

# Awareness of Saudi community toward multiple sclerosis in Qassim Region, Saudi Arabia

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## ABSTRACT

**الأهداف:** تقييم وعي المجتمع السعودي بمرض التصلب المتعدد.

**المنهجية:** تم تعميم استبيان مصمم مسبقاً على 350 مواطن سعودي في منطقة القصيم من يناير حتى يونيو 2019م يتضمن بيانات اجتماعية وأسئلة علمية لتقييم المعرفة حول مرض التصلب العصبي المتعدد.

**النتائج:** كانت غالبية المشاركين في الدراسة من الإناث البالغات بنسبة (74%)، ضمن الفئة العمرية بين 20-30 عام بنسبة (45.1%) ومن ذوي المستوى التعليمي العالي بنسبة (80.6%) وجد أن ما يقرب من ثلث المجموعة المدروسة لديهم معرفة جيدة بمرض التصلب العصبي المتعدد بنسبة (31.7%) علم نصف المجموعة المدروسة أن الجهاز العصبي المركزي هو الجهاز المصاب بمرض التصلب، وأفاد 52% أن نقص فيتامين (د) و الإصابة المسبقة بأمراض المناعة الذاتية، والفيروسات والسمنة، وجود تاريخ عائلي بالإصابة بالتصلب، هي العوامل التي تزيد من خطر الإصابة. نجد أيضاً أن 62.9% من المشاركين علموا أن عدم وضوح الرؤية وازدواجيتها، والخدر والشلل والضعف، وصعوبة التركيز من أعراض مرض التصلب. وكانت المشاركات من الإناث، والأشخاص الذين على معرفة بشخص مصاب يتمتعون بمستوى جيد من المعرفة فيما يتعلق بالتصلب المتعدد أكثر من غيرهم. وأخيراً نجد أن الحصول على المعرفة من مصادر مشتركة من الإنترنت أو وسائل التواصل الاجتماعي، وأفراد الأسرة والأصدقاء أو الجيران، والعاملين الصحيين هو الأكثر بين ذوي المعرفة الجيدة.

**الخلاصة:** معظم المشاركين في الدراسة لديهم معرفة محدودة فيما يتعلق بالتصلب المتعدد ولذلك فإن حاجة المجتمع لبرامج التثقيف الصحي أمر في غاية الأهمية.

**Objectives:** To evaluate the awareness of Saudis in Qassim region, Saudi Arabia on multiple sclerosis (MS).

**Methods:** A cross-sectional study was conducted on 350 Saudis in Qassim, Saudi Arabia between January 2019 and June 2019 using a pre-designed questionnaire including socio-demographic data and questions evaluating knowledge about MS.

**Results:** The majority of studied participants were adult females (74%), between 20-30 year-old (45.1%) and with high education level or above (80.6%). Nearly one third of the studied group had good knowledge regarding MS (31.7%). Half of the studied group knew that central nervous system (CNS) is the system affected by MS, 52% reported that vitamin D deficiency, family history of MS, personal history of autoimmune disease, viruses, and obesity are the factors which increase the risk of developing MS. Approximately, 62.9% knew that blurred and double vision, numbness, paralysis or weakness and difficulty in concentration and memorizing are symptoms of MS. Female participants and those knowing someone having MS had a significant good knowledge level regarding MS than others. Getting knowledge from combined sources from internet or social media; family, friends or neighbors and health workers was significantly more prevalent among those with good knowledge.

**Conclusion:** Most of the study participants had limited knowledge regarding MS. Planning health education programs for the public is essential.

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Multiple sclerosis (MS) is an inflammatory neurodegenerative disease affecting the central nervous system (CNS).<sup>1,2</sup> Among middle-aged adults (between 20 and 40 years), MS is considered as one of the main life-long disability chronic neurological causes which causes expressive health care and economic loads. Women are at 3 to 4 folds increased risk to be affected by MS than men.<sup>3,4</sup> Neurologically, the common manifestations are loss of coordination and balance, visual impairment, weakness, fatigue, numbness, pain, bladder dysfunction, mood changes, and cognitive dysfunction.<sup>5,6</sup> Multiple sclerosis has a complex pathophysiology. It is widely recommended as an autoimmune disease, and is mediated by autoreactive lymphocytes that cross the blood-brain barrier (BBB) and enter the CNS, causing local inflammation; producing demyelination, gliotic scarring, and axonal loss.<sup>7</sup> Pathophysiological concepts revealed that exposure to some infectious agents during childhood as well as genetics involvement played a role.<sup>8,9</sup> Data reported that females were more affected by MS than males due to genetic predisposition.<sup>3</sup> Increased risk of MS was related to some environmental factors like obesity, smoking, and low level of vitamin D.<sup>10</sup> It was reported that breastfeeding for more than 4 months is associated with lower risk for multiple sclerosis.<sup>11</sup> The etiology of the disease might be related to consanguinity and some local factors.<sup>12</sup>

Recent epidemiological data indicated higher prevalence of MS in Arabian Gulf region, with increasing incidence in Kingdom of Saudi Arabia (KSA).<sup>12</sup> In the Gulf area, environmental conditions on one side and modulated lifestyle practices in the other side were palmed as associated factors for increasing MS prevalence.<sup>12,13</sup> The objectives of the first MS multicenter registration in KSA which was carried out between 2015 and 2018 were studying the epidemiology of MS, and its pattern besides studying its clinical findings in the whole country. The result of this registration was alarming and warranted prompt community health actions as it indicated an increasing prevalence of the disease in the whole Kingdom.<sup>15</sup> Among Saudi nationality the prevalence was 61.95/100,000; whereas between the whole population it was 40.40/100,000.<sup>16</sup>

According to the available literature, community awareness of MS is generally unacceptable. This affects a person's perception of the disease, delaying the opportunity for early diagnosis and management.

Furthermore, it is essential to increase community awareness of MS, as better public understanding of the facts of the disease will engage patients more in the community, and create social activity, education, and employment opportunities. The aim of this study is to evaluate the awareness and level of knowledge regarding MS among the residents of Qassim Region.

**Methods.** This was a community-based cross-sectional descriptive study conducted in the region of Qassim, KSA between January 2019 and June 2019. Qassim region is one of the 13 administrative regions of Saudi Arabia. Located in the center of the country and occupying 3.7% of the total area of KSA. According to the report of the Saudi General Authority of Statistics in 2017, the population has reached 1423935.<sup>16</sup> Its capital city is Buraydah, which is inhabited by approximately 60% of the region's total population.

We used simple random sampling and out of the 11 cities in Qassim Region, we selected the main cities which are Buraydah, Unaizah, and Alras.

The inclusion criteria were Saudi adults aged  $\geq 18$  years who agreed to participate in the study. The exclusion criteria were employment as a health-related professional or study at any health college and patient diagnosed of MS.

The participants were interviewed randomly in different public areas in the selected cities, including shopping malls, coffee shops, social clubs, and supermarkets using a convenience non-probability sample. A total of 350 participants were interviewed and all were included in the study. Data were collected using a previously validated questionnaire after taking consent from the original authors.<sup>17</sup> The questionnaire was divided into 3 sections: A) The participants' sociodemographic characteristics, including age in years, gender, education level, employment, and marital status. B) The participants' sources of information on MS, such as the internet or social media; family, friends, or neighbors; health care workers; or other sources (education programs on TV or radio, and MS information leaflets, brochures, or posters). C) The participants' knowledge of MS. The questionnaire contained 8 Arabic close-ended questions on the system affected by MS, the most common age group and gender affected by MS, the cause and risk factors increasing the risk of developing MS, the symptoms of MS, the presence of a cure, and the presence of medications that can control MS symptoms. The answers to each question were coded as correct (scoring 1 point) or wrong (scoring 0 points). The correct answers for all 8 questions were summed for each participant. A participant was deemed

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to have good knowledge if they answered  $\geq 5$  questions correctly; answering  $< 5$  questions correctly indicated poor knowledge. The cut off was selected based on agreement between 2 MS experts and 2 statisticians to represent the level of knowledge, precisely.

Internal consistency was assessed with Cronbach's alpha<sup>18</sup> which was found to be 0.81. Additionally, the questionnaire was pretested in a pilot study on a sample of 35 participants, whose results are not included in the present study. The questionnaires were completed via face-to-face personal interviews with the participants after the purpose of the study had been explained and after their informed written consent had been obtained.

The sample size was calculated using EPI Info™ 717. We used a 95% confidence interval and 5% margin of error, and 30% prevalence of awareness of MS as in the literature. The estimated sample size was 325, and was adjusted to 350 to compensate for incomplete forms.

Relevant approval for the study was obtained from the Qassim Region Research Ethics Committee. All participants were volunteers and had the right to withdraw from the interview at any point; and the principles of the Declaration of Helsinki were followed. All data were kept confidential and used only for research purposes.

**Statistical analysis.** The IBM-compatible personal computer with Statistical Package for the Social Sciences, version 20 Windows (IBM Corp, Armonk, NY, USA) was used for data tabulation and statistical analysis. Number and percentage were used to express qualitative data, where Chi-square ( $\chi^2$ ) test was performed to test comparison between groups.  $P$ -value $<0.05$  was considered significant.

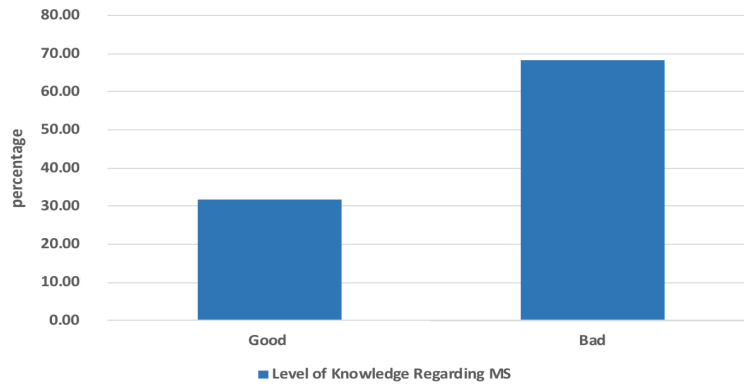
**Results.** The majority of participants were women (74%), aged 20-30 years (45.1%), with high education level or above (80.6%), employed (59.1), married (54.9%), and from Buraydah (40.6%). The most frequent source of information on MS was the Internet or social media (35.7%), followed by the combined sources of the Internet or social media; family, friends, or neighbors; and health care workers (25.4%); and family, friends, or neighbors (20.9%) (Table 1). Nearly one-third of the participants (31.7%) had good knowledge of MS, whereas 68.3% had poor knowledge of the disease (Figure 1). Frequency distribution of the knowledge questions showed that 50% of the participants knew that MS affects the CNS; 40.6% stated that 20-40-year-olds are the most common age group affected; 38.6% stated that women are more likely to develop MS than men; 15.4% identified MS as being of unknown etiology; 52% stated that vitamin

D deficiency, family history of MS, personal history of autoimmune disease, viruses, and obesity as the factors that increase the risk of developing MS; 62.9% knew that blurred and double vision, numbness, paralysis or weakness, and difficulty concentrating and remembering are symptoms of MS; 19.4% stated there is no cure for MS; and 50.6% agreed that medications can control the disease. The female participants had significantly higher MS knowledge levels than the male participants ( $p=0.02$ ). Obtaining knowledge from combined sources

**Table 1** - Characteristics of the studied population.

Characteristics	n (%)
<i>Age group (in years)</i>	
20	158 (45.1)
30	123 (35.1)
40-57	69 (19.7)
<i>Gender</i>	
Male	91 (26.0)
Female	259 (74.0)
<i>Education level</i>	
Secondary and less	68 (19.4)
High and above	282 (80.6)
<i>Employment</i>	
Employee	207 (59.1)
Unemployed	143 (40.9)
<i>Marital status</i>	
Single	159 (45.4)
Married	191 (54.6)
<i>Residence</i>	
Buraydah	142 (40.6)
Unaizah	123 (35.1)
Al-Ras	85 (24.3)
<i>Know someone having MSL</i>	
No	268 (76.6)
Yes	82 (23.4)
<i>Sources of information on MS</i>	
Internet or social media	125 (35.7)
Family, friends or neighbors	73 (20.9)
Health care workers	14 (4.0)
Combined sources*	89 (25.4)
Others†	49 (14.0)

\*Combined sources are internet or social media; family, friends or neighbors and health care workers. †Others are education program on TV or Radio, and multiple sclerosis (MS) information leaflets, brochures or posters.



**Figure 1** - Knowledge level regarding multiple sclerosis (MS) among studied population.

**Table 2** - Frequency distribution of knowledge regarding multiple sclerosis (MS) among studied participants.

Knowledge questions	n (%)
1. Which system is affected by MS?	
Incorrect/Don't know	175 (50.0)
Central nervous system	175 (50.0)
2. Which age group is affected by MS?	
Incorrect/Don't know	208 (59.4)
20-40	142 (40.6)
3. Who is affected more by MS?	
Incorrect/Don't know	215 (61.4)
Females	135 (38.6)
4. What is the cause of MS?	
Incorrect/Don't know	296 (84.6)
Unknown	54 (15.4)
5. What are the factors that increase the risk of developing MS?	
Incorrect/Don't know	168 (48.0)
Correct	182 (52.0)
Vitamin D deficiency*	54 (29.7)
Family history of MS*	42 (23.1)
Personal history of Autoimmune disease*	41 (22.5)
Viruses*	29 (15.9)
Obesity*	16 (8.8)
6. What are the symptoms of Multiple Sclerosis?	
Incorrect/Don't know	130 (37.1)
Correct	220 (62.9)
Blurred and double vision*	85 (38.6)
Numbness*	67 (30.6)
Paralysis or weakness*	53 (24.1)
Difficulty in concentration and memorizing*	15 (6.8)
7. Is there a cure for Multiple Sclerosis?	
Incorrect/Don't know	282 (80.6)
No	68 (19.4)
8. Is there medications can control multiple sclerosis symptoms?	
Incorrect/Don't know	173 (49.4)
Yes	177 (50.6)

For question #5, 182 participants correctly answered this question; the following correct words are the differentiation of those correct answers as vitamin D deficiency, Family history of MS\*, Personal history of autoimmune disease, viruses and obesity where the total of those differentiation is from the correct answer (182) as mentioned in the footnote. The same for question number 6.

**Table 3** - Relationship between socio-demographic characteristics of the studied group and their knowledge level regarding multiple sclerosis (MS).

Characteristics	Knowledge level		P-value
	Poor (n=239)	Good (n=111)	
<i>Age group (in years)</i>			
20-	110 (69.6)	48 (30.4)	0.62
30-	80 (65.0)	43 (35.0)	
40-57	49 (71.0)	20 (29.0)	
<i>Gender</i>			
Male	71 (78.0)	20 (22.0)	0.02
Female	168 (64.9)	91 (35.1)	
<i>Education level</i>			
Secondary and less	47 (69.1)	21 (30.9)	0.87
High and above	192 (68.1)	90 (31.9)	
<i>Employment</i>			
Employee	145 (70.0)	62 (30.0)	0.39
Un-employed	94 (65.7)	49 (34.3)	
<i>Marital status</i>			
Single	106 (66.7)	53 (33.3)	0.55
Married	133 (69.6)	58 (30.4)	
Values are presented as numbers and percentages (%)			

**Table 4** - Relationship between knowledge level and sources of knowledge regarding multiple sclerosis (MS) and knowing someone having MS.

Variable	Knowledge level		P-value
	Poor (n=239)	Good (n=111)	
<i>Sources of information about MS</i>			
Internet or social media	87 (69.6)	38 (30.4)	0.69
Family, friends or neighbors	55 (75.3)	18 (24.7)	0.15
Health care workers	10 (71.4)	4 (28.6)	0.79
Combined sources*	52 (58.4)	37 (41.8)	0.02*
Others <sup>#</sup>	35 (71.4)	14 (28.6)	0.61
<i>Knowing someone having MS</i>			
No	191 (71.3)	77 (28.7)	0.03*
Yes	48 (58.5)	34 (41.5)	
Values are presented as numbers and percentages (%). *Combined sources are internet or social media; family, friends or neighbors and health care workers. #Others are education program on TV or Radio and MS information leaflets, brochures or posters. Comparison was done between numbers in each row and the rest of the group. *significant result			



was significantly more prevalent among those with good knowledge than those with poor knowledge ( $p=0.02$ ). Moreover, participants who knew a person with MS had significantly better MS knowledge than those who did not ( $p=0.03$ ).

**Discussion.** Multiple sclerosis is an unpredictable, disabling inflammatory disease of the CNS. Greater awareness and education on the disease lead to the better benefits of early recognition and intervention.<sup>19</sup> Here, we report that the prevalence of good MS knowledge in the Saudi population of Qassim Region in the KSA is 31.7%. This prevalence is in agreement with the prevalence reported in other Saudi studies. A study conducted in Riyadh<sup>17</sup> involving 226 residents that evaluated MS knowledge showed that 30.3% of the respondents were aware and had good knowledge of MS. In Al-Taif, KSA, a community-based study involving 715 participants reported 26% adequate knowledge. On the other hand, the good knowledge prevalence in the present study is much better than that recorded for Majmaah, which was 12.7% average/good knowledge. Generally, public awareness of MS is poor, and this limited understanding delays early diagnosis and treatment.<sup>20-22</sup>

In the present study, nearly three-fourths of the participants were female. This agrees with the study in Al-Taif, where 65% of the participants were female.<sup>20</sup> Despite the low level of knowledge in the present study, half of the participants recognized MS as a neurological disease affecting the CNS. This agrees with Hudaif et al,<sup>17</sup> who reported a similar percentage of 61%, and was higher than that reported by Amer et al,<sup>20</sup> which was only 14%. In our study, more than 40% of the participants knew that younger people, example those aged 20-30 years old, are more affected by MS. Multiple sclerosis is most commonly first diagnosed between the ages of 20 and 40 years; over time, it results in varying levels of progressive mobility and sensory functional limitations affecting not only function but also appearance.<sup>23</sup>

This finding is in line with Hudaif et al<sup>17</sup> and better than that of Amer et al.<sup>20</sup> In the present study, 38.6% of participants answered that MS affects more women than men, as also reported by Hudaif et al<sup>17</sup> and Amer et al.<sup>20</sup> The Multiple Sclerosis International Federation reported that women and young adults are commonly affected by MS.<sup>24</sup> The average age of onset of MS is 30 years, which is the age a person typically begins a family and may not have typically reached their full earning potential; MS has a particularly destructive outcome on family, social, and professional relationships. Critical diagnosis and early treatment can prevent the irreversible long-term sequelae in patients with MS.<sup>25,26</sup>

More than half (52%) of the respondents in the present study answered that vitamin D deficiency, family history of MS, personal history of autoimmune disease, viruses, and obesity were factors that increased the risk of developing MS. This finding is much better than that in the Riyadh, KSA<sup>17</sup> and Al-Taif, KSA studies.<sup>20</sup> There is considerable evidence that vitamin D deficiency may increase susceptibility to MS.<sup>27</sup> Vitamin D deficiency is present in 28-80% of Saudi adults. On the other hand, vitamin D supplementation can eliminate disability.<sup>22</sup> In addition, adolescent obesity and smoking are considered factors that increase the risk of susceptibility for MS.<sup>28</sup> As sensory symptoms are the most common presenting symptoms of MS, nearly two-thirds of the participants (62.9%) in the present study recognized blurred and double vision, numbness, paralysis or weakness, and difficulty concentrating and remembering as common symptoms of MS. Insufficient or lack of information regarding the symptoms of the disease may be the reason behind the late presentation of patients, who miss the opportunity for better disease outcome. Some trials have revealed that early management is vital for delaying MS development, slowing its progression, and reducing disability. Thus, good MS awareness can lead to early diagnosis and prevent complications.<sup>29</sup>

Moreover, less than one-fifth of the respondents in the present study answered that there is no cure for MS, and 50.6% stated that medications can control the disease. These results agree with that of Hudaif et al<sup>17</sup> and Amer et al.<sup>30</sup>

In the present study, we compared respondents with good and bad knowledge on MS according to their sociodemographic characteristics. There was no significant relationship between knowledge level and sociodemographic data except for gender. Female participants had significantly good knowledge of MS compared to male participants. This is in contrast with Hudaif et al,<sup>17</sup> who reported no significant gender difference. This could be attributed to some knowledge gained by the public between the timing of the 2 studies, example, 6 years, besides the increasing prevalence of MS in the Kingdom in recent years.<sup>15</sup> Evidence from epidemiological studies has indicated that the Arabian Gulf region, which is located in a low-risk zone for MS, has a high prevalence of MS, with incidence increasing in Saudi Arabia, suggesting that the move to moderate-to-high prevalence is imminent.<sup>16</sup>

In the present study, the participants' most common source of information on MS was the Internet or social media, followed by the combined sources of the Internet or social media; family, friends, or neighbors, and health care workers. Combined sources were significantly more prevalent among the participants with good knowledge

than those with poor knowledge. This is supported by a significant relation between good knowledge and knowing someone who has MS. It means that when a person knows someone with MS, they would search for a source of information to obtain data on the disease to help their lover. However, Arhan et al<sup>30</sup> demonstrated that written materials can be an effective, inexpensive, and easy-to-implement strategy to improve popular understanding of a condition or its treatment, especially for the patient's family.

Our finding is in contrast with that of Hudaif et al<sup>17</sup> and Amer et al,<sup>20</sup> who found that learning from the people around them was a significant source of information on MS among their respondents. Reliance on the Internet or social media; family, friends, or neighbors to obtain MS knowledge may point to a lack of available information on the disease on social media. This is an important issue for governmental and non-governmental organizations to consider a variety of channels for disseminating trustworthy information and learning materials on MS and to communicate information to the public. A reliance on authentic sources is a key factor to believing transparent information.<sup>32</sup>

In the end, helping others better comprehend MS is the basis to spurring the improvement that changes the lives of those affected by the disease, and will eventually improve their lives and bring a permanent end to complications and disability. In this manner, broad popularization should be actualized to bring information about MS to light, with proficient treatment and to diminish the burden.<sup>31</sup>

**Study limitation.** The study was conducted in one region out of the 11 regions in KSA; therefore, results cannot be generalized to the whole population of Saudi Arabia.

In conclusion, The majority of participants had limited knowledge on MS. This was a known fact from the previous literature. However, in our study we found that the female participants had significantly higher knowledge than the male participants. Also, obtaining knowledge from the Internet or social media; family, friends or neighbors; and health workers was significantly more prevalent among those with good knowledge. In addition, participants who knew someone with MS had significantly higher knowledge levels. Thus, condensed health education programs/campaigns regarding MS for the public via various channels are essential for disseminating transparent information for the early detection and proper management of this devastating disease. Further studies are recommended to clarify the barriers beyond suboptimal knowledge.

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