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The effects of behavioral and psychological symptoms on caregiver burden in frontotemporal dementia, Lewy body dementia, and Alzheimer’s disease: clinical experience in China

Shuling Liu\textsuperscript{a,b}, Yi Jin\textsuperscript{b,c}, Zhihong Shi\textsuperscript{a,b}, Ya Ruth Huo\textsuperscript{d}, Yalin Guan\textsuperscript{a,b}, Mengyuan Liu\textsuperscript{b}, Shuai Liu\textsuperscript{a,b} and Yong Ji\textsuperscript{a,b}

\textsuperscript{a}Department of Neurology, Tianjin Huanhu Hospital, Tianjin, China; \textsuperscript{b}Tianjin Key Laboratory of Cerebral Vascular and Neurodegenerative Diseases, Tianjin Huanhu Hospital, Tianjin, China; \textsuperscript{c}Department of Nursing Management, Tianjin Huanhu Hospital, Tianjin, China; \textsuperscript{d}School of Medicine, University of New South Wales, Kensington, NSW, Australia

**ABSTRACT**

**Background and aims:** Caregivers of individuals with neurodegenerative diseases, including frontotemporal dementia (FTD), Lewy body dementia (DBL), and Alzheimer’s disease (AD), experience high levels of psychological and physical stress, likely due to behavioral and psychological symptoms of dementia (BPSD). This study is the first to simultaneously evaluate the effects of BPSD on caregiver burden in these three types of dementia.

**Method:** A total of 214 dementia patients, including probable FTD (n = 82), DLB (n = 22), and AD (n = 110), as well as their primary caregivers, were assessed using psychological inventories and cognitive evaluation. The FTD group was further divided into the three established clinical variants: behavioral variant frontotemporal dementia (bvFTD), non-fluent variant primary progressive aphasia (nfvPPA, n = 15), and semantic variant primary progressive aphasia (svPPA, n = 16). Cognitive impairment and neuropsychiatric symptoms were assessed using the Mini Mental State Examination, Montreal Cognitive Assessment, Clock Drawing Test, and Neuropsychiatric Inventory (NPI), respectively. Caregiver burden was assessed using the Zarit Burden Inventory (ZBI).

**Results:** FTD patients had higher NPI and ZBI scores than DLB and AD patients, whose scores were similar. Logistic regression analysis revealed that the factors influencing caregiver burden for each group were: FTD: total NPI scores, agitation, and aberrant motor behavior; bvFTD: total NPI scores; DLB: total NPI scores; and AD: total NPI scores, onset age, apathy, and ADL. Caregivers of bvFTD patients had the highest levels of burden, which were significantly greater than for caregivers of nfvPPA, svPPA, DLB, and AD patients.

**Conclusion:** BPSD was highly correlated with emotional burden in caregivers of FTD, DLB, and AD patients. The highest burden was observed in bvFTD caregivers.

**Introduction**

There is a growing realization of the importance of behavioral and psychological symptoms of dementia (BPSD) among patients with frontotemporal dementia (FTD), dementia with Lewy bodies (DBL), and Alzheimer’s disease (AD). BPSD have been well studied in AD, and were observed in 90% of AD patients in one study (Tariot et al., 1995). Studies of FTD have also reported BPSD (Bathgate, Snowden, Varma, Blackshaw, & Neary, 2001; Diehl & Kurz, 2002; Miller et al., 2013; Mioshi, Foxe, et al., 2013), which appear to be exacerbated compared with those observed in AD (Levy, Miller, Cummings, Fairbanks, & Craig, 1996). Specifically, FTD involves insidious changes in personality and social conduct (Perry & Miller, 2001), which are key factors differentiating it from AD. Additional symptoms associated with FTD include apathy, disinhibition, euphoria, and aberrant motor behavior, and family members involved with the care of FTD patients have high rates of burden (Lima-Silva et al., 2015; Rascovsky et al., 2011; Riedijk et al., 2006). However, behavioral changes, rather than the level of disability, appear to be correlated with caregiver burden in FTD (Boutouleau-Bretonniere, Vercelletto, Voletau, Renou, & Lamy, 2008; Mioshi, Bristow, Cook, & Hodges, 2009). Several studies have shown that caregiver burden in FTD is markedly greater than in AD (Boutouleau-Bretonniere et al., 2008; Kaiser & Panegyres, 2006; Riedijk et al., 2006).

Although BPSD have been correlated with caregiver burden in FTD and AD (Dowling et al., 2014; Gallagher et al., 2011; Lima-Silva et al., 2015), these observations remain controversial (Mioshi et al., 2009; Riedijk et al., 2008). FTD is known to present with three main clinical variants: behavioral frontotemporal dementia (bvFTD) (Rascovsky et al., 2011), non-fluent variant primary progressive aphasia (nfvPPA), and semantic variant primary progressive aphasia (svPPA) (Gorno-Tempini et al., 2011). Patients with bvFTD typically show progressive changes in behavior and interpersonal skills, while the other two variants present with a decline in language skills (Gorno-Tempini et al., 2011; Rascovsky et al., 2011). Different types of FTD may differentially affect caregiver burden (Mioshi, Foxe, et al., 2013). Compared to caregivers of AD patients, caregivers of svPPA and nfvPPA patients show similar burden, while bvFTD caregivers show higher burden (Mioshi, Foxe, et al., 2013). These differences should be taken into account by professionals involved in the treatment and care of dementia.

DBL is the second most common neurodegenerative dementia after AD (McKeith et al., 2003). The most frequently
reported BPSD in early stages of DLB include visual hallucinations and delusions (Ballard et al., 1999), which have been reported to occur in up to 60% and 80% of patients, respectively (Klatka, Louis, & Schiffer, 1996; McKeith et al., 1994). However, the appearance and distribution of BPSD, as well as caregiver burden, may be affected by many factors, including cultural backgrounds (Pang et al., 2002). A systematic review of the current literature revealed a lack of consensus amongst healthcare professionals concerning which factors can best predict caregiver burden (Zweig & Galvin, 2014).

This study was designed to: (1) determine which BPSD have the greatest impact on burden in caregivers for FTD, DLB, and AD patients; (2) compare the effects of BPSD on caregiver burden across FTD variants, DLB, and AD; and (3) identify patient and caregiver variables that contribute to caregiver burden. We hypothesized that FTD patients would have higher rates of BPSD than DLB and AD patients; moreover, we hypothesized that caregivers of bvFTD patients would have higher levels of burden than those of nfvPPA, svPPA, DLB, and AD patients.

Methods
This study was conducted at Tianjin Huanhu Neurological and Neurosurgical Hospital, which includes the only memory clinic in Tianjin. Patients with dementia attending the memory clinic between June 2014 and July 2015 were recruited. A total of 214 patients diagnosed with probable FTD (n = 82), DLB (n = 22), and AD (n = 110) and their caregivers were selected. Patients were grouped according to the following diagnostic criteria: Neary et al. criteria for FTD (Neary et al., 1998); McKeith et al. consensus of diagnosis for DLB (McKeith et al., 1996); and NINCDS-ADRDA criteria for AD (McKhan et al., 1984). FTD patients were further subdivided into the three main clinical variant groups: (1) bvFTD (n = 51), (2) nfvPPA (n = 15), and svPPA (n = 16).

A team of three dementia specialist nurses and three registered neurologists assessed all patients and their caregivers. Those patients who failed to visit the memory clinic on a regular basis or had too few visits to obtain adequate information were excluded from the study. Additionally, caregivers who were paid or who interacted with patients less than 8 h/day were excluded.

Ethics statement
This study was performed in accordance with the Helsinki Declaration and was approved by the Tianjin Huanhu Neurological and Neurosurgical Hospital Ethics Committee, Tianjin, China. Written informed consent was obtained from all patients and caregivers enrolled in the study.

Patient variables
Patients who visited the memory clinic received a thorough clinical history assessment and comprehensive physical and neurologic examinations. Neuroimaging, biochemical, and hematologic studies were performed to rule out treatable causes of dementia. In patients with atypical findings, further detailed neuropsychological evaluation was performed to assess general and specific cognitive function, as well as BPSD.

Assessment
Cognitive functioning was assessed using the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), and the Clock Drawing Test (CDT) (Shulman, 2000). The MMSE evaluates orientation, registration, attention, calculation, recall, and language. Scores on the MMSE range from 0 to 30, corresponding to the number of correct items. The MoCA evaluates visuospatial executive function, naming, attention, abstraction, language, delayed memory, and orientation. The MoCA can detect mild cognitive impairment, and scores range from 0 to 30. The CDT represents a quick and simple screening test that evaluates visuospatial function, the ability to use symbolic and graphic representation, language, semantic memory, and executive function. Scores on the CDT range from 0 to 4. Lower scores on the MMSE, MoCA, and CDT indicate greater cognitive impairment.

The Chinese version of the Neuropsychiatric Inventory (NPI) was used to assess BPSD in dementia patients via an interview with their caregivers (Cummings et al., 1994). Using the NPI, the patient’s condition during the last month before the interview was rated on the following 12 symptoms: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep disturbances, and eating abnormalities. In this paradigm, according to the established criteria-based rating scheme, the severity of each behavior was classified from 0 (absent) to 3, and the frequency of each behavior was classified from 0 (absent) to 4. The NPI score (severity × frequency) was calculated for each behavior (range of possible scores, 0—12), yielding a maximum total NPI score of 144 for the 12 behavioral manifestations. Higher scores reflect greater symptom severity. Dementia duration and family income were also assessed.

Caregiver variables
A semi-structured questionnaire was used to assess variables identified in the literature to influence caregiver burden, health, and emotional well-being. Demographic-situational items included age; gender; caregiver’s relationship with patient; duration of patient’s disease from onset; severity of dementia, assessed by Clinical Dementia Rating scale (CDR) as mild (0.5—1), moderate (2), or severe (3) (Ousset, Andrieu, Reynish, Puel, & Vellas, 2003); years caring for the patient; and time spent in patient-related activities (e.g., communication, feeding, dressing, transportation, and supervision). The degree of burden experienced by caregivers was evaluated using the Zarit Burden Inventory (ZBI; Zarit, Orr, & Zarit, 1985), which contains 22 items that are rated on a 5-point scale, ranging from 0 (none) to over-burdened (4), yielding a maximum score of 88. Higher scores reflect higher levels of caregiver distress.

Statistical analysis
Data were analyzed using the statistical package SPSS 22.0.0 for Windows (SPSS Inc., Chicago, IL, USA). Kolmogorov–Smirnov tests were used to check for normal distribution. For normally distributed data, we used analysis of variance (ANOVA) to compare groups (bvFTD, nfvPPA, svPPA, DLB, and AD), followed by post hoc tests (least significant difference [LSD] method) to investigate group differences. Given the non-
normal distribution of NPI subscale scores for FTD (including bvFTD, nfvPPA, svPPA), DLB, and AD groups, correlations between ZBI scores and NPI subscale scores were evaluated using Spearman’s correlation coefficient. To compare each NPI subscale score across FTD, DLB, and AD, we used the non-parametric Kruskal–Wallis H test with a significance level set at 0.017, following Bonferroni corrections. Categorical variables were analyzed using chi-square tests.

Logistic regression was used to identify which factors predict caregiver burden. First, continuous variables (for caregiver and patient) and ZBI scores for FTD (including bvFTD, nfvPPA, svPPA), DLB, and AD were compared using Pearson correlations for normally distributed data or Spearman correlations for non-normally distributed data. Categorical variables (for caregiver and patient) and ZBI scores of the three groups were compared using univariate analysis. Second, ZBI scores were divided into two categories (<20, no burden; >20, burden) (Zarit et al., 1985). Predictors that reached statistical significance in the correlation and univariate analysis were entered into a logistic regression model using the ‘backward-wald’ method to examine their ability to predict caregiver burden. This model was refined by discarding any variables found to be non-significant using the ‘backward-wald’ method.

Results

Demographic characteristics and clinical variables for the caregivers and patients in the five diagnostic groups are shown in Tables 1 and 2. The groups were well matched for caregiver age and relationship to patients. About half of the caregivers were spouses. More than half of the DLB and AD caregivers were female, and more than half of the bvFTD, nfvPPA, svPPA caregivers were male. More than half of all caregivers had finished middle school. ANOVA revealed a group difference in ZBI scores (F = 14.092, P < 0.001), and post hoc tests (LSD method) showed that bvFTD caregivers had significantly higher levels of burden than the other patient groups (P < 0.05). No other group differences were found.

Patients were similar in terms of gender, disease duration, severity of dementia, and cognitive assessment scores. The severity of dementia within each group ranged from mild to severe on all measures. Patient age and onset age were lower in FTD variants than in DLB and AD. ADL scores were lower in FTD variants than in DLB and AD. ANOVA revealed a group difference in total NPI scores (F = 5.375, P < 0.001), and post hoc tests (LSD method) showed that bvFTD caregivers had significantly higher total NPI scores than caregivers for other patient groups (P < 0.05). No other group differences were found.

Table 3 shows Spearman’s correlations between Zarit burden scores and the 12 NPI subscale scores. Bonferroni corrections with significance level set at 0.0042 were used for multiple comparisons. Aberrant motor behavior, hallucinations, and apathy were the symptoms most significantly correlated with caregiver burden in those caring for FTD, DLB, and AD patients, respectively. In FTD subgroup analysis, aberrant motor behavior was also the symptom most significantly correlated with bvFTD caregiver burden. No symptoms were significantly correlated with nfvPPA or svPPA caregiver burden, possibly due to the lower number of nfvPPA and svPPA patients included.

Logistic regression analysis was used to assess the influence of different factors on caregiver burden. First, we screened statistically significant variables for caregivers and patients using correlation and univariate analyses. Variables that were entered into a logistic regression model were as follows: FTD group: MMSE, CDT, MoCA, ADL, total NPI scores, and 11 NPI subscale scores (delusions, hallucinations, agitation, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep disturbances, and eating abnormalities); DLB group: MMSE, CDT, MoCA, ADL, total NPI scores, and one NPI subscale score (hallucinations); AD group: caregiver age, relationship to patient, patient age, patient onset age, MMSE, CDT, MoCA, ADL, total NPI scores, and

| Table 1. Demographic characteristics and Zarit Burden Scores for caregivers of FTD variants (bvFTD, nfvPPA, and svPPA), DLB, and AD. |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                  | FTD group (n = 82) |                  |                  |                  |                  |                  |                  |
|                  | bvFTD (n = 51) | nfvPPA (n = 15) | svPPA (n = 16) | DLB group (n = 22) | AD group (n = 110) | Test value | P-value |
| Caregiver Age    | 55.08 ± 13.18 | 60.20 ± 16.84 | 62.75 ± 14.39 | 60.18 ± 10.79 | 61.03 ± 14.71 | F = 1.516 | 0.199 |
| Female, n (%)    | 22 (43.1) | 6 (40.0) | 4 (25.0) | 15 (68.2) | 65 (59.1) | \( x^2 = 11.664 \) | 0.020 |
| Educational attainment, n (%) | Illiterate | 0 (0) | 0 (0) | 0 (0) | 0 (0) | \( x^2 = 49.841 \) | 0.000 |
|                  | Primary school | 7 (13.7) | 6 (40.0) | 4 (25.0) | 0 (0) | 8 (7.3) |
|                  | Middle school | 13 (25.5) | 4 (26.7) | 6 (37.5) | 5 (22.7) | 23 (20.9) |
|                  | High school | 22 (43.1) | 3 (20.0) | 4 (25.0) | 16 (72.7) | 31 (28.2) |
|                  | College | 9 (17.6) | 2 (13.3) | 2 (12.5) | 1 (4.5) | 46 (41.8) |
| Caregiver income, (yuan/month) | 3049.02 ± 82.16 | 3033.33 ± 61.40 | 2968.75 ± 1040.33 | 2818.18 ± 1006.47 | 2950.91 ± 1418.34 | F = 0.163 | 0.957 |
| Relationship to patient, n (%) | Son | 13 (25.5) | 3 (20.0) | 3 (18.8) | 3 (13.6) | 16 (14.5) | \( x^2 = 22.193 \) | 0.137 |
|                  | Daughter | 9 (17.6) | 1 (6.7) | 1 (6.2) | 8 (36.4) | 25 (22.7) |
|                  | Husband | 16 (31.4) | 7 (46.7) | 9 (56.2) | 4 (18.2) | 26 (23.6) |
|                  | Wife | 11 (21.6) | 4 (26.7) | 3 (18.8) | 7 (31.8) | 36 (32.7) |
|                  | Other | 2 (3.9) | 0 (0) | 0 (0) | 0 (0) | 7 (6.4) |
| Years of caregiving | 3.36 ± 1.99 | 2.90 ± 0.97 | 4.44 ± 2.87 | 3.52 ± 1.35 | 3.18 ± 1.02 | F = 1.637 | 0.166 |
| Hours of caregiving/day | 12.57 ± 9.01 | 12.60 ± 9.98 | 16.38 ± 9.19 | 13.14 ± 9.16 | 12.40 ± 8.74 | \( x^2 = 2.925 \) | 0.570 |
| Sole caregiver, n (%) | 31 (60.8) | 6 (40.0) | 10 (62.5) | 12 (54.5) | 68 (61.8) | \( x^2 = 29.52 \) | 0.000 |
| ZBI (range ≥<88) | 35.78 ± 24.56 | 20.47 ± 15.31 | 19.87 ± 16.74 | 17.50 ± 16.88 | 14.25 ± 12.56 | F = 14.092 | 0.000 |

Note: Data are represented as mean ± SD or %. \( x^2 \): chi-square test, subdividing R x C table for multiple comparisons with alpha correction set at 0.005; F: analysis of variance (ANOVA) with post hoc tests (LSD method) for multiple comparisons. bvFTD: behavioral variant frontotemporal dementia, FTD: frontotemporal dementia, nfvPPA: non-fluent variant primary progressive aphasia, svPPA: semantic variant primary progressive aphasia, DLB: Lewy body dementia, AD: Alzheimer’s disease, ZBI: Zarit Burden Inventory.

\( ^a \)svPPA < DLB and AD (P < 0.005); \( ^b \)bvFTD > nfvPPA, svPPA, DLB, and AD (P < 0.01).
10 NPI subscale scores (delusions, hallucinations, agitation, depression, anxiety, apathy, disinhibition, irritability, aberrant motor behavior, and sleep disturbances). Second, we used the 'Backward-wald' method to examine how well each factor predicted caregiver burden. As shown in Table 4, independent predictors for caregiver burden for each patient group were: (1) FTD: total NPI scores (OR = 1.186, \( P < 0.001 \)), agitation (OR = 0.654, \( P < 0.006 \)), and aberrant motor behavior (OR = 1.429, \( P = 0.013 \)); (2) DBL: total NPI scores (OR = 1.537, \( P = 0.008 \)); and (3) AD: total NPI scores (OR = 1.059, \( P = 0.001 \)), apathy (OR = 1.132, \( P = 0.013 \)), ADL (OR = 1.049, \( P = 0.010 \)), and patient onset age (OR = 0.930, \( P = 0.029 \)). In FTD subgroup analysis, total NPI scores predicted caregiver burden for the bvFTD group (OR = 1.305, \( P = 0.009 \)). There were no statistically significant predictors for the nfvPPA and svPPA groups, possibly due to the lower number of nfvPPA and svPPA patients included (see Table 4).

Figure 1 shows NPI subscale scores (symptom severity \( \times \) frequency) in FTD, DBL, and AD patients. Depression, anxiety, and euphoria were similar across FTD, DBL and AD patients, but statistical differences were observed in the other nine subscales. The most frequent BPSD observed in each patient group were: FTD: agitation (71.95%), disinhibition (68.29%), and irritability (57.32%); DBL: hallucinations (86.36%), delusions (63.63%), and anxiety (59.09%); and AD: apathy (47.27%), depression (44.55%), and irritability (41.82%).

### Note

- Spearman correlation; following Bonferroni correction, significance level was set at \( P < 0.0042 \). BPSD: behavioral and psychological symptoms of dementia. bvFTD: behavioral variant frontotemporal dementia, nfvPPA: non-fluent variant primary progressive aphasia, svPPA: semantic variant primary progressive aphasia, FTD: frontotemporal dementia, DBL: Levy body dementia, AD: Alzheimer's disease, NPI: Neuropsychiatric Inventory, and ZBI: Zarit Burden Inventory.
Discussion

This study suggests that significant differences exist in BPSD and caregiver burden across different types of dementia and that BPSD contribute to caregiver burden. For FTD, DLB, and AD patients, the BPSD that were most highly correlated with caregiver burden were aberrant motor behavior, hallucinations, and apathy, respectively, but total NPI scores also increased caregiver burden for all three forms of dementia.

Other predictors of caregiver burden included agitation and aberrant motor behavior in FTD and apathy, ADL, and patient onset age in AD. In FTD subgroup analysis, aberrant motor behavior was the symptom most significantly correlated with bvFTD caregiver burden, but total NPI scores were also significant predictors. Caregivers of bvFTD patients had higher burden scores than caregivers of nfvPPA, svPPA, DLB, and AD patients, and caregivers of DLB and AD patients had similar levels of burden.

The behavioral changes noted in FTD patients in this study were similar to those observed in previous reports (Diehl, Forstl, Jansen, & Kurz, 2004; Tanaka et al., 2015). Moreover, our finding that hallucinations were the most predominant symptom in DLB patients supports visual hallucinations as an essential feature of DLB in the consensus criteria of McKeith et al. (1996).

Our observation that FTD was characterized by a much younger age of onset than AD or DLB is consistent with a previous study (Kaiser & Panegyres, 2006). Moreover, we found that patients with FTD had the highest mean NPI total scores and associated caregiver burden. Differences in caregiver burden among FTD patients with different variants may be of profound clinical importance. Caregivers of bvFTD patients had greater burden than caregivers managing patients with svPPA or nfvPPA, as well as AD and DLB (Mioshi, Foxe, et al., 2013). Among the five patient groups, bvFTD patients had the most severe BPSD, as measured by the NPI. Consistent with previous observations, aberrant motor behavior in FTD patients was strongly associated with caregiver burden (Mourik et al., 2004). The similar levels of burden reported by nfvPPA, svPPA, and AD caregivers may be due to the similarity of the patients’ persistent clinical symptoms (i.e. cognitive deficits with few behavioral changes) (Mioshi, Foxe, et al., 2013). The bvFTD subtype of FTD is a clinical syndrome

### Table 4. Logistic regression analysis using ZBI scores from FTD, bvFTD, DLB, and AD patients as the dependent variable.

<table>
<thead>
<tr>
<th>Groups</th>
<th>Independent primary variable</th>
<th>B coefficient</th>
<th>Std. error</th>
<th>Wald</th>
<th>P-value</th>
<th>Exp (B)</th>
<th>95% CI for Exp (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FTD group</td>
<td>Total NPI scores</td>
<td>0.170</td>
<td>0.047</td>
<td>13.24</td>
<td>0.000</td>
<td>1.186</td>
<td>1.082 – 1.299</td>
</tr>
<tr>
<td></td>
<td>Agitation</td>
<td>0.425</td>
<td>0.156</td>
<td>7.425</td>
<td>0.006</td>
<td>0.654</td>
<td>0.482 – 0.888</td>
</tr>
<tr>
<td></td>
<td>Aberrant motor behavior</td>
<td>0.357</td>
<td>0.144</td>
<td>6.122</td>
<td>0.013</td>
<td>1.429</td>
<td>1.077 – 1.895</td>
</tr>
<tr>
<td></td>
<td>Constant</td>
<td>–3.740</td>
<td>0.922</td>
<td>16.468</td>
<td>0.000</td>
<td>0.024</td>
<td>–</td>
</tr>
<tr>
<td>bvFTD group</td>
<td>Total NPI scores</td>
<td>0.286</td>
<td>0.102</td>
<td>6.741</td>
<td>0.009</td>
<td>1.305</td>
<td>1.067 – 1.595</td>
</tr>
<tr>
<td></td>
<td>Constant</td>
<td>–8.028</td>
<td>3.023</td>
<td>7.052</td>
<td>0.008</td>
<td>0.000</td>
<td>–</td>
</tr>
<tr>
<td>DLB group</td>
<td>Total NPI scores</td>
<td>0.430</td>
<td>0.229</td>
<td>3.532</td>
<td>0.048</td>
<td>1.537</td>
<td>0.982 – 2.405</td>
</tr>
<tr>
<td></td>
<td>Constant</td>
<td>–11.151</td>
<td>5.832</td>
<td>3.655</td>
<td>0.056</td>
<td>0.000</td>
<td>–</td>
</tr>
<tr>
<td>AD group</td>
<td>Total NPI scores</td>
<td>0.058</td>
<td>0.015</td>
<td>14.408</td>
<td>0.000</td>
<td>1.059</td>
<td>1.028 – 1.092</td>
</tr>
<tr>
<td></td>
<td>Apathy</td>
<td>0.124</td>
<td>0.050</td>
<td>6.121</td>
<td>0.013</td>
<td>1.132</td>
<td>1.026 – 1.248</td>
</tr>
<tr>
<td></td>
<td>ADL</td>
<td>0.037</td>
<td>0.022</td>
<td>6.577</td>
<td>0.010</td>
<td>1.049</td>
<td>1.014 – 1.096</td>
</tr>
<tr>
<td></td>
<td>Patient onset age</td>
<td>–0.073</td>
<td>0.034</td>
<td>4.758</td>
<td>0.029</td>
<td>0.930</td>
<td>0.870 – 0.993</td>
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<tr>
<td></td>
<td>Constant</td>
<td>0.418</td>
<td>2.173</td>
<td>0.037</td>
<td>0.847</td>
<td>1.519</td>
<td>–</td>
</tr>
</tbody>
</table>

Note: ZBI scores from FTD, bvFTD, DLB, and AD as the dependent variable, respectively. FTD: frontotemporal dementia, bvFTD: behavioral variant frontotemporal dementia, DLB: Lewy body dementia, AD: Alzheimer’s disease. NPI: Neuropsychiatric Inventory: ZBI: Zarit Burden Inventory, ADL: activities of daily living, NPI: Neuropsychiatric Inventory.

However, the most frequently reported symptoms did not show the strongest correlation with caregiver burden in FTD.

### Figure 1. Mean NPI subscale scores (symptom severity × frequency) for BPSD in FTD, DLB, and AD.

Note: Kruskal–Wallis H test with significance level set at 0.017 following Bonferroni corrections for multiple comparisons. BPSD: behavioral and psychological symptoms of dementia, FTD: frontotemporal dementia, DLB: Lewy body dementia, AD: Alzheimer’s disease, NPI: Neuropsychiatric Inventory. *FTD vs. DLB, P < 0.017; †FTD vs. AD, P < 0.017; ‡DLB vs. AD, P < 0.017.
characterized by progressive deterioration of personality, social comportment, and cognition (Rascovskky et al., 2011). In our study, total NPI scores predicted bvFTD caregiver burden. NPI scores and behavioral changes appear to be correlated with caregiver burden in FTD (Boutoleau-Bretonniere et al., 2008; Mioshi et al., 2009). In contrast, we did not observe any significant variables predicting caregiver burden in nfvPPA or svPPA.

DBL remains the second most common neurodegenerative dementia after AD (McKeith et al., 2003). In this study, compared to the AD group, the DLB group exhibited increased behavioral changes associated with a higher frequency of hallucinations. DLB caregivers have previously been shown to have greater distress than AD caregivers. A survey of 611 DBL caregivers highlighted their burden experiences and the impact of BPSD on subjective burden (Leggett, Zatir, Taylor, & Galvin, 2011). In this study, total NPI scores predicted DLB caregiver burden. However, we observed no statistical differences between DBL and AD caregivers in NPI total scores or ZBI scores, possibly due to the lower number of DBL patients included.

Like previous studies (Miller et al., 2013; Nagatomo et al., 1999), we found patient cognitive assessment scores were not related to caregiver burden. However, deterioration in particular cognitive domains (i.e. emotion-processing skills) was associated with caregiver burden. We speculate that such cognitive domains are relevant to BPSD. Our findings were somewhat different from a previous study, which showed dementia caregiver burden to be related to younger patient age and lower scores on emotion and memory tests (Miller et al., 2013). However, these differences could be explained by the different cultural backgrounds of the patients and caregivers.

The findings of our study have important implications for intervention with caretakers of FTD, DLB, and AD patients. Although targeted behavioral interventions remain important, our results indicate that interventions that aim to improve caregiver understanding of the specific BPSD related to FTD, DLB, and AD may be beneficial. It is crucial that caregivers have the opportunity to learn and accept BPSD and its accompanying behavioral changes (Rosness, Haugen, & Engelad, 2008). This will lead caregivers towards an acceptance of the theory of dementia, thereby allowing them to adjust their expectations and helping them to overcome the difficulties associated with caring for those suffering from neurodegenerative disease. Additional research on caregiver burden in those caring for FTD, DBL, and AD patients is especially important given the increasingly younger onset of clinical dementias (Mioshi, Foxe, et al., 2013; Noyes et al., 2010). Based on these observations, we suggest the implementation of a structured caregiver program based upon the work of Hebert et al. and Mioshi et al. (Hebert et al., 2003; Mioshi, McKinnon, Savage, O’Connor, & Hodges, 2013), which we believe will bring practical benefit to caregivers dealing with dementia.

Although this study included a total of 214 patients with FTD, DLB, and AD, the numbers of DLB and FTD patients were small due to the comparatively low incidence of these dementias. This limitation should be kept in mind when considering possible generalizations based on our findings. Moreover, caregiver groups in this study were relatively small, and the caregiver burden assessment metric was unidimensional. A longitudinal study following caregivers from diagnosis to the end stages of the disease would likely provide an enhanced understanding of caregiver burden as the disease progresses and elucidate the impact of time on caregiver burden. Another limitation was the use of older diagnostic criteria for FTD (Neary et al., 1998) rather than newer criteria for bvFTD (Rascovskky et al., 2011) and the primary progressive aphasia (Gorno-Tempini et al., 2011). This may limit interpretability of the results, as some participants may have been incorrectly classified, particularly in combination with a lack of pathological or genetic data to aid diagnosis.

Conclusion

This study highlights differences in BPSD across dementia subtypes, including aberrant motor behavior in FTD, hallucinations in DLB, and apathy in AD. Furthermore, the extent of BPSD was significantly correlated with caregiver burden. Caregivers of nfvPPA, svPPA, and AD patients showed similar levels of emotional burden, and caregivers of bvFTD patients showed higher emotional burden than DLB and AD caregivers. These novel observations are important for the planning and delivery of support for families of dementia patients, reinforcing the need to focus on BPSD in the design of individualized support programs.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References


