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Relationship between the number of behavioral symptoms in dementia and caregiver distress: what is the tipping point?

Paul B. Arthur^{1,2}, Laura N. Gitlin³, John A. Kairalla⁴, William C. Mann^{2,5}

¹Department of Occupational Therapy, St. Catherine University, Minneapolis, Minnesota, USA

²North Florida/South Georgia Department of Veterans Affairs Medical Center, Center of Innovation on Disability and Rehabilitation Research, Gainesville, Florida, USA

³Center for Innovative Care in Aging, Johns Hopkins University, Baltimore, Maryland, USA

⁴Department of Biostatistics, University of Florida, Gainesville, Florida, USA

⁵Department of Occupational Therapy, University of Florida, Gainesville, Florida, USA

Abstract

Background: Behavioral and psychological symptoms of dementia (BPSD) are a primary manifestation of brain dysfunction in dementia and a great challenge in caregiving. While BPSD are historically associated with caregiver distress, it is unclear whether there is an identifiable point where BPSD number is associated with heightened caregiver distress. The purpose of this study was to determine if such a tipping point exists to assist clinicians in identifying caregiver compromise.

Methods: Analyses were performed with three datasets totaling 569 community-dwelling persons with dementia and their caregivers. Each included identical demographic, BPSD, cognitive, and caregiver well-being measures. Linear regression was performed with 16 BPSD symptoms on caregiver well-being measures and predictive values determined with receiver operating characteristic (ROC) curves and pre-defined scores for clinically significant distress.

Results: Of the 569 persons with dementia, 549 (96%) displayed at least one BPSD, mean of 5.7 (SD = 3.06) symptoms in the past month. After controlling for covariates, BPSD symptom number was significantly associated with caregiver depression and burden ($p < 0.01$ for both models). Findings indicate 4 BPSD has strong predictive values for depression (sensitivity 85%,

Correspondence should be addressed to: Paul B. Arthur, Department of Occupational Therapy, St. Catherine University, 601 25th Avenue South, Old Main 436, Minneapolis, Minnesota 55454, USA. PBArthur824@StKate.edu.

Description of authors' roles

P. B. Arthur developed the study concept and primary design and assumed primary conceptual development and writing responsibility of manuscript. L. N. Gitlin, principal investigator for analyzed data, provided significant background, and narrative knowledge, assisted with the write up of the manuscript and provided critical review and edits. J. A. Kairalla provided significant design and methodological advice, data interpretation, and critically reviewed manuscript, and W. C. Mann oversaw scientific integrity of the project and provided critical review of the manuscript.

Ethics approval and consent to participate

This study was approved by the University of Florida Institutional Review Board (IRB # 16U0053).

Conflict of interest

None.

specificity 44%, area under ROC curve 0.62, $p < 0.01$), and burden (sensitivity 84%, specificity 43%, area under ROC curve 0.67, $p < 0.01$).

Conclusions: Caring for persons with four or more BPSD appears to reflect a tipping point for clinically meaningful distress. Findings have implications for clinicians working with persons with dementia and their caregivers and suggest need for continuous monitoring of BPSD and identification of at risk caregivers.

Keywords

Alzheimer's disease; dementia; neuropsychiatric symptoms; behavioral and psychological symptoms of dementia (BPSD); carers

Background

Behavioral and psychological symptoms of dementia (BPSD) are a primary manifestation of brain dysfunction in Alzheimer's disease (Lyketsos *et al.*, 2011). Symptoms including delusions, hallucinations, agitation, aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability, and aberrant motor behaviors, occur for all disease etiologies and across all stages of dementia (Mega *et al.*, 1996). Symptoms are nearly universal, can cause considerable distress to caregivers (Ornstein and Gaugler, 2012), and have been cited as one of the most challenging aspects of caregiving (Gitlin *et al.*, 2012).

Decreased cognition, coupled with BPSD may result in challenging situations for caregivers faced with their own lifestyle/role changes. There are many studies testing pharmacological (Van De Glind *et al.*, 2013) and non-pharmacological (Livingston *et al.*, 2014) management of BPSD, though less preliminary research has been reported regarding the quantifiable influence of BPSD on caregiver well-being. As BPSD is a clinical feature of dementia that will likely occur along the disease trajectory, it is important to understand the point at which the presence of behavioral symptoms becomes too challenging for caregivers to manage. This can inform clinical and research stakeholders to when intervention is necessary to help caregivers better manage BPSD and to assume a preventive stance.

There are 15.7 million informal caregivers of persons with dementia (Alzheimer's Association, 2015) largely furloughing their lives to provide such support, with many facing a most difficult aspect of caregiving: BPSD. Caregiver depressive symptoms primarily involve mood disturbances resulting from caregiver demands. Alternatively, caregiver burden may be described as a culminating negative reaction from the provision of care and impact on the caregiver's social, occupational, and personal roles (Sherwood *et al.*, 2005) which generally makes it a broader construct. Depressive symptoms and caregiver burden have been described as interrelated and part of overall well-being, particularly for family caregivers of persons with dementia (Clyburn *et al.*, 2000).

Research suggests that as many as 80% of caregivers of persons with Alzheimer's disease experience high levels of stress (Schulz *et al.*, 2002) and nearly 40% experience depressive episodes (Robinson *et al.*, 2009). Care demands paired with caregiver resources (or lack thereof) can lead to psychological distress, increased medical susceptibility, and for stressed

caregivers, a greater risk of mortality compared to age and gender-matched non-caregiving controls and non-stressed caregivers (Schulz and Beach, 1999). Many caregivers of persons with dementia experience financial challenges and social isolation leading to a decreased quality of life, increased risk of abuse, and an increased likelihood of institutionalization (Cooper *et al.*, 2015).

There is a notable lack of understanding to the existence of a clinically meaningful tipping point where presence of BPSD becomes too overwhelming for caregivers. The purpose of this study was to determine whether there was a discernable cut-off point as to the number of BPSD caregivers manage that leads to clinical consequences. The identification of a tipping point may lead to clinical guidance addressing when caregivers are at the highest risk for depressive symptoms and excessive burden, warranting intervention.

Methods

This study was approved by the University of Florida Institutional Review Board (IRB # 16U0053). The observational study employed a sample from three trials consisting of 569 caregivers and persons with dementia who had participated in completed clinical trials: Project ACT ($n = 272$) (Gitlin *et al.*, 2010a), Project COPE ($n = 237$) (Gitlin *et al.*, 2010b), and Project TAP ($n = 60$) (Gitlin *et al.*, 2008). A cross-sectional design using baseline values (e.g. prior to random assignment and intervention) from the three trials was employed to examine the association between the risk factor (BPSD) and the outcomes of interest (caregiver depression and burden), while controlling for common covariates. Datasets from the studies were merged to create a single analytic sample to determine which risk factors independently or jointly were significantly predictive of caregiver well-being.

Measures

Detailed information about measures is found in Table 1. Information regarding caregiver well-being was collected using two psychometrically-sound measures (Gitlin *et al.*, 2010b). These included the 10-Item Center for Epidemiologic Studies Depression Scale (CES-D) (Irwin *et al.*, 1999) and the Zarit Short-Form Burden Scale (Bédard *et al.*, 2001). Caregiver health was derived from four investigator-developed items. Caregiver's reported: (1) their health at baseline, (2) their health compared to 3 years prior, (3) the impact of their health on participation in desired activities, and (4) their health compared to peers. The Agitated Behavior in Dementia Scale (ABID) (Logsdon *et al.*, 1999) was used to collect care recipient BPSD. The ABID measures 16 BPSD including: (1) verbal aggression, (2) physical aggression, (3) self-harm, (4) screaming/crying out, (5) destroying property, (6) refusing help, (7) wandering, (8) arguing, (9) inappropriate sexual behavior, (10), inappropriate social behavior, (11), restlessness, (12) anxiety, (13) agitation, (14) waking up at night, (15) delusions, and (16) hallucinations. Available participant demographic/contextual variables included age, race/ethnicity, formal education, functional dependence, cognitive level, socioeconomic status, relationship type, hours spent in caregiving, gender, health, and behavioral medication use.

Data analysis

Demographic information was analyzed using descriptive statistics and frequencies for variables described above. Univariate linear regression was used to identify demographic and contextual variables that were least significant (highest p values) to exclude them from the analysis. Backwards selection criteria were used to identify covariates with an entry criteria of $p = 0.20$ to allow a parsimonious model to test our primary independent variable (IV) with. Historically significant variables including cognition, health (person with dementia and caregiver), and behavioral medication number were included in all models regardless of their qualification in the backwards selection. Stratification (dummy) variables were included to differentiate possible effect location shifts among the three combined studies (ACT, COPE, and TAP). To determine if regression was appropriate, seven assumptions were considered: dependent variable (DV) measured a continuous level, IV measured at continuous or categorical levels, linear relationships between IV and DV, no significant outliers, independence of observations (Durbin–Watson statistic), homoscedasticity, and normal distribution of residuals. Upon meeting assumptions, separate linear regression analyses were performed with both DVs (caregiver well-being measures) along with parsimonious covariate models and BPSD.

Our primary aims were to examine the relationship of the number of BPSD and caregiver well-being, and to determine if a cut-off, or tipping point could be identified linking BPSD number with negative caregiver well-being. Testing for the primary covariate of interest, BPSD number, was performed as added-last tests of significance at the $\alpha = 0.05$ level within post-selection multivariable models. We hypothesized that caregiver well-being would be negatively impacted by an increase in BPSD. However, we did not have a hypothesis as to the specific cut-off point predictive of a clinical level of depressive symptoms and perceived burden, or that point would vary by outcome. The analysis used the itemized number of BPSD, as reported in the ABID, and a cumulative representation for each caregiver measure of well-being. To determine a cut-off point, we transformed and dichotomized depressive symptoms (CES-D) based on previous report with scores ≥ 10 implying significant depression (Andresen *et al.*, 1994) and burden (Zarit) scores were transformed and dichotomized for scores >17 implying significant burden (Bédard *et al.*, 2001).

Results

Caregivers

The characteristics of caregivers of persons with dementia are found in Tables 2 and 3. Caregivers mean self-reported health was 8.5 (SD = 2.4), with a range of 3–13, suggesting good health and few recent health changes. Caregivers reported spending an average of 27.8 (SD = 26.1) hours per week caring for persons with dementia (range 0–126). Caregiver burden, as measured by the Zarit Short Form was reported at a mean of 21.5 (SD = 9.3), median 21.0, suggesting that the average caregiver was at a significant level of burden (criteria >17). Caregiver depression, as measured by the CES-D was at an average of 9.1 (SD = 5.7), median 9.0, with 252 (44%) of caregivers meeting the criteria for significant depression.

Persons with dementia

Characteristics of persons with dementia are located in Table 2. Of 16 BPSD, persons with dementia displayed an average of 5.7 (SD = 3.1) symptoms within the past month (Table 3). BPSD were normally distributed, with six BPSD being the mode (13.4% of sample) and an observed range of 0–15. The most commonly occurring BPSD were: arguing (67.3% of sample), anxiety (66.6%), restlessness (64.5%), verbal aggression (53.6%), refusal of care (53.1%), agitation (53.1%), and waking and getting up at night (51.1%) (Table 3).

BPSD and caregiver well-being

Table 4 shows the results of the linear regression with the depression variable (CES-D) alongside identified covariates and BPSD. The adjusted R^2 value was 0.34. When controlling for the selected covariates, BPSD was significantly associated with the depressive outcome ($p = 0.001$). One-unit change in the number of BPSD predicted 0.24 points higher on the CES-D.

Table 5 shows the results of the linear regression with the burden variable (Zarit) alongside selected covariates and BPSD. The adjusted R^2 value was 0.27. BPSD was significantly associated with burden ($p < 0.001$), indicating a one-unit change in the number of BPSD predicted 0.7 points higher on the burden score.

Identifying a tipping point

We found that the presence of 4 BPSD had strong predictive value for clinical depression with sensitivity 85%, and specificity 44% (Figure 1). This cut point, indicated by the red circles in Figure 1, had the highest Youden Index (a measure of overall diagnostic value calculated as Sensitivity+Specificity-1), or 0.51. The area under ROC curve for this model was 0.62 ($p = 0.01$ vs. a null of 0.5), showing significant predictive ability. Of importance is that the presence of 4 BPSD also had strong (and best) predictive values for burden, with sensitivity 84% and specificity of 43%. The Youden index was 0.41. The area under the ROC curve for this model was 0.67 ($p = 0.01$).

Discussion

We report findings on the relationship between BPSD and two dimensions of caregiver well-being: depression and burden. Results indicate that BPSD are significantly associated with caregiver well-being as measured by depressive symptoms and burden, when controlling for covariates, a finding supported by a number of previous studies (Dukle *et al.*, 2014; Fauth and Gibbons, 2014). Of importance, is that we show that a unit change in BPSD predicted a gradual linear decrease in the caregiver well-being outcomes, suggesting identification of a tipping point may be feasible.

By combining the data from three separate trials, we could examine these relationships in a relatively large community-dwelling dementia caregiver sample. The demographic profile of this combined sample was similar to those reported in other dementia caregiving studies (Steinberg *et al.*, 2008), suggesting our results may be generalizable. Like other dementia caregiver studies, close to half of the sample (44%) were at risk for clinical depression, as

reported on the CES-D, and approximately 70% were at risk for burden per their scores on the Burden Inventory using Bédard *et al.*'s (2001) conservative estimates. Despite caregivers reporting good physical health, it was evident that caregiving was a stressful emotional experience with negative psychological consequences.

The importance of this study lies in its identification of a tipping point by which BPSD overwhelm the caregiver, resulting in negative psychological consequences. While there is a linear relationship between number of BPSD and psychological well-being, this study is the first, to our knowledge, to show that four or more behavioral symptoms of any type are related to clinically meaningful depressive symptoms and burden. The possibility of predicting caregiver's susceptibility to depression and burden by identifying BPSD number has great clinical utility. Identifying the threshold of BPSD that is most suggestive of caregiver distress may best allow for more resourceful and targeted interventions. Also, when confronted with time constraints, clinicians may not have the time or knowledge to identify caregivers at risk. Thus, our finding suggests that caregivers reporting four or more behavioral symptoms should be targeted for intervention or, at the minimum, referral to resources (support groups, respite care, clinical trials) to help manage such symptoms.

The design of this study was a secondary data analysis, naturally limiting our control of the collection and measurement variables. This limited our ability to examine all variables of interest, particularly as it pertained to BPSD, and understanding the context in which behaviors occur. This also limited our ability to identify exhaustive medical comorbidities that may influence caregiver well-being as well as robust pharmacologic histories. As the ABID does not measure severity, it may also be that just one BPSD, if severe enough, could influence caregiver well-being, though this risk should be minimal secondary to the large sample size.

While sensitivity for predictive values was high (85%, and 84%, respectively), specificity was quite low (44% and 43%) suggesting a heightened risk for false positives. While true, for clinical screening purposes, high sensitivity, and negative predictive value are more important than high specificity and positive predictive value (Strik *et al.*, 2001). Despite a notable sample size, generalizability of the study may be questioned as study participation was voluntary and our sample was generally white, educated, and financially stable. Additionally, participants in this study may have higher incidences of BPSD and caregiver distress as the interventions tested addressed these manifestations. Future research is warranted in understanding the relationship of BPSD to caregiver well-being and the context in which behaviors occur and for diverse samples to confirm these findings.

Conclusion

By examining the interaction between the number of BPSD and caregiver well-being, this study adds incrementally to the understanding of the impact of this clinical feature. This study provides additional evidence to suggest that the well-being of caregivers of persons with dementia is compromised, particularly as the number of behavioral symptoms increases. The management of four or more behaviors appears to be a clinically meaningful tipping point, negatively effecting psychological health.

Clinicians should help caregivers prevent, manage and reduce BPSD regardless of the number occurring. However, those at most risk appear if four or more behaviors are occurring. There are effective intervention approaches to help caregivers better cope and manage these symptoms yet few families have access to them (Gitlin *et al.*, 2010a; Gitlin, 2012). Our study suggests the importance of implementing these programs, particularly for those at most risk.

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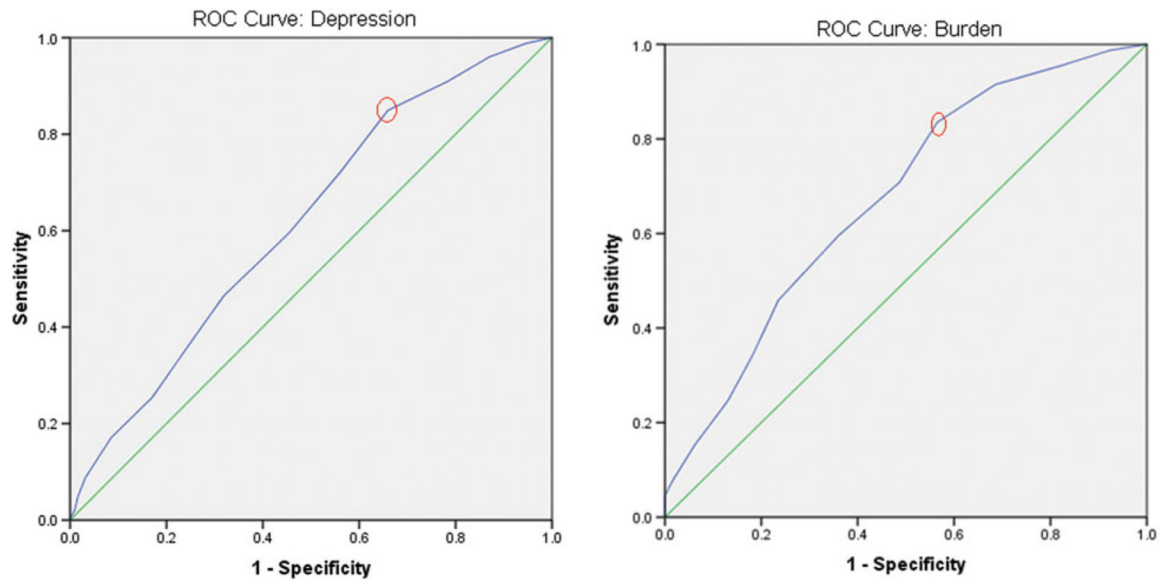


Figure 1.
(Colour online) ROC curves.

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Table 1.

Assessment measures

MEASURE	PURPOSE	RESPONSE FORMAT	CRONBACH'S α
The agitated behavior in dementia scale (Modified) (ABID). (Logsdon <i>et al.</i> , 1999)	Measures presence, frequency of, and caregiver reaction from agitated symptoms in persons with dementia	For each behavior (0–16), caregivers note “yes or no;” counted as a score from 0–16	0.72
Zarit Short-Form Burden Scale (Bedard <i>et al.</i> , 2001)	Measures burden when caring for cognitively impaired adults with 12 items.	Scores range from 0–48, with scores over 17 indicating high levels of CG burden	0.87
The 10-item center for epidemiologic studies depression scale (CES-D). (Irwin <i>et al.</i> , 1999)	Measures depressive symptomology in caregivers with 10 items.	Scores range from 0–30, where high scores imply greater depressive symptoms and scores of 10 or greater are predictive of significant depressive symptoms	0.81
The mini mental state exam (MMSE). (Folstein <i>et al.</i> , 1975)	Measures cognitive function in persons with dementia and other disorders with five domains: orientation, registration, attention and calculation, recall, and language.	Scores range from 0–30, with scores less than 24 suggesting cognitive impairment (10–20 moderate; 0–10 severe)	Individual items not available in dataset
The caregivers assessment of functional dependence and upset (CAFU). (Gitlin <i>et al.</i> , 2005).	Measures physical dependence of persons with dementia and caregiver reaction.	Scores based on binary level of assistance for 15 activities of daily living. Scores range from 0–15 with higher scores indicating greater dependence	0.85
Caregiver health	Caregiver self-assessment of their health	4-times with scores ranging from 3–13, with higher scores indicating better health	0.74
Person with dementia health	Measures caregiver assessment of person with dementia health	Single item with score ranging 1–5, with 1 being poor, 5 being excellent	Single item
Person with dementia pain	Measures caregiver assessment of the pain in person with dementia	Scores range from 4–20, with higher scores indicating greater impact on daily activity (due to pain)	0.89
Person with dementia behavioral medications	Measures number of behavioral medications	Range from 0–3 collected	Single item

Table 2.

Dyad demographics

	CAREGIVERS (N = 569)	PERSONS WITH DEMENTIA (N = 569)
Age		
Mean (SD)	64.35(12.5)	81.4 (12.4)
Range	25–100	53–102
Gender, n (%)		
Male	94 (16.5)	231 (40.6)
Female	475 (83.5)	338 (59.4)
Hispanic	13 (2.3)	11 (1.9)
Race, n (%)		
White	408 (71.7)	409 (71.9)
Black	148 (26.0)	148 (26.0)
Native American/Alaskan Native	-	2 (0.4)
Asian	1 (0.2)	1 (0.2)
Other	12 (2.1)	9 (1.6)
Marital Status, n (%)		
Married	390 (68.5)	285 (50.1)
Widowed	19 (3.3)	228 (40.1)
Divorced	76 (13.4)	42 (7.4)
Never Married	75 (13.2)	13 (2.3)
Separated	9 (1.6)	1 (0.2)
Health Status	8.5 (2.4)	3.0(1.2)
Pain		9.89(4.2)
MMSE		12.89(8.1)
Function		12.2 (2.9)
Behavioral medication use		0.40 (.638)
CG Relationship to CR (%)		
Spouse	260 (45.7)	
Non-Spouse	309 (54.3)	
Education (%)		

	CAREGIVERS (N = 569)	PERSONS WITH DEMENTIA (N = 569)
Less than high school	32 (5.6)	
High school graduate	151 (26.5)	
Some college/associates	172 (30.2)	
College	126 (22.1)	
Post-graduate	87 (15.3)	
Refused	1 (0.1)	
Employment (%)		
Yes	206 (36.2)	
No	363 (46.5)	
Employment Type (% of employed)		
Full-time	126 (61.2)	
Part-time	76 (36.9)	
Unknown	4 (0.02)	
Financial Difficulty (%)		
Not at all	196 (34.4)	
Not very	133 (23.4)	
Somewhat	198 (34.8)	
Very	42 (7.4)	
Hours spent caring per week	27.7 (26.1)	
Significant Depression	252 (44.3)	
Significant Burden	397 (69.9)	

Note: Significant depression; 10-item Center for Epidemiologic Studies Depression Scale score 10; Significant burden Zarit Short-Form score >17.

Table 3.**BPSD counts**

(N = 569)	
BPSD reported (%)	
0	20 (3.9)
1	31 (5.4)
2	41 (7.2)
3	54 (9.5)
4	63 (11.1)
5	66 (11.6)
6	76 (13.4)
7	53 (9.3)
8	47 (8.3)
9	48 (8.4)
10	38 (6.7)
11	15 (2.6)
12	9 (1.6)
13	7 (1.2)
14	0 (0.0)
15	1 (0.2)
16	0 (0.0)

Note: Behavioral and Psychological Symptoms of Dementia (BPSD).

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Table 4.

Regression analysis for BPSD and independent variables associated with depression (CES-D)

VARIABLE	UNSTANDARDIZED B	SE B
Constant	21.19	2.46
MMSE score (cognition)	0.03	0.03
CG health	- 0.89	0.09
CR health	0.23	0.19
CG sleep hours (x 3 days)	- 0.23	0.05
CG education (<HS-post grad)	- 0.33	0.18
Financial difficulty	0.30	0.23
CG age years	- 0.04	0.02
CG married	- 0.83	0.51
CR white	- 1.35	0.48
CG male	- 1.53	0.59
Daily hours spent in CG	0.09	0.04
CR pain	0.08	0.05
Study	0.04	0.33
Behavioral medications	0.50	0.33
BPSD number	0.21	0.07

Note: $R^2 = 0.34$; Behavioral and Psychological Symptoms of Dementia (BPSD).

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Table 5.

Regression analysis BPSD and independent variables associated with Burden (Zarit)

VARIABLE	UNSTANDARDIZED B	SE B
Constant	8.12	9.07
MMSE score (cognition)	0.14	0.05
Function score	0.16	0.14
CG health	- 0.68	0.15
CR health	- 0.09	0.32
CG sleep hours (× 3 days)	- 0.19	0.08
CG employed	1.03	0.82
CG age years	- 0.11	0.04
CR married	- 1.28	1.01
CR white	- 5.75	0.81
Related to CR	22.16	8.06
CG married	- 0.26	0.95
CG male	- 2.61	0.99
CR pain total	0.10	0.09
Study	0.50	0.54
Behavioral medications	0.92	0.57
BPSD number	0.69	0.13

Note: R² = 0.27; Behavioral and Psychological Symptoms of Dementia (BPSD); Zarit Short-Form (Zarit).