



Research Article

# Multiple Sclerosis Awareness in Jordan, and How Does It Affect the Time of Diagnosis

**Yacoub Bahou\***, **Mohammad Y Al Ma'ani**, **Lisa J Mahmoud**, **Yazeed S Balkar**, **Haytham A Dwaik**, **Sama A Bani Ahmad**, **Layla S Abbasi**

Internal medicine department/neurology section; Jordan University Hospital, P.O. Box 13046, Amman, Jordan

**\*Corresponding author:** Yacoub Bahou, Internal medicine department/neurology section; Jordan University Hospital, P.O. Box 13046, Amman, Jordan

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## Abstract

**Objective:** To assess the public awareness of Multiple Sclerosis (MS) in Jordan and the relationship between awareness about the disease and the timing of the diagnosis. The results will be compared with other Middle Eastern and European studies.

**Methods:** Cross-sectional study through an online survey among the general population and MS patients using the Multiple Sclerosis Knowledge Questionnaire (MSKQ). The symptoms of the first MS attack were also assessed.

**Results:** There were 507 participants, 393 among the general population, and 114 MS patients. The majority of the participants were females (72.1%), and the most common age group was in the range of 25-44 years. Among the 507 participants, 98 were medical professionals, with 13 MS patients. The most common symptoms of the first attack of MS were unsteadiness and numbness/weakness in lower limbs (67.5%, 67.5%, and 65.8% respectively). The mean delay between the onset of symptoms and diagnosis of MS was 23 months. Regarding overall awareness, the mean number of correct answers according to the MSKQ was 7.16. Most participants were aware that MS is a disease of the central nervous system (72%), autoimmune (54%), and not contagious (82%), but a few participants knew about the effect of MS on lifespan (17%), and the percentage of MS cases in Jordan (6%). There was a significant difference in the level of awareness in favour of females, medical professionals, and MS patients. The age group 45-60 years had the highest score for MS awareness. There was a clear correlation between the awareness about MS and the level of education of the participants, but not the father's or mother's education. Among the 114 patients with MS, 51(44.7%) were diagnosed after the first attack.

**Conclusion:** According to the MSKQ, the mean number of correct answers was 7.16, which is acceptable but still suboptimal, but can be improved by educational programs to the healthcare providers and the public about MS.

## Introduction

Multiple Sclerosis (MS) is the most common non-traumatic disabling disease in young adults, due to an autoimmune demyelinating injury of the central nervous system. The incidence of MS is increasing worldwide, together with the socioeconomic impact of the disease. The underlying cause of MS and mechanisms behind this increase remain obscure, although complex gene-environment interactions almost certainly play a role. Changes in diagnostic methods and criteria mean that people with MS can be diagnosed increasingly early in their disease course, leading to a better prognosis [1].

A lack of knowledge about the disease symptoms may cause patients to present late and miss the opportunity for better disease outcomes.

A diagnostic delay in MS could reduce the available therapeutic options. Therefore, there is a need to increase awareness of this entity and its diverse symptom presentation [2]. Based on these facts, better MS awareness will lead to early diagnosis and prevention of complications. As shown in studies from other countries [3-8], an early diagnosis of MS will give a better prognosis and less ability to develop significant complications.

According to El-Salem [9], Jordan is a medium-high-risk country for MS, with a prevalence higher than was previously reported, possibly representing an increase in incidence. Due to this, and because, to our knowledge, no previous studies on public awareness about MS were done in Jordan, therefore our study aims to assess the public awareness about MS in Jordan, and how awareness and knowledge about MS in general and its common symptoms lead to consulting a neurologist, and how this will affect the time of diagnosis and starting the treatment. Results will be compared with other reports [3-7,10-14].

## Methods

This is a cross-sectional study that consists of 2 questions, the 1<sup>st</sup> one is directed toward determining the general population's awareness of MS, and the 2<sup>nd</sup> one aims to find the relationship between awareness about the disease and the timing of the diagnosis.

The study was conducted among the general population through an online survey of 18 questions according to a questionnaire named 'The Multiple Sclerosis Knowledge Questionnaire' [15]. Only 18 out of the 25 questions which are included in this questionnaire were used because the remaining 7 questions dealt with medical details which we thought are hard to be understood by the general population. It addressed questions

related to MS pathogenesis, epidemiology, age of onset, risk of transmission to family members, its effect on life span as well as tests used for diagnosis. The answers were taken as 'TRUE' (Maximum) and were given 1 point or 'FALSE' (Minimum) and were given 0 points. We added another question introduced by ourselves regarding the most common symptom(s) in the first attack of MS. The questions were translated into Arabic for the purpose of the study, so the survey was given in the Arabic and English languages. We included the general Jordanian population above the age of 18 years, and the data was collected from a randomized sample of 393 participants.

The study was also conducted among MS patients by using the same online based survey in Arabic and English to assess the awareness of MS patients about their disease. A sample of 114 patients with MS was recruited with the help of Nemat Al-Tawfiq Center for Training and Rehabilitation, a non-profit company in Jordan that is determined to provide access to care and services for people affected by MS. We have also calculated the delay between the onset of symptoms and the MS diagnosis for these 114 patients.

## Statistical analysis

The questionnaire items and general methodology were reviewed by experts in the field of neuro medicine by face validity. Cronbach's alpha was used as a measure of internal consistency. Simple descriptive analyses were used throughout the study: Min, Max, Mean, Median, Std.

T-Test and ANOVA were used to compare the two means and analysis of the difference between them respectively and test hypotheses. Scheffe's method was used as a post hoc test for multiple comparisons.

## Results

### Demographic characteristics

A total of 507 participants answered the questionnaire with 366 females (72.1%) and 141 males (27.9%). The most common age group of the participants was in the age range of 25-44 years (n=185). Whereas MS patients represented 22.5% (n=114) of the participants, only 98 medical professionals were found (19.3%), and among them 85 medical students without MS and 13 with MS. When assessing the results' reliability, Cronbach's Alpha value was used and yielded a value of 0.85. Spearman-Brown also yielded a value of 0.85 and Guttman Split-Half Coefficient was 0.84.

As shown in Table 1, the most common symptoms of the first attack of MS were unsteadiness, weakness/numbness in lower limbs, and fatigue.

Symptoms of the first attack		
Symptom	Number of patients (n=114)	Percentage
Unsteadiness	77	67.5%
Weakness in lower limbs	77	67.5%
Numbness	75	65.8%
Generalized fatigue	71	62.3%
Tingling	62	54.4%
Difficulty in concentration	50	43.9%
Loss of vision	47	41.2%
Sphincter disturbance	34	29.8%
Depression	47	41.2%

**Table 1:** Symptoms of the first attack.

### Overall awareness

Table 2 shows the results of the survey according to the questionnaire which was used [15]. The mean number of correct answers was 7.16 across all participants. Most participants were aware that MS is a disease of the central nervous system (72%), autoimmune (54%), and not contagious (82%), but a few participants knew about the effect of MS on lifespan (17%), and the percentage of people affected by MS in Jordan (6%). Therefore, the questionnaire items with the highest mean score were items 1 and 6 with respective means of 0.72 and 0.82 while the ones with the lowest means were items 4 and 5 with respective means of 0.17 and 0.06. Out of the 393 participants without MS, 46 heard about MS from an MS patient.

No	Item	Minimum	Maximum	Mean	Percentage
1	Multiple sclerosis is a disease of:	0= All body organs, don't know	1 = The central nervous system	0.72	72%
2	Multiple sclerosis is a disease of the immune system:	0 =False-Don't know	1 = True	0.54	54%
3	The causes of multiple sclerosis are still not completely clear. The most important causes seem to be:	0 = Diet and smoking-Alcohol consumption-Don't know	1 =Infection, genetic and immunogenic factors	0.42	42%
4	Multiple sclerosis significantly shortens lifespan:	0 =True-Don't know	1 =False	0.17	17%
5	In Jordan, multiple sclerosis affects:	0 =About 0.04%-About 0.4%-Don't know	1 =About 0.004%	0.06	6%
6	Multiple sclerosis is a contagious disease:	0 =True-Don't know	1 =False	0.82	82%
7	A parent with multiple sclerosis passes the disease on to his/her children via the chromosomes:	0 =True-Don't know	1 =False	0.44	44%
8	The likelihood of a relative of a patient with multiple sclerosis having the disease is:	0 =The same as a person with no MS in the family-Much higher (greater than 30%) than a person with no MS in the family-Don't know	1 =Slightly higher (less than 5%) than a person with no MS in the family	0.18	18%
9	Multiple sclerosis can manifest at any age, but typically occurs:	0 = Before 20 years- Between 40-60 years-Don't know	1 =Between 20-40 years	0.49	49%

10	Multiple sclerosis occurs in:	0 =Women and men about equally-Men about twice as often as women- Don't know	1 = Women about twice as often as men	0.38	38%
11	Pregnancy worsens multiple sclerosis:	0 =True-Don't know	1 =False	0.23	23%
12	“Relapsing–remitting” multiple sclerosis is characterized by:	0 =Slow and progressive deterioration in functioning (increase in disability) followed, after months or years, by attacks (relapses)- Don't know	1 =Repeated attacks (relapses) at more or less frequent intervals	0.27	27%
13	“Benign” multiple sclerosis is characterized by:	0 =Minimal deterioration in functioning (disability) one year after disease onset- Don't know	1 = Minimal deterioration in functioning (disability) 15–20 years after disease onset	0.24	24%
14	At present there is no single test/examination that can diagnose multiple sclerosis with certainty:	0 =False-Don't know	1 =True	0.32	32%
15	Magnetic resonance imaging (MRI) is the examination most commonly used to confirm the multiple sclerosis diagnosis:	0 =False-Don't know	1 =True	0.55	55%
16	What is the most commonly used test to follow up on patients:	0 =Lumbar puncture-CBC-Don't know	1 =MRI	0.40	40%
17	Lumbar puncture is performed to assess the cerebrospinal fluid for antibodies (oligoclonal bands) that indicate an immune reaction typical of multiple sclerosis:	0 =False-Don't know	1 =True	0.33	33%
18	At present there is no treatment that can cure multiple sclerosis:	0 =False-Don't know	1 =True	0.61	61%
<b>total</b>		0.00	16.00	7.16	71.6%

**Table 2:** Overall awareness according to MSKQ.

### Group-specific awareness

According to what is shown in Table 3, there seems to be significant differences in the awareness of participants related to the three following variables: gender, being a medical professional, and being an MS patient.

Gender	N	Mean	t	sig
Male	141.00	5.96	-3.76	0.00
Female	366.00	7.63		
Medical professional/ student (yes or no)	N	Mean	t	sig
No	409.00	6.58	-6.90	0.00
Yes	98.00	9.57		
Multiple Sclerosis patient	N	Mean	t	sig
No	393.00	6.06	-16.12	0.00
Yes	114.00	10.96		

**Table 3:** Group-specific awareness.

The analysis showed that females had a mean of 7.63 (SD 4.12) whereas males had a mean of 5.96 (SD 4.62). When comparing the two groups, the t-test was (- 3.76) and the P value was (0.00) when rounded to two decimal places, showing a significant difference in the level of awareness between both genders in favour of females.

The study also showed that medical professionals had a mean of 9.57 (SD 3.75) whereas non-medical professionals had a mean of 6.58 (SD 4.25). As for the t-test, it had a value of (- 6.90) and the P value was (0.00), showing a significant difference in the level of awareness between the two groups in favour of the medical professionals.

When analyzing the MS patients, the patients' group had a mean of 10.96 (SD 2.36) whereas the non-MS patients had a mean of 6.06 (SD 4.14). A significant difference was found in the level of awareness between the two groups in favour of the patients when calculating both the t-value and the P-value which were (-16.12) and (0.00) respectively.

When comparing the level of awareness of different age groups, we had to use a different method which was the Scheffe test and ANOVA as could be seen in Table 4, which showed that the group with the lowest mean was in the age range 18-24 yrs. while the one with the highest score was in the age range of 45-60 yrs.

Age	N	Mean
18-24	134	6.157
25-44	185	7.649
45-60	150	7.733
more than 60	37	6.189

**Table 4:** Level of awareness of different age groups.

However, to analyze the significance of these differences, we used the ANOVA test (Table 5), in which we observed a significant difference between age groups where the F-value between groups was 4.81 and the significance value (0.00) which means that the different age groups had a significant variation in their awareness level. When further analyzing these differences, we found that the age groups 25-44 yrs, and 45-60 yrs, were the only ones to have a statistically significant difference when compared to the other age groups, with significance levels of 0.02 for both groups.

Source	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	263.16	3	87.72	4.81	0
Within Groups	9152.88	502	18.23		
Total	9416.04	505			
(I) Age		Mean Difference (I-J)		Sig.	
18-24	25-44	-1.49		0.02	
	45-60	-1.58		0.02	
	more than 60	-0.03		1	
25-44	45-60	-0.08		1	

	more than 60	1.46	0.31
45-60	more than 60	1.54	0.28

**Table 5:** Analysis of the level of awareness between age groups by using ANOVA.

The same methods of analysis were used to analyze the differences between different levels of education. However, certain groups had a low number of participants, so the entire data had to be rearranged and grouped as follows: 1= High school diploma and undergraduate; 2= Higher diplomas; 3= Bachelor's degree; 4= Master's degree, Doctorate, and others. As shown in Table 6, group 2 had the highest mean value of 7.88, and Group 1 had the lowest mean with a value of 5.70. When using ANOVA, a significant difference was found between the groups with an F- value and significance level of 5.17 and 0.00 respectively. The only statistically significant difference was found between group 1 compared to groups 2, 3 and 4, where the significance levels were (0.00), (0.04), and (0.03) respectively.

Education	N	Mean	Std. Deviation		
1.00	92.00	5.70	4.45		
2.00	113.00	7.88	4.09		
3.00	235.00	7.21	4.24		
4.00	67.00	7.78	4.41		
Total	507.00	7.16	4.32		
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	282.65	3.00	94.22	5.17	0.00
Within Groups	9171.41	503.00	18.23		
Total	9454.06	506.00			
Education		Mean Difference (I-J)	Sig.		
1.00	2.00	-2.19	0.00		
	3.00	-1.51	0.04		
	4.00	-2.08	0.03		
2.00	3.00	0.68	0.59		
	4.00	0.11	1.00		
3.00	4.00	-0.57	0.82		

**Table 6:** Analysis of the level of awareness according to the level of education by using ANOVA.

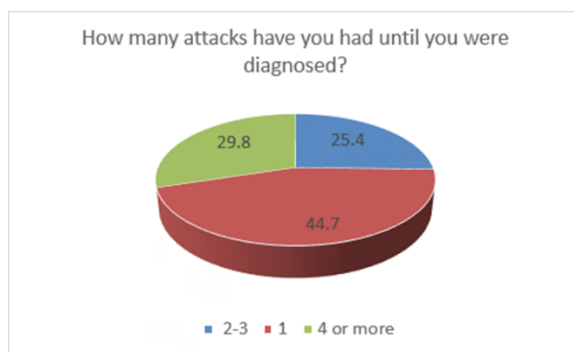
As shown in Table 7, when using ANOVA, no significant difference was noted in the level of awareness between age groups related to the father's education (level of significance=0.97) and the mother's education (level of significance level = 0.35).

Father's education	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	24.48	6.00	4.08	0.22	0.97
Within Groups	9429.58	500.00	18.86		
Total	9454.06	506.00			
Mother's education	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	125.90	6.00	20.98	1.12	0.35
Within Groups	9328.16	500.00	18.66		
Total	9454.06	506.00			

**Table 7:** Analysis of the level of awareness according to the father's or mother's education by using ANOVA.

### Patient-specific data

As shown in Chart 1, when analyzing the data specifically related to MS patients, the chart shows that the majority of patients were diagnosed after one attack (n=51, 44.7%), followed by patients diagnosed after 4 or more attacks (n=34, 29.8%) and those diagnosed after 2-3 attacks (n=21, 25.4%).



**Chart 1:** Number of attacks preceding the diagnosis.

For the 114 MS patients, the delay between the onset of symptoms and the MS diagnosis had a minimum of 1 month and a maximum of 156 months, with a mean of 23 months.

### Discussion

Several points emerge from this study of public awareness about MS in Jordan.

Regarding demographic characteristics, most of the participants (366 out of 507 or 72.1%) were females and 27.9% were males, which is in accordance with the study from Jeddah [4].

Regarding overall awareness, Table 2 has shown that most of our participants were aware that MS is a disease of the central nervous system (CNS) (72%), autoimmune (54%), and

not contagious (82%). This is in full agreement with a study from Saudi Arabia [5], in which 93% of their MS patients were aware that MS is a disease of the CNS, autoimmune (79%), and not contagious (90%). However, this latter study found that MS is not hereditary in 64.5% of patients, higher than the percentage of 44% found in our study.

Out of 393 of our participants without MS, 46 heard about MS from an MS patient. This is important because, according to Amer [3], learning from surrounding people, especially someone with MS, was the only source of information with significantly higher knowledge and attitude scores.

Regarding group-specific awareness, our study showed a significant difference in the level of awareness between both genders in favour of females, which is in agreement with Giordano

[15]. This might be explained by the presence of a majority of females among our participants. In addition, the higher incidence of MS in females might affect the exposure of female participants to more MS patients, thus affecting their knowledge about the disease. We also found that the age group 18-24 years had the least level of awareness compared to the age group 25-44 years. This is in contradistinction with other reports [3,4] which demonstrated no significant variation in knowledge about MS between gender and age groups. This might be explained by the fact that the age group 25-44 years is the one most affected by MS, and they are more exposed to MS patients than younger participants, thus increasing their knowledge about the disease. However, the study from Jeddah [4] agrees with ours regarding the presence of a higher average score in their MS knowledge questionnaire between participants with MS (average score 13.92) and non-MS (average score 7.42).

Our study has shown a correlation between the educational level and knowledge and awareness about MS because according to Table 6, participants in group 2 (higher diploma) had the highest mean (7.88) in the level of awareness compared to those with high school diploma who had the lowest one (5.7). This is in accordance with other reports [4,5,15] which concluded that MS knowledge is positively correlated with the educational level. Other studies [10,11] noted that a lower education level was associated with a delay in diagnosis of MS. Maybury [16] noted that it is possible that greater knowledge about MS leads to better adjustment to the disease.

Our study has demonstrated no significant difference in the level of awareness between age groups related to the father's or mother's education level. This might be explained by the fact that parents in the Jordanian community have less interest in medical knowledge compared to other fields.

The mean diagnostic delay in our MS patients was 23 months. This is in accordance with other reports from Europe [10,11,12,14], in which values ranged between 15 and 36 months. However, one study from Iran [13] found a lower mean of 7 months, which is surprising.

Demir [7] concluded that there is a need for improved awareness among patients as well as clinicians on initial manifestations of MS to enable admission or referral to an MS center and to prevent delay in diagnosis.

According to Giovannoni [8], delays often occur before a person with symptoms suggestive of MS sees a neurologist. Campaigns to raise awareness of MS are needed, as are initiatives to improve access to MS healthcare professionals and services, with a clear treatment goal to maximize neurological reserve, cognitive function, and physical function by reducing disease activity.

In conclusion, our study shows that MS awareness in Jordan is suboptimal, similar to other reports [4- 6,17]. There was a long delay between the onset of MS symptoms and diagnosis (Mean =23 months). Therefore, awareness about MS should be improved by providing educational programs for healthcare providers and the general public.

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