

Impact of Multiple Sclerosis on Family and Employment A Retrospective Study in the Aegean District of Turkey

Muhtesem Gedizlioglu, MD; Hatice Mavioglu, MD; Fatma Uzunel, Neurology Nurse; Pinar Ce, MD, PhD; Meral Oguz, PsyD; Ayse Sagduyu, MD; Behiye Özer, MD, PhD; Yasar Zorlu, MD, PhD; Egemen Idiman, MD; and Hasan Korkmaz, MD

Dr. Gedizlioglu is an Associate Professor and Head of the Neurology Clinic at SSK Izmir Teaching Hospital in Izmir, Turkey. Dr. Mavioglu is a member of the Department of Neurology at Celal Bayar University in Manisa, Turkey. Ms Uzunel is a Specialist Nurse of Neurology at Dokuz Eylül University in Izmir, Turkey. Dr. Ce is in the Department of Neurology at SSK Izmir Teaching Hospital. Dr. Oguz is a psychologist at Dokuz Eylül University. Dr. Sagduyu is an Associate Professor in the Department of Neurology at Ege University in Izmir. Dr. Özer is Deputy Chief of the Neurology Clinic at Atatürk Health Center in Izmir. Dr. Zorlu is Chief of the Neurology Clinic at SSK Tepecik Teaching Hospital in Tepecik, Turkey. Dr. Idiman is a Professor and Head of the Neurology Department of Dokuz Eylül University. Dr. Korkmaz works in the Department of Neurology at Celal Bayar University.

Abstract

We investigated many of the effects of multiple sclerosis (MS) on patients in the Aegean District of Turkey who have had the disease for longer than one year to establish their social and occupational needs. Questions covered income, marital status, employment status of patient and spouse, housing, employment status of children, special care needs, and what changes had occurred in any of the preceding areas due to the illness. Our survey questionnaire yielded responses from 246 MS patients (ages 16-65; 87 men, 159 women) from the outpatient departments of six centers in Izmir, Turkey. The survey was conducted from March 2, 1998, to March 5, 1999. Survey results were tabulated and analyzed statistically for correlations between factors and were similar to other reports from western countries. Men reported reduced income and higher unemployment than women, many of whom were housewives. First-degree relatives carried the burden of caregiving. Disease duration and higher Expanded Disability Status Scale (EDSS) scores were strongly correlated with changes in employment, marital status, and housing. Higher EDSS scores had a negative impact on the spouse's work and the patient's need for care. Among disease types, secondary progressive MS (SPMS) also negatively affected the family structure. The disease had little effect on children's employment status.

Multiple sclerosis (MS) is a slowly progressive demyelinating disease of the central nervous system that typically first presents in patients between the ages of 20 and 40. It can have a serious impact on quality of life and family relations.¹ In addition to the more customary topics of specific medical and physical therapies, the psychosocial and cultural aspects of management have attracted much interest among MS societies. However, sociocultural surveys are poorly represented among all other published studies on MS.^{2,3} Unfortunately (and despite an expressed interest in the needs of MS patients and their families), it is difficult to say that

patients' social and psychological needs are being fully met. An important first step is determining the current status of these people in their country of residence. We carried out a detailed survey to reveal the social and occupational status of MS patients in the Aegean district of Turkey, including changes attributable to the disease. The six participating centers were the SSK Izmir Teaching Hospital; Celal Bayar University, Manisa; Dokuz Eylül University, Izmir; Ege University, Izmir; Atatürk Health Center, Izmir State Hospital; and SSK Tepecik Teaching Hospital.

The primary goal of this study was to determine the status of MS patients in a particular community who had lived with the disease for a number of years, as well as the situation of their families. It was hoped that the documentation of patients' economic, occupational, and marital status would help to better understand their problems. A second goal of the survey was to uncover the changes the disease caused in patients' lives. We evaluated the effect of the Expanded Disability Status Scale (EDSS), disease type, disease duration, age, and sex on patients' current status.

Patients

The 246 respondents to the survey questionnaire were outpatients from six university or teaching hospitals in Izmir and Manisa (aka the Izmir Study Group). The Izmir Study Group was composed of people who had had MS for at least one year, but not longer than 45 years. The study population represents 18.8% of the total MS population of the region, and is representative of the total MS population. The 246 respondents represent 100% of the patients who received the survey.

Methods

Questionnaire

Patients from all six centers completed a three-page questionnaire and a written consent form. The questionnaire included queries regarding income, occupational status, marital status, and education. Respondents replied to questions about their living arrangements, their hobbies, their need for care, who provided their care, and their smoking and drinking habits. The questionnaire asked about any changes in their behavior or the behavior of their children, their living situation, their place of residence, and their social and spare time activities. Overall, the intention was to determine the effects of MS on the patient and the family. The questions were a mixture of several types: yes/no, multiple-choice, and open-ended. The survey was conducted from March 3, 1998 to March 5, 1999.

In addition to the 25 numbered items, the questionnaire asked about patients' age and sex, duration of MS, and EDSS at the time of testing (as stated by the physician). Information about the current subtype of MS (relapsing remitting MS [RRMS], secondary progressive MS [SPMS], and primary progressive MS [PPMS]) was also gathered to determine the relationship between these factors and changes experienced by the MS patients and their families.

Statistical Evaluation

All the data were collected at one center and recorded for computer analysis. The present situation of our sample of patients was represented by income, education, marital status, place of residence, employment, profession, drinking and smoking, hobbies, and the effect of the disease on the patient's children, caregivers, spouse, and friends. The impact of EDSS, duration and type of disease, age, and sex on the variables was analyzed by using the Mann-Whitney U test, *t*-test, chi-square test, and Fisher exact test.

Results

The results of the study are presented in three ways: Demographic information to reflect current status was tabulated as frequency of occurrence (Table 1); the effects of MS on lifestyle, family relations, employment, etc, were tabulated similarly (Table 2); a statistical analysis was performed to determine the relevance of EDSS scores, type of disease, duration of disease, and sex to the changes caused by MS (Table 3). EDSS scores had a greater influence than any other single factor. The impact of the disease was greater for men than women in terms of unemployment, decline in income, need for caregiving, and change of residence (see Figure).

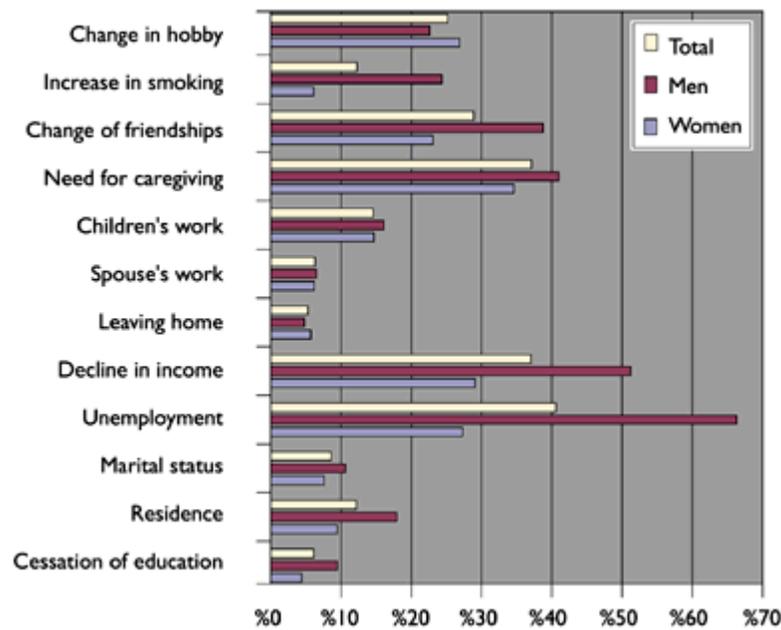


Figure. Impact of MS on Lifestyle Measurements (Men, Women, and Total).

Table 1. Patient Demographics.

Age (y ± SD)	Mean: 38.19 ± 9.2; range: (16-65)
Gender (n = 246)	Men: 87 (35.3%); women: 159 (64.7%)
Disease duration (from diagnosis) (y ± SD)	Mean: 7.81 ± 6.77; range: (1-45)
Disease type	RRMS: 167 (67.9%); SPMS: 68 (27.6%); PPMS: 11 (4.5%)
EDSS at the time of form application (± SD)	Mean: 3.28 ± 1.82; range: (0-9)

RRMS = relapsing remitting multiple sclerosis (MS); SPMS = secondary progressive MS; PPMS = primary progressive MS; EDSS = Expanded Disability Status Scale.

Of the 246 survey respondents, 159 were women (64.7%) and 87 (35.3%) were men (Table 1). The majority of the patients had RRMS (67.9%). The job of housewife had the largest response, reflecting the study's female majority and the national characteristics of Turkey's population: 35% of the respondents declared themselves housewives, and 21% of the spouses of respondents were housewives.

Table 2. Responses to the Multiple Sclerosis Status Questionnaire.

Item Number	Parameter	Patient Response (percentage)
1	Educational level (graduated)	Elementary school: (4.1); high school: (45.1); college: (26.8); PhD: (0)
2	Cessation of education due to illness	Yes (6.1); No (93.9)
3	Marital status	Not married: (18.3); married: (72.4); spouse deceased: (3.3); divorced: (6.5)
4	Any change in marital status due to disease	Yes (8.6); no (91.4)
5	RESIDENCE	
	Type of home	Barracks: (5.7); one-story house: (26.5); apartment: (64.5); mansion: (3.3); nursing home (0)
	Ownership of house	Self: (29.9); rent (24.5); spouse: (45.6)
	Features of house	One room: (1.6); two-three rooms: (35.7); four or more rooms: (62.7)
6	Any change in residence due to disease	Yes: (12.2); no: (87.8)
7	Profession	Unemployed: (16.7); housewife: (35); office worker: (18.7); self-employed: (8.5); manual laborer: (6.5); farmer: (2.0); retired: (12.6)
8	Change in occupation due to disease	Yes (positive): (2.5); yes (negative): (40.9); no: (56.6)
9	Level of income	Very low: (26.2); low: (37.1); medium: (25.7); high: (11)
10	Any change in income due to illness?	Yes (positive): (3); yes (negative): (37); no: (60)
11	Living arrangements	Alone (1.2); with parents: (22.8); with any relative: (1.2); spouse-children: (74.8); friends: (0)
12	Number of people in the family	One person (5.6); two-four people: (78.7); more than four people: (15.7)

13	Any family member leaving home due to illness?	Yes (5.3); no: (94.7)
14	DRINKING AND SMOKING HABITS	
	Alcoholic beverage (type, amount)	Heavy: (0); moderate: (0), mild drinking: (6.8)
	Smoking	Yes (43.6); no (56.4)
15	Change in smoking due to illness	Yes (increase): (12.3); yes (decrease): (14.1); no: (73.6)
16	Do you have any hobbies? If yes, state...	Yes: (40.7); no: (59.3)
17	Any change in hobby due to illness?	Yes: (25.2); no: (74.8)
18	Spouse	Retired: (21.0); actively working: (58.0); housewife: (21.0)
19	Change in spouse's work due to illness?	Yes: (6.3); no: (93.7)
20	Children	Living together with patient: (85.7); living apart: (14.3)
21	Children's work	Preschool age/student: (87.8); actively working: (7.4); unemployed: (4.7)
22	Any change in children's school/employment status due to illness?	Yes: (14.6); no: (85.4)
23	Need for care giving?	Yes: (37.1); no: (62.9)
24	Identity of caregiver	Spouse: (45.6); parents: (30); child: (10.0); any relative: (14.4)
25	Any change of friendships due to illness?	Yes: (28.9); no: (71.1)

Table 3. Statistically Significant* Variables.

	Patients (%)	EDSS (P)	Type of disease (P)	Duration of disease (P)	Sex (P)
Reduction in income	37.0	.011	>.05	>.05	.006 (men)
Unemployment	40.9	<.05	<.05 (SPMS)	.011	<.05
Spouse's work	6.3	.005	.009 (PPMS)	>.05	>.05
Marital status	8.6	<.05	.001 (SPMS)	.025	>.05
Cessation of education	6.1	>.05	>.05	.07	>.05
Effect on children	14.6	>.05	>.05	>.05	>.05
Change in residence	12.2	>.05	.009 (SPMS)	.042	>.05
Leaving home	5.3	.001	.002 (SPMS)	>.05	>.05
Change in hobby	25.2	>.05	>.05	>.05	>.05
Caregiver need	37.1	.022	>.05	>.05	.02 (men)
Increase in smoking	12.3	>.05	>.05	>.05	>.05 (men)
Change of friendship	28.9	>.05	>.05	>.05	.009 (men)

* $P < .05$ is considered to be statistically significant.

EDSS = Expanded Disability Status Scale; SPMS = secondary progressive multiple sclerosis; PPMS = primary progressive multiple sclerosis.

The joint income level of patients was generally low or very low (63.3%), and 37% of the patients reported that their income had declined because of the illness. This decline was related to EDSS scores and was more marked for men than for women. The parent's illness had little influence on his or her child's occupation or education. Although only 6.3% of patients reported that MS had a negative influence on the spouse's work, higher EDSS scores did correlate to this response. PPMS was also strongly predictive of a negative impact on the spouse's work. Of the respondents, 18.7% were office workers and 16.7% were unemployed. Close to half of the respondents (40.9%) said there was a negative change in their occupation because of the disease, and over half (56.6%) said there was no change.

Nearly half of the patients had a high school education. A large majority of patients (93.9%), however, indicated that their disease had no influence on their education.

Slightly fewer than three quarters of the respondents were married. Only 8.6% reported a changed marital status resulting from their disease. The type of MS (particularly SPMS) had a statistically significant effect ($P = .001$) on marital status (Table 3). To a lesser extent, disease

duration affected marital status ($P = .025$). Marital status was also influenced by EDSS scores ($P < .05$).

Family members remained together despite the disease. The majority of the married patients (74.8%) continued to live with their spouse and children, and 22.8% lived with their parents. Most households were made up of two to four people (78.7%), and 15.7% of households were comprised of more than four people. In only 5.3% of the families had one of the family members left home primarily because of the illness; in this small group, EDSS scores tended to be higher and SPMS more common ($P = .001$ and $P = .002$, respectively). The majority of patients (91.0%) were living in either apartments or in simple one-story houses that belonged to them or their spouse (75.1%).

Several of the questionnaire items covered other psychosocial and cultural aspects of the effects of MS. Over one third of the patients (37.1%) reported that they needed help with aspects of daily living. For most of the patients, the caregiver was a first-degree relative, usually a spouse (45.6%), parent (30.0%), or other relative (14.4%). None of the patients lived in a nursing home (Table 2). Men, as well as all patients with higher EDSS scores, were more likely to need a caregiver ($P = .02$ and $P = .022$, respectively; Table 3).

Many patients (particularly men, $P = .009$), reported losing their old friends (39% of men and 28.9% of the total study population). They also increased their smoking (12.3% for total study population) ($P > .05$).

Among patients who had a hobby (40.7%), most were able to continue pursuing it despite their illness. About a quarter of all patients (25.2%) were forced to make a change.

The impact of disease on male and female patients was analyzed independently by percent (Figure I). The largest differences—all of which were greater for men than women—were in the values for unemployment, income loss, increase in smoking, change of friendships, change in residence, and need for caregiving.

Discussion

Questionnaire

Most of our patients reported low or very low monthly joint income. This is an alarming situation to which civil services and MS societies should consider responding, as there is a need to organize resources for assisting patients. MS exhausts the financial resources of a family and causes economic problems, even in high income groups.

Men were more likely than women to indicate that they had undergone a change in occupation and a reduction of income. Other studies revealed a similar gender difference in that the men experienced a greater impact on their occupation and income than the women.^{3,4} Catanzaro and Weinert reported a 39% negative work impact for men and 19% for women.³ Like most women in the Turkish population, most of the female respondents were housewives, which was the largest occupational group in our heavily female study population. When interference with daily housework was included, 40.9% patients experienced a negative impact on their occupation and 37.0% reported an income reduction due to disease (these findings reflect our sample's gender distribution). Only 2.5% of patients reported a better work situation, probably unrelated to their disease.

Our reported unemployment figures are much lower than those reported for North America.⁵ For his population in Halifax, Nova Scotia, Murray⁶ reported a job loss of 71%; La Rocca,⁴ for his population in New York, reported 77%; and Jackson,⁷ for his population in Vancouver,

British Columbia, reported 76%. Conversely, Spanish figures reported by Yelamos⁸ (55.6%) are lower and are closer to ours. However, nearly all of the patients in the North American studies had been employed outside the home before their illness and then became unemployed. In our sample, nearly half of the patients either never worked for pay or were housewives, for whom unemployment is scarcely represented. In Murray's study, 33% of women were performing housework, though they had previously been employed outside the home.⁶ Legal and social customs of different countries might also contribute to the difference.

Understandably, one might expect that marriage to a patient with unexpected bouts of serious functional loss would be quite difficult.¹ Nonetheless, only 8.6% of patients in our study sample reported a change of marital status due to disease. A similar rate was reported by Stenager.⁹ Most of our study patients were married and living with their spouse and children, but more severe disease tended to have a more destructive effect on family relationships. EDSS scores were much higher in the divorced group, as in Stenager's findings.⁹ Similarly, SPMS and longer duration of disease adversely affected marriages. Traditional cultural mores that discourage divorce in the Turkish population might influence the preservation of marriages. Higher EDSS scores ($P = <.05$) and a higher percentage of SPMS ($P = .001$) were the most predictive variables for this group.

Most of the respondents had a high school education. Since the average age of the patients was mid-30s and the average duration of the disease was about eight years, the disease did not seem to affect their education. Only 6.1% of patients discontinued their education because of MS.

MS seemed to have less of an effect on the patient's children than on the patient's spouse. Most children (85.7%) remained in the household with their parents. This result agrees with other reports, although we did not evaluate the psychological burden on the family.²

Only a few people in our study were forced to leave their homes for reasons linked to their illness. EDSS scores were predictive, as was increased incidence of SPMS. Stenager reported similar figures, with marked effect of greater handicap.⁹

The need for caregiving services is clearly demonstrated in repeated reports from other studies.^{2,9,11} Our survey reported that the majority of the burden of caregiving falls upon spouses. For that reason, it is important that caregivers receive psychosocial services to assist the family. Also, it is notable that no patient was reported to be living in a nursing home. This may reflect the lack of sufficient facilities for the disabled, because other studies have shown that a reasonable proportion of patients need such services.¹²

We found changes in the spare-time and social behaviors of our MS respondents. About one fourth of our respondents reported a change in hobby. Most of our patients, however, continued with their previously established hobbies. We felt that the change in their hobby was unrelated to high EDSS, because the most reported hobby was fine handwork (embroidery and crochet). This does not agree with the findings of Stenager's study, in which spare-time activities were reportedly affected by moderate disability—probably attributable to strain.¹³ Stenager and colleagues reported that social contacts may not be seriously affected until late in the course of illness.⁹

Correspondingly, we found that nearly one third of the men in our study reported social isolation. Men also experienced greater change in their employment, income, smoking, and friendships. This might be explained by changing their lifestyle from work outside the home to being unemployed at home, versus the prevailing existing lifestyle of women—predominantly within the home.

Statistical Analysis

As a whole, the statistical analysis showed a marked correlation between having MS and a negative change in marital and occupational status, reduced income, spouse's work, patient's need for care giving, and higher EDSS scores. Similarly, patients with SPMS had a higher incidence of divorce, unemployment, or leaving home. The items for which there were correlations generally agreed with those found in the literature, although our absolute rates are quite a bit lower.^{4,9}

LaRocca reported a mean EDSS of 4.6 in his study of employment rates of MS patients.⁴ In contrast, the mean EDSS in our study was 3.2, which may be an independent factor for our reported lower unemployment rate. Higher EDSS was the strongest predictor of unemployment. Reduced income and disruption of marriage were also strongly predicted by EDSS in our sample, reflecting the findings of published reports.^{3,4,7,8,14}

Conclusions

From our survey of MS patients from the Izmir Study Group, we observed significant changes in their lives during the course of the disease. As in western countries, the families suffered economically from reduced income. In our study, men reported greater reduction of income than women, as a great many of the women are housewives who had never worked for pay. The patients, especially the men, frequently suffered from social isolation. A heavy burden was placed on the caregivers—usually the spouse or another first-degree relative—but no patient lived in a nursing home. The families remained together, seldom divorcing, which may reflect the local cultural and social norms. The statistical analysis showed several interactive effects on the lives of the MS patients and their families, particularly for patients with higher EDSS scores, SPMS disease, and longer disease duration.

References

1. Kalb RC. The impact of multiple sclerosis on the family. *Int MS J.* 1996;3(2):65-69.
2. MS Forum. Economic evaluation and consequences of MS. In: Arnason B. Ed. *Psychosocial Factors in Multiple Sclerosis.* Schering AG 1995, 15-17.
3. Catanzaro M, Weinert C. Economic status of families living with multiple sclerosis. *Int J Rehabil Res.* 1992;15:209-218.
4. LaRocca N, Kalb R, Kendall P, Scheinberg L. The role of disease and demographic factors in the employment of patients with multiple sclerosis. *Arch Neurol.* 1982;39:256.
5. Hakim EA, Bakheit AM, Bryant TN, et al. The social impact of multiple sclerosis—a study of 305 patients and their relatives. *Disabil Rehabil.* 2000;22(6):288-293.
6. Murray TJ. The psychosocial aspects of multiple sclerosis. *Neurol Clin.* 1995;13:197-223.
7. Jackson MF, Quaal C, Reeves MA. Effects of multiple sclerosis on occupational and career patterns. *Axone.* 1991;13:16-17, 20-22.
8. Yelamos MS, Yelamos MM, Hernanden Regadera JJ, et al. The social and work related impact of multiple sclerosis. *Neurologia.* 1999;14:107-110.

9. Stenager E, Stenager EN, Knudsen L, Jensen K. Multiple sclerosis: the impact on family and social life. *Acta Psychiatr Belg.* 1994;94:165-174.
10. DesRosier MB, Catanzaro M, Piller J. Living with chronic illness: social support and the well spouse perspective. *Rehabil Nurs.* 1992;17:87-91.
11. Dewis ME, Niskala H. Nurturing a valuable resource: family caregivers in multiple sclerosis. *Axone.* 1992;13:87-94.
12. Kraft GH, Freal JE, Coryell JK. Disability, disease duration, and rehabilitation service needs in multiple sclerosis: patient perspectives. *Arch Phys Med Rehabil.* 1986;67:164-168.
13. Stenager E, Knudsen L, Jensen K. Multiple sclerosis: the impact of physical impairment and cognitive dysfunction on social and sparetime activities. *Psychother Psychosom.* 1991;56:123-128.
14. Matthews WB. Clinical aspects, course and prognosis. In: Matthews WB, ed. *McAlpine's Multiple Sclerosis.* 2nd ed. Edinburgh, Scotland: Churchill Livingstone; 1991:151-152.