PAPER

Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms

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Background: We studied the level of distress in caregivers of patients with recently diagnosed multiple sclerosis (MS), and their relation to clinical characteristics.
Methods: Caregivers of patients with MS and Parkinson's disease completed measures of distress and quality of life. MS patients underwent neurological, neuropsychiatric and neuropsychological examinations. Multivariate regression analyses were used to explore the relationship between patient variables and caregiver distress.
Results: Caregivers of patients with MS experienced high levels of distress and reduced quality of life related to caregiving. The level of distress was similar to that reported by elderly spouses of patients with longstanding Parkinson's disease. Psychiatric symptoms and cognitive impairment in patients with MS were associated with caregiver's distress and quality of life, even after controlling for level of disability (all p values <0.01). Patients' physical impairment was associated with caregiver distress, but not with caregiver quality of life.
Conclusion: Caregivers of patients with MS experience high levels of distress and reduced quality of life. Psychiatric symptoms and cognitive impairment contributed significantly to caregiver distress, over and above the effect of disability due to neurological symptoms.

At the time of diagnosis, many patients with multiple sclerosis (MS) are in stable relationships, which are inevitably affected by the advancing disease. The partners have to cope with not only the presence of the disease, but the added fact of an unpredictable prognosis, including the possibility that their partner may become severely physically and cognitively impaired.[1–3] They therefore face lifestyle and role adjustments that can give emotional distress and reduced quality of life.[4]

Studies in other neurological diseases such as Alzheimer's disease and Parkinson's disease (PD) have shown that caregiving is associated with a high degree of emotional and social distress,[5] and that both mental and physical symptoms manifest as a result. Furthermore, caregiver distress has important implications for institutional placement[6] and even the course of the disease.[7 8]

Few studies have explored the strain on caregivers of MS patients, and most of the studies undertaken so far have had important methodological limitations related to small and selected patient samples.[9–12] Furthermore, most studies have usually not employed quantitative research methods, but rather unstructured indepth interviews[11] or focus group interviews.[12] A recent systematic review of the needs and experiences of caregivers of MS patients showed that providing care for a person with MS can have a detrimental effect on the caregiver's psychological health.[13] Thus there is a need for effective interventions towards helping caregivers continue their essential role but also maintaining themselves in the process.[13]

In this study, we investigated the level of distress and effect on quality of life experienced by caregivers of a representative and well characterised cohort of recently diagnosed MS patients. In addition, we explored the relationship between caregiver distress and patients' neurological, psychiatric and cognitive symptoms. We hypothesised that (1) caregivers would report adverse effects on their psychological and social health and that (2) there is a relationship between the clinical presentation of MS and the type of caregiver distress. Specifically, we hypothesised that the level of burden related to caregiving would correlate with degree of physical impairment, while the caregivers emotional distress would be associated with the severity of psychiatric and cognitive disturbances.

METHODS

Subjects

The study comprised caregivers of 93 patients diagnosed with MS[14] in the counties of Rogaland and Hordaland, Western Norway, during 1998–2000. Two patients did not want to inform family members or friends that they had MS, one had moved abroad, one patient came from another continent and had severe difficulties understanding the Norwegian or English language, three patients did not want to participate and seven patients completed only parts of the evaluation programme. Three caregivers refused to participate. Thus 76 patient–caregiver couples were available for inclusion. A semistructured interview provided information regarding disease history, drug use and demographics. The main sources for patient recruitment were the files of the Departments of Neurology, Stavanger University Hospital (Rogaland) and Haukeland University Hospital (Hordaland), which are responsible for the neurological healthcare services in the study area with a total population of approximately 700 000 inhabitants. Patients diagnosed with MS in the area are referred to these two departments. The population in the area is stable, ethnically homogenous and the public health care system in the area has been well established for many years. The patients provided written informed consent, and the local regional ethics committee approved the study.

Fifty-eight spouses of home dwelling patients from a community based study of PD were included for comparison. Mean (SD) age of the PD patients was 72.0 (7.6) years, mean

Abbreviations: EDSS, Expanded Disability Status Scale; GHQ, General Health Questionnaire; LTS, Long Time Storage; MS, multiple sclerosis; NPI, Neuropsychiatric Inventory; PD, Parkinson's disease

Hoehn and Yahr[15] stage 2.9 (0.9) and the mean Mini-Mental State Examination score[16] 26.2 (4.9).

Table 1 Demographic and clinical characteristics of the 76 MS patients included in the study and of the non-participants

	Patients	Non-participants
Age	42.0 (10.0)	45.0 (9.4)
Sex (M/F ratio)	24/52	1/9
Education (y)		
9	5	1
12	48	4
>12	23	5
Duration of disease (y)	8.3 (7.4)	9.9 (10.7)
Time since diagnosis (y)	2.6 (0.9)	2.8 (1.0)
Disability from working		
No disability	33	4
Partly (50–70% disabled)	15	0
100% disabled	28	6
Marital status at evaluation		
Single	16	2
Partner	60	8
Subtype MS and neurological impairment		
Initial course		
Remitting relapsing	69	8
Primary progressive	7	2
At testing		NA
Remitting relapsing	59	
Secondary progressive	10	
Primary progressive	7	
EDSS score	3.3 (1.4)	4.2 (2.2)
FSS score	4.9 (1.8)	5.5 (1.74)
Mental symptoms		
NPI total score	8.9 (10.6)	–
BDI score	10.7 (9.4)	–
PASAT, % correct	42.9 (12.6)	–
SDMT	41.6 (13.1)	–
SRT–LTS	36.2 (16.5)	–
SRT–CLTS	26.3 (16.8)	–
SRT–intrusions	1.2 (2.8)	–
SRT–DR	6.9 (3.1)	–
Dementia interview (dementia/no dementia)	7/69	–

BDI, Beck Depression Inventory; CLTS, Consistent Long Term Retrieval; DR, Delayed Recall; EDSS, Expanded Disability Status Scale; FSS, Fatigue Severity Scale; LTS, Long Time Storage; MS, multiple sclerosis; NPI, Neuropsychiatric Inventory; PASAT, Paced Auditory Serial Addition Test; SDMT, Symbol Digit Modalities Test; SRT, Selective Reminding Test.
Values are mean (SD) scores or number of patients.
Comparison between groups, made by the Student's t test and Cross-tab (χ^2, Fisher's exact test), as appropriate, showed no differences between the groups.

Measures

Caregivers

Caregiver distress was evaluated using the Relative Stress Scale,[17] a self-administrated questionnaire which consists of 15 items. It is designed to assess the degree of distress and social upset experienced by a relative as the result of caring for a person with physical and/or behavioural debilities. Each item is assessed using a scale from 0 to 4 (never, rarely, sometimes, frequent, always), with higher scores indicating more severe stress. Three subscales have been defined as follows: a personal distress scale (items 1–6: relation to the patient, eg, ''Do you feel you can no longer cope with the situation?''); a life upset scale (items 7–11: degree of life changes produced by having to care for the patient, eg ''Has the quality of your life been reduced as a consequence of…? How much has your social life been affected?'') and a negative feeling scale (items 12–15: negative feelings towards the patient, eg ''Do you ever feel embarrassed by your…?'').

The Neuropsychiatric Inventory (NPI) Caregiver Distress Scale was used to further explore the relationship between specific psychiatric symptoms and caregiver distress. The NPI Caregiver Distress Scale measures caregiver distress related to each of the 12 neuropsychiatric symptoms assessed by the NPI on a 0 to 5 scale. The scale[18] has been proven to be a reliable and valid measure of subjective caregiver distress in relation to neuropsychiatric symptoms, as measured by the NPI.[19]

Quality of life was evaluated by the General Health Questionnaire (GHQ) quality of life 12 item version, constructed from the original GHQ, using items that have been selected for their dimensional approach to quality of life,[20] and focuses on the last 2 weeks. The level of stress was assessed using a scale from 0 to 3 (better than usual, same as usual, less than usual, much less than usual).

Patients with MS

Neurological assessment

Clinical neurological examination, including scoring of the Kurtzke Expanded Disability Status Scale (EDSS),[21] of patients with MS was performed.

Fatigue was assessed by Krupp's Fatigue Severity Scale that comprises nine items related to fatigue and its consequences on everyday activities. The Fatigue Severity Scale has been shown to possess sensitivity, reliability and internal consistency in the assessment of fatigue.[22]

Psychiatric assessment

A psychiatrist (NF) or a trained research nurse administered the 12 item version of the NPI to MS patient caregivers, usually within 1 month of the neurological examination.[19]

The Beck Depression Inventory was included to explore the level of depressive symptomatology. The Beck Depression Inventory is a valid and reliable questionnaire of depressive symptoms in both depressed and medical populations.[23 24]

Neuropsychological assessment

Three neuropsychological tests were administered in accordance with standard recommendations.

- *Paced Auditory Serial Addition Test*[25] is a serial addition task used to assess capacity and rate of information processing and sustained and divided attention.[25] The 3 s interval version was performed.
- *Symbol Digit Modalities Test*[25] is used to assess the visual scanning and tracking aspect of attention as well as motoric speed, and allows comparison between oral and written responses. The oral version was used to avoid motor problems that may interfere with the ability to perform the task.
- *Buschke Selective Reminding Test*[25] measures verbal learning and memory during a multiple trial list learning task. Measures included Long Time Storage (LTS), Consistent Long Term Retrieval and Delayed Recall. Intrusions were recorded for each trial. A word was assumed to have entered LTS when it was recalled on two consecutive trials without a reminder between trials. If a word was recalled consistently from LTS, without reminding, it was assumed to have been in Consistent Long Term Retrieval from the first point of continuous recall.

A structured caregiver based interview of cognitive impairment according to the DSM IV dementia criteria[26] was administered.

Statistics

Analyses consisted of descriptive analysis and calculation of proportions. The level and specific nature of caregiver distress and quality of life was described using the subscale means of the Relative Stress Scale and the GHQ. Differences between groups were analysed using one way ANOVA (with Scheffe's

Table 2 Distress scores in the different MS caregiver groups and the control group of PD spouses

	MS spouses	PD spouses	p Value*	MS children	MS parents	MS friends	p Value†
n	55	58		6	8	7	
Sex (M/F)	36/19	37/21	NS	3/3	4/4	2/5	NS
Age (y)	45.0 (9.1)	70.8 (8.3)	<0.001	24.2 (7.0)	55.8 (17.4)	49.6 (12.1)	0.015
Personal distress scale	5.6 (4.2)	5.8 (4.6)	NS	3.8 (2.3)	5.5 (5.6)	0.9 (0.9)	0.01‡
Life upset scale	4.1 (3.9)	5.5 (5.4)	0.003	1.8 (2.6)	3.0 (3.3)	0.3 (0.8)	0.008
Negative feeling scale	3.0 (2.3)	2.9 (2.6)	NS	2.2 (1.2)	0.9 (3.1)	0.3 (0.8)	0.001‡
RSS total score	12.6 (9.5)	14.2 (11.2)	0.04	7.8 (4.9)	9.4 (9.2)	1.4 (1.1)	0.001‡
GHQ	14.1 (4.3)	14.3 (5.2)	NS	13.5 (2.1)	13.5 (3.1)	12.1 (1.3)	NS

GHQ, General Health Questionnaire, 12 item version; MS, multiple sclerosis; PD, Parkinson's disease; RSS, Relative Stress Scale.
Life upset, negative feelings and personal distress scales are subscales of the RSS. Higher scores denote more severe distress.
Values are mean (SD) scores.
*Comparison MS and PD spouses.
†Comparison of the four MS caregiver groups
‡Scheffe's post hoc test: statistically significant difference between spouses and friends.

post hoc test) or the Student's t test for continuous and normally distributed variables, the Kruskall–Wallis or Mann–Whitney tests for non-normally distributed continuous variables data and the χ^2 test for categorical variables. Significance levels of 0.05 were used for these analyses. Demographic and clinical characteristics as explanatory factors of caregiver distress were identified with Spearman rank correlations. To control for possible intercorrelations among the variables, multiple linear regression analysis was used. In this procedure, the different predictors were examined separately with the patient age, gender, education and neurological disability status as fixed independent control variables. GHQ and the Relative Stress Scale subscores served as dependent variables, and the demographic and clinical variables which correlated with each of the dependent variables at the 0.05 level served as independent variables. Analyses were made using the Statistical Package for Social Sciences (SPSS) for Windows, version 12.

RESULTS

Clinical and demographic characteristics

The characteristics of the patients and caregivers are shown in tables 1 and 2. There were no statistically significant differences between the 10 non-included patients completing only parts of the evaluation programme and the 76 subjects who completed the study, in terms of demographic or clinical variables (table 1).

Caregiver distress

The caregiver group of the MS patients consisted of 55 (72%) spouses, 6 (8%) adult children, 8 (11%) parents and 7 (9%) close friends. The spouse group reported significantly higher levels of total caregiver distress and reduction in quality of life compared with the other groups, whereas close friends reported lower levels of caregiver distress and less reduction in quality of life compared with the other groups (table 2). Because of the small numbers, the only statistically significant differences

Table 3 Spearman correlations between measures of caregiver (spouse) distress and demographic and clinical characteristics of patients with MS

	Measures of caregiver distress			
Patient characteristic	**GHQ**	**Personal distress**	**Life upset**	**Negative feelings**
Age (y)	0.123	0.237	0.350**	0.163
Sex	0.110	0.138	0.126	0.257
Education (y)	–0.101	–0.029	–0.102	0.111
Duration of disease (y)	0.134	0.122	0.295*	0.000
Duration since diagnosis (y)	0.058	0.056	0.086	0.093
EDSS	0.134	0.426***	0.442***	0.299*
FSS total score	0.132	0.153	0.313*	0.227
FSS mean score	0.147	0.168	0.326*	0.231
BDI	–0.033	0.307*	0.356***	0.266
NPI total	0.317*	0.553***	0.555***	0.490***
PASAT	–0.201	–0.226	–0.382***	–0.062
SDMT	–0.072	–0.205	–0.399***	–0.164
SRT–LTS	0.005	0.148	–0.157	0.112
SRT–CLTS	–10.16	0.093	–0.220	0.133
SRT–intrusion	0.011	0.087	0.044	0.087
SRST–DR	–0.002	0.035	–0.174	–0.026
DSM-IV dementia	–0.307*	–0.502***	–0.490***	–0.517***

BDI, Beck Depression Inventory; CLTR, Consistent Long Term Retrieval; DR, Delayed Recall; EDSS, Expanded Disability Status Scale; FSS, Fatigue Severity Scale; GHQ, General Health Questionnaire; LTS, Long Time Storage; MS, multiple sclerosis; NPI, Neuropsychiatric Inventory; PASAT, Paced Auditory Serial Addition Test; SDMT, Symbol Digit Modalities Test; SRT, Selective Reminding Test.
DSM-IV dementia is coded as 0 = dementia, 1 = no dementia.
*p<0.05, ***p<0.005.

Table 4 Relative contribution of clinical characteristics to distress in the spouses of patients with MS (linear regression analysis,* p values)

	GHQ			Personal distress			Life upset			Negative feelings		
	R^2	Beta†	p Value	R^2	Beta†	p Value	R^2	Beta†	p Value	R^2	Beta†	p Value
Basic model*	0.015	–	0.854	0.046	–	0.503	0.164	–	0.029	0.110	–	0.116
EDSS	0.024	0.115	0.504	0.176	0.438	0.008	0.241	0.336	0.030	0.178	0.315	0.050
FSS total score	0.023	0.080	0.624	0.041	0.096	0.554	0.205	0.234	0.117	0.149	0.192	0.212
BDI	0.026	–0.108	0.458	0.190	0.080	0.184	0.208	0.216	0.104	0.129	0.139	0.313
NPI total	0.239	0.523	<0.001	0.284	0.540	<0.001	0.386	0.520	<0.001	0.254	0.419	0.003
PASAT	0.056	–0.210	0.155	0.087	–0.214	0.140	0.240	–0.289	0.031	0.123	–0.118	0.404
SDMT	0.025	–0.106	0.479	0.091	–0.225	0.123	0.288	–0.371	0.005	0.175	–0.267	0.056
DSM-IV dementia	0.197	–0.441	0.002	0.366	–0.586	<0.001	0.413	–0.517	<0.001	0.479	–0.629	<0.001

BDI, Beck Depression Inventory; EDSS, Expanded Disability Status Scale; FSS, Fatigue Severity Scale; GHQ, General Health Questionnaire; MS, multiple sclerosis; NPI, Neuropsychiatric Inventory; PASAT, Paced Auditory Serial Addition Test; SDMT, Symbol Digit Modalities Test.
DSM-IV dementia is coded as 0 = dementia, 1 = no dementia.
*Patient age, sex and education are fixed independent control variables. All predictors were examined separately after including the demographic variables age, sex and education.
†Standardised beta coefficient.

were found between spouses and friends on the Relative Stress Scale total score, and personal distress and negative feeling subscales.

As expected, the spouses of PD patients were older than the spouses of MS patients, but there were no significant gender differences. Total mean score for the Relative Stress Scale was 12.6 (9.5) for MS caregivers and 14.2 (11.2) for the control group of PD caregivers ($p = 0.044$) (table 2). This difference was accounted for by the mean life upset scale score, with a score of 4.1 (3.9) for MS caregivers and 5.5 (5.4) for the control group ($p = 0.003$). There were no statistically significant differences between groups for the personal distress and negative feeling subscales or the GHQ (table 2).

Association between clinical symptoms and caregiver distress

Univariate correlations between measures of caregiver distress and demographic and clinical characteristics of the MS patients are shown in table 3. The caregiver distress scales were not normally distributed and thus the Spearman correlation test was used. To obtain a homogeneous caregiver group, only the spouses were included in these analyses. There were highly significant correlations between the caregiver distress scales and measures of disability, cognition and neuropsychiatric symptoms. There were also significant correlations between quality of life, neuropsychiatric symptoms and cognition, as measured by the dementia interview.

To further explore the relative contribution of clinical characteristics to caregiver distress and quality of life in the spouse group, patient age, gender and education were used as independent fixed control variables in linear regression analyses (table 4). Statistically significant associations between the NPI total score and the three relative stress subscales and the GHQ scale were found. Significant associations were also found between the dementia interview and all of the relative stress subscales and the GHQ scale. Significant associations were further found between EDSS and personal distress and life upset subscales, and between two of the neuropsychological tests, Paced Auditory Serial Addition Test and Symbol Digit Modalities Test, and the life upset scale. All of the predictors were examined separately. When EDSS was added in the analysis as an independent fixed control variable, all associations between the caregiver distress and GHQ scales with psychiatric and cognitive measures remained statistically

Table 5 NPI items and caregiver distress scores in the total group and in those with the symptom present

	All patients (n = 76)	Patients with symptoms present	All caregivers (n = 76)	Caregiver distress score when symptom is present in patient		
NPI item	Item score (mean (SD))	Proportion with non-zero score (n (%))	Item score (mean (SD))	Item score (mean (SD))	No (%) with at least moderate distress*	% of all
Delusions	0.24 (1.45)	2 (2.6)	0.17 (0.84)	4.33 (0.58)	3 (100)	3.9
Hallucinations	0	0	0	0	0	0
Agitation/aggression	0.51 (1.27)	15 (19.7)	0.51 (1.2)	2.5 (1.3)	8 (50)	10.5
Depression	1.43 (1.87)	44 (57.9)	1.3 (1.5)	2.3 (1.3)	23 (51.1)	30.3
Anxiety	0.53 (1.36)	13 (17.1)	0.4 (1.0)	2.4 (1.2)	9 (64.3)	11.8
Euphoria	0.04 (0.20)	3 (3.9)	0.04 (0.25)	0.75 (0.96)	0	0
Apathy	1.45 (2.79)	22 (28.9)	0.7 (1.3)	2.3 (1.4)	12 (52.2)	15.8
Disinhibition	0.18 (0.86)	5 (6.6)	0.17 (0.7)	2.6 (1.14)	3 (60)	3.9
Irritability/lability	1.03 (1.66)	30 (39.5)	0.8 (1.4)	2.0 (1.6)	11 (35.5)	14.5
Aberrant motor behaviour	0.18 (0.89)	4 (5.3)	0.08 (0.5)	1.5 (1.9)	1 (25)	1.3
Sleep disturbance	1.66 (2.25)	31 (44.7)	0.42 (1.0)	0.94 (1.37)	6 (17.1)	7.9
Appetite disturbance	1.55 (2.67)	24 (31.6)	0.14 (0.68)	0.46 (1.18)	2 (8)	2.6
Total NPI	8.88 (10.60)	61 (80.3)	4.7 (6.5)	5.97 (6.79)	39 (62.9)	51.3

NPI, Neuropsychiatric Inventory.
*Number and percentage of caregivers who reported the symptom to be present, who reported at least a moderate distress score of 3, on the NPI caregiver distress item.

significant (data not shown). Thus psychiatric symptoms and cognitive impairment were significantly associated with caregiver distress and quality of life over and above the effect of motor disability.

NPI caregiver distress scale

At least moderately severe distress (ie, a score of 3 or higher) was reported in 51.3% of the carers for at least one neuropsychiatric symptom assessed by the NPI Caregiver Distress Scale. The highest mean caregiver distress scores were found for depression, followed by irritability, apathy and agitation (table 5). When only caregivers of patients with a non-zero score on each item were included, delusions had the highest mean score, followed by disinhibition, agitation and anxiety. Thus although uncommon, when these symptoms occurred, they posed considerable stress for the caregiver.

DISCUSSION

We found that caregivers experienced high levels of distress and reduced quality of life related to caregiving, similar to that experienced by spouses of patients with PD. Spouses presented with higher levels of distress as well as reduced quality of life compared with the other MS caregiver groups. As hypothesised, patients' psychiatric symptoms and cognition were associated with both caregiver distress and quality of life, even after adjusting for age, gender, education and physical impairment. Patients' physical impairment was however not associated with caregiver quality of life, but only with caregiver distress. Hence mental symptoms were the most powerful and consistent determinants of both caregiver distress and quality of life.

Our study has confirmed previous reports showing the importance of depression in patients with MS, for caregiver distress.[4] In addition, our findings extend previous research by evaluating the effects of a wide variety of neuropsychiatric symptoms on the caregiver. Depression is the most common psychiatric symptom in MS,[1 27 28] and was found to be a significant contributor to caregiver distress. Thus depression in patients with symptoms such as loss of mental energy, initiative, dysphoric mood and feelings of worthlessness, were also found to be associated with depressive symptoms in spouses/caregivers. This may weaken the relationship and make the caregiving relationship less satisfying, thereby reducing the motivation and investment of the caregiver in the process.

Delusions, disinhibition, agitation/aggression and irritability were the most disturbing psychiatric symptoms for the caregivers. These burdensome symptoms are often resistant to reasoning and may be difficult to manage. They may also be associated with socially unacceptable behaviour and hence lead to untoward lifestyle adaptations and social isolation for both patient and caregiver when severe or longstanding. The supportive relationship between patient and spouse can thus be seriously undermined and even lead to a worsening of the patient's psychiatric symptoms.

Impaired cognition is common in MS,[1 2 29] and was associated with distress and reduced quality of life among the caregivers, consistent with a previous study.[30] Impaired memory and information processing speed may challenge both the caregivers' coping strategies and feelings, and may change the relationship from one of equal partners to one in which the caregiver is forced to adopt a parenting role, having to remember and initiate most chores. The caregiver may also feel that the patient, because of the cognitive impairment, has changed his/her personality and become a different person than the person he/she married. The significant relationship between physical disability, as measured by EDSS and caregiver distress, was in accordance with the finding of Hakim *et al*, who reported this to be a strong indicator of stress among relatives.[31] Thus our results strongly suggest that motor, cognitive and psychiatric symptoms contribute significantly, and independent of age, sex and education, to distress and reduced quality of life in caregivers of patients with MS.

There are methodological limitations that need to be taken into consideration when interpreting our findings. One limitation is the relatively small patient sample, although the sample size is still larger than the samples included in most previous studies,[9–11 30] and comparable with a representative MS sample.[32] Furthermore, only a limited amount of information was available regarding the caregivers' physical and mental health and caregiving situation, which may be related to the caregivers' perceived level of distress and quality of life. Secondly, psychiatric symptoms were assessed by a caregiver based interview. Thus it is possible that some psychological symptoms might not have been captured. Furthermore, caregiver distress may have resulted in increased reporting on the NPI and the dementia interview. A recent study has however shown that cognitive impairment, depression and anxiety reduce the self-awareness and accuracy of self-reporting of neurobehavioral symptoms in MS, suggesting that a caregiver based interview may nevertheless represent the preferred source to obtain information concerning the psychiatric morbidity of patients with MS.[33]

The study did not include a normal spouse group for comparison, which limits the ability to draw conclusions regarding the magnitude of distress and reduction of quality of life. However, the perceived distress and quality of life did not differ significantly from that of the spouses of PD patients, which have previously been shown to have significantly reduced quality of life compared with non-caregiver populations.[5] However, the MS and control groups differed with regard to age, which presents challenges in comparing the groups as older and younger caregivers may have different coping strategies of caregiving, and also different additional caregiving burdens. Elderly carers may face additional challenges related to ageing. On the other hand, they may have reduced expectations which may buffer them against distress. Both MS and PD are progressive neurological disorders with physical, cognitive and psychiatric symptoms, thus posing similar types of challenges for caregivers. Therefore, our data support the conclusion that the MS spouses did experience reduced quality of life and increased distress compared with the normal population.

Mental disturbances have been reported to have a negative impact on patients' psychosocial functioning, employment[2] and physical outcome.[36] Our findings demonstrate that they also contribute substantially to the high level of emotional and social distress experienced by caregivers of MS patients, especially spouses. Thus assessing the caregivers' situation is important in the management of patients with MS, and providing support for caregivers may improve the health not only of the caregivers, but also of the patients themselves. This should be explored in future studies.

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