

# Factors Underlying Caregiver Stress in Frontotemporal Dementia and Alzheimer's Disease

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## Key Words

Caregiver · Carer · Stress · Depression · Activities of daily living · Frontotemporal dementia · Alzheimer's disease

## Abstract

**Background:** Frontotemporal dementia (FTD) has devastating effects on patients and caregivers, yet the factors underlying caregiver stress are poorly understood. **Methods:** 108 caregivers (79 = FTD, 29 = Alzheimer's disease) participated in a postal survey. Self-report measures of perceived stress, depression, social networks, as well as patient-based measures of behaviour change and activities of daily living were completed. **Results:** Depression was a cardinal feature in FTD caregivers, and it accounted for more than 58% of stress scores. Both depression and stress were significantly higher than in AD. Neither the severity of behaviour changes nor functional disability explained caregiver stress. **Conclusion:** Caregiver stress is a multidimensional construct, and FTD caregivers should receive more support than currently available. Depression plays a key role in coping ability.

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## Background

Frontotemporal dementia (FTD) is characterized by focal atrophy of the frontal and temporal lobes. It encompasses three clinical variants: a behavioural variant, where changes in social conduct and personality prevail (bv-FTD), and two language variants: semantic dementia and progressive non-fluent aphasia [1, 2].

FTD is a devastating progressive syndrome that affects patients' lives and has profound implications for their families. In bv-FTD, the decline of cognitive abilities and the marked behavioural changes are core characteristics [2]. These behavioural changes can include apathy, disinhibition, emotional blunting, stereotypic behaviour, and in conjunction with cognitive decline ultimately lead to severe disability in everyday life [3]. In semantic dementia and progressive non-fluent aphasia, changes tend to be primarily contained within the language domain, but in a proportion of semantic dementia patients behavioural changes have also been reported [4]. Nevertheless, language difficulties alone can be very challenging, limiting social participation of both patients and caregivers and ultimately also creating distress for both. With changes of this nature and intensity, it is not surprising that family members who are directly involved

**Table 1.** Mean values (SD in parentheses) of patient age, length of symptoms, activities of daily living for FTDCD, FTDNH, and ADCD and their respective caregivers' age and sex

	FTDNH (n = 34)	FTDCD (n = 45)	ADCD (n = 29)	FTDCD vs. FTDNH	FTDCD vs. ADCD
Patient age, years	66.8 (7)	68.8 (8.7)	70.4 (7.9)	n.s.	n.s.
Length of symptoms	10.2 (4.5)	8.3 (4.2)	7 (4.3)	n.s.	n.s.
BADLs	7.1 (15.3)	40.4 (22.8)	64 (39.9)	**	n.s.
IADLs	0.1 (0.8)	17.3 (22.4)	32 (34.3)	**	n.s.
Caregiver age, years	62 (10.5)	63.5 (10.2)	69.9 (7.1)	n.s.	*
Caregiver sex (female), %	82	76	69		

\* p < 0.05; \*\* p < 0.001.

with patients present with high rates of burden and stress [5]. Recent studies have shown that the caregiver burden in FTD is much greater than in Alzheimer's disease (AD) [6–8] and controls [9]. Behavioural changes rather than the level of disability appear to be correlated with caregiver distress and burden in FTD [7], although very few studies have been conducted. It is almost certain that other factors such as individual characteristics of caregivers including gender [10], personal resources, family psychodynamics [11], coping strategies and caregiver health are likely to play an important role in the genesis of stress, since these factors emerge repeatedly in studies of families coping with other dementias [12, 13].

We hypothesized that caregivers of FTD patients who are living at home would have higher rates of stress than those who are living in nursing homes; moreover, we expected caregivers of FTD patients to be more stressed than those of AD patients. We expected to find a strong association between activities of daily living impairment, behaviour change and stress, especially for the caregivers of FTD patients. We also wanted to investigate how depression and gender would impact on the caregivers' perception of stress.

## Methods

### Participants

Data from the caregivers of 79 FTD and 29 AD patients were collected. In the FTD group, 45 patients were living at home (FTDCD), and 34 were nursing home residents (FTDNH). All AD patients were living at home. Patient age and length of symptoms was matched for the two sets of groups we compared [AD community dwellers (ADCD) vs. FTDCD; FTDCD vs. FTDNH]; caregiver age was significantly higher for AD. Female caregivers were in the majority for the three groups (table 1).

Caregivers were contacted via the Pick's Disease Association UK, and the Alzheimer's Association UK, who kept their identities anonymous. All had been diagnosed by a behavioural neurologist in a major teaching centre. Questionnaires were sent by post, and caregivers who were interested in participating signed the consent form and returned their questionnaires. Caregivers were paid GBP 15 for their participation. Ethics approval was obtained at the Anglia Ruskin University Research Ethics Committee.

### Instruments

#### Patient – Behaviour Change

Changes in patient behaviour were measured with the 12-item Neuropsychiatric Inventory Questionnaire (NPI-Q) [14]. We used two scores derived from the NPI-Q, the number of symptoms endorsed by the caregivers (range 0–12), as well as the severity of the symptoms endorsed (range 0–36).

#### Patient – Activities of Daily Living

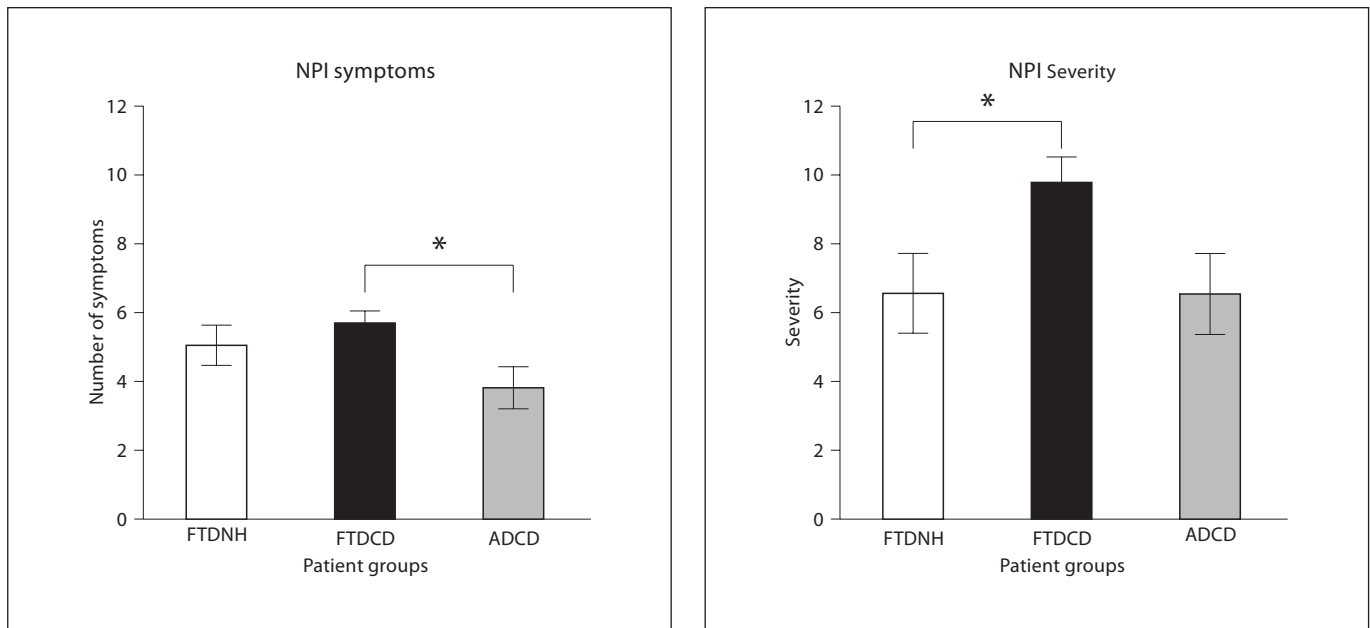
A modified version of the Disability Assessment of Dementia (DAD) [15] adapted for the postal survey was used (format change only, i.e. questions were answered with a tick for yes). The DAD includes 40 questions and generates scores of basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs), correcting for non-applicable questions that did not pertain to the patients premorbid routine (e.g. cooking, looking after finances). Scores are given in percentage of ability.

#### Caregiver – Stress

We measured caregiver burden with the Perceived Stress Scale (PSS) [16], a 10-item scale that measures perceived stress. Items were designed to identify how unpredictable, uncontrollable and overloaded respondents find their lives. Cutoff for perceived stress was calculated by the mean of the age group (45–65 and over) plus 1.5 SD, which was 22.1 [17].

#### Caregiver – Depression

Depression was assessed with the Center for Epidemiological Studies Depression Scale (CES-D Scale) [18], a self-report depression scale. The possible range of scores is 0–60, with the higher scores indicating the presence of more symptomatology. Patients with a score of 16 or greater are considered depressed.



**Fig. 1.** Number of symptoms endorsed on the NPI-Q and severity of symptoms on the NPI-Q for FTDNH, FTDCD and ADCD. Means are shown; error bars represent SEM. \*  $p < 0.05$ .

#### Caregiver – Social Network

We used the social network index [19] to assess the number of high contact roles and number of people in the caregivers' social network.

#### Data Analyses

Most variables were normally distributed. Log transformations were required for CES-D, IADLs, BADLs and number of people in social network, since they were positively skewed for some of the patient groups. Though we used log-transformed values for the statistical analyses, the data are represented in their original scores to facilitate clinical interpretation. Independent  $t$  tests were used to compare three subgroups: FTD community dweller patients, FTD patients living in nursing homes, and AD patients living at home. We used logistic regression analyses to identify which factors predict caregiver stress. Alpha was set at 0.05.

## Results

### FTD Patients, Community Dwellers versus Nursing Home

#### Activities of Daily Living

As expected, patients living in nursing homes were significantly more impaired than patients living in the community for both IADLs ( $t = 6.220$ ,  $d.f. = 78$ ,  $p < 0.001$ , two-tailed) and BADLs ( $t = 4.991$ ,  $d.f. = 79$ ,  $p < 0.001$ , two-tailed) as assessed on the DAD (table 1).

#### Behavioural Change

As shown in figure 1, community dwellers scored significantly higher than nursing home residents on the severity rate component of the NPI ( $t = 2.297$ ,  $d.f. = 80$ ,  $p < 0.05$ , two-tailed). Their number of symptoms was also higher, but did not reach significance.

### FTD versus AD Patients Living at Home

#### Activities of Daily Living

On the DAD, FTDCD and ADCD were equally impaired on both IADLs and BADLs (table 1), with very severe impairment on IADLs and moderate to severe disability on BADLs.

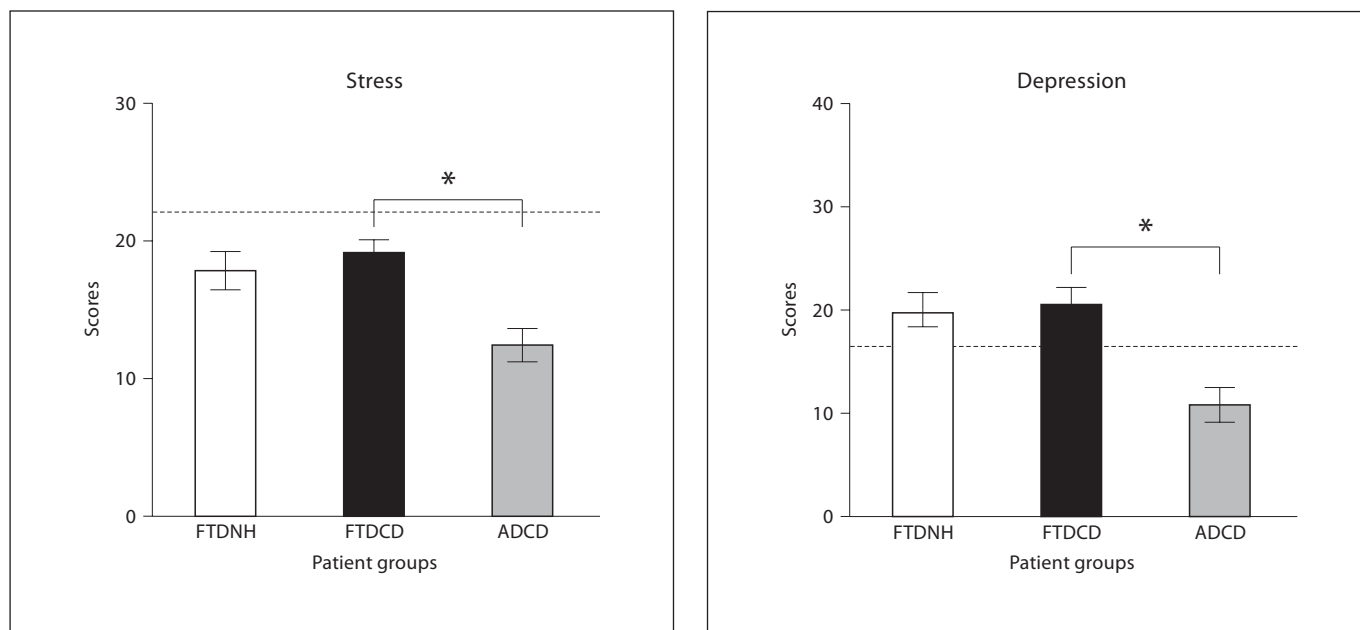
#### Behavioural Change

FTDCD patients had a significantly higher number of symptoms endorsed on the NPI than ADCD ( $t = 5.815$ ,  $d.f. = 51$ ,  $p < 0.001$ ), but in terms of severity of symptoms there was no significant difference (fig. 1).

### Caregivers of FTDCD Patients versus FTDNH

#### Caregiver Stress and Depression

Somewhat surprisingly, self-rated stress was equivalent in carers of the two FTD subgroups with no significant difference on their scores. Levels of depression were likewise equivalent according to the CES-D (fig. 2).



**Fig. 2.** Scores on the PSS and CES-D for caregivers of FTDNH, FTDCD and ADCD. Means are shown; error bars represent SEM. \*  $p < 0.05$ .

#### Social Network

Caregivers of institutionalized FTD patients had a significantly higher number of people (FTDNH range 2–103; FTDCD range 3–50) in their social network (FTDNH = 29, SD = 21; FTDCD = 17, SD = 12;  $t = 2.455$ , d.f. = 80,  $p < 0.05$ , two-tailed).

#### *Caregivers of FTD versus Caregivers of AD Living in the Community*

##### Caregiver Stress and Depression

The percentage of FTDCD caregivers presenting with high stress (mean plus 1.5 SD) was higher than for ADCD caregivers (31.1 vs. 10.3%). The former group was also significantly more stressed, even after controlling for caregiver age and length of symptoms. The level of depression for FTDCD carers was twice that of ADCD carers (57.8 vs. 24.1%), which was significantly higher even after controlling for caregiver age and length of symptoms. Interestingly, female caregivers reported significantly higher levels of stress and depression, for both FTDCD and ADCD ( $p < 0.05$  for all).

#### Social Network

There was no significant difference in the richness of social networks between the groups both in terms of high contact roles (FTDCD = 5.4, SD = 6; ADCD = 5, SD = 5)

and number of people in the network (FTDCD = 17, SD = 12; ADCD = 22, SD = 12).

#### *Which Variables Explain Perceived Stress of Caregivers of FTD Patients?*

A linear regression (stepwise method) was performed using the PSS as the dependent variable, and patient- and caregiver-related independent variables (NPI number of symptoms and severity score, BADLs, IADLs, patient length of symptoms, CES-D, number of people in social network and number of high contact roles). Only one variable entered the model, level of depression according to the CES-D, explaining 58.2% of the variance of PSS scores ( $\beta = 0.739$ ,  $p < 0.001$ ).

#### *Which Variables Explain Perceived Stress of Caregivers of AD Patients?*

Although AD group did not score above cutoff, some caregivers had high levels of stress. We explored, therefore, which factors explained their variance of scores on the perceived stress measure. We divided the analyses in two parts due to the small numbers. The first linear regression was run using the PSS as the dependent variable, and patient-based variables (NPI number of symptoms, NPI severity score, BADLs, IADLs, length of symptoms) as independent variables. No variable entered the model.

The second linear regression used caregiver-based variables (CES-D, number of people in social network and number of high contact roles), and a significant model emerged including CES-D and number of high contact roles in the social network, accounting for 54.4% of the variance on PSS scores (CES-D:  $\beta = 0.689$ ,  $p < 0.001$ ; number of high contact roles:  $\beta = 0.310$ ,  $p = 0.025$ ).

## Discussion

We hypothesized that caregivers of FTD patients who are living at home would have higher rates of stress than those who are living in nursing homes; we also anticipated caregivers of FTD patients to be more stressed than AD patients. The latter was confirmed, but surprisingly, our results revealed similar rates of stress and depression for carers of FTD patients who were community dwellers and nursing home residents. We also expected to find a strong association between activities of daily living impairment, behaviour change and stress, especially for caregivers of FTD patients. Contrary to this prediction, however, functional disability and behaviour change did not explain caregiver stress; more importantly, caregiver depression revealed itself as a cardinal characteristic of FTD caregivers, and also a major factor, as we will discuss below.

Recent studies have shown that caregivers of FTD patients present with higher levels of stress than those caring for patients with AD [6, 20], and this stress is higher if the patients are still living at home [8]. Our results corroborated higher levels of stress for FTD, but did not show a differentiation between community and nursing home residents. Nursing home patients were predictably more functionally disabled than community dwellers (which probably triggered institutionalization), but the fact that they are now in professional hands rather than in their own homes might be expected to reduce carer stress; yet we found that caregivers of nursing home residents were still at high levels of stress, suggesting that other factors could account for high stress scores.

The best variable explaining stress was depression, accounting for more than 58% of the variance. Although recent studies [8, 20] have identified behavioural change as the main factor explaining caregiver distress, the discrepancy between our results and these studies may be due to methodological differences. Other studies on FTD caregiver burden have relied on the distress scores of the NPI, generating a stress score that is uni-dimensional, i.e., based on the distress prompted by the behavioural symptom asked [6, 8, 20]. For our study we used an inde-

pendent and well-established scale which measures perceived stress.

This discrepancy also illustrates the complexity of caregiver stress. Assuming that stress is a multi-faceted construct [16], it is not surprising that a caregiver-related variable, such as depression, explains stress better than a patient-based variable. This finding demonstrates that caregiver distress is not only associated with severity of symptomatology of patients, or functional disability [7]. For caregivers of AD patients, stress was also explained by the number of high contact roles. This factor did not enter the FTD model, despite the fact that caregivers of nursing home residents had a richer social network. It is also interesting to note that female caregivers reported higher levels of stress and depression, corroborating previous studies [10, 17]. These findings emphasise the complexity of caregiver burden, and the fact that internal and external factors might play different roles in stress.

The identification of depression as a cardinal characteristic of FTD caregivers was a disturbing finding. Depression was high for both FTD subgroups, and significantly higher than AD. The devastating course of FTD clearly affects those involved with the patient, and caregivers require more support than is currently available. A better understanding of caregiver burden factors can also guide health professionals in providing better referrals to services, since most caregivers tend to report that they do not need community support [21].

Future studies should also explore other variables that might explain caregiver burden. Premorbid relationship and other caregiver personality characteristics, such as risk of depression, hours spent with patient, number of health services already involved, might offer a more detailed picture of factors underlying caregiver stress. In addition, longitudinal studies would allow understanding on how burden increases or decreases with the progression of the disease.

This study demonstrates that caregiver burden in FTD is a complex construct involving factors other than patient symptoms. It shows that the use of stress measures based only on behaviour change does not reflect the extent of stress caregivers suffer, and also reveals important implications on the provision of caregiver support and health policies.

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