



Multiple Sclerosis Awareness and Knowledge Among Community of The Eastern Region, Saudi Arabia

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Abstract:

Background and objective

Multiple sclerosis (MS) is a central nervous system disease. MS is the most common neurological disease that disables young adults. MS prevalence has increased in every world region since 2013. In 2015, a national MS registry was launched in KSA to register all MS patients with confirmed diagnoses according to the 2010 McDonald Criteria. The overall prevalence of MS at the country level was reported to be 40.40/100,000 of the total population. The projected prevalence was estimated to be much higher among Saudi nationals (61.95/100,000 Saudi nationals). The prevalence was higher among female, younger, and educated individuals. However, in Eastern Saudi Arabia (SA), no studies are assessing the knowledge and awareness of MS among the Eastern Community. Due to a lack of knowledge and awareness of the nature of the disease, MS continues to be a significant health issue, despite increased research and clinical attention. This study aims to estimate the level of awareness of multiple sclerosis (MS) among residents in eastern Saudi Arabia. Because the literature shows a remarkably lack of knowledge of MS in Saudi Arabia. As the community gains a better understanding of the disease's facts, patients will become more involved in their communities, resulting in increased social awareness, education, and employment opportunities.

Methods

This is a cross-sectional study conducted in 2023. 391 participants, ages 18 to 45, were included in the study and given a self-administered web-based questionnaire. The study uses the general knowledge about multiple sclerosis (MS) actual (MSKQ-21) with 21 items to assess the knowledge regarding MS as one of the two measurements, together with sociodemographic data.

Results

A total of 391 participants were enrolled in this study. The total sample of 73.7 percent had a poor knowledge level regarding multiple sclerosis (MS), while 26.3 percent had a good knowledge level. However, it was found that about one-third of the participants had an overall good awareness of multiple sclerosis (MS). More than half of them heard about multiple sclerosis (MS).

Conclusion:

The reports that the level of knowledge score was below average, which indicates poor knowledge of MS—almost two-thirds of low awareness—were alarming. Planning health education programmes for the public is crucial. This can be improved by conducting educational and raising awareness programmes using various types of media.

Key words: MS; Multiple sclerosis; knowledge; Awareness

Introduction

Multiple sclerosis (MS) is a central nervous system disease. The immune system of the body attacks myelin, which coats nerve cells. MS is the most common neurological disease that disables young adults. MS is an unpredictable disease; symptoms range from numbness and tingling to blindness and paralysis. Although it is still impossible to anticipate the progression, severity, and particular symptoms of MS in any one person, improvements in research and therapy are enabling a better understanding and bringing us closer to a world free of MS. (1)

According to the World Health Organisation's Atlas of MS, the prevalence of MS has increased globally in recent years. MS prevalence has increased in every world region since 2013. According to the data, the global MS population has increased from 2.3 million in 2013 to 2.8 million in 2020. (2) The average age of diagnosis is 32 years, and the pooled incidence rate across 75 reporting countries is 2.1 per 100,000 people per year. Females are twice as likely as males to have MS. (3)

In 2015, a national MS registry was launched in KSA to register all MS patients with confirmed diagnoses according to the 2010 McDonald Criteria.

The overall prevalence of MS at the country level was reported to be 40.40/100,000 total population and 61.95/100,000 Saudi nationals. Around 3 out of every 4 patients (77.5%) were 40 years of age or younger. The female-to-male ratio was 2:1. The prevalence was higher among females and young, educated individuals across all five regions of Saudi Arabia.

However, compared to past rates, Saudi Arabia's projected prevalence of MS through this national study is 40.40 per 100,000 people, putting the Kingdom above the low-risk zone as per the Kurtzke classification. The projected prevalence was estimated to be much higher among Saudi nationals (61.95/100,000 Saudi nationals). The prevalence was higher among female, younger, and educated individuals. Further studies are needed to assess the risk factors associated with increased prevalence in Saudi Arabia. Multiple Sclerosis Patients in Saudi Arabia: Prevalence of Depression and its Extent of Severity shows that 89.9% (n = 214) of the patients showed mild to severe depression symptoms (55.46% of the females and 34.4% of the males; p = 0.474). High levels of depression symptoms were found among MS patients in Saudi Arabia. The relationship between MS and psychiatric conditions exists despite the uncertainty of its pathogenesis. Further longitudinal studies should be carried out to obtain more valid outcomes. Neurologists treating MS patients can play a role in studies related to the condition by actively investigating depressive symptoms and providing the data. (4)

According to a study conducted in Jeddah Saudi port in 2021, the mean knowledge score was lower than the national average, implying that the community had very little knowledge. People are still unfamiliar with the disease, even though the Western region has the highest number of MS cases in the country. A study conducted in Turkey found that while patients and their families had good awareness about MS, the public had a poor

comprehension of the condition. (5) However, in Saudi Arabia (SA), no studies are assessing the knowledge and awareness of MS among the Eastern Community.

Due to a lack of knowledge and awareness of the nature of the disease, MS continues to be a significant health issue, despite increased research and clinical attention. Although there is no effective treatment for MS, raising awareness and reducing apprehension can help bridge the gap between the community and patients. As the community gains a better understanding of the disease's facts, patients will become more involved in their communities, resulting in increased social activity, education, and employment opportunities.

All these data support the hypothesis that early diagnosis and community education and counselling are highly required, compared to the poor level of knowledge. This study aims to estimate the level of knowledge about multiple sclerosis (MS) among residents of Saudi Arabia and explore the associated variables that help early diagnose and counsel the majority of residents.

Materials and Methods

Study Design:

This is a community-based cross-sectional study that was conducted in Saudi Arabia from November 8, 2023, to December 8, 2023

Study Population and Sampling:

The target population of this study included all adult residents in eastern Saudi Arabia. A minimum sample of 385 was required, as calculated via an electronic sample calculator, at a 95% level of confidence and a 5% margin of error. The inclusion criteria for this study consist of all residents aged 18–45 who were either Saudi or not Saudi.

Data collection tool:

Data was collected through a web-based survey. Questions were adapted from a questionnaire for multiple sclerosis (MS) based on DSM-IV criteria, and other related questions on demographics were formulated accordingly.

The questionnaire includes two areas of the study: (1) sociodemographic information, region of residence, age, gender, employment, and educational level; (2) participant awareness regarding multiple sclerosis (MS) by the Arabic version of the Multiple Sclerosis Knowledge Questionnaire (MSKQ-21) (6). (MSKQ-21) is a self-assessment tool. A interdisciplinary panel created multiple-choice statements to assess MS knowledge regarding MS. The right response earned one point. The maximum score that may be obtained by completing this survey is 21, so the minimum score is zero.

Before distribution, the questionnaire steps were done and formulated in the Arabic colloquial language, which is the primary language of the target group. 2/ A pilot survey was conducted to

ensure clarity, accuracy, and validity with the assistance of college professors from the neurology department for translating the English scientific terms, and 3/ the results were reviewed with a professional translator.

The questionnaire was distributed electronically to the target group using Google Forms and shared across the Kingdom of Saudi Arabia via social media links. Personal data collection is done using a private account with a password. There is no assumption of risks because there will not be direct contact with the participants. The estimated time to fill out forms is 4 to 5 minutes. Responses collected are 440; only 391 were included and 49 were excluded according to the criteria of exclusion mentioned before.

The study uses the general knowledge about multiple sclerosis (MS) actual (MSKQ-21) with 21 items to assess the knowledge regarding MS as one of the two measurements, together with sociodemographic data.

Ethical Consideration

The Institutional Review Board at King Faisal University, Saudi Arabia, approved this study. The ethical clearance obtained is Ref. No. KFU-REC-2023 OCT-ETHCS1535. All participants must give written consent prior to any data collection. A cover letter was included on each questionnaire, which included an explanation

about the purpose of the study, the use of data, the benefits of doing this research, the right to participate, whether to complete the survey or not, and the confidentiality and anonymity of the data.

Data Analysis

The International Business Machines (IBM) Statistical Package for the Social Sciences version 23.0 (SPSS) was used to analyze the data. The descriptive analysis was done to display the mean, standard deviation, and frequencies for categorical data. The chi-square test was used to assess for the presence of any association between categorical variables. The results were considered statistically significant when $P = 0.05$ at 95% confidence.

Results:

The total number of participants fulfilling the inclusion criteria who completed the study questionnaire was 391. The participants ages ranged from 18 to 45 years and above, with a mean age of 31.7 ± 12.6 years old. A total of 220 (56.3%) participants were female. As for educational level, 242 (61.9%) were university graduates, 60 (15.3%) had post-graduate degrees, and 89 (22.8%) had a secondary level of education or below. Exactly 230 (58.8%) were employed, 85 (21.7%) were students, and 76 (19.4%) were not working or retired (table 1).

Table 1: Personal characteristics of study participants in Eastern region, Saudi Arabia

Personal data	No	%
Age in years		
15-25	86	22.0%
26-35	144	36.8%
36-45	69	17.6%
> 45	92	23.5%
Gender		
Male	171	43.7%
Female	220	56.3%
Educational level		
Below secondary	14	3.6%
Secondary	75	19.2%
University graduate	242	61.9%
Post-graduate	60	15.3%
Employment		
Unemployed	76	19.4%
Student	85	21.7%
Employed	230	58.8%

The assessment of the general knowledge of multiple sclerosis in the Eastern region of Saudi Arabia is presented in Table 2. Exactly 84.4% of the study participants were aware that multiple sclerosis is a disease of the central nervous system, and 62.7% reported that the central nervous system consists of the brain, spinal cord, and optic nerve. A total of 66.2% were aware that it is a disease of the immune system, but only 6.9% knew that multiple sclerosis

significantly did not shorten lifespan. Also, 63.7% of the participants were aware that multiple sclerosis can manifest at any age but typically occurs between 20 and 40 years, and 50.9% were aware that infection and genetic factors are the most likely causes. About 10.5% of parents with multiple sclerosis don't pass the disease on to their children via the chromosomes.

Table 2: General knowledge of study participants regarding multiple sclerosis, Eastern region, Saudi Arabia

General knowledge		No	%
Multiple sclerosis is a disease of	The central nervous system	330	84.4%
	All body organs	21	5.4%
	Don't know	40	10.2%
The central nervous system consists of:	Brain, spinal cord and optic nerves	245	62.7%
	Brain and spinal cord	87	22.3%
	Brain and peripheral nerves	18	4.6%
	Brain	14	3.6%
	Don't know	27	6.9%
Multiple sclerosis significantly shortens lifespan	True	301	77.0%
	False	27	6.9%
	Don't know	63	16.1%
Multiple sclerosis is a disease of the immune system	True	259	66.2%
	False	74	18.9%
	Don't know	58	14.8%
Multiple sclerosis can manifest at any age, but typically occurs	Before 20 years	34	8.7%
	Between 20–40 years	249	63.7%
	Between 40–60 years	49	12.5%
	Don't know	59	15.1%
The most important causes seem to be	Infection and genetic factors	199	50.9%
	Diet and smoking	77	19.7%
	Alcohol consumption and infection	41	10.5%
	Don't know	74	18.9%
A parent with multiple sclerosis passes the disease on to his/her children via the chromosomes	True	269	68.8%
	False	41	10.5%
	Don't know	81	20.7%

The results of participants' MS knowledge regarding clinical features are presented in Table 3. Exactly 22.8% of the study participants were aware that the likelihood of a relative of a patient with multiple sclerosis having the disease is slightly higher (less than 5%) than a person with no MS in the family. Also, 14.3% were aware that multiple sclerosis injures both myelin and axon, and

53.2% said that women do it about twice as often as men. Only 8.2% were aware that pregnancy doesn't worsen multiple sclerosis. A total of 45.3% reported that "Relapsing-remitting" multiple sclerosis is characterized by repeated attacks (relapses) at more or less frequent intervals, and 44% were aware that "Benign" multiple sclerosis is characterized by minimal deterioration in functioning (disability) 15–20 years after disease onset.

Table 3: Knowledge of study participant regarding MS clinical features in Eastern region, Saudi Arabia

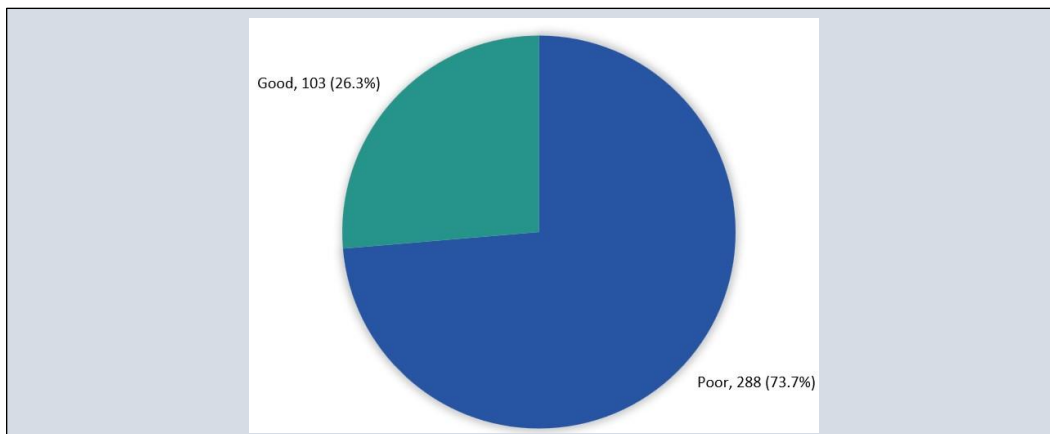
MS clinical features		No	%
The likelihood of a relative of a patient with multiple sclerosis having the disease is	Slightly higher (less than 5%) than a person with no MS in the family	89	22.8%
	Much higher (greater than 30%) than a person with no MS in the family	156	39.9%
	The same as a person with no MS in the family	57	14.6%
	Don't know	89	22.8%
Multiple sclerosis injures	Both myelin and axon	56	14.3%
	The myelin only	177	45.3%
	The axon (nerve fiber)	89	22.8%
	Don't know	69	17.6%
Multiple sclerosis occurs in	Women about twice as often as men	208	53.2%
	Men about twice as often as women	46	11.8%
	Women and men about equally	63	16.1%
	Don't know	74	18.9%
Pregnancy worsens multiple sclerosis	True	258	66.0%
	False	32	8.2%
	Don't know	101	25.8%
“Relapsing–remitting” multiple sclerosis is characterized by	Repeated attacks (relapses) at more or less frequent intervals	177	45.3%
	Slow and progressive deterioration in functioning followed, after months or years, by attacks	129	33.0%
	Don't know	85	21.7%
“Benign” multiple sclerosis is characterized by	Minimal deterioration in functioning (disability) 15–20 years after disease onset	172	44.0%
	Minimal deterioration in functioning (disability) one year after disease onset	129	33.0%
	Don't know	90	23.0%

The knowledge of the diagnosis and treatment of study participants regarding multiple sclerosis in the Eastern region of Saudi Arabia is presented in Table 4. As for diagnosis, 70.1% said that magnetic resonance imaging (MRI) is the examination most commonly used to confirm the multiple sclerosis diagnosis; 57.5% said that MRI is repeated at intervals to better follow the disease course over time; 65% said that a lumbar puncture is performed to assess the cerebrospinal fluid for antibodies (oligoclonal bands) that indicate an immune reaction typical of multiple sclerosis; and 28.6% said that a lumbar puncture should not be repeated at intervals to better follow the disease course over time. A total of 66.5% were aware that now there is no single test or examination that can diagnose multiple sclerosis with certainty, and 41.9% said that a definite diagnosis of multiple sclerosis can require repeated MRIs. As for treatment, 70.8% were aware that at present there is no treatment that can cure multiple sclerosis, and only 15.1% were aware that disease-modifying drugs are effective in relapsing-remitting" multiple sclerosis.

Table4: Knowledge of diagnosis and treatment of study participants regarding multiple sclerosis, in Eastern region, Saudi Arabia

Diagnosis and treatment	No	%	
At present there is no single test/examination that can diagnose multiple sclerosis with certainty	True	260	66.5%
	False	50	12.8%
	Don't know	81	20.7%
Magnetic resonance imaging (MRI) is the examination most commonly used to confirm the multiple sclerosis diagnosis	True	274	70.1%
	False	44	11.3%
	Don't know	73	18.7%
MRI is repeated at intervals to better follow disease course over time	True	225	57.5%
	False	87	22.3%
	Don't know	79	20.2%
Lumbar puncture is performed to assess the cerebrospinal fluid for antibodies (oligoclonal bands) that indicate an immune reaction typical of multiple sclerosis	True	254	65.0%
	False	42	10.7%
	Don't know	95	24.3%
Lumbar puncture is repeated at intervals to better follow disease course over time	True	177	45.3%
	False	112	28.6%
	Don't know	102	26.1%
A definite diagnosis of multiple sclerosis	Can require repetition of MRI	164	41.9%
	Is always possible at first disease attack	135	34.5%
	Don't know	92	23.5%
At present there is no treatment that can cure multiple sclerosis	True	277	70.8%
	False	34	8.7%
	Don't know	80	20.5%
Disease modifying drugs are effective in	“Relapsing–remitting” multiple sclerosis	59	15.1%
	“Primary progressive” multiple sclerosis	69	17.6%
	Both of them	158	40.4%
	Don't know	105	26.9%

The overall knowledge of participants regarding multiple sclerosis in the Eastern Region of Saudi Arabia is presented in Figure 1. A total of 103 (26.3%) had a good knowledge level regarding multiple sclerosis, while 288 (73.7%) had a poor knowledge level.

Figure 1: Overall knowledge of participants regarding multiple sclerosis, in Eastern region, Saudi Arabia

Factors associated with participants knowledge regarding multiple sclerosis are presented in Table 5. Exactly 37.7% of participants aged 36–45 years had an overall good knowledge regarding MS compared to 20.8% of others aged 26–35 years with recorded statistical significance ($P = .048$). Also, 30.6% of university graduates had a good knowledge level of MS, versus 35.7% of those who had a lower secondary level of education and 11.7% of others with a post-graduate degree ($P = .018$). Other factors showed an insignificant association with participants knowledge level of MS.

Table4: Knowledge of diagnosis and treatment of study participants regarding multiple sclerosis, in Eastern region, Saudi Arabia

Factors	Overall knowledge level				p-value
	Poor		Good		
	No	%	No	%	
Age in years					.048*
15-25	62	72.1%	24	27.9%	
26-35	114	79.2%	30	20.8%	
36-45	43	62.3%	26	37.7%	
> 45	69	75.0%	23	25.0%	
Gender					.252
Male	121	70.8%	50	29.2%	
Female	167	75.9%	53	24.1%	
Educational level					.018*\$
Below secondary	9	64.3%	5	35.7%	
Secondary	58	77.3%	17	22.7%	
University graduate	168	69.4%	74	30.6%	
Post-graduate	53	88.3%	7	11.7%	
Employment					.501
Unemployed	60	78.9%	16	21.1%	
Student	61	71.8%	24	28.2%	
Employed	167	72.6%	63	27.4%	

P: Pearson X^2 test

§: Exact probability test

* $P < 0.05$ (significant)

Discussion:

A chronic disease that affects the central nervous system, which includes the brain, spinal cord, and optic nerves, multiple sclerosis (MS) frequently results in disability. (7) MS can cause a wide range of symptoms, such as muscle weakness, lack of coordination, and issues with speech, vision, and bladder control. (8, 9) Although there is no known cure for multiple sclerosis (MS), there are therapies that can help control symptoms and halt the disease's development, such as prescription drugs, physical therapy, and lifestyle modifications. (10) The public needs to be kept informed and made aware about MS, including its symptoms, available therapies, and effects on people's life. In doing so, it contributes to lowering the stigma associated with MS and enhancing the lives of individuals who are affected.

The purpose of the current study was to evaluate the level of public awareness about multiple sclerosis in the Eastern Region of Saudi Arabia. The results of the survey indicated that only 25% of the participants had a general understanding of multiple sclerosis.

Given that the majority of participants were aware that multiple sclerosis is a condition affecting the central nervous system, their overall level of disease awareness was more than sufficient. Approximately two-thirds are aware that multiple sclerosis is an immune system illness and that, while symptoms can appear at any age, they usually do so between the ages of 20 and 40. Of the study participants, about half are aware that the most likely causes are hereditary factors and infections. Conversely, a relatively small percentage of people are aware that multiple sclerosis does not substantially reduce life expectancy and that a parent who has the condition does not pass it on to their offspring through the chromosomes. Regarding the clinico-epidemiological aspects of the disease, a far lower level of information was noted. The probability that a relative of a patient with multiple sclerosis would have the condition is less than 5%, which is about one-fifth of the study participants' knowledge. It has also been shown that inadequate knowledge about multiple sclerosis damages both myelin and axons. Merely 8.2% of people are aware that multiple sclerosis does not worsen during pregnancy. Conversely, less than 50% of respondents said that "relapsing-remitting" multiple

sclerosis is characterized by recurrent attacks at irregular intervals, and about 50% said that women experience relapses twice as frequently as men do. Additionally, they are aware that "benign" multiple sclerosis is typified by a minimal decline in functioning (disability) 15-20 years after the disease onset. A much higher level of knowledge about the diagnosis and management of the disease was reported; the majority knew that the most common test for multiple sclerosis diagnosis is magnetic resonance imaging (MRI); over half said that MRI is repeated periodically to better track the disease's progression; and roughly two-thirds knew that lumbar puncture is used to check the cerebrospinal fluid for antibodies (oligoclonal bands), which are indicative of an immune reaction common to multiple sclerosis. Just about 25% of respondents said that periodic lumbar punctures were unnecessary to better track the progression of the disease over time. Less than half of respondents stated that a second MRI may be necessary for a definitive diagnosis of multiple sclerosis, despite the fact that nearly two-thirds of respondents are aware that there is currently no single test or examination that can do so. Regarding therapy, the majority of participants are aware that there is currently no cure for multiple sclerosis, and only 15.1% are aware that medications that change the condition can help people with relapsing-remitting multiple sclerosis. Farran EK et al. (11) documented comparable results in Jeddah, where the average MSKQ score was 7.42 4.5 (as opposed to 9.4 4.2 for the current study). Hudaif HS et al. (2012)(12) also found that in Taif City, the study group's mean knowledge score was 8.74 \pm 2.7. This supported the finding that in Riyadh, less than a third of respondents (30.3%) said they knew about MS but had a low knowledge score. (13); Around one-third of the investigated group in the Al-Quassim region showed good knowledge of MS (31.7%), according to Al-Hamdan NA et al. (14). Of the study group, half were aware that multiple sclerosis (MS) is a disease that affects the central nervous system, 52% were aware of risk factors, and roughly 62.9% were aware of symptoms. Comparably, in the western area, 46% of respondents had little understanding of MS, 31% had moderate knowledge, and 22.5% had strong knowledge. (15) A study of MS patients found that they had a satisfactory level of knowledge about the disease, with the mean correct response for men and women combined being 58%. The majority of patients knew that multiple sclerosis (MS) is an autoimmune illness (79%), a central nervous system disease (93%), not communicative (90.5%), or hereditary (64.5%). (16) Other research involving MS patients showed that a study's mean score for interferon awareness was low. (17) In a different study, the average knowledge score was 6.4 (SD 2.4), with almost 34% of the responses being accurate. (18) According to a poll, just 21% of MS patients feel they are adequately informed about the risks associated with therapy. (19) Because MS affects millions of individuals globally, it is imperative to raise awareness of the condition. We can lessen stigma and support those who are coping with MS by raising awareness of the illness. Moreover, greater knowledge can encourage the creation of novel therapies and, eventually, a cure for multiple sclerosis.

Conclusion:

In conclusion, we concluded that the mean knowledge score was below average, indicating extremely low community knowledge. MS patients deal with physical, mental, and financial difficulties

throughout their lives. As a result, the community needs to be highly informed in order to help reduce the stigma associated with their illness and enhance their quality of life. Therefore, it is essential to increase disease awareness among the general public. Running educational campaigns and programs across a range of media can be accomplished.

Condensed health education programs and campaigns for the general population on MS are critical for distributing transparent information for the early detection and proper management of this disease. Further studies are recommended to clarify the barriers beyond suboptimal knowledge.

Disclosure statement

We hereby (authors) declare the following: Payment/services information: We declared that no financial support was received from any organization for the submitted work. Financial relationships: we declared that we have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. Other relationships: we declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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