

Multiple Sclerosis Patients Knowledge in Saudi Arabia

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ABSTRACT

Objectives: To assess Multiple Sclerosis (MS) patients' knowledge in Saudi Arabia (SA) and in which aspect of the disease do patient need more awareness.

Methods: A cross-sectional web-based survey has been conducted between June and August 2017. It consisted of 2 parts: sociodemographic and 23 multiple choice questions chosen from the previously validated MS Knowledge Questionnaire (MSKQ). The survey has been sent to 500 MS patients.

Results: A total of 218 MS patients filled the questionnaire where only 200 included in the study. Female MS patient represents 66% of all the participants. More than half of the patients had achieved their bachelor degree. The total mean of the correct answer for both male and female found to be 58.98%(±SD 15.06%). Most patients were aware that MS is a disease of central nervous system (93%), autoimmune disease (79%), not contagious (90.5%), or inherited (64.5%). However, few patients were aware that there is no single test to diagnose MS (28.5%), and intravenous injection of contrast during MRI reveals new lesions (18.5%). Only (37%) knew what is "Relapsing–remitting"MS. The MS knowledge is positively correlated with the educational level.

Conclusion: Patients with MS in SA have less knowledge in the disease's types, workups, and treatment efficacy. While in contrast, they have more awareness of the disease's pathophysiology. Patient's awareness programs should aid more knowledge among MS patients in SA.

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Multiple sclerosis (MS) is an autoimmune, chronic, inflammatory disease of the central nervous system; its behavior is highly varied and unpredictable, and the cause, until now, is not known.¹ Nevertheless,

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it appears to be multifactorial; it involves a combination of genetic and environmental factors.¹⁻³ Moreover, it is a common autoimmune disease of the central nervous system.^{4,5}

The prevalence of MS in the Middle East is low to medium.⁶ Incidences of MS in the Gulf countries including Saudi Arabia, in particular, suggest an indication of its increase.⁷ The Prevalence of the disease in Saudi Arabia has not been studied yet. Not to mention that MS awareness and knowledge is sub-optimal in the country.⁴

Patients' knowledge of pathophysiology, types, diagnostic modalities and medication effectiveness is critical to facilitate decision-making, achieving emotional stability, and help the patient cope with the disease. Because of the lack of published research in this area, as the literature review of this study indicates, the aim of this study is to measure patient's knowledge of MS.

Methods. This study has conducted a web-based survey in Arabic, "MS Patients Knowledge in Saudi Arabia," where patients recruited with the help of ARFA" patient support group for MS in Saudi Arabia." "www.arfams.org.sa" is an authenticated society by Ministry of Social Affairs in Saudi Arabia. Its base is in Saudi Arabia, and it is a non-profit organization that helps people affected by MS by facilitating professional education and providing programs and services that are of help to them and their families. This cross-sectional survey has been conducted over a period of 3 months, between June 2017 and August 2017. It consists of 23-multiple choice items, following a validated questionnaire carried out in Italy, MSKQ-25, to assess the current survey.⁸ There has been an exception of 2 questions, which was about the disease's prevalence in Italy (Q3), and it has been deleted in the current survey because there has been no study in Saudi Arabia to determine the prevalence accurately yet. The second deleted question (Q20) was about MS diagnosis because of unclarity of the question.

We included MS patients with age from 18 years old or above. Unconfirmed or suspected cases were excluded. The questionnaire is divided into 2 sections; the first section is a sociodemographic information that consists of 6 items including gender, age, marital status, educational level, occupation, and residence. The second section is 23 Questions from the MSKQ-25 (Multiple Sclerosis Knowledge Questionnaire) self-administered instrument.⁸ Permission to use this tool has been taken from the corresponding author. We used the Statistical Package for Social Sciences (SPSS

Table 1 - Comparing patient who have more knowledge with those who have less knowledge in regard to their demographics.

Table 1	N	MSKQ score <60% N=90 (45%) Patient	MSKQ score ≥60% N=110(55%) Patient	Average MSKQ Score out of the 23 questions selected (±SD)
<i>Gender*</i> (<i>p-value=0.32</i>) <i>n (%)</i>				
Male	68(34)	32(47.1)	36(52.9)	13.19(±4.10)
Female	132(66)	58(43.9)	74(56.1)	13.76(±3.08)
<i>#Social status**</i> (<i>p-value=0.51</i>) <i>n (%)</i>				
Married	96(48)	44(45.8)	52(54.2)	13.54(±3.32)
Single	86(43)	36(41.9)	50(58.1)	13.77(±3.56)
Divorced	18(9)	10(55.6)	8(44.4)	12.72(±3.80)
<i>Age[‡]</i> (<i>p-value=0.35</i>) <i>n (%)</i>				
From 18-30 year	85(42.5)	37(43.5)	48(56.5)	13.61(±3.69)
From 30-45 year	97(48.5)	43(44.3)	54(55.7)	13.73(±3.19)
From 45-55 year	18(9)	10(55.6)	8(44.4)	12.44(±3.75)
<i>Educational level[†]</i> (<i>p-value=0.07</i>) <i>n (%)</i>				
Less than high school	19(9.5)	11(57.9)	8(42.1)	11.89(±3.99)
High school	52(26)	28(53.8)	24(46.2)	13.08(±3.50)
Diploma	25(12.5)	11(44)	14(56)	13.44(±3.56)
Bachelor	103(51.5)	40(38.8)	63(61.2)	14.13(±3.23)
PhD	1(0.5)	0(0)	1(100)	16
<i>Occupation [†]</i> (<i>p value=0.003</i>) <i>n (%)</i>				
Student	15(7.5)	5(33.3)	10(66.7)	14.27(±2.43)
Teacher	32(16)	8(25)	24(75)	14.72(±3.27)
Health care provider	14(7)	2(14.3)	12(85.7)	16.29(±2.84)
Engineer	8(4)	4(50)	4(50)	12.13(±3.98)
Military	7(3.5)	4(57.1)	3(42.9)	11.86(±4.71)
Unemployed	99(49.5)	54(54.5)	45(45.5)	13.03(±3.28)
Retired	6(3)	4(66.7)	2(33.3)	11.33(±4.76)
Other	19 (9.5)	9(47.4)	10(52.6)	13.79(±3.38)
<i>Residence[†]</i> (<i>p-value=0.28</i>) <i>n (%)</i>				
Western region	41(20.5)	15(36.6)	26(63.4)	13.98(±3.47)
Eastern region	43(21.5)	21(48.8)	22(51.2)	12.88(±3.37)
Northern region	22(11)	11(50)	11(50)	12.59(±4.80)
Sothern region	20(10)	8(40)	12(60)	13.70(±3.80)
Central region	74(37)	35(47.3)	39(52.7)	13.99(±2.89)

*Using T-test, †using one-way ANOVA, ‡none of the participants were widowed

Inc, Chicago, IL, USA) version 16 to do the analysis. Chi-square, ANOVA, and T-test were used to calculate the *P*-value. Differences were considered statistically significant at a level of <0.05.

Results. The response rate was 43.6% (218 from 500). 18 cases were excluded because 13 were not sure about the diagnosis of MS and 5 were duplicated cases. A total of 200 cases included in the analysis. The average MSKQ score of the whole group is 13.57±SD 3.46 (58.98%±SD15.06) out of the 23 questions. The minimum score is 4 (17.4%), and the maximum score is 21(91.3%) out of 23. The median is 14(60.9%), and the mode is 16 (69.6%).

Table 1 shows the demographics of all the patients

with their average MSKQ score. Only 19 (9.5%) with the educational level of less than a high school and the rest are equivalent or higher. 99 (49.5%) were unemployed. The majority of the participants 74(37%) were from the central region of Saudi Arabia.

In addition to that Table 1 shows the average MSKQ score across various demographics. The mean score of the female was slightly higher than the male without statistical significance.

There is no difference in the average score concerning the age, residence and the social status of the patients. There is an increase in the average MSKQ score with the increase of the level of education. However, it did not reach the statistical significance. Looking into the occupation part, patient working in the healthcare

Table 2 - distribution of the correct response by patient.

Questions	Contents	MSKQ* Score(divided according to score%)			Correct answer N=200(%)
		<60(%) n=90	60 to <75(%) n=85	≥75 (%) n=25	
1	Organs involved in MS	78(86.7)	85(100) [§]	23(92) [§]	186(93) [§]
2	CNS composition	51(56.7)	54(63.5)	16(64)	121(60.5)
4†	MS impact on life expectancy	32(35.6)	66(77.6)	23(92) [§]	121(60.5)
5	MS as immune disease	63(70)	71(83.5)	24(96) [§]	158(79)
6	MS as a contagious disease	71(78.9)	85(100) [§]	25(100) [§]	181(90.5) [§]
7	MS etiology	8(8.9) [‡]	7(8.2) [‡]	11(44)	26(13) [‡]
8	MS transmission to offspring	43(47.8)	65(76.5)	21(84)	129(64.5)
9	MS transmission to other family member	9(10) [‡]	18(21.2) [‡]	15(60)	42(21) [‡]
10	Myelin/axon damage	50(55.6)	71(83.5)	18(72)	139(69.5)
11	Age of onset	56(62.2)	76(89.4)	23(92) [§]	155(77.5)
12	Sex ratio in MS prevalence	67(74.4)	80(94.1) [§]	25(100) [§]	172(86)
13	Myelin function	48(53.3)	72(84.7)	22(88)	142(71)
14	Tests used to diagnose MS	20(22.2) [‡]	24(28.2)	13(52)	57(28.5)
15	Role of MRI in MS diagnosis	85(94.4) [§]	83(97.6) [§]	25(100) [§]	193(96.5) [§]
16	Role of gadolinium injections during MRI	7(7.8) [‡]	17(20) [‡]	13(52)	37(18.5) [‡]
17	Role of MRI in disease follow up	62(68.9)	78(91.8) [§]	25(100) [§]	165(82.5)
18	Role of lumbar puncture	22(24.4) [‡]	45(52.9)	22(88)	89(44.5)
19	Frequency of lumbar puncture	17(18.9) [‡]	46(54.1)	21(84)	84(42)
21†	Definition of remittent MS	13(14.4) [‡]	43(50.6)	18(72)	74(37)
22	Benign MS	12(13.3) [‡]	34(40)	19(76)	65(32.5)
23	Impact of pregnancy on MS	30(33.3)	73(85.9)	23(92) [§]	126(63)
24	Curative treatment	74(82.2)	84(98.8) [§]	24(96) [§]	182(91) [§]
25	Types of MS disease targeted by current therapies	25(27.8)	31(36.5)	13(52)	69(34.5)

*MSKQ multiple sclerosis Knowledge questionnaire (taken with permission from Giordano et al. 2010), †question number 3 and 20 are deleted from the MSKQ (refer to text for explanation), (‡=<25%, §=>90%)

scored higher with statistically significant *p*-value (0.003).

Table 2 show the percentage of the correct answer regarding each question. We divided them into three groups according to their score. 90 patients scored less than 60% while only 25 scored more than or equal to 75%. Questions 1, 6, 15, and 24 were the most correctly answered by the participants. Questions 7, 9, and 16 were answered only by a small proportion (i.e., less than 25%).

From the pathophysiological aspect, 93% of patients answered that MS is a disease of central nervous system. 60.5% of them are aware that central nervous system consists of the brain, spinal cord, and optic nerves. 79% of patients know that it is an autoimmune disease. 69.5% answered that MS injures the myelin. 71% know that myelin facilitates and speeds up the signals transmission between neurons, while the rest, 22.5 %, selected "I do not know". Most of the participants recognize correctly the most affected age 77.5% and the gender ratio as well 86% (Table 2).

Considering the reasons for the disease, the majority of patients (68%) do not know what the actual cause of illness is, 19% think that Diet and smoking cause the disease, while (13%) believe that genetic together with infection play a major role in having the disease. Most of them believe it is not a contagious illness (90.5%), while only 2% believe it is, the rest did not know (7.5%).

In regard to the awareness of Genetic rule, some participants (5.5%) believe that the disease can be transmitted via the chromosome from parents to their children, the majority, (64.5%), believe it is not, while the rest (30%) do not know. Around one fifth 21% of the patient participated recognized correctly that having a relative with MS put the person at slightly higher risk of developing MS. On the other hand, 4.5% think that having a relative with MS will increase the risk significantly. 27% of the patient believe that it does not change the risk and 47.5% choose "I don't know."

Around one third (28.5%) know that there is no single test to diagnose MS and almost (56.5%) believe

that there is a single diagnostic test to confirm the diagnosis of MS. Nearly all (96.5%) agree that MRI is the examination most commonly used to confirm the diagnosis of MS. By comparing MRI with Intravenous injection (gadolinium), only 18.5% of the participants know that gadolinium during MRI reveals new lesions, 1.5% believe it reveals old lesion, while the rest of them either don't know 27.5% or think it reveals both old and the new lesion 52.5%. Eighty-two and five percent are aware that MRI at repeated intervals is better to follow the disease course over time, while 4.5% think the repeated MRI is not a better way to monitor the disease course and 13% do not know. In comparison, 42% are aware that Lumbar puncture at repeated intervals is not a better way to follow disease course over time, 49.5% do not know if it is better to follow disease course over time, and 8.5% think it is better to follow disease course over time. Fifty-one percent of the participants do not know that Lumbar puncture sample shows immunological reaction, while 44.5% do know. Only 4.5 % are sure that Lumbar puncture sample does not demonstrate any immunological response.

Considering "Relapsing–remitting" MS, which is the most common type, 37% know that it is a form of repeated relapses at more or less frequent intervals. One third (32.5%) think it is a slow and progressive deterioration in functioning and 30.5% do not know. Regarding "Benign" MS, 54% of patients do not know what "Benign" MS is. Thirty-two and five percent know it is a minimal deterioration in functioning in 15–20 years after disease onset, while only 13.5% think it is a decline in functioning in one year after disease onset.

Considering Treatment efficacy, 91% of the patient knows that there is no cure for MS. Moreover, 34.5% think treatment is only effective in "Relapsing–remitting" MS, only 2.5% believe that it is effective in "Primary progressive" MS, and 44.5% think it is effective in both.

Considering disease prognosis in general 60.5% of the patients know that MS does not shorten lifespan significantly, while 7% believe it does, the rest do not know 32.5%. About the effect of pregnancy on MS, 63% know it does not get worse during pregnancy, 5.5% think it does, while 31.5% do not know.

Discussion. The average MSKQ score of the whole group is 13.57 ± 3.46 out of the 23 questions. The minimum score is 4 (17.4%), and the maximum score is 21 (91.3%) out of 23. This result is comparable to another cohort of MS patient filled the same MSKQ.⁹ Their average was 15.6 ± 3.9 . The minimum and highest scores were 3 and 24 out of

25. We used the same questionnaire except deleting 2 questions (see reasons above).

If we further compare the result of the 2 surveys, they are exactly the same in questions with highest correct answers (Table 2). These were questions about: "MS as a contagious disease," "organ involved in MS," "role of MRI in the diagnosis of MS" and "absence of curative treatment" (Q6, Q1, Q15, and Q24 respectively).⁹ On the other hand, the lowest answered questions differ largely. They only share the item number 16 about "the role of Gadolinium injection during MRI" (Table 2). Other lowest score were in the Q7 "MS etiology" and Q9 "MS transmission to other family members."

There are only a few other studies carried out assessing patient knowledge. The mean score knowledge about the interferon in one study was low.¹⁰ In another study¹¹ the mean score of knowledge was 6.4 (SD 2.4) corresponding to a 34% of possible correct answers. This also applies to knowledge about the risk of treatment with MS medication. A survey showed that only 21% of the MS patient have adequate knowledge about treatment risk before engagement in any basic education program.¹²

Although in one old survey the younger patient tends to know more about the disease, there was no association between the patient knowledge and with the length of illness or level of disability.¹³ The majority of the patient in this survey did not consider MS as an infectious (97.2%). On the other hand (86.1%) agree that it is not a hereditary disease.¹³ In our group, 90.5% agree that MS is not contagious. On the other hand, only 64.5% and 21% answered correctly when asked about the MS transmission to offspring and other family members (Q8 and Q9 respectively).

In our cohort, there was no statistically significant difference in the knowledge among different age group. On the other hand, one knowledge assessment study among MS patient found a negative correlation between the knowledge and age.¹¹

One of the limitations of our study is that we lack the disease duration. Although there are discrepancies between the studies carried out in the past, one found no correlation¹³ and one concluded that the highest knowledge about the disease found in a patient with short disease duration.¹¹

Patient knowledge about the disease is crucial especially dealing with a lifelong chronic illness. It can help them in various aspect of the disease. Patient, good understanding about the illness is essential also to avoid the fear of the future as one study found that good patients' knowledge was associated with less fear of disease progression.¹⁴ There are many elements regarding MS that need more education. However, the

most chosen area of interest for MS patient include symptomatic treatment, MRI, relapses, and role of complementary medicine.¹¹

In Conclusion, MS patients in Saudi Arabia have less knowledge about some aspects of the disease's types, investigation modality, treatment efficacy and genetic role, while, in contrast, they have more awareness of the disease's mechanism and nature. Patient awareness programs should aid more knowledge among MS patients in Saudi Arabia and be delivered by medical health providers. Having more knowledge of the disease leads to a sense of understanding. This will help in achieving the emotional stability and aid more compliance to medications.

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