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Challenges of patients with multiple sclerosis in receiving health care services in Iran

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Multiple Sclerosis; Iran; Challenge; Health Services; Quality of Life

Abstract

Background: Multiple sclerosis (MS) is a debilitating, non-traumatic, neurological disorder in young adults and can reduce quality of life (QoL) by interfering with the ability to work, leisure activities, and routine living tasks. Various studies have shown the dissatisfaction of people with MS in different areas of care services. Regarding the patients' weakness with care and services, we sought to identify the challenges for patients with MS in receiving care and services in Iran.

Methods: This cross-sectional study was conducted in 2016-2018 using a researcher-made questionnaire (designed by MS Specialists in an MS research center). The questionnaire examined the care challenges in four areas: 1) costs of medication, hospitalization, and rehabilitation services, 2) family support, insurance system, and job protection, 3) access to transportation system and treatment team, 4) quality of the provided care and services.

Results: Completed questionnaires were received from 945 respondents. The mean age of responders was 35.92 years. In total, 731 (77.8) participants were women and 208 (22.2) were men. Academic education was reported among 615 (65.3) participants and 367 (40.2) were employed during the study, while 99 (10.5) of the subjects were not able to walk a minimum of 20 meters.

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The prioritization of care services challenges was as follows: the cost of pharmaceutical services (49.1), lack of telephone counseling (47.4), uninsured home rehabilitation (44.7), lack of qualified care centers (41.2), and rehabilitation costs (40.2).

Conclusion: We found that patients who could not walk at least 20 meters and unemployed individuals had more problems and lower QoL. The patients who had non-academic education had more challenges with the cost of medication, transportation, and lack of familial support. This study shows the challenges of MS patients in receiving health care in Iran that vary in age, education, employment, and ability to walk. As the abovementioned challenges are of great importance in determining the QoL of people with MS, an appropriate solution is provided in this study to overcome these challenges.

Introduction

Multiple sclerosis (MS) is a chronic neurodegenerative disease leading to long term disability in young adults.[1] MS manifests with different signs such as visual and sensory impairment, limb weakness, bladder impairment[2] and bowel dysfunction,[2] balance problems, sexual[2,3] and sleeping problems[4] that reduce quality of life (QoL). Fatigue is experienced by most of the patients with MS is considered as one of the main factors that reduce their QoL.[5]

Patients with MS experience a varied range of signs and as a result require a different level of health care[6] based on their level of disability, which is measured using the Expanded Disability Status Scale (EDSS),[7] disease duration,[8] and type of MS.[9]

Patients with advanced stages of MS require more care,[10] support of family and friends, health care services, and daily life management.[11]

In addition to the abovementioned MS symptoms, its emotional symptoms such as depression[9] and anxiety[12] also have negative effects on QoL, so patients with MS need an advanced system of care.[10]

The prevalence of MS has risen in Iran in the last two decades.[13] The prevalence of MS was 148.06 per 100000 population in Tehran, Iran, in 2017.[14]

Some of the challenges of MS patients include rehabilitation, assistive devices, transportation services, medical and health insurance, and social supports.[10] Social supports has positive effects on QoL,[15] the role of social support is important because self-esteem is mediated in the relationship of Mental Composite Score (MCS) with it.[16]

Relationship with the MS healthcare team and family members[17] is of great importance because, with the progression of the disease, the ability of the patient for self-care may decrease and the responsibility of patient care shift to their family.[18] Moreover, failure to follow-up, difficulty to access to health care services, long wait for receiving service,[19] the financial burden of disease that has negative effects on QoL, MS patients are affected by the direct and indirect costs of the disease. Direct medical costs of MS in the United States are more than $10 billion per year.[20] which is due to patient's use of costly medication and treatments.[18]

Some of the indirect costs of this disease are costs of decreased employment, assistive devices, personal care and home remediation related to patients' disability,[20] treatment expenses, and information about self-care.[19] Employment influences the QoL of MS patients. Based on several studies there is an association between unemployment and poor QoL.[21]

In contrast, MS patient's satisfaction with their job and the combination of employment with high education levels have positive effects on QoL.[22,23] High level of education has positive effects on QoL.[22] Various studies have shown the dissatisfaction of MS patients with different areas of the care systems such as rehabilitation services,[24] equipment, physiotherapy and wheelchairs,[25] vocational services,[26] and coordination between services.[27] Regarding the patient's dissatisfaction with care services, we sought to identify the challenges of MS patients in receiving health care in Iran.

Materials and Methods

This cross-sectional study was conducted in 2016-2018 among MS patients who referred to Sina Hospital (a tertiary care referral center) in Tehran, Iran.

MS diagnosis was confirmed for all cases by neurologists using the 2017 McDonald criteria.[28]

In Sina Hospital, there are neurology and MS wards, and a specialized MS clinic that provide services to patients from all over the country.

The research instrument used in this study was a researcher made-questionnaire designed in the MS research center of Tehran University of Medical Sciences, Iran.

The questionnaire was designed to determine the main epidemiological variables including demographic characteristics and the challenges of

MS patients in receiving health care services in Iran.

The demographic characteristics obtained in this questionnaire include the patient's sex, age, education level, marital status, employment status, and ability to walk.

The face validity of the questionnaire was determined through the comments and views of a panel of 7 experts. Their ideas and comments helped to revise the items to seem valid.

These experts evaluated the appearance of the questionnaire in terms of feasibility, readability, consistency of style and formatting, and the clarity of the language used.

The initial questionnaire was completed by about 67 MS patients in a pilot study, and after the essential review, the indicators of receiving health-related services were included as the final variables in the different categories.

This questionnaire examines the challenges of healthcare delivery in four domains:

I. Costs of medication, hospitalization, and rehabilitation services

II. Familial support, insurance system, and job protection

III. Access to transportation system and treatment team

IV. Quality of the provided care and services.

The items of the questionnaire are scored based on a 5-point Likert scale (very low, low, moderate, high, and very high).

The 3 trained interviewers described the purpose of the study for the patients and after obtaining consent from the patients, face-to-face interviews were conducted with all individuals.

If less than 50 items of a questionnaire were answered, it would be excluded by researchers. The statistical analysis was performed by SPSS software (version 23, IBM Corp., Armonk, NY, USA).

The chi-square test and independent-sample t-test were used to compare the determined variables. Two-tailed P-values < 0.05 were considered significant.

Ethical consideration: The objectives of the study were explained to all participants before entering the study and they filled out a written informed consent form. This study was conducted under the supervision of the National Institute for Medical Research (NIMAD) ethics committee. The official registration code for this study is: IR.NIMAD.REC.11397.432.

Results

Epidemiological data: The final dataset that was included in the study analysis consisted of 945 responders. The mean age of the responders was 35.92 years (minimum 18 and maximum 68 years).

The descriptive characteristics of the participants are presented in table 1.

There was no significant difference between men and women in terms of education (P = 0.183) and marital status (P = 0.106).

There was a significant difference between men and women in terms of employment status (P ≤ 0.010); 46.1% women were housewives and 33.4% were employed, while 64.3% men were employed. Moreover, 31 patients were disabled (according to patient's self-report), of which, 14 were women (2% of women) and 17 were men (8.5% of men).

Table 1. The descriptive and demographic characteristics of the patients with multiple sclerosis (MS)

Variable	Value
Gender [n (%)]	
Male	208 (22.2)
Female	731 (77.8)
Age group (year) [n (%)]	
18-28	184 (19.7)
29-38	443 (47.4)
39-48	212 (22.7)
49-58	88 (9.4)
59 and above	8 (0.8)
Education level [n (%)]	
Non-academic education	327 (34.7)
Academic education*	615 (65.3)
Marital status [n (%)]	
Single	319 (33.8)
Married	561 (59.5)
Divorced	53 (5.6)
Widowed	10 (1.1)
Number of children [n (%)]	
0	126 (21.7)
1	223 (38.4)
2	179 (30.9)
3 and more	52 (9.0)
Employment status [n (%)]	
Employed	367 (40.2)
Unemployed	162 (17.8)
Housewives	328 (36.0)
Retired	24 (2.6)
Disabled	31 (3.4)
Ability to walk at least 20 meters [n (%)]	
Yes	842 (89.5)
No	99 (10.5)

*Academic education means college education.

Furthermore, 15.9% of men were not able to walk a minimum of 20 meters, while this figure was 8.7% among women; thus, MS was more debilitating in men.

Table 2. Patient's experiences regarding the challenges of receiving health care services

Challenges	Very high	High	Medium	Low	Very low
	n (%)				
Cost of pharmaceutical services	229 (24.4)	231 (24.7)	218 (23.3)	92 (9.8)	167 (17.8)
Costs of hospitalization	102 (12.2)	148 (17.6)	200 (23.8)	146 (17.4)	243 (29.0)
Rehabilitation costs	150 (22.4)	120 (17.9)	104 (15.5)	77 (11.5)	220 (32.8)
Uninsured home rehabilitation	177 (29.4)	92(15.3)	63 (10.5)	48 (8.0)	222 (36.9)
Transportation systems to hospitals and health centers	186 (20.9)	150 (16.9)	154 (17.3)	97 (10.9)	302 (34.0)
Long waiting lists for visiting the doctor	195 (21.2)	152 (16.5)	185 (20.1)	132 (14.3)	256 (27.8)
Lack of follow up of the patient's condition by the nurse	127 (14.5)	106 (12.1)	133 (15.2)	129 (14.8)	379 (43.4)
Lack of timely access to the treatment team	173 (19.4)	142 (15.9)	151 (16.9)	132 (14.8)	295 (33.0)
Lack of telephone counseling	279 (30.7)	152 (16.7)	136 (14.9)	73 (8.0)	270 (29.7)
Lack of home visits	233 (26.6)	99 (11.3)	94 (10.7)	84 (9.6)	365 (41.7)
Lack of familial support	106 (11.5)	53 (5.7)	101 (10.9)	91 (9.9)	572 (62.0)
Lack of job support at work	192 (27.3)	70 (9.9)	96 (13.6)	68 (9.7)	278 (39.5)
Lack of qualified care centers	197 (25.9)	116 (15.3)	121 (15.9)	75 (9.9)	251 (33.0)

The prioritization of care services challenges is as follows: the cost of pharmaceutical services (49.1), lack of telephone counseling (47.4), uninsured home rehabilitation (44.7), lack of qualified care centers (41.2), rehabilitation costs (40.2), lack of home visit (37.9), transportation systems to hospitals and health centers (37.8), long waiting lists for a doctor's appointment (37.7), lack of job support (37.2), lack of timely access to the treatment team (35.8), costs of hospitalization (29.8), lack of follow up of the patient's condition by the nurse (26.7), and lack of familial support (17.2) (Table 2).

Gender had no significant effect on any of the challenges except challenge of lack of job support (Table 3). There was significant difference between men and women in terms of challenge of lack of job support (P= 0.010). To examine the relationship between gender and lack of timely access to the treatment team (P = 0.030).

There was a significant correlation between age and challenge of lack of familial support (P = 0.020). Marital status had no significant effect on any of the challenges (Table 3). There was a significant correlation between the level of education and the challenges of medication's cost (P ≤ 0.010), transportation systems (P ≤ 0.010), and lack of familial support (P ≤ 0.010).

To examine the correlation between educational status and lack of job support (P = 0.020), a significant relationship was observed.

Therefore, there was no significant relationship between the level of education and lack of job support (P = 0.060).

Table 3. Correlation between the challenges and descriptive characteristics of the patients according to the p-value

Challenges	Gender	Marital status	Educational level	Employment status	Ability to walk
	n (%)				
Cost of pharmaceutical services	0.070	0.680	< 0.001*	< 0.001*	< 0.001*
Costs of hospitalization	0.620	0.870	0.150	< 0.001*	0.020*
Rehabilitation costs	0.330	0.480	0.070	0.010*	< 0.001*
Uninsured home rehabilitation	0.550	0.180	0.200	0.020*	< 0.001*
Transportation systems to hospitals and health centers	0.290	0.960	< 0.001*	< 0.001*	< 0.001*
Long waiting list for visiting the doctor	0.590	0.600	0.150	0.440	0.010*
Lack of follow up of the patient's condition by the nurse	0.590	0.990	0.840	0.680	0.050*
Lack of timely access to the treatment team	0.030*	0.420	0.270	0.78	0.1400
Lack of telephone counseling	0.780	0.430	0.270	0.57	0.230
Lack of home visits	0.680	0.790	0.590	0.28	0.010*
Lack of familial support	0.790	0.920	< 0.001*	< 0.001*	0.130
Lack of job support at work	0.010*	0.230	0.020*	< 0.001*	0.350
Lack of qualified care centers	0.120	0.600	0.590	0.120	< 0.001*

*Items in bold indicate a significant p-value.

Employment status had significant correlations with some challenges. Those who were employed or retired had less challenges with costs of medication ($P \leq 0.010$), costs of hospitalization ($P \leq 0.010$), and rehabilitation costs ($P = 0.010$), uninsured rehabilitation at home ($P = 0.020$), transportation systems to hospitals and health centers ($P \leq 0.010$), and lack of familial support ($P \leq 0.010$). There was a relationship between employment status and lack of job support ($P \leq 0.010$). There were significant correlations between the ability to walk at least 20 meters and MS patients' challenges.

Those who did not have this ability had more problems with costs of medication ($P \leq 0.010$), costs of hospitalization ($P = 0.020$), rehabilitation costs ($P \leq 0.010$), uninsured rehabilitation at home ($P \leq 0.010$), transportation systems to hospitals and health centers ($P \leq 0.010$), long waiting lists for visiting the doctor ($P = 0.010$), lack of follow up of the patient's condition by the nurse ($P = 0.050$), and lack of home visits ($P = 0.010$).

To examine the relationship between the ability to walk and lack of qualified care centers ($P \leq 0.010$), as regards 49.5% of patients who did not have this ability responded high and very high challenges for receiving health care services. Thus, there was no significant relationship between the ability to walk and the lack of qualified care centers ($P = 0.220$).

Discussion

The current study examined the challenges of MS patients regarding receiving health care services in Iran. In this study, employed and retired patients had fewer problems in terms of costs of medication, costs of hospitalization, rehabilitation costs, and uninsured rehabilitation at home, transportation to hospitals and health centers, and lack of familial support. Patients who could not walk at least 20 meters had problems with the costs of medical services, hospitalization, rehabilitation, and home-based rehabilitation. They also had problems related to the transportation systems' facilities, Long waiting list for visits with a doctor, lack of follow-up by a nurse, and lack of home visits.

Ytterberg et al. performed a study on MS patients who required care services and found that most of the patients reported the need for rehabilitation, assistive devices, and transportation service.[27] In addition, severe MS was correlated with a higher perceived demand for nearly all the aforementioned services.[27]

In this study, the cost of pharmaceutical services was the most important challenge for patients. Tintore et al. found that cost is one of the challenges in managing the disease-modifying therapy (DMT) among patients with MS.[29]

According to the results of this study, patients who could not walk at least 20 meters had more problems with rehabilitation costs and uninsured home rehabilitation compared to those with the ability to walk. Moreover, the challenge of rehabilitation was one of the major problems of patients.

Forbes et al. showed that MS patients who were most affected by the disease needed more socio-environmental support, rehabilitation, and non-professional care.[30]

Gottberg et al. indicated that patients were satisfied with other health care units except for access to rehabilitation.[31]

The present study showed the cost of pharmaceutical services, uninsured home rehabilitation, and rehabilitation costs to be fairly important challenges.

Results of the study by Catanzaro and Weinert revealed that most of the families had health care insurance; however, insurance support was insufficient to cover the cost of illness in approximately one-third of them.[32]

In our study, 37.8% of the patients reported transportation services to hospitals and health centers as an important problem.

In a study conducted by Ponzio et al., more than 41 of the patients reported facilitation in transportation as a social care need.[6] Egger et al. revealed that the feasibility of using a wheelchair is not enough for 39.5% of patients.[33]

In our study, people with non-academic education or with walking disabilities were more likely to have transportation services problems and it was less common among employed people.

Syed et al. showed that for people with low incomes or uninsured populations, transportation services are an important problem.[34]

In our study, patients did not regard the lack of follow up of the patient's condition by the nurse as a problem of great importance.

Ytterberg et al. reported that MS patients were satisfied with nurses in different areas of care.[27]

In our study, the lack of telephone counseling was one of the most important challenges and it was a common need among all groups of patients.

Zissman et al. studied telemedicine for patients suffering from MS and found that patients were satisfied with telecare.[35]

Results of the study by Bombardier et al. on the efficacy of telephone counseling showed that there was a big improvement in health activities of patients who received telephone counseling.[36]

The prioritization of our challenges showed that lack of familial support was the least important and a minority of patients had problems with it. The results of the study by Galushko et al. also showed that patients were more willing to receive familial support.[11]

In our study, there was no difference between women and men regarding the problems of lack of familial support.

In a study by McCabe et al., women reported that they did not receive satisfactory family counselling and relationship.[37]

In our study, the problems associated with lack of job support were not related to level of education, walking ability, and age of patients, but they were related to gender and men had more problems with lack of job support.

The results of the study by Raggi et al. showed that the EDSS, duration of the disease, age of patients, fatigue, and walking problems had a direct relationship with the MS work-related difficulties.[38]

The study by Salter et al. showed that disability had a negative impact on employment in MS.[39] Furthermore, Frndak et al. reported a higher rate of disability and advanced stages of the disease among those who had lost their job.[40]

In our study, patients also found the lack of qualified care centers to be a major problem. Holmoy et al. found that a great majority of MS patients were satisfied with the care services provided at a specialized rehabilitation center.[41]

In summary, in our study, we concluded that patients who could not walk at least 20 meters and unemployed individuals had more problems with most areas and required higher governmental and health care support and consideration. Elderly patients could not take care of themselves and they needed more familial support. Patients who had non-academic education were older and unemployed, so they had more problems with expenses and personal care and they had more challenges with the cost of medication, transportation, and lack of familial support.

Conclusion

This study shows the challenges of MS patients in receiving health care that vary based on age, education, employment, and ability to walk. The abovementioned challenges are of great importance in determining the QoL of people with MS, so an appropriate solution is recommended in this study to overcome these challenges.

Conflict of Interests

The authors declare no conflict of interest in this study.

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