

Caregiver Burden, Health-Related Quality of Life and Coping in Dementia Caregivers: A Comparison of Frontotemporal Dementia and Alzheimer's Disease

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Key Words

Caregiver burden · Health-related quality of life · Coping strategies

Abstract

Frontotemporal dementia (FTD) is the second most prevalent dementia after Alzheimer's disease (AD). We compared 29 FTD and 90 AD caregivers with respect to burden, health-related quality of life (HQoL) and coping. FTD caregivers were more burdened than AD caregivers, and caregivers of patients who were demented for shorter duration had lower HQoL. We furthermore compared the 29 FTD caregivers with 34 caregivers of institutionalized FTD patients to understand their specific caregiver issues. Caregivers of FTD patients institutionalized after shorter dementia duration were most burdened and affected in their HQoL. Overall, passive coping strategies were associated with increased burden and decreased HQoL. We recommend that FTD caregivers be offered more support than AD caregivers. Furthermore, we suggest that interventions target passive coping strategies.

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Introduction

Frontotemporal dementia (FTD) is the second most common type of presenile neurodegenerative dementia after Alzheimer's disease (AD). The estimated prevalence of FTD in the Netherlands is 2.7 per 100,000 inhabitants [1]. The pathology of FTD differs from AD in that it is restricted to the frontal and/or temporal lobes, and it presents with presenile onset more frequently than AD. The core clinical features of FTD comprise early decline in interpersonal conduct (disinhibition), early impairment in regulation of personal conduct, early emotional blunting and early loss of insight, all preceding memory decline [2]. In contrast, AD patients typically suffer from memory problems from the early phases of the disease onward, whereas personality changes and behavioral problems usually arise in more advanced stages of the disease [3]. As FTD advances, patients develop progressive disturbance of executive functions, loss of initiative, mental flexibility and organization. Language is impaired, eventually resulting in aphasia. Behavioral alterations such as pacing and repetitive stereotyped behaviors also develop progressively [3].

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The care for patients with AD before their institutionalization is known to represent a significant burden to the well-being and quality of life of caregivers, which is predominantly determined by behavioral problems [4–8]. FTD typically presents with more pronounced behavioral problems than AD [9]. To date, little is known about the burden that caring for FTD patients represents to informal caregivers. FTD is largely unknown to the general public and therefore FTD behavioral symptoms are not met with understanding and support from the community. In addition, the health care system is not well acquainted with FTD, which is therefore often misdiagnosed, and adequate knowledge about specific interventions to relieve FTD caregiver burden is lacking.

The aim of the current study was to differentiate FTD caregiver burden from AD caregiver burden. This approach was chosen because the general and the medical public are well aware of AD and AD caregiver burden has been studied quite extensively. AD therefore, was an ideal starting point for the comparison. Our aim was to elucidate the specific dementia symptoms that might be burdening FTD caregivers and the differential influence of dementia type on caregiver burden, health-related quality of life (HQoL) and use of coping strategies. The burden that caregivers experience as a consequence of the caring process is a major determinant of patient institutionalization [10, 11]. Maintaining HQoL in the process of care is an essential component of psychological well-being of caregivers, which, in turn, may affect the quality of provided care. Furthermore, it is important to understand which coping strategies are adequate in relieving caregiver burden and maintaining HQoL and whether these are dementia specific.

A recent study compared FTD and AD neuropsychologically and functionally and found that FTD patients were more severely affected [12], suggesting that caregiving in FTD possibly has a greater impact on caregivers than caregiving in AD [13]. Given the greater impact on social conduct and the more prevalent behavioral disturbance in FTD, we expected caregiver burden to be greater, HQoL to be more decreased and coping strategies to be used more intensively.

Little is known about how FTD caregivers, in terms of their psychological well-being, are adjusting to the situation that the patient is no longer living at home. From clinical experience it is known that some caregivers feel relieved that their partner is now well taken care of, whereas other caregivers feel burdened by guilt feelings about having institutionalized the patient. We aimed to assess the burden and quality of life as well as coping of

these caregivers in order to evaluate whether special attention needs to be paid to this subset of caregivers. In order to include these caregivers, we stratified data on the basis of domicile.

Methods

Participants

FTD Patients and Caregivers

Between January 1994 and June 2002, neurological and psychiatric outpatient clinics and psychogeriatric nursing homes in the Netherlands were enquired yearly about the presence of suspected FTD patients. FTD patients were diagnosed according to the Lund-Manchester criteria [14]. Neuroimaging and neuropsychological assessments supported the diagnosis [15]. Patients affected by the sporadic type as well as the familial type were included. Primary FTD caregivers were recruited for participation in our longitudinal psychological study on caregiver burden between December 2001 and June 2002. The study addressed FTD patients in their home environment (FTDH patients) as well as FTD patients in a nursing home (FTDN patients). The Medical Ethics Committee of the Erasmus Medical Centre approved the study. We obtained informed consent from all caregivers. Informed consent by proxy was obtained for the investigation of patient characteristics. At the time of the study 111 patients were eligible. Twenty-four primary caregivers could not be contacted because they had either moved or died. Of the remaining 87, 17 decided not to participate, 4 could not participate due to major health complaints and 3 did not respond to our invitation letter. Finally, a total of 63 participants were included in our study, representing a response rate of 72.4%.

AD Patients and Caregivers

The Maastricht Study of Behavior in Dementia (MAASBED) is a 2-year follow-up study conducted by the University of Maastricht. The MAASBED studied the course and risk factors of behavioral and psychological symptoms of dementia in AD patients and their caregivers. A total of 90 primary AD caregivers were compared with 63 primary FTD caregivers at baseline. The 90 consecutively referred patients with AD (DSM-IV) generally did not suffer from the relatively more severe familial type of AD. Trained psychologists conducted patient and caregiver assessments, and data assessment was discussed regularly to minimize differences between both settings. In the current study, data of AD patients and caregivers were used as a point of reference in order to address the specific issues surrounding the informal care for FTD patients, that are little known at present.

Patient Characteristics

Sociodemographic characteristics included gender, age, patient's domicile (home or nursing home) and duration of the dementia in months (as valued by the caregivers).

Neuropsychiatric disturbance was assessed using the Neuropsychiatric Inventory (NPI) [16]. This fully structured informant interview evaluates 10 domains of neuropsychiatric disturbance: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, and aberrant motor behavior. Scores range from 1 to 12 for each composite domain, with

higher scores indicating stronger symptoms. To minimize administration time, the screening strategy of exploring in-depth only those behavioral domains with positive responses was applied. The Dutch version of the NPI was proven to be reliable and valid [17].

Caregiver Characteristics

Sociodemographic characteristics included gender, age, educational level and type of relationship to the patient (i.e. spouse, child, parent, other).

Burden due to neuropsychiatric disturbance of the patient was measured using the NPI. The caregiver was asked to rate the distress experienced in response to neuropsychiatric disturbance on a 6-point Likert scale ranging from 0 'not at all' to 5 'extremely' for each of the 10 domains. These ratings add up to a total distress score, with a maximum of 50.

Burden of caregiving was measured by rating 'How is taking care of the patient burdening you?' on a visual analogue scale ranging from 0 'not at all' to 10 'extremely'.

HQoL was measured using the Short Form 36 health survey questionnaire (SF-36), which is a generic measure [18]. It consists of 36 items representing eight functional dimensions: Physical functioning, Physical role limitations, Pain, Energy/vitality, Emotional role limitations, Social functioning, Mental health, and General health perceptions. One additional item measures Health change over the past year. Scores on each dimension range from 0 (worst health state) to 100 (best health state). The first four dimensions add up to the Physical Component Summary (PCS) and the latter to the Mental Component Summary (MCS). The SF-36 has been tested and has satisfactory validity [19]. PCS and MCS reliability were 0.82 and 0.85, respectively.

Coping styles were assessed using the Utrecht Coping List which measures seven general coping styles: Seeking distraction (8 items), Expressing emotions (3 items), Seeking social support (6 items), Avoiding (8 items), Fostering reassuring thoughts (5 items), Passive coping (7 items), and Active coping (7 items) [20]. Caregivers rated 44 items on a four-point scale ranging from 1 'hardly ever use that style' to 4 'very often use this style'. Its validity has been established [21] and reliability in the current study ranged from 0.52 to 0.86.

Statistical Analyses

The method of exact testing was used to detect differences in categorical data; ANCOVAs were conducted for continuous data. The analyses were conducted whilst adjusted for gender and age of the caregiver. Dementia duration and caregiver age were dichotomized using the mean as the cut off. ANCOVAs were conducted to detect interaction effects of caregiver age and dementia duration on quality of life and caregiver burden. The Bonferroni correction for multiple testing was applied, thus all analyses were tested at the 0.025 significance level. Regression analyses were used to assess significant predictors of caregiver burden and HQoL. The analyses are presented separately for the comparison of caregivers of FTDH patients with caregivers of AD patients, and separately for caregivers of FTDH patients with caregivers of FTDN patients. The results are individually presented for sociodemographic data, behavioral disorders of the patients, caregiver distress as a result of behavioral disorders, caregivers' HQoL and caregiver coping. All statistical analyses were two sided ($p < 0.05$) unless the Bonferroni correction was applied.

Results

FTDH Patients and Their Caregivers Compared with AD Patients at Home and Their Caregivers

Patient Characteristics

Sociodemographic Characteristics

Table 1 displays the sociodemographic characteristics of the patients and their caregivers. A total of 29 FTDH patients and 90 AD patients living at home were included in the study, 11 FTDH and 32 AD patients were male. FTDH patients were on average 60.0 years old (range 43–79), which was significantly younger ($p < 0.001$) than AD patients, who were on average 78.2 years old (range 56–99). Duration of dementia was significantly ($p < 0.01$) longer in FTDH patients than AD patients (mean 42.3, range 6–120, and mean 59.2, range 24–111, respectively).

Neuropsychiatric Disturbance

Table 2 displays the neuropsychiatric symptoms reported by the primary caregivers.

FTDH patients and AD patients differed significantly in occurrence of neuropsychiatric symptoms. Significantly more FTDH patients suffered from euphoria ($p < 0.001$), apathy ($p < 0.001$), disinhibition ($p < 0.001$) and aberrant motor behavior ($p < 0.001$), whereas significantly more AD patients suffered from depression ($p < 0.025$). Overall, AD patients suffered significantly less frequently from neuropsychiatric symptoms than FTDH patients ($p < 0.001$). FTDH patients experienced more intense neuropsychiatric symptoms than AD patients, with p values approximating significance ($p = 0.04$).

Caregiver Characteristics

Sociodemographic Characteristics

Table 1 displays the sociodemographic characteristics of the patients and their caregivers. A total of 29 caregivers of FTDH patients and 90 caregivers of AD patients were included in the study. Sixteen caregivers of FTDH patients and 35 AD caregivers were male. Caregivers of FTDH patients were significantly younger ($p < 0.05$) than AD caregivers (mean 57.1, range 32–76, and 63.5 years, range 36–90, respectively). Caregivers of FTDH patients and AD caregivers did not differ in educational level. FTDH caregivers significantly more often were spouses of the patients than AD caregivers ($p < 0.001$).

Table 1. FTD and AD caregiver and patient characteristics stratified by domicile

	AD (n = 90)	FTDH (n = 29)	FTDN (n = 34)	p ¹	
				AD vs. FTDH	FTDH vs. FTDN
Patients					
Males, n (%)	32 (36)	11 (38)	18 (53)	0.123	0.010
Mean age (SD)	78.2 (9.0)	60.0 (8.6)	61.2 (10.5)	0.001	0.634
Mean duration of dementia (SD)	42.3 (29.8)	59.2 (23.9)	98.4 (42.6)	0.006	0.001
Caregivers					
Males, n (%)	35 (39)	16 (55)	8 (24)	0.827	0.312
Mean age (SD)	63.5 (12.4)	57.1 (10.7)	57.1 (12.5)	0.015	0.997
Educational level					
Low, n (%)	32 (36)	8 (29)	10 (29)	0.386	0.249
Medium, n (%)	33 (36)	11 (40)	14 (41)		
High, n (%)	25 (28)	9 (31)	10 (30)		
Type of relationship to patient					
Spouse, n (%)	47 (52)	27 (93)	24 (71)	0.001	0.061
Child, n (%)	43 (48)	2 (7)	10 (29)		

AD = Alzheimer disease; FTDH = frontotemporal dementia patients living at home; FTDN = frontotemporal dementia patients living in a nursing home. Figures in bold indicate statistically significant differences.

¹ The Bonferroni correction for multiple testing was applied to test for significance.

Table 2. Neuropsychiatric disturbance in 90 AD patients, 29 FTDH patients and 34 FTDN patients

	Del	Hal	Agi	Dep	Anx	Eup	Apa	Dis	Irr	Abb
AD symptoms										
% present	34	11	30	57	46	7	62	13	42	36
Mean	5.3	5.9	4.6	5.7	5.2	4.5	5.0	4.3	5.1	6.3
SD	3.5	3.5	2.5	3.7	4.0	3.3	2.9	3.7	3.7	3.4
FTDH symptoms										
% present	24	14	45	24	45	41	90	72	48	83
Mean	3.7	3.3	5.1	4.4	5.2	4.5	6.4	4.9	4.9	7.0
SD	2.4	1.0	2.6	3.6	3.7	4.0	2.9	3.4	2.9	3.0
FTDN symptoms										
% present	3	0	32	9	12	21	100	35	12	74
Mean	9.0	0	5.7	4.7	4.8	6.4	10.8	7.6	4.3	7.7
SD	n.a.	0	4.2	6.4	2.9	3.2	2.1	3.7	2.6	2.3
Presence AD vs. FTDH difference	0.46	1.00	0.23	0.02	0.38	0.00	0.00	0.00	0.38	0.00
Mean AD vs. FTDH difference	0.48	0.22	0.31	0.33	0.90	0.33	0.17	0.90	0.92	0.45
Presence FTDH vs. FTDN difference	0.09	0.09	0.60	0.04	0.01	0.39	0.04	0.08	0.01	0.29
Mean FTDH vs. FTDN difference	0.06	n.a.	0.50	0.34	0.90	0.66	0.00	0.05	0.57	0.51

Subscales of the NPI: Del = delusions; Hal = hallucinations; Agi = agitation; Dep = depression; Anx = anxiety; Eup = euphoria; Apa = apathy; Dis = disinhibition; Irr = irritability; Abb = aberrant motor behavior. Figures in bold indicate statistically significant differences.

Burden due to Neuropsychiatric Disturbance of the Patient

FTDH caregivers and AD caregivers did not differ significantly in the emotional burden they experienced due to neuropsychiatric disturbance in the patients.

Burden of Caregiving

ANCOVAs demonstrated that FTDH caregivers felt significantly more burdened by the process of caring ($p < 0.01$) than AD caregivers (mean 5.6, SD 0.46, and mean 4.2, SD 0.28, respectively). In regression analysis, caregiver burden was predicted significantly by the coping strategy of seeking distraction ($\beta = 0.20$; $p < 0.025$) and by the neuropsychiatric symptoms anxiety ($\beta = 0.27$; $p < 0.01$) and disinhibition ($\beta = 0.24$; $p < 0.01$), together explaining 31% of variance. It was exploratively tested whether type of caregiver relationship to the patient (e.g. spouse or child) was of relevance to caregiver burden. It appeared that there was no statistical difference between the different types of relationships.

Health-Related Quality of Life

ANCOVAs demonstrated a two-way interaction effect ($p < 0.025$) existed on the Mental Component Scale (MCS). Older caregivers of FTDH patients who had been demented for longer duration had the highest MCS scores (mean 83.3, SD 6.89). In contrast, younger caregivers of AD patients who had been demented for shorter duration had the lowest MCS scores (mean 63.7, SD 4.16). This implies that HQoL was more affected in caregivers of AD patients who have been demented for shorter duration. In regression analysis, MCS scores were predicted significantly by passive coping ($\beta = -0.56$, $p < 0.001$), explaining 37% of variance.

No significant differences were found between FTDH caregivers and AD caregivers on the Physical Component Scale (PCS).

Coping

FTDH and AD caregivers did not differ significantly in their use of coping strategies. Both FTDH and AD caregivers made most use of active coping strategies (mean 2.7, SD 0.61, and mean 2.5, SD 0.48, respectively) and reassuring thoughts (mean 2.5, SD 0.50, and mean 2.5, SD 0.48, respectively), and both groups made least use of passive coping strategies (mean 1.6, SD 0.38, and mean 1.7, SD 0.48, respectively).

FTDH Patients and Their Caregivers Compared with FTDN Patients and Their Caregivers

Patient Characteristics

Sociodemographic Characteristics

Table 1 displays the sociodemographic characteristics of the patients and their caregivers. A total of 34 FTDN patients were included in the study. Eleven FTDH patients and 18 FTDN patients were male ($p < 0.01$). FTDN patients were on average 61.2 years old (range 37–77). Duration of dementia was significantly ($p < 0.001$) longer in FTDN patients than in FTDH patients (mean 98.4, range 42–220, and mean 59.2, range 24–111, respectively).

Neuropsychiatric Disturbance

Table 2 displays the neuropsychiatric symptoms reported by the primary caregivers.

FTDH patients suffered significantly more from anxiety ($p < 0.01$) and irritability ($p < 0.01$) than FTDN patients, whereas FTDN patients suffered from higher levels of apathy than FTDH patients. The difference in disinhibition approximated significance; FTDH patients experienced higher levels of disinhibition than FTDN patients ($p = 0.05$). Overall, FTDH patients experienced neuropsychiatric symptoms more frequently than FTDN patients ($p < 0.01$).

Caregiver Characteristics

Sociodemographic Characteristics

Table 1 displays the sociodemographic characteristics of the patients and their caregivers. A total of 34 caregivers of FTDN patients were included in the study. Eight caregivers of FTDN patients were male. FTDN caregivers were on average 57.1 years old (range 34–77). FTDN caregivers did not differ significantly in educational level or in the type of relationship to the patient from FTDH caregivers.

Burden due to Neuropsychiatric Disturbance of the Patient

FTDH caregivers experienced significantly more emotional burden due to the neuropsychiatric disturbance of the patient than FTDN caregivers ($p < 0.001$).

Burden of Caregiving

ANCOVAs demonstrated that a two-way interaction effect (fig. 1) approximated significance ($p = 0.04$); caregivers of FTDN patients who had been demented for shorter duration were more heavily burdened (mean 8.8, SD 1.50) than caregivers of FTDN patients who had been

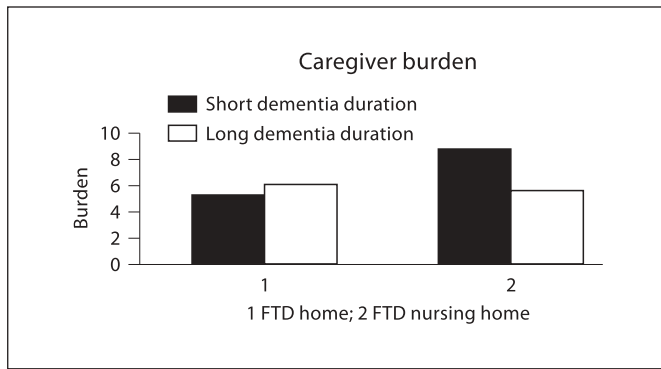


Fig. 1. Two-way interaction effect for dementia duration and patient domicile on caregiver burden.

demented for longer duration (mean 5.5, SD 0.46) and caregivers of FTDH patients who had been demented for shorter or longer duration (mean 5.2, SD 0.76, and mean 6.0, SD 0.76, respectively).

In regression analysis, burden of caregiving was predicted significantly by passive coping ($\beta = 0.43$; $p < 0.001$), explaining 25% of variance.

Health-Related Quality of Life

ANCOVAs demonstrated two (near) significant one-way interaction effects on the MCS. First, FTDN caregivers had lower ($p = 0.027$) MCS scores than FTDH caregivers (mean 59.4, SD 6.00, and mean 75.0, SD 3.24, respectively). Second, caregivers of FTD patients who had been demented for shorter duration had significantly lower ($p < 0.025$) MCS scores than caregivers of FTD patients having been demented for longer duration (mean 59.0, SD 6.32, and mean 75.4, SD 2.55, respectively). In regression analysis, MCS scores were predicted significantly by passive coping ($\beta = -0.55$; $p < 0.001$), explaining 31% of variance.

No significant differences were found between caregivers of FTDH and FTDN patients on the PCS.

Coping

FTDH caregivers did not differ significantly from FTDN caregivers in their use of coping strategies. Both FTDH and FTDN caregivers mostly used active coping strategies (mean 2.7, SD 0.61, and mean 2.6, SD 0.57, respectively) and reassuring thoughts (mean 2.5, SD 0.50, and mean 2.33, SD 0.56, respectively), and both groups made least use of passive coping strategies (mean 1.6, SD 0.38, and mean 1.7, SD 0.39, respectively).

Discussion

FTDH Patients and Their Caregivers Compared with AD Patients and Their Caregivers

In the current study, informal caregivers of FTDH patients and AD caregivers were compared with respect to caregiver burden, HqoL, and coping.

Our study demonstrated that caring for FTDH patients differed significantly from caring for AD patients. FTD patients were more affected in terms of dementia symptoms [9]. In congruence with the literature, FTDH patients presented significantly more often with aberrant motor behavior, disinhibition, apathy and euphoria symptoms, whereas AD patients suffered significantly more from depressive symptoms [22–24]. In line with the findings reported by Cummings and McPherson [25], apathy was most prevalent in both FTD and AD. The amount of overall neuropsychiatric disturbance was mostly observed in FTDH patients. The specific neuropsychiatric symptoms causing emotional burden differed between FTDH and AD, but the amount of experienced emotional burden due to these symptoms did not. The neuropsychiatric symptoms of anxiety and disinhibition were particularly burdening to both FTDH and AD caregivers.

FTD caregivers did feel more burdened by the caring process in general, suggesting that other factors add up to the experienced burden in addition to neuropsychiatric disturbance. FTD caregivers have more trouble finding support in the health care system since FTD is much less prevalent and known than AD. The higher levels of FTD caregiver burden we found suggest that support offered to FTDH caregivers by the health care system should be improved and intensified. Health care providers should be aware of the important differences between FTDH and AD caregivers. More research will be necessary to identify which factors contribute to the higher burden FTD caregivers experience to enhance tailor-made support.

In accordance with the AD literature [26, 27], we found that caregivers of AD patients who had been demented for shorter duration were most affected in their HqoL. Caregivers of patients (both FTDH and AD) who had been demented for relatively longer duration had higher HqoL, suggesting there may be adaptation over time. FTDH patients, on average, had been demented for relatively longer duration than AD patients, and their caregivers were less affected in their HqoL, supporting the notion of adaptation of time. Follow-up data are needed to further investigate this notion.

In terms of coping strategies, there were no differences between FTDH and AD caregivers. It may therefore be concluded that, in our study, coping strategies were used independently of dementia type. We did find that the use of passive coping strategies contributed significantly to decreased HQoL. Interventions aimed at improving HQoL in dementia caregivers may thus benefit from targeting the use of inadequate coping strategies like passive coping.

In summary, FTDH caregivers have to treat patients with more diverse and intense neuropsychiatric symptoms than AD caregivers. FTDH caregivers feel more burdened by the process of caring than AD caregivers. Irrespective of dementia type, passive coping and caring for patients who had been demented for shorter duration was associated with decreased HQoL.

FTDH Patients and Their Caregivers Compared with FTDN Patients and Their Caregivers

In the current study, we were able to include FTDH patients and their caregivers as well as FTDN patients and their caregivers. We inspected caregiver burden, HQoL and coping in order to enhance our understanding of the specific caregiver issues once the FTD patient is institutionalized compared to when the FTD patient is living at home.

FTDN patients experienced apathy the most and other neuropsychiatric symptoms the least, which is congruent with findings from other studies that diversity in neuropsychiatric disturbance decreases with advancing stages of FTD [28]. In FTDH patients, anxiety and irritability was observed more frequently than in FTDN patients. Overall, in FTDH patients more intense neuropsychiatric symptoms were observed than in FTDN patients. In accordance with the lower presence and intensity of neuropsychiatric symptoms, caregivers of FTDN patients felt significantly less burdened emotionally by neuropsychiatric symptoms than caregivers of FTDH patients. A previous study on FTD also found more behavioral problems to be associated with more caregiver distress [29]. More specifically, caregivers of FTDN patients who had suffered from FTD for a shorter period of time felt most heavily burdened by the caring process in general. An explanation could be that over time caregivers adapt to their circumstances and as a consequence feel less burdened. Caregivers who had experienced a longer disease period may be recognized by their social environment and subsequently may have been more encouraged to give in with regard to institutionalization. Moreover, in the early phases, FTD patients may seem unaffected to the social environment, especially since these patients typi-

cally lack disease insight. Institutionalization of the patients, then, is difficult to explain to the environment, which may respond with rejection.

We found that the caregivers who felt most heavily burdened also had the lowest HQoL compared with the other FTD caregivers. Our findings thus demonstrate that caregivers of patients who were institutionalized after relatively short dementia duration were seriously affected in their psychological well-being. To these caregivers, support aimed at relieving burden and improving their HQoL should be offered without delay. From clinical experience, it is known that FTD caregivers often have great difficulties finding the professional support they need. Recognition by health care professionals of the greater support needs would aid these caregivers in finding support more quickly. Swift caregiver support may even benefit the postponement of institutionalization [30]. This would be beneficial to the caregiver who would be partly relieved, to the patient who would be cared for by a loved one at home for longer and to the health care system, which would spend less money on home care than on institutionalized care.

Caregivers of FTDH and FTDN patients did not differ in their use of coping strategies. Irrespective of the patient's domicile, the use of passive coping strategies contributed to increased caregiver burden and decreased HQoL. Interventions aimed at decreasing burden and improving HQoL may thus benefit from targeting the use of inadequate coping strategies like passive coping.

In summary, we found that caregivers of FTDN patients institutionalized after relatively shorter dementia duration were particularly burdened and affected in their HQoL. To these caregivers in particular, recognition of the greater need for support may be an important aid in finding support faster.

A limitation of the current study is that the data were cross-sectional. Longitudinal follow-up data will be needed to further investigate the role of dementia duration, burden and institutionalization, and these data will be published in due time. Our sample was quite small, which is a limitation to generalizability. However, we did include 72.4% of all FTD patients who were known to us nationwide.

Conclusion

FTD caregivers in our study were more heavily burdened by the caring process than AD caregivers. Caregivers of FTD patients institutionalized after relatively

shorter dementia duration were most burdened and affected in their HQoL. We therefore recommend that caregivers of FTD patients be offered improved and intensified support and that special attention be paid to caregivers of already institutionalized patients. Furthermore, we suggest that interventions aimed at relieving burden and improving HQoL of caregivers target the inadequate coping strategy of passive coping. Further research will be necessary to assess what factors cause caregiving in FTD to be more burdening than caregiving in AD.

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