

# Caregiver Burden and Needs in Frontotemporal Dementia

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## Abstract

**Background:** It is well known that burden among caregivers of patients with frontotemporal dementia (FTD) is high. However, little is known about the specific problems, the factors that contribute to caregiver burden, and the needs of the FTD caregivers—particularly those needs that are accessible by external support strategies. **Objective:** We developed a standardized questionnaire that addressed burdens, problems, and the actual needs of FTD caregivers. A total of 94 caregivers were interviewed. **Results:** It appears that changes in the patients' behavior and in the interpersonal relations between caregivers and patients are associated with caregiver depression. The most important needs and requests of the caregivers included information and psychosocial support through educated staff, financial support as well as the education of medical staff about the disease. **Conclusions:** Support strategies should focus on information and psychosocial support. Given the low prevalence of FTD, internet- and telephone-based strategies appear suitable.

## Keywords

caregiver burden, caregiver support, frontotemporal dementia

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## Introduction

Frontotemporal dementia (FTD) is a clinically and pathologically heterogeneous syndrome, characterized by a progressive decline in behavior and/or language associated with a degeneration of the frontal and/or anterior temporal lobes. FTD is subdivided into 3 main variants that can be distinguished based on the early and predominant symptoms.<sup>1</sup> Behavioral variant frontotemporal dementia (bvFTD) represents the most common clinical phenotype and is characterized by early decline in social behavior and personal conduct, emotional blunting, and loss of insight. Semantic dementia (SD) is defined as a disorder of language, semantic memory, and recognition. Although semantic deficits dominate the clinical picture, behavioral alterations also occur in SD.<sup>2</sup> Progressive nonfluent aphasia (PNFA) is characterized by a disorder of language expression and motor speech with agrammatism and effortful speech while sparing other cognitive domains in the early stages of the disease.

With progression of FTD, a gradual decline in the cognitive abilities becomes obvious and patients develop marked impairment in everyday life. In the later disease stages, patients need help even with basic activities of daily living.

FTD is a devastating progressive syndrome that affects patients' lives and has profound implications for their families. It is well known that FTD caregivers are highly stressed and

burdened because of their caring experience. Burden and stress are higher among FTD caregivers than among caregivers of patients with Alzheimer disease (AD) or other dementias.<sup>3-5</sup> Specific problems of FTD caregivers include delayed diagnosis, young age of patients, behavioral problems, depression, lack of information, lack of suitable care facilities, and poor self-care.<sup>6</sup> As the clinical picture of FTD is distinct from the most common form of dementia, AD, interventions for caregivers, including self-help groups and educational programs, which are usually tailored to the needs of patients with AD, are often not suitable for FTD caregivers. Most care facilities, nursing homes or day centers, are also tailored to older clients, and

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staff are often unable to cope with the problems that occur in FTD.

A previous systematic literature review of this group has shown that hardly any studies have been performed to identify the actual needs of FTD caregivers.<sup>6</sup> However, knowledge about the specific problems and the resulting needs of FTD caregivers—especially those needs that are accessible by external support strategies—is crucial for the development of helpful and effective caregiver interventions. The literature review also revealed that no randomized controlled trials of caregiver interventions exist at all for FTD. There are only a handful of publications about FTD caregiver support groups, respite care, or advanced practice nursing. Thus, it is unclear, which kind of interventions is actually suitable to help caregivers, specifically, which have positive effects on caregiver stress and burden.

With the present study, we aimed to identify the problems of FTD caregivers, examine which factors contribute to caregiver strain and depression, explore the actual needs of caregivers, and investigate how helpful different support strategies and interventions really are.

## Methods

### Questionnaire

A standardized questionnaire that addressed burdens, problems, and the actual needs of FTD caregivers was developed. The survey included questions regarding demographic data and the living situation of persons with FTD and caregivers, the history of the disease, and the modes of patient care including the *Resource Utilization in Dementia lite*.<sup>7</sup> We also asked how burdensome the specific symptoms and impairments of the patients were for the caregivers. Furthermore, the caregivers were asked about changes in the financial situation and the patient—caregiver relationship due to the disease.

Caregiver strain was measured with the *Caregiver Strain Index*.<sup>8</sup> This is a brief, 13-question tool that measures objective caregiver burden. This measure represents the major domains cited in the literature on caregiver burden: employment, financial, physical, social, and time. Items are scored dichotomously as applying or not. Seven or more “yes” answers indicate a great level of strain.

Caregiver depression was measured using the *Beck Depression Inventory, second edition (BDI-II)*, a 21-item multiple-choice, self-reporting questionnaire.<sup>9</sup> The BDI-II is composed of items relating to depression such as sadness, hopelessness, or agitation as well as physical symptoms such as changes in appetite or sleeping patterns. The BDI-II scores range from 0 to 63 points with a score >13 indicating a clinically significant depression.

Finally, the caregivers were asked whether they have received support or have participated in interventions. If so, they were asked to rate how helpful several support services and interventions had been or might be for them or other FTD caregivers. Participants were asked to conduct their ratings based on a list of 45 support services and interventions relating to the

following domains: information, psychosocial support for relatives, help through care outside of home, help through support at home, financial support, safety issues, therapies for the patients, and raising awareness. The support services and interventions were either already available or not yet available but conceivable. They were chosen based on our practical experience with caregiver needs with our FTD caregiver support groups, on our previous literature review about problems, burdens, and needs of FTD caregivers,<sup>6</sup> a worldwide email inquiry about services for FTD caregivers, and a detailed review of the Alzheimer literature regarding problems and needs of AD caregivers.<sup>10,11</sup>

### Participants

The study protocol was approved by the local institutional review board.

The study aimed to interview 100 caregivers within 6 months. Participants were recruited from 4 German FTD caregiver support groups, from caregivers who had registered themselves as FTD caregivers at the German Alzheimer Association and from the centers of the German FTD Consortium.<sup>12</sup> Two hundred packages with a letter that explained the purpose of the study, an informed consent form, detailed instructions, the questionnaire, as well as a copy of the questionnaire were sent either to the caregivers directly or to the moderators of the caregiver groups with a request to pass them on. The caregivers were instructed to complete the questionnaire along with the informed consent form, return it, and keep the copy of the questionnaire. Immediately after the questionnaire arrived at our center, a telephone interview was performed with the aim to explain the kind of caregiver support and interventions in detail and to recheck and clarify the answer of the caregivers.

### Statistical Methods

Statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS), v20.0 (SPSS Inc, Chicago, Illinois). Patient characteristics are described by mean  $\pm$  standard deviations. The caregiver strain index (CSI) and BDI-II scores were compared between the 2 groups defined by respective binary variables with the Mann-Whitney *U* test. The CSI and BDI-II scores with variables with more than 2 categories were compared with the Kruskal-Wallis test. Spearman correlation was used to compare continuous variables. *P* values are 2 sided and subject to a local significance level of <.05. *P* values were unadjusted for multiple testing because of the exploratory nature of the study.

## Results

### Demographic Data of the Caregivers and Patients

A total of 104 caregivers participated in the study. In 10 cases, the patients had already died; therefore, only 94 caregiver interviews were considered for the analysis. Demographic data of the caregivers and patients are shown in Table 1. Diagnoses according to the recent nomenclature as delivered by the

**Table 1.** Demographic Data of 94 Caregivers and Patients.

Caregivers	
Sex: female/male, %	72/28
Age	59.11 ± 11.74 (24-78)
Relationship to patient: wife/husband/child (in-law)/other (parents, siblings, friends), %	61/19/12/8
Patients	
Sex: female/male, %	32/68
Age	63.94 ± 10.08 (28-82)
Age at diagnosis	60.41 ± 9.89 (22-79)
Living: alone/with spouse/with child/with other person/in a nursing home, %	6/72/5/6/18
Nursing care level <sup>a</sup> (none/1/2/3), %	32/26/22/20

<sup>a</sup> In Germany, the nursing care level is crucial for the amount of long-term care insurance payments: Persons with a nursing care level are persons who need help with body care, food, or mobility and in the household. On average, the patients need to be cared for at least 90 minutes per day in nursing care level I, 3 hours in level II, and 5 hours in level III. More than 45 minutes in level I, 2 hours in level II, and 4 hours in level III must be dedicated to basic care.

caregivers and reevaluated by the interviewer were bvFTD in 87% and primary progressive aphasia (SD and PNFA) with behavioral symptoms in 13%.

Of the caregivers, 72% lived together with the patients in the same household. The caregivers knew the patients for a mean time of 38.31 ± 13.22 years (10-59). In all, 31% of the caregivers had to care for other persons in their household, in most cases children. Caregivers indicated that they had supervised or cared for the patients on average of 10.1 ± 8.8 hours per 24 hours (0-24) in the month before the interview.

When the first symptoms occurred, 14 patients had children who were younger than 18 years. At the time of the interview, 3 patients had children that were younger than 18 years.

### Caregiver Depression and Strain

The mean BDI-II score was 15.37 ± 8.66 (2-40). With regard to the scores on the BDI-II, 25% of the caregivers had no depression (0-8 points), 27% had minimal depression (9-12), 21% had mild depression (13-19), 19% had moderate depression (20-28), and 7% had severe depression (>29). One caregiver did not complete the BDI-II.

The mean score of the *Caregiver Strain Index* was 7.8 ± 2.91 (0-13). Of the caregivers, 60% had a score of 7 or higher, indicating to a great level of strain.

### Which Symptoms or Impairments of Daily Living Are Burdensome and Influence Caregiver Strain and Depression?

Table 2 shows the percentage of patients who showed specific symptoms or impairments. In cases where the symptom/impairment was present, the caregivers were asked to state whether or not the symptom/impairment was burdensome for them.

Several symptoms and impairments were burdensome for more than 80% of the caregivers, changes in personality, particularly aggression, lack of manners, occurrence of misdemeanors, inflexibility, egocentric behavior, lack of empathy,

**Table 2.** Percentage of Patients Who Showed Specific Symptoms and Impairments of Daily Living and Percentage of Caregivers Who Found the Behavior or Impairment of Daily Living Burdensome.<sup>a</sup>

	Symptom/Impairment Present, %	Burden, If Symptom/Impairment Present, %
Aggression	34	94
Need for supervision at home	57	90
Lack of manners	54	90
Difficulties swallowing	30	89
Changes in personality	98	89
Misdemeanor	19	89
Dependency	79	89
Inflexibility	69	88
Walking disability	30	85
Speech problems	91	84
Egocentric behavior	61	84
Spatial disorientation	44	83
Addictions	18	82
Irritability	31	82
Stool incontinence	48	80
Gambling	4	80
Lack of empathy	81	80
Reduced sleep	15	79
Restlessness	62	79
Bedridden	10	78
Depression	34	77
Urinary incontinence	60	76
Neglect of personal hygiene	71	75
Impulsive behavior	67	74
Apathy	77	71
Need for help with personal care	76	70
Excessive spending of money	11	70
Memory loss	95	66
Compulsive behaviors	61	65
Lack of insight into disease	81	63
Decreased appetite	20	61
Need of help with eating	65	56
Jocularity	15	50
Sexual disinhibition	13	50
Increased appetite	56	43
Increased sleep	82	25

<sup>a</sup> The caregivers were asked if the symptom was present (yes/no) and if so, the caregivers were asked to report if the symptom was burdensome (yes/no).

addictive behavior like excessive drinking or smoking, irritability, and gambling were as burdensome as the need to supervise the patient at home, the patient's dependency on the caregiver (ie, the patient cannot or is not willing to occupy him/herself) as well as physical impairments including difficulties in swallowing, walking disabilities, and incontinence.

Difficult behavioral symptoms such as aggression and egocentric behavior as well as patient's reduced sleep correlated with higher caregiver depression scores. In contrast, care-related issues, physical impairments including incontinence, the need for supervision and care as well as speech problems correlated with increased caregiver strain. Furthermore, apathy and compulsive behaviors seemed to influence caregiver strain. For a detailed overview see Table 3.

Caregivers were asked an open question as to the most burdensome symptom/impairment; 45% indicated the behavioral disturbances were the most burdensome, 25% identified problems with communication, and 30% of the caregivers stated that the need for care is most burdensome.

Furthermore, the caregivers were asked about “the worst” aspect of the disease. The most frequent answers were (1) the loss of a loved one, (2) the unstoppable progression of the disease, and (3) their own helplessness.

### Association Between Caregiver and Patient Characteristics With Caregiver Depression and Strain

Associations between caregiver and patient characteristics with caregiver depression and strain are shown in Table 4. More female caregivers than male caregivers had depression. Further, more caregivers of male patients had a clinically significant depression, not surprising given that caregivers in the current study were predominantly females caring for their husband. Moreover, younger age of the patient at diagnosis and a worsening of the caregiver—patient relationship caused by the disease were also associated with caregiver depression.

There were no differences in depression between spouse and adult children caregivers, between caregivers of patients who lived at home or in a nursing home, between caregivers who lived or did not live in the same household with the patient or between caregivers who had more or less support from other persons or external support services.

Likewise, the amount of time the caregiver spent for caring the patient, the number of persons and support services that were involved in the care, and the nursing care level (an indication of the intensity of the patient’s care) were not associated with caregiver depression. However, these factors correlated with higher caregiver strain. Furthermore, caregiver strain was higher in female caregivers and younger caregivers. In addition, patients’ age, age at onset, and age at diagnosis negatively correlated with caregiver strain. A difficult financial situation increased caregiver strain. Finally, caregiver strain and caregiver depression correlated significantly.

### Influence of the Disease on the Caregiver—Patient Relationship

Furthermore, caregivers were asked about the influence of the disease on the relationship between themselves and the patient. Of the caregivers, 20% stated that the disease had improved their relationship, 30% said the relationship was unchanged, and the relationship had worsened for 50%.

Of the caregivers who stated that the relationship had improved, 67% were wives, 6% husbands, 11% children, and 17% other.

### Changes in the Patients’ Financial Situation

In order to gain insight into changes in the patients’ financial situations, the caregivers were asked a number of questions.

**Table 3.** Influence of the Symptom/Impairment on Caregiver Strain and Caregiver Depression.<sup>a</sup>

	Influence on the Beck Depression Inventory Score P Value	Influence on the Caregiver Strain Index Score P Value
Aggression	.036 <sup>b</sup>	.324
Need for supervision at home	.382	.000 <sup>b</sup>
Lack of manners	.149	.192
Difficulties swallowing	.993	.007 <sup>b</sup>
Changes in personality	.269	.626
Misdemeanor	.125	.005 <sup>b</sup>
Dependency	.518	.002 <sup>b</sup>
Inflexibility	.275	.924
Walking disability	.782	.041 <sup>b</sup>
Speech problems	.721	.014 <sup>b</sup>
Egocentric behavior	.008 <sup>b</sup>	.278
Spatial disorientation	.997	.030 <sup>b</sup>
Addictions	.031 <sup>b</sup>	.627
Irritability	.324	.369
Stool incontinence	.673	.004 <sup>b</sup>
Gambling	.145	.503
Lack of empathy	.459	.332
Decreased sleep	.007 <sup>b</sup>	.689
Restlessness	.299	.905
Bedridden	.034 <sup>b</sup>	.591
Depression	.35	.641
Urinary incontinence	.807	.014 <sup>b</sup>
Neglect of personal hygiene	.079	.067
Impulsive behavior	.306	.314
Apathy	.284	.013 <sup>b</sup>
Need for help with personal care	.455	.000 <sup>b</sup>
Excessive spending of money	.865	.5
Memory loss	.983	.659
Compulsive behaviors	.813	.031 <sup>b</sup>
Lack of insight into disease	.735	.883
Decreased appetite	.317	.346
Need of help with eating	.358	.000 <sup>b</sup>
Jocularity	.463	.758
Sexual disinhibition	.103	.102
Increased appetite	.062	.073
Increased sleep	.21	.779

<sup>a</sup> Comparisons of Caregiver Strain-Index and BDI-II scores are due to the 2 groups (symptom/impairment present vs not present) defined by the respective binary row variables.

<sup>b</sup> Statistically significant (  $P < .05$  ).

For example, it was asked whether the statement “money is tight” applied before the onset of the disease and whether it applies now. Answers are listed in Table 5.

### Assessment of Available and Potential Support Services and Interventions

A particular focus of the interview was the kind of support the caregivers had received and how actual or potential support services/interventions are judged by caregivers. Caregivers were asked to assess the helpfulness of a support service or intervention even if they had not received it or participated. Details are shown in Table 6.

**Table 4.** Association Between Caregiver and Patient Characteristics With Caregiver Depression and Caregiver Strain.

	BDI-II Score	CSI Score
<b>Caregiver characteristics</b>		
Caregivers' sex (male/female)	$P = .001^a$ (female > male)	$P = .007^a$ (female > male)
Caregivers' age	$r = -.177$ $P = .089$	$r = -.269$ $P = .009^a$
Relationship between caregiver and patient (spouses and steady partners versus children/children in-law)	$P = .294$	$P = .958$
Length of caregiver—patient relationship (in years)	$r = .046$ $P = .661$	$r = .144$ $P = .166$
Caregiver living together with the patient (yes/no)	$P = .572$	$P = .865$
<b>Patient characteristics</b>		
Patients' sex (male/female)	$P = .002^a$ (male > female)	$P = .112$
Patients' age	$r = -.181$ $P = .083$	$r = -.248$ $P = .016^a$
Patients' age at onset of the disease	$r = -.196$ $P = .060$	$r = -.291$ $P = .004^a$
Patients' age at diagnosis	$r = -.205$ $P = .048^a$	$r = -.272$ $P = .008^a$
<b>Patients' care</b>		
Patient is living in a nursing home (yes/no)	$P = .698$	$P = .397$
Hours of care and support provided by the caregiver in the last month (hours/d)	$r = .006$ $P = .957$	$r = .488$ $P < .001^a$
Number of persons and support services that are involved in patient care	$r = -.103$ $P = .325$	$r = .227$ $P = .028^a$
Nursing care level (none, 1, 2, 3)	$P = .581$	$P = .016^a$
<b>Caregiver—patient relationship, financial situation, strain, and depression</b>		
Extent of change of the relationship (worsened/not worsened)	$P = .001^a$ (worsened > not worsened)	$P = .103$ (worsened > not worsened)
Financial problems (money is tight: "yes/neither—nor/no")	$P = .069$ (yes > neither—nor > no)	$P = .031^a$ (yes > neither—nor > no)
Caregiver strain ( <i>Caregiver Strain Index</i> score)	$r = .342$ $P = .001^a$	

<sup>a</sup>Statistically significant.

**Table 5.** Changes in the Financial Situation.

Is Money Tight?	Before the Onset of the Disease, %	Now, %
No	87	63
Yes	5	26
Undecided	8	11

To summarize, the caregivers rated information as most helpful, followed by psychosocial support through trained personnel, and financial support for the caregivers. Fourth most helpful was outside-home care assistance followed by home-based care assistance. Less important were nonpharmacological treatments for the patients and safety issues like video monitoring or alarm systems. Raising awareness was assessed as helpful by virtually all caregivers.

The 3 top most helpful interventions identified by the caregivers (for the question "which of the given support services are most, second most, and third most helpful) were (1) the complete and thorough explanation of the diagnosis, (2) continued support by a doctor who knows about the disease, and (3) to inform and educate doctors on the disease.

Caregivers were also asked whether there were any additional wishes. Many caregivers answered something to the effect of, "all-inclusive information packages." That is, they do not wish to ask various people about medical, social, legal, and financial issues; rather they wish there was someone who had a thorough understanding of FTD, knew about broader caregiver issues, and could redirect caregivers to appropriate services for assistance.

## Discussion

The aims of the present study were to identify the problems of FTD caregivers, to examine which factors contribute to caregiver strain and depression, and to investigate the actual needs of caregivers.

An advantage of the present study was the relatively high number of caregivers that participated. As much as it could be concluded from the caregiver reports about symptoms, need of care and nursing care level, caregivers of patients across all disease stages were surveyed. Of the caregivers, 72% were female, consistent with the fact, that the majority of family caregivers are female.<sup>13</sup>

**Table 6.** Utilization and Assessment of Available and Potential Support Services and Interventions by the Caregivers.

	Utilized, %	Quite or Very Helpful (If Utilized or Not), %
Information		
Continued support by a doctor who knows about the disease	66	90
Information about legal questions	53	90
Complete explanation of the diagnosis	74	88
Educational support group for caregivers	54	84
Information material for lay persons	73	82
FTD website	64	82
Having a doctor inform additional close relatives or friends	26	72
FTD conference for caregivers	40	70
Genetic counseling	18	56
Psychosocial support for relatives		
Counseling service with trained personnel	43	89
Ongoing psychosocial counseling	27	89
Case management—personal counselor	11	81
House visits by trained personnel	10	77
Service that can bring together people with similar problems	36	76
Telephone hotline	6	69
Psychotherapy for relatives	22	63
Opportunity to “chat” with other caregivers (email, social media, etc)	24	53
Psychological support for underaged children	2	46
Help through care outside of home		
Day care center/day care service specialized for FTD	2	89
Nursing home specialized for FTD	1	75
Day care center/day care service	43	72
Short-term care	23	63
Vacation with patient (specialized for dementia)	10	62
Health “cure” (spa) for patients and caregivers	11	59
Nursing home	21	43
Financial support		
Financial support for the caregiver	54	86
Help through support at home		
Emergency assistance in care	7	73
Nursing service at home	30	70
Housekeeping	31	68
Neighborly assistance	28	62
Help with personal care by nurses	21	61
Meals on wheels	7	27
Safety issues		
Monitoring movements via GPS device	4	49
Alarm that goes off when patient leaves the house or a certain area	1	42
Video surveillance at home	1	26
Video surveillance attached to the patient	1	26
Therapies for the patient		
Occupational therapy	50	66
Physical therapy	37	57
Speech therapy	31	46
Raising awareness		
Education of doctors		100
Education of nurses		99
Education of health insurance staff		96
Education of police		83
Education of judges		86
Awareness campaigns for lay persons		85

Abbreviations: FTD, frontotemporal dementia; GPS, global positioning system.

Of the caregivers, 60% had a score >7 in the *Caregiver Strain Index*, indicating that they had great strain. About 50% of the caregivers had clinically significant levels of depressive symptoms. These results are consistent with the

findings of other studies that have investigated caregiver burden in FTD.<sup>6</sup>

It remains unclear whether the numbers of caregivers with depression described in the various studies are higher or lower

than in the whole population of FTD caregivers. As in many other studies, the caregivers in the present study were mostly recruited from caregiver support groups. It is possible that these caregivers have already learned how to effectively cope with the disease, how to manage the behavioral symptoms, and how to seek support and therefore are less distressed. On the other hand, our long-standing experience with caregiver support groups suggests that participation is biased toward those caretakers who suffer disproportionately under the situation. Conversely, the caregivers who cope well do not tend to see the benefit of a support group.

The present study showed that changes in personality, particularly aggression, lack of manners, occurrence of misdemeanor, inflexibility, and egocentric behavior were the most burdensome symptoms as reported by the caregivers. The need to supervise the patient at home and physical impairments, especially swallowing difficulties and walking disability were very burdensome as well. Taken together behavioral symptoms, physical impairment, and the need of care were equally burdensome as reported by the caregivers.

Objective caregiver burden, comprising those tasks required to care for the patient, was measured using the *Caregiver Strain Index*. Caregiver strain was associated with younger age of the caregiver and patient, female gender of the caregiver, patient's need for supervision at home, the patient's dependency on the caregiver, physical impairments including incontinence and the need for care, cognitive impairments such as speech problems and spatial disorientation as well as apathy and compulsive behavior. Furthermore, caregiver strain was associated with a higher amount of care, a higher nursing care level and the amount of persons and support services that were involved in the care of the patient, with high nursing care levels, and a high amount of care implying a greater need for care. Financial problems also increased caregiver strain.

These findings provide specific directions for developing programs to help relieve strain: help at home with supervision and care is particularly necessary to unburden the caregivers, to provide them with the possibility to take leave from the home and receive respite. Supervision of the patient might also be achieved using video technology and/or alarm systems. Educative programs with the aim to help the caregivers to communicate with the patients in spite of word-finding problems and deficits of speech comprehension might also ameliorate caregiver strain.

Patient characteristics associated with caregiver depression scores were female gender of the caregiver and male gender of the patient as well as a worsened caregiver—patient relationship. Regarding the symptoms and impairments of the patients, caregiver depression was associated with patients' aggressive, egocentric and addictive behavior, and reduced sleep. Among the care-related issues, only being bedridden increased caregiver depression. Caregiver depression was positively correlated with caregiver strain.

Evidently, the reasons for caregiver depression, particularly the patients' behavioral changes are less able to be influenced than the factors that are associated with caregiver strain. Psychotherapeutic strategies seem to be appropriate to treat

caregiver depression. These strategies should aim to enable the caregivers to develop adaptive coping strategies. Having identified "the worst" aspects of the disease, namely, the loss of a loved one, the unstoppable progression of the disease and the caregivers' own helplessness, it may also be important to include elements from the mourning literature.

So far, just 1 small study has investigated the influence of patient and caregiver characteristics beyond and above the symptoms of the patients on caregiver burden; Mioshi et al found that caregiver burden in FTD was influenced by disease severity, relationship changes, and caregiver depression.<sup>14</sup>

A few prior studies have investigated the correlation between behavioral disturbances and caregiver burden as well as psychosocial distress. Different methodologies make the results of these studies hard to compare. However, all studies uniquely conclude that behavioral symptoms have a particular strong impact on caregiver distress. A recent study showed that behavioral symptom severity in FTD was negatively associated with caregiver mental health.<sup>15</sup> Specifically, Mourik et al found that caregiver distress is strongly related to the symptom cluster agitation/psychosis, followed by the cluster anxiety/depression.<sup>16</sup> In a study from the Netherlands, de Vugt et al found that apathy was not only the most common behavioral symptom but also the most distressing symptom for FTD caregivers, followed by disinhibition.<sup>17</sup> Lillo et al have shown that also in amyotrophic lateral sclerosis, where behavioral changes mirror those found in FTD, caregiver burden is strongly predicted by behavioral symptoms rather than physical disability.<sup>18</sup>

When interpreting the results of the present study, one needs to keep in mind that we did not correct for multiple comparisons. We chose an exploratory, descriptive approach with the aim to illuminate trends and, therefore, begin to tease out the problems of these caregivers. This is the precondition for the development of any appropriate interventions and support strategies that aim to ameliorate caregiver depression and strain.

The needs assessment demonstrates that caregivers deem most of the presently existing and potential support strategies and interventions as helpful. Information and psychosocial support through staff knowledgeable in FTD as well as financial support for the caregivers are considered as most helpful.

Delivering support and developing interventions in FTD is generally difficult. This is mostly due to the relatively low prevalence of the disease, especially in rural regions, the heterogeneity of FTD, the different needs of the caregivers, the different socioeconomic backgrounds of the patients and caregivers, the different access to informal and formal support, and so on. For example, organizers of support groups frequently experience difficulties to recruit sufficient participants. Numerous caregivers are not able to leave the patients for a couple of hours or they have to go to work or they have other obligations and do not find the time to attend intervention groups or meetings. The delivery of information and psychosocial support should take this into account. Hence, Internet- and telephone-based strategies seem to be highly recommendable in order to reach as many caregivers as possible and to cover as many different problems as possible. A detailed (multilingual) webpage would

be desirable as well as elaborate webinars, individual counseling via email telephone and email. Skype may even provide the opportunity for virtual home visits.

The present study has a number of limitations. First of all, a personal interview would have been preferable to the telephone interview in order to avoid misunderstandings and any vagueness. However, as efforts and costs would have been many times higher, we decided to perform a telephone interview. Second, the patients' diagnoses had been delivered by the caregivers. Due to the recruiting strategy via support groups, however, it can be assumed that the participating caregivers are highly educated and are familiar with the patients' condition. Even so, an accurate diagnosis is not a prerequisite for the participation in caregiver support strategies and interventions that are tailored for FTD. It does not make a large difference for the caregiver whether the patient suffers from FTD, from frontal AD or from other progressive neurodegenerative or vascular diseases that cause a frontal lobe syndrome. Third, we decided not to use existing interviews like the Frontal Behavior Inventory or the Neuropsychiatric Inventory and standardized ADL-inventories for assessing the symptoms of the patients. We used a list of all symptoms and impairments that occur during FTD. If we had chosen existing inventories, we would have had to accept considerable overlaps and repetitions that we were able to avoid using a customized list of symptoms and impairments. Finally, it was difficult for caregivers to hypothetically assess the usefulness of support strategies or interventions that they had never tried. However, one of the aims of the telephone interview was to explain the kind of potential support and interventions in detail, so they were able to judge the extent of their helpfulness.

## Conclusion

Caregiver burden is associated with patients' behavioral symptoms, physical impairment, the need of care and financial problems as well as a younger age of patient and caregiver. Of course, problems and needs are individually different, depending on living situations, age and symptoms of the patients, severity of the disease, availability of support and help as well as socioeconomic backgrounds, and the caregivers' personality. Taken together, it appears that the care aspect influences caregiver strain in particular, whereas changes in the patients' behavior and to the interpersonal relations between caregivers and patients are associated with caregiver depression. These results should be considered when designing interventions with an aim to improve caregiver strain and depression.

Our study demonstrated that caregivers assess support and interventions as most helpful, if they focus on information and support by trained staff. Given the low prevalence of FTD—especially in rural regions—Internet- and telephone-based strategies would be the most suitable solution.

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