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A Holistic Look at Patients With Multiple Sclerosis: Focusing on Social Life, Household and Employment Issues

Multiple Sklerozlu Hastalara Bütünsel Bir Yaklaşım: Sosyal Yaşam, Aile Hayatı ve İş Sorunları

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Summary

Objective: This study identifies the impact of multiple sclerosis (MS) on patients' employment status, social and family life. Additionally, the purpose of the study was to explore the problems related to completing outdoor and indoor household tasks, the effect of disease on relatives, familial support perceived by patients, and the attitudes of relatives toward the disease.
Materials and Methods: A descriptive design utilizing a questionnaire developed by the researchers and comprised of open-ended and non-rated questions was used in the study. According to the sample size formula for given population size, 101 patients with MS were recruited from the neurology clinic.
Results: In comparison with pre-disease frequency, 71.3% of patients had a decreased social activity level. Even though 49.5% of patients reported to have a household problem, 94.1% perceived at least one kind of support from family members. The rates of difficulties in maintaining indoor and outdoor tasks were 35.6% and 40.6%, respectively.
Conclusion: Patients' mean symptom number of symptoms negatively correlated with household issues, maintaining indoor and outdoor tasks, social activity level and employment status ($p<0.05$). Post-disease social activity level was associated with long duration of diagnosis, unemployment and transportation difficulties outside the home ($p<0.05$). *Turk J Phys Med Rehab 2011;57:19-24.*

Key Words: Multiple sclerosis, social contact, relationship, employment, housework

Özet

Amaç: Bu çalışma multipl skleroz (MS) hastalarının iş durumu, sosyal hayatı ve aile yaşamı üzerindeki etkisini tanımlamaktadır. Ayrıca çalışmanın amacı, ev içi ve dışındaki görevlerin tamamlanmasında yaşanan sorunlar ile; yakınlar ve hasta tarafından algılanan aile desteği üzerine hastalığın etkisini ve yakınların hastalığa yönelik tutumunu belirlemek amaçlanmıştır.
Gereç ve Yöntem: Tanımlayıcı tasarıma sahip çalışmada, araştırmacılar tarafından geliştirilen, açık uçlu ve derecelendirilmemiş sorulardan oluşan anket formu kullanılmıştır. Örneklem hesaplama formülüne göre; nöroloji kliniğinden 101 MS hastası çalışmaya alınmıştır.
Bulgular: Hastalık önceki sıklıkla karşılaştırıldığında, hastaların %71,3'ünün sosyal faaliyet seviyesi düşmüştür. Hastaların %49,5'i ailevi sorunlar yaşasa da, %94,1'i aile üyelerinden en az bir çeşit destek almıştır. Ev içi ve ev dışındaki işleri sürdürmekteki zorluk oranları sırasıyla %35,6 ve %40,6 olmuştur.
Sonuç: Hastaların ortalama semptom sayılarının ailede yaşanan sorunlar, ev içindeki ve dışındaki görevlerin sürdürülmesi, sosyal faaliyet seviyesi ve iş durumu ($p<0,05$) ile negatif şekilde ilişkili olduğu saptanmıştır. Hastalık sonrası sosyal faaliyet seviyesinin; uzun süre önce tanı alma, işsizlik ve ev dışındaki ulaşım zorluklarıyla bağlantılı olduğu belirlenmiştir ($p<0,05$). *Türk Fiz Tıp Rehab Derg 2011;57:19-24.*

Anahtar Kelimeler: Multipl skleroz, sosyal etkileşim, ilişki, iş durumu, ev işleri

Introduction

Multiple sclerosis (MS) is a chronic and progressive disease of the central nervous system (CNS) that is generally considered to be autoimmune and characterized by widespread lesions, plaques and demyelination in the brain and spinal cord (1,2). MS is a universal disease affecting 30 people per 100,000 with a range of 5-80 (3). Regionally, the median estimated prevalence of MS is greatest in Europe, followed by the Eastern Mediterranean, the Americans, the Western Pacific and South-East Asia. The prevalence of MS in Turkey is similar to this global estimation (3). Regarding gender differences, the occurrence of disease is more common in females, with a female/male ratio of 2:1 (4,5).

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Because of the widespread development of plaques in the CNS, patients with MS suffer from broad range of symptoms. The most common presenting symptoms of MS are motor weakness, dysfunction or spasticity, sensory problems such as numbness and tingling, fatigue, visual disturbances, disturbed balance, vertigo, bladder and bowel problems, pain, heat and exercise intolerance, cognitive or behavioral problems and sexual dysfunction (6,7). The onset of MS symptoms is around 30 years of age (4,7). Because the onset of disease is at early stage of life, the effect of symptoms on patients with MS is notably disruptive and the loss in productivity can be substantial (1,4,7,8).

MS is not only a medical problem, but is also a social phenomenon that impacts beyond the individual. Getting diagnosed with MS changes the lives of both patients and relatives entirely (9,10). Disease-related functional decline will often interfere with the opportunities to perform their customary roles and family responsibilities (8,12). Especially difficulties in standing for a long period of time, walking, writing, memory/ concentration problems and fatigue are the reasons to stop working or for early retirement (5,9). The impact of MS on family dynamics and family budget is considerably detrimental owing to the employment issues, the expenditure of treatment and care, and changing roles of family members including the spouse or child as a caregiver (5,10,13,14).

Social participation and recognition by others are the key elements for coping with the disease and the symptoms. In this respect, patients with MS need to be encouraged to participate in social life and to engage in social activities (9). But the literature indicates that patients with MS tend to establish social relationships with relatives and other people with MS (15,16,17). In addition, they relinquish most of former social activities (10).

In Turkey, a study regarding familial, social and working problems of patients with MS has not been conducted yet. Owing to strong adherence to customs, closed structure of the families and less legitimate and economic support to disabled people in Turkey (18), the impact of MS on individual and family might be different from in other countries. The aim of this study was to identify patients' economic and employment status, social and family life issues since getting diagnosed with MS. Additionally, the purpose of the study was to explore the problems related to completing outdoor and indoor household tasks, the effect of disease on relatives, familial support perceived by patients, and the attitudes of relatives toward the disease.

Materials and Methods

A descriptive design utilizing a questionnaire comprised of open-ended and non-rated questions was used in the study. Participants were recruited from the neurology clinic of one university hospitals in Turkey. Since the admission rate of patients with MS was known (80 patients per year), the sample size formula for given population size was used. The sample size was calculated at 101, based on this formula. 101 consecutive patients were recruited from the neurology clinic over a period of 13 months. All adult patients aged 17 years and over were recruited into the study. No other inclusion or exclusion criteria were used in this study.

The research instrument consisted of a questionnaire developed by the researchers and included the following sections: first, general characteristics of patients; second, questions related to household tasks including shopping, paying bills, as well as questions regarding attitudes of relatives toward patients, difficulties lived with the household, the kind of support from family, social contacts and engaging in social activities outside the home, difficulties experienced when socializing; third, existence of disease symptoms (5,9,10,16).

In order to attain patients' intact expressions without any restriction, open-ended questions were utilized in this study. So as to evaluate the content validity of the questionnaire, two experts' opinions were obtained and necessary corrections were made in the form according to their suggestions. Since the questionnaire implemented in the present study did not contain numerical ratings, a small pilot study was conducted with 10 MS patients to ensure that the open-ended questions were posed explicitly. As there was no negative feedback from patients, the format and content of the questionnaire were not changed.

Official permission was obtained from the institution included in the sampling. Informed consent was obtained from the patients after verbal and written explanations of the study objectives; confidentiality of information was ensured.

The data were analyzed using the Statistical Package for Social Sciences 10.0 (SPSS). The chi-square test was used to determine statistical significance between categorical variables. Because the data were normally distributed according to the Kolmogorov-Smirnov Z test (Kolmogorov-Smirnov Z=1.315, p=0.063), the independent samples t-test was used to compare the mean number of symptoms for dependent variables including household problems, employment status, maintaining indoor and outdoor tasks, existence of social contacts and social activity level.

Results

Study Population

Of the patients, 55 (54.5%) had diagnosis of MS for more than four years, 50 (49.5%) were between 31 and 45 years of age (mean age: 34.9, SD: 10.8, min.: 17, max.: 63), 66 (65.3%) were female, 77 (76.2%) had further than high school education, 44 (43.6%) were unmarried and 11 (10.9%) were divorced due to disease symptoms and marital conflict, 48 (47.5%) were unemployed and 13 (12.9%) had termination of employment or premature retirement due to disease symptoms, 63 (62.4%) perceived their economic condition as "moderate" and 42 (41.6%) had transportation difficulties outside the home. The patients had mean 5.9 symptoms of MS such as fatigue (n=85, 84.2%), gait and balance problems (n=75, 74.3%), pollakiuria (n=57, 56.4%), pain (n=56, 55.4%), bowel problems (n=54, 53.5%), emotional disorders (n=54, 53.5%), urinary incontinence (n=50, 49.5%), visual problems (n=42, 41.6%), cognitive problems (n=19, 18.8%), speech disorders (n=16, 15.5%) and sexual problems (n=15, 14.9%).

Table 1. Distribution of household problems and involvement in social life.

Household problem fields, n: 50*	**N (%)**
Communication	35 (70)
Overprotective attitude of the family	8 (16)
Care-related issues	8 (16)
Working conditions/economical difficulties	6 (12)
Denial of the disease	5 (10)
Unable to go outside with family	4 (8)
Being able to maintain housework, n: 101	
Yes	65 (64.4)
Partial	31 (30.7)
No	5 (4.9)
Being able to maintain outdoor tasks (paying bills and shopping), n: 101	
Yes	60 (59.4)
No	41 (40.6)
Existence of social contacts, n: 101	
Yes	86 (85.1)
No	15 (14.9)
Current social activity level, n: 101	
Once a week and higher	33 (32.7)
Once every 2-3 weeks	23 (22.8)
Once a month and lower	21 (20.8)
None/rare	24 (23.8)
Difficulties experienced at social environment, n: 101*	
Gait and balance problems	55 (54.4)
Fatigue	14 (13.9)
Excessive distance to toilet	10 (9.9)
Being hit by other people while walking	8 (7.9)
Visual problems	6 (5.9)
Disease exacerbation	5 (4.9)
High stairs	4 (4)
Pain	3 (3)
Cigarette smoke	3 (3)
Economical problems	3 (3)
Transportation problems	2 (2)

*Percentages do not sum to 100% due to multiple answers.

Household Problems, Involvement in Social Life and Social Activity Level

Half of the patients (49.5%) experienced household problems including communication issues, overprotective attitude of the family, care-related issues, difficulties in working and monetary conditions, family members' denial of the disease, and inability to go outside with the family. Besides, almost half of the patients had some degree of difficulties in maintaining indoor (partial: n=31, 30.7%; unable to do: n=5, 4.9%) and outdoor housework (unable to do: n=41, 40.6%) (Table 1). Nearly all patients (n=95, 94.1%) had support from the family members including moral and tangible support such as economical, housework, self-care, transportation and treatment assistance. According to patients' expressions, the attitudes of family members toward them were usually "positive" (n=45, 44.5%) and "supportive" (n=41, 40.6%). However, some family members were "unable to understand the disease and symptoms" (specifically invisible symptoms such as fatigue and balance problems) (n=11, 10.9%), some were "overprotective" (n=8, 7.9%) or "adopted the disease", the rest were "denying" (n=3, 3%) or "disregarding" (n=2, 2%) the disease.

As regards to patients' social involvement, most of them (n=86, 85.1%) had at least one social contact (Table 1). Among socially active patients, the most frequent activities were shopping (19), going to the cinema/theatre (17), dining (10), walking outside (9), meeting up with friends at home (9), picnic (7), playing games (7), going on a holiday (4) and going to the park (4). Most of the patients were engaging in social activity at least once a week (n=33, 32.7%) and once every 2-3 weeks (n=23, 22.8%). But, others had a social activity once a month or less (n=21, 20.8%) and were not or hardly ever (n=24, 23.8%) participating in a social group (Table 1). In comparison with pre-disease frequency, the majority (n=72, 71.3%) had a decreased social activity level. Besides, almost half of the patients felt themselves restless and anxious (n=39, 38.6%), insecure (n=13, 12.9%), desperate (n=10, 9.9%), unhappy (n=8, 7.9%), lonely (n=5, 4.9%), tired (n=3, 3%), worthless (n=3, 3%), jealous and ashamed (n=2, 2%) at the social environment. The rest (n=49, 48.5%) noted that they were comfortable at social occasions. Among difficulties experienced at social environment, gait and balance problems (n=55, 54.4%), fatigue (n=14, 13.9%), excessive distance to toilet (n=10, 9.9%), being hit by other people while walking (n=8, 7.9%), problems related to visual disorders (n=6, 5.9%), disease exacerbation (n=5, 4.9%), high stairs (n=4, 4%), pain (n=3, 3%), cigarette smoking (n=3, 3%), monetary problems and difficulties in transportation (n=2, 2%) were stated (Table 1).

The Variables Influential on Household Problems, Maintaining Housework, Employment Status, and Social Activity Level

According to the statistical analysis, patients who had household problems (6.9 vs. 5.0), difficulties in performing indoor (7.5 vs. 5.1) and outdoor tasks (7.1 vs. 5.1), decreased social activity level (6.6 vs. 4.4) and who had not got a paid-job (6.4 vs. 5.2) and social contacts (7.2 vs. 5.6) reported more symptoms of MS ($p<0.05$) (Table 2). Besides, most of the patients who could not maintain indoor housework were unmarried/divorced (n=25, 69.4%) and were not going outside home alone (n=32, 88.9%) ($p<0.05$). The factors which had a negative correlation with maintenance of outdoor tasks were unemployment (n=32, 78%), transportation difficulties outside the home (n=29, 70.4%), and inability to go outside the home alone (n=37, 90.2%) ($p<0.05$). The variables influential on existence of social contacts were the time of diagnosis (4 years and above) (n=12, %80), unemployment (n=13, 86.7%), inability to go outside home alone (n=12, 80%), and transportation difficulties outside home (n=11, 73.3%) ($p<0.05$). Regarding post-disease social activity level, decrease in social activity was statistically significant for patients diagnosed with MS more than four years ago (n=45, 62.5%), unemployed (n=51, 70.8%) and experiencing transportation difficulties outside the home (n=38, 52.8%) ($p<0.05$) (Table 3). Although not seen in the tables, there were no significant differences in maintaining indoor-outdoor tasks and post-disease social activity level regarding age and gender (χ^2=0.161, p=0.688; χ^2=0.043, p=0.836; χ^2=0.025, p=0.874; χ^2=2.493, p=0.114; χ^2=1.706, p=0.426; χ^2=1.860, p=0.173).

Discussion

The findings of this study substantiated the idea that patients with MS tend to be well-educated, with a high proportion (76.2%) of at least high school education. As a result of high education level, patients with MS usually were experienced workers (13). However, the literature indicates that most of the patients were unable to sustain their jobs owing to negative effects of disease and its symptoms (5,9,12). Similarly, our findings showed that almost half of the patients (47.5%) were unemployed and some (12.9%) gave up working or retired early due to the disease. In this study, high unemployment rate was a striking finding when comparing the rate of 15.5% for the total population of Turkey. Probably, the patients in this study did prefer not to enter the workforce because of the relapsing nature of the disease. Disability and dependency associated with MS, economic stains originating from medical and care expenses as well as loss of the job have a destructive impact on marriages and relationships (13). Because of the burden of disease on family members, the divorce rate was found to be high in patients with MS (5,10,16). When considering 2.1% as a rate of divorce in the Turkish society, the patients in this study showed to have a five-fold increased risk of divorce (10.9%) (18). Additionally, the view that MS affects patients' marriage was supported by our findings indicating that patients who could not do housework were most likely unmarried or divorced ($p<0.05$).

It has been suggested in the literature that patients with MS usually received moderate support from family members and the amount of support varied with the severity of symptoms and the level of dependency (19,20). These studies indicated that patients applied to family assistance for self-care, transportation and housework (16,21). Accordingly, the proportion of support in our study was significant with a 94.1% rate mostly including moral support. However, because of fluctuating nature of symptoms, family members could have difficulties in comprehending the course of disease (13). Our findings attested that family members were unable to understand particularly invisible symptoms of MS such as fatigue and balance problems.

Table 2. The difference between total number of disease symptoms by household problems, employment status, and social activity level.

Household problems	Mean number of symptoms±SD	t	p
Yes (n: 50)	6.9±2.4	3.656	0.000
No (n: 51)	5.0±2.6		
Employment Status			
Employed (n: 40)	5.2±2.8	-2.175	0.032
Unemployed (n: 61)	6.4±2.4		
Maintaining indoor tasks			
Yes (n: 65)	5.1±2.5	- 4.436	0.000
No (n: 36)	7.5±2.3		
Maintaining outdoor tasks			
Yes (n: 60)	5.1±2.8	-3.666	0.000
No (n: 41)	7.1±1.9		
Existence of social contacts			
Yes (n: 86)	5.6±2.7	-2.057	0.042
No (n: 15)	7.2±1.8		
Post-disease social activity level			
The same (n: 29)	4.4±2.5	3.768	0.000
Decreased (n: 72)	6.6±2.7		

Table 3. The variables influencing maintenance of housework, existence of social contacts and social activity level.

	Maintaining indoor housework				
Marital Status	Yes		No		χ2
	n	%	n	%	p-value
Married	35	53.8	11	30.6	4.172
Unmarried+ Divorced	30	46.2	25	69.4	0.041
Being able to go outside the home alone					
Yes	49	75.4	4	11.1	35.844
No+ Rarely	16	24.6	32	88.9	0.000
	Maintaining outdoor tasks				
Employment status	Yes		No		χ2
	n	%	n	%	p-value
Employed	31	51.7	9	22	7.792
Unemployed+ termination of employment	29	48.3	32	78	0.005
Being able to go outside the home alone					
Yes	49	81.7	4	9.8	47.662
No+ Rarely	11	18.3	37	90.2	0.000
Difficulties in transportation outside the home					
Yes	13	21.7	29	70.7	22.160
No	47	78.3	12	29.3	0.000
	Existence of social contacts				
The time of diagnosis	Yes		No		χ2
	n	%	n	%	p-value
3 years-↓	43	50	3	20	3.504
4 years-↑	43	50	12	80	0.051
Employment status					
Employed	38	44.2	2	13.3	3.875
Unemployed+ termination of employment	48	55.8	13	86.7	0.049
Being able to go outside the home alone					
Yes	50	58.1	3	20	5.999
No+ Rarely	36	41.9	12	80	0.014
Difficulties in transportation outside the home					
Yes	31	36	11	73.3	5.856
No	55	64	4	26.7	0.016
	Post-disease social activity level				
The time of diagnosis	Decreased		The same		χ2
	n	%	n	%	p-value
3 years-↓	27	37.5	19	65.5	5.462
4 years-↑	45	62.5	10	34.5	0.019
Employment status					
Employed	21	29.2	19	65.5	9.951
Unemployed+ Termination of employment	51	70.8	10	34.5	0.002
Difficulties in transportation outside the home					
Yes	38	52.8	4	13.8	11.379
No	34	47.2	25	86.2	0.001

A vast majority of studies suggested that most patients have some degree of restriction on their social activity arising from MS (11,12,16). While depending on the severity of symptoms, nearly all patients experienced a decrease in social involvement and some ceased to engage in any kind of social occasion (12,16). In accordance with the literature, our findings indicate that most patients' (71.3%) social activity level declined owing to the symptoms of disease and a considerable amount of patients (23.8%) were not participating in any social activity. Even if the patients could sustain certain social activities, some of them felt themselves restless and anxious, insecure, desperate, unhappy, lonely, tired, worthless, jealous and ashamed. Additionally, in the present study, it was observed that the patients suffered from the symptoms of disease, most frequently gait-balance issues and fatigue, during the social occasions. The patients of present study also reported some environmental difficulties including excessive distance to toilets, being hit by other people while walking, high stairs, cigarette smoking and transportation problems. According to the literature, logical problems were attributed to the reason for this 'shrinkage' of their social life and for the limitation on patients' participation in activities outside the home such as lack of toilets and wheelchair access, stairs and narrow passages (10). Attitudes of others, discrimination or stigma were also great barriers to having a social life (10,17).

Owing to the early onset of disease, patients with MS and their families mostly were obligated to cope with loss of roles and changing circumstances in their lives (13,16). Depending on patients' coping level and social support resources, this young patient population usually felt anger, resentment and guilt (13). According to the studies, the most destructive and prevalent symptoms of disease were fatigue and mobility problems. These symptoms were identified as the main reason for limitation in social activities (1,16). In these cases, patients prefer reducing their social activities to preserve energy (9).

The severity and the frequency of symptoms were reported as the prominent barriers to maintain indoor and outdoor tasks, to engage in social occasions and to remain at work force. Particularly with certain symptoms such as physical disability, fatigue, depression and cognitive impairment, patients with MS have little chance to keep their position at the work place or get a promising career (14,15). Besides, the course of disease and the frequency of symptoms were the most significant factors to impact on family dynamics (1,5,10,13,22,23). Correspondingly, our findings affirmed the influence of symptom frequency on patients' family and working life. Our findings also indicated that the patients who were unemployed had transport difficulties outside the home and were unable to go outside the home alone, could not do outdoor tasks. This findings implied that maintaining outdoor tasks require a high level of function including not only able to sustain employment but also able to transfer outside independently (1,11,16). Besides, the findings of present study suggested that employment status, going outside the home independently and the time of diagnosis also defined the existence of social contacts and post-disease social activity level. The main conclusion from this finding was that as the time of diagnosis increased, patients' well-being and level of independence are decreased (5,11,16,23). Consequently, MS affected patients' all aspects of outside functioning negatively.

The limitations of this study were that the results can merely represent the study population. It cannot be assumed that the sample used was representative of the entire population of patients with MS in Turkey. Additionally, the study was of a small scale and depended on self-report data of patients to the open-ended questions. This potentially limits the generalizability of the findings.

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