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The Experience of Caregiving: Differences Between Behavioral Variant of Frontotemporal Dementia and Alzheimer Disease

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Abstract

Objective—To examine caregiver strain, depression, perceived sense of control, and distress from patient neuropsychiatric symptoms in family caregivers of persons with Alzheimer disease (AD) and behavioral variant of frontotemporal dementia (bvFTD) and determine whether group differences exist.

Methods—Family caregivers were recruited from the Memory and Aging Center in San Francisco, California. Analyses of cross-sectional data on 53 family caregivers (AD = 31, bvFTD = 22) were performed. The Mann-Whitney U test was used to contrast groups.

Results—There were statistically significant differences between the AD and bvFTD caregivers in strain, distress, and perceived control but not in depression. On average, bvFTD caregivers experienced greater strain and distress, more depressive symptoms, and lower perceived control.

Conclusions—Findings support that experiences of AD and bvFTD caregivers may differ. Further study is needed to identify possible explanatory factors for these group differences.

Keywords

Alzheimer disease; caregiver; depression; distress; frontotemporal dementia; perceived control; strain

Frontotemporal dementia (FTD) encompasses a heterogeneous group of progressive neurodegenerative syndromes.¹ In contrast to Alzheimer disease (AD), in which memory problems are a hallmark of the illness, social misconduct, passivity, and loss of executive function, have been found to be common early symptoms of FTD.² Compared to AD patients, FTD patients have been found to experience more neuropsychiatric morbidity, including greater disinhibition and aberrant motor behavior.³ One type of FTD, behavioral variant of FTD (bvFTD), often presents with a broad range of behavioral and

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neuropsychiatric symptoms, including personal neglect, social avoidance, wandering, and altered preference for carbohydrates.⁴

The demands and challenges of providing care for a loved one with bvFTD can be daunting due to the emotional, cognitive, and behavioral symptoms.⁴ Appropriate care management involves a family-centered approach tailored to the specific needs of family caregivers. Given the different trajectories of symptoms between AD and FTD, understanding differences in caregiver mental health and emotional well-being by diagnostic group could provide valuable insight and help direct future research on FTD caregivers as well as the development of targeted interventions.

Previous comparative studies between FTD and AD family caregivers suggest that FTD caregivers experience higher levels of burden and distress.^{5–7} Boutoleau-Bretonnière et al.⁵ compared Activities of daily living and caregiver burden in FTD and early-onset AD; findings revealed that functional disability was similar in FTD and AD patients but caregiver burden was higher in FTD. De Vugt et al.⁶ compared spousal caregivers of patients with AD and FTD and found that FTD caregivers reported higher general burden; furthermore, FTD caregivers were less satisfied with the patient as a care recipient and with themselves as a caregiver. Riedijk et al.⁷ also found that FTD caregivers were more burdened by the caregiving process than AD caregivers.

Previous studies have not focused on caregiver strain and perceived control when comparing the caregiving experiences of FTD and AD caregivers. Perceived control has been defined as “the perception that salient or valued aspects of one's life are manageable.”⁸(p. 208) Understanding how individuals view their level of control within the context of caregiving could have important clinical implications. Assisting FTD caregivers develop effective strategies for gaining more control over their lives and managing patient behavioral problems may help decrease caregiver burden and distress.

The purpose of this comparative, cross-sectional study is to examine caregiver strain, depression, perceived control, and distress from patient neuropsychiatric symptoms in family caregivers of persons with AD and bvFTD and determine whether group differences exist. This study is unique in focusing on caregiver strain and perceived control when comparing the experiences of AD and bvFTD family caregivers.

METHODS

Participants were recruited from the Memory and Aging Center at the University of California San Francisco for enrollment in a study entitled, “The Experience of Family Caregiving.” Family caregivers completed a set of questionnaires to assess their observations of the patient and experiences as a caregiver of someone with a cognitive and/or behavioral disorder. Eligibility criteria for this study included serving as primary family caregiver for a person diagnosed with AD or bvFTD. The diagnosis of FTD and AD was established using the Neary criteria⁹ and NINCDS-ADRDA.¹⁰ A total of 22 bvFTD caregivers and 31 AD caregivers were included. For participants with repeated measures, the first administrations of the questionnaires were included in the analyses. Informed consent

was obtained for all study participants and followed protocol established by the University of California San Francisco Committee on Human Research.

The questionnaires were completed by caregivers and took approximately 30 to 60 minutes to complete. The Clinical Dementia Rating (CDR) total score^{11,12} was used to assess the severity of the patients' functional impairment. The CDR box score is included as it provides a more quantitative measure of functional impairment.¹³ The Neuropsychiatric Inventory (NPI) was used to assess patient neuropsychiatric symptoms.¹⁴ To assess the impact of patient neuropsychiatric symptoms on their caregiver, the NPI caregiver distress score was calculated.¹⁵ The Beck Depression Inventory-II (BDI-2) was used to assess the severity of self-reported depression in caregivers.¹⁶ A 15-item Perceived Control Questionnaire (PCQ-15) was used to assess the caregivers' perceived sense of control,^{17,18} which has been worded appropriately for completion by family caregivers. The 13-item Caregiver Strain Index (CSI) was used to assess caregiver strain (18, $\alpha = 0.86$). The psychometric properties of these measures have been well established.

Statistical Analyses

All analyses were conducted using SPSS version 16.0 (SPSS, Inc., Chicago, IL). Because most variables were not normally distributed, Mann-Whitney *U* tests were conducted to compare the bvFTD and AD caregivers in terms of strain, depression, distress from patient symptoms, and perceived control. Alpha was set at 0.05 for all analyses (2-tailed).

RESULTS

Caregiver and Patient Characteristics

The AD and bvFTD caregivers were matched by age ($U = 338, z = -0.054, p = 0.96, r = 0.007$) and gender ($p = 0.52$) (Table 1). The majority of caregivers were female (AD: women = 22, men = 9; bvFTD: women = 18, men = 4), spouses (AD: spouses = 83.9%; bvFTD: spouses = 81.8%) and living with the patient (AD = 90.3%, bvFTD = 81.8%). The average age was 63 for the caregivers and 65 for the patients.

There were statistically significant group differences in CDR box scores ($U = 212, z = -2.33, p = 0.02, r = 0.32$). In addition, there was a statistically significant difference in NPI between the two groups ($U = 100, z = -4.35, p < 0.05, r = 0.60$), with the bvFTD patients having a higher mean NPI score (bvFTD = 50.82, AD = 24.45). There were no statistically significant group differences in patient age ($U = 338.5, z = -0.045, p = 0.96, r = 0.006$).

Comparison Between bvFTD and AD Groups

Mann-Whitney *U* tests revealed statistically significant differences between the AD and bvFTD caregivers on the CSI ($U = 204, z = -2.49, p = 0.013, r = 0.34$), NPI-distress ($U = 167.5, z = -3.13, p = 0.002, r = 0.43$), and PCQ-15 ($U = 187, z = -2.78, p = 0.005, r = 0.38$). There were no statistically significant difference between the AD and bvFTD caregivers on the BDI ($U = 233, z = -1.95, p = 0.051, r = 0.27$). Median scores were higher for bvFTD caregivers on the CSI (AD = 5.00, bvFTD = 8.00), NPI-distress (AD = 12.00, bvFTD =

24.00), and BDI (AD = 5.00, bvFTD = 8.50) but lower on the PCQ-15 (AD = 51.92, bvFTD = 43.97).

CONCLUSIONS

Findings from this study indicate that the experiences of AD and bvFTD family caregivers are different. bvFTD caregivers experienced greater strain, greater emotional distress, and lower perceived control compared to AD caregivers; these differences were statistically significant. While the bvFTD caregivers also reported higher levels of depression, this result did not reach statistical significance. However, the *p* value for depression was 0.051, which is very close to the set alpha value of 0.05.

The findings pertaining to caregiver distress and depression are consistent with prior studies. In the study conducted by De Vugt et al.,⁶ the FTD caregivers viewed caregiving as more distressing than AD caregivers. Similarly, our study found that bvFTD caregivers were more distressed from patient neuropsychiatric symptoms. Furthermore, Moishi et al.²⁰ found that levels of depression for FTD caregivers were twice that of AD caregivers, even after controlling for caregiver age and length of symptoms. In contrast, De Vugt et al.⁶ found that depression occurred less often among FTD caregivers; however, it was experienced as highly distressing for FTD caregivers when it was present. Although our study found no statistically significant group differences in depression, on average the bvFTD caregivers experienced greater depressive symptoms.

This study has a number of limitations. First, the sample size was small. Despite the small sample size, this study still found statistically significant group differences in caregiver strain, control, and emotional distress. Second, most variables were not normally distributed. Although results from the Mann-Whitney *U* and *t* tests were consistent, results should still be interpreted with caution. Third, there were statistically significant differences between the bvFTD and AD patients in neuropsychiatric symptoms and cognitive and functional impairment. The bvFTD patients, on average, had greater neuropsychiatric symptoms and worse cognitive and functional impairment. Whether these patient factors are associated with the differences noted for the caregivers was not an issue explored in this study but should be examined in future research. It is possible that the greater behavioral disturbances associated with bvFTD explains why the bvFTD caregivers experienced higher levels of strain. Patient behavioral changes have also been found to be correlated with caregiver burden,⁵ but few FTD caregiving studies have been conducted. Consequently, whether patient behavioral problems explain the differences found between AD and FTD caregivers is unclear. Further study is needed to determine the impact of patient behavioral problems on FTD caregivers.

Despite the limitations, this study has implications for clinicians and future research. This study compared AD and bvFTD family caregivers' perceived control, a concept which has not been studied previously in FTD caregiving. These findings reinforce the importance for clinicians to examine how bvFTD caregivers perceive their ability to manage various caregiving responsibilities and patient behavioral disturbances. When designing caregiver interventions, it is important that clinicians consider the caregiver's perceived control over

their lives and help them develop strategies for gaining more control over their caregiving situation. Further study is needed to identify explanatory factors for these group differences, such as how caregivers perceive their knowledge and confidence in handling the severe behavioral disturbances associated with FTD.

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TABLE 1

A Comparison Between bvFTD and AD Groups

	AD (n = 31)	bvFTD (n = 22)	Test Value	p
Caregiver				
Age, mean (SD), years	61.00 (63.26 ± 8.45) ^a	63.50 (62.73 ± 5.32)	<i>U</i> = 338.00	0.96
Male/female, n	9/22	4/18		Fisher's test=0.52
CSI total (0-13) ^b	5.00 (5.68 ± 3.56)	8.00 (8.14 ± 3.34)	<i>U</i> = 204.00	0.01
BDI-2 (0-63) ^c	5.00 (7.35 ± 6.46)	8.50 (11.64 ± 9.43)	<i>U</i> = 233.00	0.051
PCQ-15 (15-60) ^d	51.92 (49.47 ± 7.04)	43.97 (43.64 ± 7.76)	<i>U</i> = 187.00	0.005
NPI caregiver distress (0-60) ^e	12.00 (14.87 ± 9.68)	24.00 (25.32 ± 10.83)	<i>U</i> = 167.50	0.002
Patient				
Age, mean (SD), years	64 (65.81 ± 8.53)	65.5 (64.95 ± 5.24)	<i>U</i> = 338.5	0.96
CDR score ^f 0/0.5/1/2/3, n	0/8/16/6/1	0/3/11/4/4		
CDR box score (0-18) ^g	5.00 (6.63 ± 4.00)	8.00 (8.82 ± 3.62)	<i>U</i> = 212.00	0.02
NPI total (0-144) ^h	20.00 (24.45 ± 18.02)	50.50 (50.82 ± 18.07)	<i>U</i> = 100	<0.05

Notes:

^aFor each group, the median (with mean ± SD in parentheses) and associated p value for the Mann-Whitney *U* test is provided unless otherwise specified.

^bHigher total CSI scores indicate greater caregiver strain.¹⁹ A score of 7 or higher has been shown to indicate clinically significant caregiver strain.¹⁹

^cHigher BDI scores indicate greater depressive symptoms.¹⁶

^dThe total score on the PCQ-15^{17, 18} ranges from 15 to 60, with higher scores reflecting greater levels of perceived control.

^eThe total NPI caregiver distress score ranges between 0 and 60, with higher scores reflecting greater caregiver emotional distress from patient neuropsychiatric symptoms.¹⁵

^fThe CDR score assesses cognitive performance in the following six categories: memory, orientation, judgment and problem solving, community affairs, home management and hobbies and personal care.¹¹⁻¹² A global CDR = 0 indicates no dementia; a global CDR = 0.5 indicates very mild dementia, and a global CDR of 1, 2, and 3 indicates mild, moderate and severe dementia.¹¹⁻¹²

^gThe CDR box score is the sum of the individual scores in the six CDR categories and provides a more quantitative measure of cognitive and functional impairment.¹³ The CDR box score ranges from 0 to 18, with a higher score indicating greater dementia severity.¹³

^hThe NPI assesses 12 neuropsychiatric symptoms common in dementia patients: delusions, hallucinations, agitation, dysphoria/depression, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night-time behavior disturbances, and appetite and eating disorders.¹⁴ Higher scores on the NPI indicate greater neuropsychiatric disturbances.¹⁴