RESEARCH ARTICLE

A support group for caregivers of patients with frontotemporal dementia

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Abstract Several recent articles have pointed out that caregivers of patients with frontotemporal dementia (FTD) need counselling and support. To date, however, no support groups have been provided other than those available to caregivers of patients with Alzheimer's disease (AD). At our outpatient unit for cognitive disorders we initiated a specific support group for caregivers of patients with FTD. This pilot project had four objectives: 1) to provide information, advice and support to caregivers, 2) to learn more about the specific problems and needs of family carers of patients with FTD and to explore the differences to caregiver burden in AD, 3) to encourage mutual support and development of coping strategies, 4) to evaluate the intervention using a questionnaire completed by the caregiver. Eight spouse caregivers of patients diagnosed with frontotemporal dementia (FTD) participated in special support groups. Seven weekly sessions of 90 minutes' duration were held. To evaluate the program participants were asked to complete a questionnaire about their satisfaction with the support group immediately after the final session. Six months after the intervention they received a questionnaire by mail gathering information on coping efficacy. It became obvious that many problems faced by caregivers of patients with FTD are different from those encountered in AD. During group meetings participants were encouraged to express their own needs and to deal with painful emotions, including aggression, anger, mourning and guilt. Caregivers felt relieved by sharing their problems with others. They were able to learn from each other and to share

coping strategies. The group also helped to establish new social relations contacts and even friendships. The participants rated the program as useful and said that benefits were sustained even six months after termination. We conclude from these initial observations that caregiver support groups are a useful component in the management of patients with FTD. Such groups should be tailored to the specific problems and needs of these caregivers. To maintain benefits, self-help groups are recommended even in the absence of professional input.

Keywords caregiver; education; frontotemporal dementia; non-cognitive symptoms; support group

Introduction

Frontotemporal degeneration is the second-largest degenerative cause of dementia after Alzheimer's disease (AD) (Brun & Passant, 1996). Nerve cell loss in the frontal and/or temporal cortex results in characteristic symptoms that are usually first noticed at a presenile age. Two major clinical subtypes can be differentiated which are determined by the distribution of the neurodegenerative process in the cortex. A predominantly frontal localization is associated with *frontotemporal dementia* (FTD), featuring non-cognitive behavioral changes, which occur early in the course of the disease and continue to be the most prominent symptoms until late stages. When the anterior temporal lobes are primarily affected *semantic dementia* (SD) ensues, which is characterized by a progressive loss of the meaning of words, objects and faces. Because patients with SD eventually develop the typical behavioral changes of FTD, SD will be treated as a subtype of FTD in this article.

Often the onset of FTD is marked by increasing indifference and carelessness. Changes in social conduct become apparent, including disinhibited, tactless and sometimes aggressive behaviors. Patients typically show symptoms of either overactivity – including ideas of grandiosity, unreasonable purchases, reckless financial transactions and traffic rule violations – or signs of apathy such as disinterest and social withdrawal. In many patients with FTD, behavior is stereotyped, repetitive and determined by rituals. Typically they have little or no insight into their own condition. Cognitive deficits also occur early but are less conspicuous than in AD. These include impairments in the domains of attention, abstraction, planning and problem solving, whereas in most cases memory, orientation, primary language tools, perception and visuospatial functions are well preserved in the early stages of FTD. Impairment of memory and orientation becomes obvious only as the disease progresses, and it remains less severe than in AD

at comparable clinical stages (Lund and Manchester Groups, 1994; Neary, 1999). It is well established that caring for a demented patient imposes a heavy strain on caregivers. Non-cognitive behavioral symptoms contribute more to this burden than cognitive impairment (Coen, Swanwick, O'Boyle, & Coakley, 1997) and typically precipitate nursing home admissions (Steele, Rovner, Chase, & Folstein, 1990; Haupt & Kurz, 1993). Because changes in behavior and personality predominate in frontal lobe syndromes while cognitive impairment is often mild, it may be predicted that the problems faced by caregivers are partly different in FTD compared with AD.

This assumption prompted us to initiate a support group for caregivers of patients who were diagnosed with FTD at our outpatient unit for cognitive disorders. The project had four objectives: 1) to provide caregivers with a medical model of FTD, with legal and financial advice, and with information on available help, 2) to learn more about the specific problems and needs of FTD caregivers, considering possible differences to caregiver burden in AD, 3) to encourage mutual support among caregivers and to stimulate the development of coping strategies, 4) to evaluate the intervention using a questionnaire on caregiver-reported satisfaction and coping efficacy.

Methods

Selection of participants

Fourteen spouse caregivers of patients with FTD were invited to participate in a specific support group. Eight female spouses accepted (age range 46 to 69 years). In seven patients (age range 51 to 70 years) FTD was diagnosed according to Lund-Manchester criteria (Lund and Manchester Groups, 1994). Three of them had a more temporal localization of the atrophic process (SD). One patient had Binswanger's disease with pronounced frontal symptoms (Van-Swieten & Caplan, 1993). According to their capacity for independent living, patients had dementia of all degrees of severity. Most, however, were at a mild stage of FTD. The average duration of disease was 3.75 years. With one exception, all patients belonged to the lower middle class and had had an education lasting less than 10 years. Seven patients were living in the community; one patient had been admitted to sheltered living one year after the diagnosis. Four families had adult children, who did not live in the household. Three spouses were employed, one of them in a part-time job. The support group consisted of regular weekly sessions of 90 minutes' duration held over a period of seven weeks. Participants attended all sessions. A psychiatric (JD) and a neurologic (TM) resident acted as group moderators.

Table 1 **Contents of the intervention**

Educational elements	Medical information about FTD
	Explanation of symptoms and behaviors
	Information on legal, financial and insurance issues
	Information on resources and services
Therapeutic elements	Exchange of personal experience
	Encouragement of mutual support
	Facilitation of expressed emotion
	Development of coping strategies

Contents and structure of the intervention

Group sessions were intended to be educational and therapeutic (Table 1). Educational elements included a medical model of FTD explaining symptoms and behaviors, and giving information on legal, financial and insurance issues, and information about locally available resources and services. Therapeutic elements were the exchange of personal experience, encouragement of mutual support, facilitation of expressed emotion, and development of coping strategies, in particular regarding the management of non-cognitive behavioral symptoms. Sessions were structured according to a predetermined curriculum, which was presented to the participants at the first session to ensure that all important issues would be covered (Table 2). In session 1 the objectives and limitations of the support group were defined, and participants' expectations were discussed. In session 2 medical information about FTD was given. Sessions 3 and 4 dealt with problems and burdens at different stages of FTD. Financial, legal and insurance issues associated with FTD were discussed by an experienced social worker in session 5. In the next meeting the group discussed where to get help. As a final activity the group visited a nursing home for the mentally handicapped. The structured physician-moderated sessions were followed by monthly self-help meetings among caregivers without professional participation.

Table 2 **Structure of the intervention**

Session 1	Introduction: objectives, discussion of limitations and expectations
Session 2	Medical information about FTD
Session 3	Problems and burdens at the early stage
Session 4	Problems and burdens during the progression of the disease
Session 5	Information on financial, legal and insurance issues (social worker)
Session 6	How to get help
Session 7	Visit to a nursing home for the mentally handicapped

Table 3 **Program evaluation after the final session (n = 8 participants)**

	excellent	good	not bad	poor
How do you rate the quality of the group?	2	6	0	0
How did the group meet your needs?	1	5	2	0
	definitely yes	rather yes	rather no	definitely no
Have you been content with information and support	6	2	0	0
Would you recommend the group to another person in your situation?	6	2	0	0
	information about the disease	social worker	speak about burden and problems	meeting with people in a similar situation
Which contents mostly met your needs?	1	1	3	5

Program evaluation

The intervention was evaluated by the participants (Table 3) immediately after the final session. The interview about satisfaction with the group was adapted from a questionnaire for participants of a support group for caregivers with AD (Yale, 1995). Six months after the intervention we mailed

Table 4 **Program evaluation after 6 months**

	yes	no
During the group activity I received relevant information about FTD	8	0
The group activity has improved my way of communicating with physicians	8	0
After the program I can represent the patient's interests more effectively	8	0
The group has improved my understanding of the disease and of the patient	8	0
After the group I experience less conflict between the patient and myself	7	1
As a consequence of the group I feel less burdened	6	2
The group has helped me to care more for myself	6	2
The group made me more conscious of my own needs	3	5
The program has encouraged me to take up my own interests and hobbies	3	5
I experience fewer feelings of guilt when doing something for myself	4	4
I have attended the monthly meetings with other group participants	7	1
I received understanding and support from caregivers	7	1
The experiences and suggestions of other caregivers were helpful	7	1

a 14-item questionnaire to all participants (Table 4) inquiring whether the information had improved the comprehension of symptoms and behaviors, whether it had made coping more effective and had allowed caregivers more time for themselves, and whether it had relieved feelings of self-blame. Items were answered as yes or no. Caregivers were also asked whether they had attended the self-help extension groups that followed the intervention.

Results

Education about FTD and associated financial and legal issues

Uncertainty and unrealistic beliefs about the disease may result in exaggerated expectations but also in untoward pessimism. Several group participants expressed doubt about whether a disease was present because they were aware of the patient's preserved abilities as opposed to the changes in personality. Caregivers require comprehensive information about the disease in order to enhance their understanding of patients and to avoid unnecessary feelings of self-blame. In particular, a medical model of FTD is helpful to explain the changes in the patients' behaviors as consequences of a brain disease. In this context we found it helpful to demonstrate to the participants 18-FDG positron emission tomography scans showing the typical pattern of metabolic deficits in FTD. These images visualize the topography of the neurodegenerative process and are very convincing to lay persons. They facilitate acceptance that the patients are suffering from an organic brain disease and that the changes in behavior and personality are symptoms of this disease rather than purposeful malevolence.

Caregivers felt that the information given by the social worker was very helpful. In particular, the issues of advanced directives, enduring power of attorney and safeguards against uncontrolled spending of money were of interest. Also, caregivers were uncertain whether they could be held responsible for any damage the patient might cause.

Specific problems and needs of caregivers of FTD patients

The participants took advantage of the opportunity to discuss their emotions with regard to their spouse's illness. The most burdensome symptoms of FTD were offensive, egocentric and quarrelsome behaviors, but also apathy, indifference and loss of interest. Lack of insight is another great problem for caregivers. It can cause very unpleasant and even dangerous situations. In addition to the changes in the patients' behavior, feelings of hopelessness and of being trapped were most troublesome to the

participants. Most caregivers said the group helped them to become aware of and to deal with their emotions for the first time. All were mourning over a loved one who was no longer the person they had known for a long time. 'To let go of someone who is in fact very much present', as one participant put it, is a long and painful process that cannot be undertaken unless the disease has become accepted. To facilitate acceptance the group dealt actively with the psychological mechanisms of defense and repression. These included denial of disease and search for alternative explanations of the patients' behavioral changes. The group participants were not only moved by feelings of mourning, however, but also by emotions, which they found difficult to verbalize. In particular if disinhibition and tactlessness were prominent features of the patient's behavior the caregivers experienced aggressiveness and anger as a consequence of being repeatedly offended. Because these emotions toward the spouses were new and unaccustomed, caregivers tried to deny or repress them, or felt guilty for feeling this way. The group discussed extensively whether and to which degrees such emotions are acceptable and whether they might even represent understandable and healthy reactions. On the other hand, the participants emphasized how important it is to realize that the patients' abnormal behaviors are symptoms of the disease and should not be misinterpreted as a personal offense.

Some participants felt that dealing with their spouse's disease had positive aspects, including greater solidarity within the family. Some said that the disease had led them to adopt responsibility and take decisions – for instance, in financial matters. The change of social roles was seen as a process of maturation.

Mutual support and development of coping strategies

The group discussed intensively how to cope with the patients' partial or complete anosognosia. It was mentioned that lack of insight protects patients from depression, embarrassment and despair, which are frequently experienced by patients with AD. Uniformly, caregivers found that trying to convince patients of their illness was useless. It was suggested that little lies and pretenses are more effective – for example, declaring that an appointment with the neurologist was required for a routine blood test. It is important not to feel guilty when being untruthful. Several participants said they felt embarrassed when being with the patient in public because they were ashamed of their behavior. The group explained these feelings as expressing a subconscious identification with the spouse. It was recommended that caregivers should try to become aware of this identification and gradually correct it because the spouse's personality had changed.

Most participants complained about increasing social isolation, because

of the withdrawal of friends. The group argued that friends may have been irritated, repelled or frightened by the patient's behavior, or may have felt unwelcome. As a possible solution it was suggested that they should tell friends about the disease and discuss their concerns with them, to clear up misunderstandings.

As a result of group discussions the participants realized how important it was to look for psychological compensation and regeneration. Caregivers can continue to bear the burden of living with the patient only if they adequately judge their powers and use their energy economically. Although self-pity was seen as negative initially, participants gradually learned that it may have a protective effect and be a signal to better take care of one's own needs. Uniformly, they appreciated the support and solidarity of the group and agreed to continue with monthly self-help meetings.

Program evaluation

Six months after the intervention participants were asked to complete a program evaluation form (Table 3). All caregivers stated that the support group had improved their knowledge and understanding of the disease. Interestingly, only three participants said they had learned to take better care of their own needs and pursue their own interests, although this had been strongly emphasized in the group discussions. The seven caregivers, who met as a self-help group after the structured, physician-moderated intervention, described this activity as very useful. They felt that the meetings provided much supportive empathy and many suggestions from other caregivers. Also, the group was seen as an opportunity to establish new social contacts and even make friends.

Discussion

We previously described our experience of caregiver support groups in AD (Kurz, Feldmann, Müllers-Stein, Rüster, & Lauter, 1987) and now report on a similar group intervention for caregivers of patients with FTD. It became clear that some of the problems and burdens faced by this group were no different from those encountered by family members of AD patients. Common problems include the change of a loved one, the acceptance of disease and loss, the process of mourning, and a significant reversal of social roles. Bitterness and frustration over their own fate, the difficulties of living with the patient, the withdrawal of friends and financial hardship are also shared by caregivers of patients with dementia irrespective of the underlying cause.

In addition, however, caregivers of patients with FTD have to deal with

Table 5 **Determinants of caregiver burden: A comparison between FTD and AD**

Similar in FTD	Loss of a loved one
	Mourning
	Role reversal
	Social isolation
	Financial burden
Different in FTD	Patients are relatively young
	Predominance of changes in behavior and personality
	Relative lack of cognitive impairment
	Disease less obvious and comprehensible
	No established pharmacological treatment
	Little information on natural course
	Disease is not known to the general public
	Behavioral change less well accepted as expression of disease

specific problems (Table 5). As previously reported by Hall and Talerico & Evans (Hall, 1999; Talerico & Evans, 2001), caregivers' emotional reactions to the change of a loved one into an indifferent, tactless, disinhibited or offensive individual are not only grief and sadness, but frequently also aggressiveness, doubt and rejection. In contrast to AD, FTD strikes at a relatively young age. In the presenile period a progressive brain disease is an even heavier blow that at an advanced age, because at the onset of symptoms many patients are still at work, have undertaken financial commitments and have plans for the future. Therefore the disease causes dramatic changes for the whole family, not only in terms of economic difficulty. Furthermore, caregivers of patients with FTD are often faced with lack of appreciation from friends and from the general public. Typically, the only cause of cognitive impairment and behavior change in older age that is known to the lay person is AD.

Research has not made as much progress in FTD as in AD. This may in part be explained by the relatively low prevalence of FTD, which is estimated to be 0.025 to 0.05 percent in the population at risk (Kurz & Jellinger, 2002). One practical consequence is that general practitioners and even specialists have no answers to the caregivers' questions, in particular concerning treatment and prognosis.

Because problems are different, support groups for caregivers of patients with AD are not entirely appropriate for caregivers of patients with FTD. It may be assumed that insufficient knowledge about the disease, inadequate coping strategies and lack of support all contribute to premature admissions to nursing homes of patients with FTD.

The experience in our pilot project suggests that a group size of eight participants may be optimal. We also feel that a caregiver support intervention should be long term. Seven meetings are not sufficient to enable

the difficult and often painful process of learning and adjustment to be completed. Also, seven sessions are not enough to shift the focus of the group activity from the patients' behaviors to caregivers' lives. It certainly requires more time to encourage caregivers to accept their own requirements and to support them in developing adequate strategies to satisfy their needs. Longer-term interventions may also more adequately deal with emotional problems and taboo topics including violence and sexuality.

Until now the self-help group has met 15 times. The feedback we received on the monthly meetings that followed the structured intervention was very positive, and these gatherings continued for more than six months. This could indicate that group activities without professional input, similar to the concept of self-help groups in AD, are valuable for caregivers of patients with FTD.

The present study shows the feasibility and usefulness of a support group for caregivers of patients with FTD, but it has several limitations. The participants of the support group were a small and selected group of caregivers who sought help for their problems and may not be representative of FTD caregivers in general. Also, the comparison of caregiver burden between FTD and AD was not based on the use of identical assessment instruments in the two diagnostic categories. Furthermore, a randomized controlled study is needed to determine the efficacy of a caregiver support program in terms of reducing caregiver burden or delaying nursing home admissions. Therefore, further research is needed to confirm and extend our findings on caregiver problems in FTD and to study the psychological and health economic outcomes of caregiver counseling.

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