between study variables.

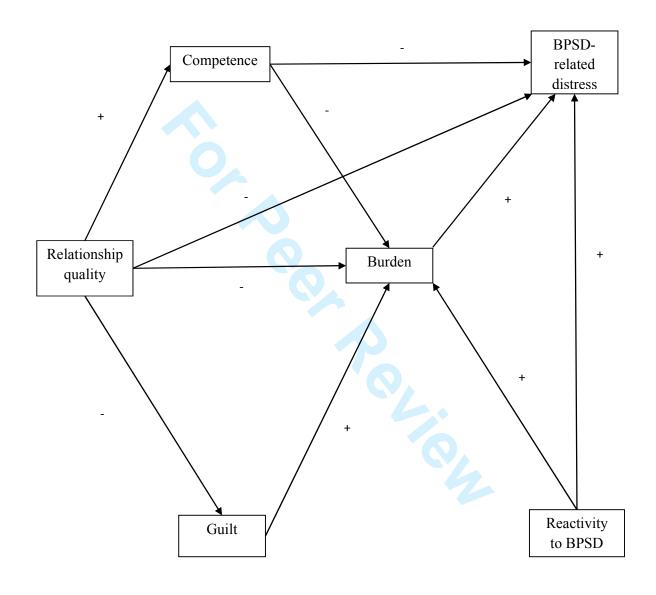
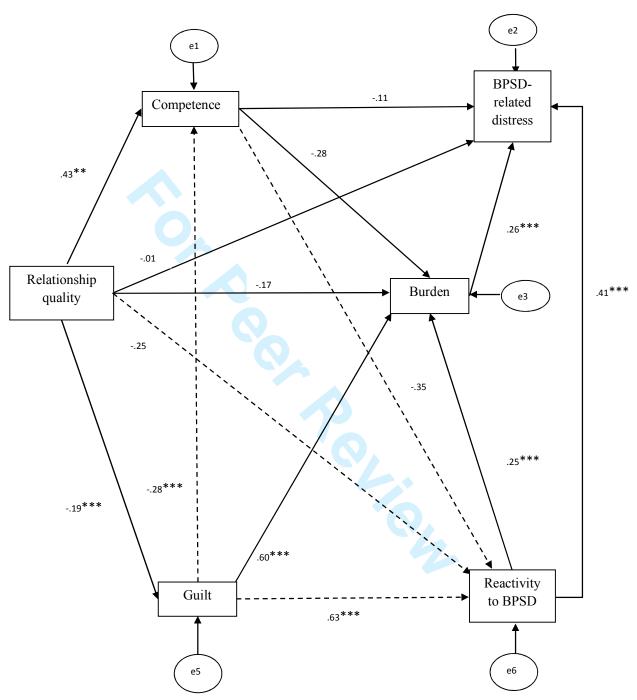


Figure 2. Final path model of relationships between study variables.



\*\* p < .01 (2-tailed), \*\*\* p < .001 (2-tailed), solid line = original pathways, dashed line = modified pathways.

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# **Conflict of interest**

None declared

### **Description of authors' roles**

Esme Moniz-Cook designed the study from which the participants were recruited. All authors devised the objective of the current study. Alexandra Feast participated in data collection, conducted statistical analyses and wrote the initial draft. All authors revised the manuscript critically and approved the final version for publication.

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