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

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Key words

Behavioral symptoms; caregivers; dementia; path analysis; psychosocial factors; psychological stress; regression analysis.

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Key points

- Caregiver psychosocial factors explained 56% of the variance in BPSD-related distress. After controlling for these psychosocial factors frequency of BPSD was no longer a significant predictor of BPSD-related distress.
- Caregiver reports of relationship quality, guilt, perceived sense of competence, reactivity to BPSD, and burden mediated the relationship between BPSD frequency and BPSD-related distress. No psychosocial factors were moderators.
- The path model explained 41% of the variance in BPSD-related distress and provided a good fit to the data.
- Caregiver psychosocial factors contribute to BPSD-related distress and must be taken into account when planning intervention programmes.

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Objective:

To examine caregiver factors as predictors of BPSD-related distress and their potential mechanisms.

Method:

Informal caregivers of people with dementia (*n* = 157) recruited from 28 community mental health teams in six 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 of BPSD-related distress included hierarchical multiple regression, mediation, moderation, and path analysis.

Results:

Caregiver psychosocial factors explained 56% of the variance in BPSD-related distress. After controlling for these factors, 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 achieved a good fit to the data ($X^2 = 23.920$, $df = 19$, $p = .199$).

Conclusions:

Caregiver psychosocial factors including sense of competence, guilt, burden, and reactivity to BPSD contribute to BPSD-related distress. Tailored interventions for managing behaviour

problems in family settings could focus on these factors associated with BPSD-related distress to minimise distress in families.

Introduction

BPSD are described as a major source of distress for the caregiver (Tan et al., 2005; Craig et al., 2005; Bandeira et al., 2007) but it is the 'BPSD-related distress', rather than the presence of BPSD (Chan et al., 2003) that is an important predictor of breakdown of care at home (Gaugler et al., 2011). Frequent BPSD are not necessarily the most distressing for caregivers (Fauth & Gibbons, 2014). In understanding caregiver burden Campbell et al. (2008) reported that neither cognitive function, level of dependence nor the presence of BPSD are significant predictors of caregiver burden. Rather, caregiver psychosocial factors, such as sense of competence, quality of relationship with their relative, and personality (neuroticism) are predictors of burden (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). 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 could influence the strategies they feel able to utilise, and potentially the course of BPSD in home settings (de Vugt et al., 2004). Furthermore, personality characteristics of the caregiver were found to influence BPSD-related distress through burden as a mediator (Melo et al., 2011). Burden may also act as a mediator between other psychosocial variables and BPSD-related distress. Additionally, burden has correlated significantly with caregiver reactivity to BPSD (Teri et al., 1992), and BPSD-related distress (Jackson et al., 2014). A significant association was also found between reactivity to BPSD and BPSD-related distress (Jackson et al., 2014).

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 were significantly associated with lower levels of BPSD-related distress (Crellin et al., 2013). Furthermore, competence was found to have significant negative correlations with burden and BPSD-related distress, and was found to significantly negatively predict burden and BPSD-related distress (van der Lee et al., 2015). Greater levels of guilt made a significant contribution to caregiver burden (Gonyea et al., 2008), and guilt was found to significantly correlate with burden (Roach et al., 2013).Moreover, psychosocial factors such as the caregiving relationship, rather than the characteristics of the person with dementia (Iecovich, 2011), were associated with caregiver stress and burden (Steadman et al., 2007). A lack of closeness was found to be associated with increased distress in the caregiver (Williamson & Schulz, 1990), which may have been due to the guilt the caregiver experienced about no longer loving the person with dementia (Jarret, 1985). Both relationship quality and competence were found to be important themes when understanding BPSD-related distress (Feast et al., in press), and an association was identified between these two psychosocial variables by Quinn et al. (2012) and Townsend and Franks (1997).

The current study builds upon the work by Gonyea et al. (2008), Melo et al. (2011), Roach et al. (2013), and van der Lee et al. (2015) by identifying how a range of psychosocial factors influence BPSD-related distress individually and in combination, by conducting multiple analyses with a large sample size. Developing a path model of BPSD-related distress will create a platform on which a conceptual model of BPSD-related distress can be created, since current conceptual models of coping do not focus on BPSD-related distress and place minimal emphasis on caregiver psychosocial factors. In accordance with the Stress-Process Model (SPM; Pearlin et al., 1990), we hypothesised that caregiver psychosocial factors, rather than the presence of BPSD alone, would be stronger predictors of BPSD-related distress. With the identification of the caregiver factors which may be associated with BPSD-related distress, intervention programmes can be tailored to reduce BPSD-related distress in family settings.

Method

Participants

Participants were recruited through Challenge FamCare, an NIHR-funded longitudinal study of 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). We recruited participants through 28 community mental health teams (CMHTs) across six NHS community mental health organisations across England. The majority of interviews were conducted in the caregivers' homes or at their local CMHT. The sample comprised 157 caregivers and their relatives with dementia residing in their own homes. Two participants were deleted following missing value analysis. This research is part of a PhD thesis which is currently under review (Feast, 2015).

Inclusion criteria for family caregivers were: a) not paid for providing care; b) aged 18 or over; c) reporting at least five problems on the 24-item Revised Memory Behaviour Problem Checklist (RMPBC) (Teri et al., 1992); d) able to understand and speak English. Inclusion criteria for people 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 receiving palliative care.

Measures

Frequency of behavioural problems was measured using The RMBPC (Teri et al., 1992). The RMBPC (Teri et al., 1992) measures the caregiver's reaction to the reported behaviour. Scale reliability was good, with Cronbach's alphas of 0.84 for behaviour and 0.90 for caregiver reaction

(Teri et al., 1992). The validity of the reaction subscale was demonstrated by significant correlations with measures of depression and burden (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). High content validity was identified via a Delphi panel; the NPI was not significantly different from the BEHAVE-AD (Reisberg et al., 1987), indicating good concurrent validity. Internal consistency reliability was good with a Cronbach's alpha of 0.88 (Cummings et al., 1994).

The 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 (Cronbach's coefficient alpha of 0.82) 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 (Cronbach's alpha: 0.86) and concurrent validity (correlation with 9-item guilt scale used by Wells & Jorm, 1987: 0.71).

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 a good test-retest reliability coefficient of 0.85, and an acceptable construct validity shown by significant modest correlations between subscales (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. Construct validity was supported by the high Pearson correlation between the Sense of Competence Questionnaire (Vernooij-Dassen et al.,1996) and the SSCQ, and good internal consistency (0.76) was reported (Vernooij-Dassen et al., 1999).

Quality of life was measured by the EQ-5D (EuroQol group, 1990). 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. Inter-rater reliability of person with dementia and carer proxy rating were of fair agreement as determined by Kappa scores (Orgeta et al., 2014). Carer ratings were associated with activities of daily living scores and measures of depression and anxiety adding to construct validity (Orgeta et al., 2014).

Thus all measures incorporated in the analyses had adequate psychometric properties and were used with people with dementia and their caregivers in community settings.

Data analyses

Analyses were conducted on baseline data. 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), applying the bootstrapping procedure outlined by Preacher and Hayes (2004).

To test the hypothetical model (Figure 1) an exploratory path analysis was conducted using AMOS (Analysis of Moment Structures) (Arbuckle, 2003; Version 23). The hypothetical model was developed in line with existing empirical evidence, as well as the correlation, mediation and moderation analysis conducted in this current study.Maximum likelihood 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). We interpreted non-significant Chi-squareds with ratios of Chi-squared to degrees of freedom less than 2 or 3 (Schreiber et al. 2006), NFI and CFI values greater than 0.90 (Bentler & Bonett, 1980) and RMSEA values less than 0.05 as indicating an acceptable fit (Kline, 2005). Global fit indices, modification indices (MI), correlation of residuals, standardised residuals, and existing empirical research, guided the re-specification of the model (Kline, 2011). Re-specification was guided by the correlation matrix in the current analysis if existing empirical evidence was unavailable. All relevant statistical assumptions inherent in the application of Structural Equation Modelling (SEM) were examined and affirmed in preliminary analyses. These included: multicollinearity, normal distribution of data (inspection of histograms, skewness, kurtosis), outliers (inspection of Z-scores), heteroscedasticity, normal distribution of residuals, independence of residuals, and linear relationship between predictor and outcome variables.

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 the following categories: 1) 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 Tables 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, as reported in supplementary online material S1.

Insert Table 4

Path analysis

The overall goodness of fit of the hypothetical model was evaluated, resulting in a significant Chi-square ($X^2 = 59.723$, $df = 5$, $p < 0.001$), showing that the model was a poor fit (Figure 1). 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 fit.

Insert Figure 1

As no previous empirical work could guide the re-specification, the correlation matrix was inspected. A significant negative moderate association was identified between competence and reactivity to BPSD. This association is also in agreement with Nogales-Gonzales et al. (2015), who found that competence moderated the relationship between BPSD frequency and reactivity to BPSD. The fit of the model after step 1 was $X^2 = 32.8$, $df = 20$, $p = 0.036$, CFI = 0.967, NFI =

0.918, and RMSEA = 0.064, indicating that the model still did not fit the data, as reported in supplementary online material S2.

As above no previous empirical work could guide the re-specification. A significant positive moderate association was identified between guilt and reactivity to BPSD. Furthermore, guilt was found to be a dimension of burden (Springate & Tremont, 2014), and guilt was found to be a factor in numerous factor analyses of the Zarit Burden Interview (Zarit et al., 1980) by Ankri et al. (2005), Knight et al. (2000), Siegert et al. (2010). In addition, burden was shown to be significantly correlated to reactivity to BPSD (Jackson et al., 2014). Therefore, a pathway was added in step 2 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 (Figure 2). The X^2 to degrees of freedom ratio was calculated to be less than two (X^2 = 1.25), indicating an excellent fit (Schreiber et al. 2006).

Insert Figure 2

Discussion

This study is the first to examine the mechanisms through which caregiver psychosocial factors can influence BPSD-related distress. Furthermore, this study addresses the inadequacy of the SPM (Pearlin et al., 1990) when understanding BPSD-related distress by providing a platform to develop a conceptual model of 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. Relationship quality, competence, guilt, burden, and reactivity to BPSD were mediators in the relationship between BPSD frequency and BPSD-related distress, but none of the psychosocial factors moderated this relationship. Thus these psychosocial variables are imperative when understanding BPSD-related distress. The unique conclusions of the path analysis were that increased burden and increased reactivity to BPSD both directly exacerbated BPSD-related distress. In contrast, greater relationship quality and greater competence decreased BPSD-related distress. Increased guilt indirectly influenced increased BPSD-related distress through reduced competence, greater burden, and greater reactivity to BPSD.

This study extends findings of Melo et al. (2011) by accounting for a further 41% of the variance in BPSD-related distress as a result of including different psychosocial factors such as guilt, competence, and relationship quality rather than personality characteristics alone. It also compliments research by Campbell et al. (2008) and Fauth and Gibbons (2014) that 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 (Campbell et al., 2008; de Vugt et al. 2004), 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 negatively predict 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; 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. We had not foreseen the exclusion of relationship quality, but the grouping of this variable with competence and guilt, both significant predictors of BPSD-related distress might account for this weak predictive relationship. Previous research has focused on relationship quality and depression (Ablitt et al., 2009), stress, and burden (Iecovich, 2011; Lyonette & Yardley, 2003; Steadman et al., 2007) rather than specifically with BPSD-related distress, more research is needed to understand why relationship quality displayed a non-significant association.

Increased reactivity to BPSD resulted in greater levels of BPSD-related distress. This was consistent with the findings of de Vugt et al. (2004), who noted that caregivers who used 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 caregivers with greater levels of competence may be less likely to experience BPSD-related distress and reactivity to BPSD 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 caregivers with greater levels of competence had more positive gains and experienced less burden when confronted with BPSD. Furthermore the novel association between competence and reactivity to BPSD is partially supported by previous research whereby competence was found to moderate the relationship between BPSD frequency and reactivity to BPSD (Nogales-Gonzales et al., 2015). More research is necessary to fully understand this association. The association between relationship quality and competence was a substantial link in the path analysis and also in the correlation analysis, which was also seen by Quinn et al. (2012) and Townsend and Franks (1997).

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). The direct association between guilt and relationship quality has not yet been explored, therefore future research is needed. Furthermore, previous research has not examined the association between guilt and reactivity to BPSD, however this was seen to have a significant relationship in the path analysis. This novel association is reasonable due to the previous research identifying guilt as a dimension of burden (Springate & Tremont, 2014), and the association identified between burden and reactivity to BPSD (Jackson et al., 2014).

Burden was the most common mediator in the final model. 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), and is a multidimensional construct.

Cross-sectional data were collected, therefore it is recommended that caregiver factors be assessed longitudinally to test for causality. Some of the re-specifications were guided by the current empirical work when associations between particular variables have not been examined previously, therefore the final model was extended in a way which was consistent with the empirical work. Where possible, re-specifications were guided by previous and current empirical work, modification and fit statistics, and were ensured to make theoretical sense. We have employed recommended statistical methods (Kline, 2011), 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 & Chan, 2011).

Since many large scale studies have not explored the variables in this study, future studies should collect this information in order for the path model to be cross-validated with independent data. Nevertheless, this path model is a plausible novel model based on representative data collected from numerous sites in the UK, has important implications, and has generated hypotheses for others to test. This research provides a basis for future researchers to develop this model in order to further our understanding of BPSD-related distress. Furthermore, existing conceptual models of carer coping such as SPM (Pearlin et al., 1990) do not focus on BPSD-related distress and do not place enough emphasis on phenomenological caregiver psychosocial factors. The final path model has a narrower, more explicit focus, making the model better placed to inform the theoretical understanding of BPSD-related distress, to create a conceptual model of BPSD-related distress, and to inform future interventions.

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. Once this model is validated using independent samples it will be possible to advocate multi-component interventions for the management of BPSD which include support for addressing certain caregiver psychosocial factors. Specifically, more support is needed to improve the quality of the caregiving relationship, 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 BPSD in family settings which targets these caregiver factors would provide the opportunity to test the model generated in this study. The findings indicate that certain caregiver psychosocial factors may put caregivers at risk of experiencing BPSD-related distress. Thus these factors are important mechanisms to target when aiming to reduce the level of BPSD-related distress.

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

Variables	1	2	3	4	5	6	7	8	9	*M* (SD)
1. BPSD-related distress	-									13.37 (9.63)
2.Frequency of BPSD	0.61**	-								31.62 (12.00)
3. Relationship quality	-0.39**	-0.34**	-							53.02 (8.74)
4. Caregiver competence	-0.43**	-.042**	0.71**	-						24.72 (5.96)
5. Caregiver guilt	0.37**	0.34**	-0.33**	-0.44**	-					6.08 (4.97)
6. PwD HRQOL (FC- rated)	-0.27**	-0.26**	0.07	0.07	-0.06	-				0.47 (0.32)
7. Caregiver HRQOL	-0.15	-0.11	0.21*	0.09	-0.16*	-0.15	-			0.88 (0.20)
8. Caregiver burden	0.60**	0.48**	-0.46**	-0.50**	0.52**	-0.35**	-0.18*	-		20.45 (10.00)
9. Reactivity to BPSD	0.70**	0.68**	-0.38**	-0.41**	0.40**	-0.26**	-0.16	0.52**	-	19.85 (11.99)

* $p<0.05$ (2-tailed)**$p<0.01$ (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 *Change*	*B*	*SE*	*β*	*t*
Step1	0.49	0.24**	0.24**				
Relationship quality				0.18	0.11	-0.16	-1.64
Confidence				-0.36	0.17	-0.22*	-2.09
Guilt				0.43	0.15	0.22**	2.78
Step 2	0.54	0.29**	0.05**				
PwD health-related quality of life				-10.21	3.13	-.23**	-3.26
Step 3	0.72	0.52**	0.23**				
Reactivity to BPSD				0.46	0.05	0.57**	8.44
Step 4	0.75	0.56**	0.04**				
Burden				0.25	0.07	0.27**	3.54
Step 5	0.75	0.57**	.01				
Frequency of BPSD				0.12	0.06	0.14	1.78

β weights and significance levels of predictors of caregiver distress as measured by the NPI

* p <0.05 (2-tailed), ** p <0.01 (2-tailed).

Table 3. Significant predictors of BPSD-related distress

	R	R^2	R^2 *Change*	*B*	*SE*	*β*	*t*
Step1	0.48	0.23**	0.23**				
Competence				-0.54	0.13	-0.33**	-4.14
Guilt				0.44	0.15	0.23**	2.86
Step 2	0.53	0.28**	0.05**				
PwD health-related quality of life				-6.94	2.14	-0.23**	-3.24
Step 3	0.72	0.52**	0.24**				
Reactivity to BPSD				0.46	0.05	0.58**	8.67
Step 4	0.75	0.56**	0.04**				
Burden				0.25	0.07	0.28**	3.67

* $p < 0.05$ (2-tailed), ** $p < 0.01$ (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.

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Conflict of interest

None declared

Description of authors' roles

Professor 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, and Professor Ian Russell provided specialist statistical guidance.

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