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

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ABSTRACT

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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to have good knowledge if they answered ≥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 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™. 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 (χ²) 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   | (%)  |
| Age group (in years)                    |     |      |
| 20                                           | 158 | (45.1)|
| 30                                           | 123 | (35.1)|
| 40-57                                        | 69  | (19.7)|
| Gender                                      |     |      |
| Male                                         | 91  | (26.0)|
| Female                                       | 259 | (74.0)|
| Education level                            |     |      |
| Secondary and less                         | 68  | (19.4)|
| High and above                             | 282 | (80.6)|
| Employment                                 |     |      |
| Employee                                    | 207 | (59.1)|
| Unemployed                                  | 143 | (40.9)|
| Marital status                              |     |      |
| Single                                      | 159 | (45.4)|
| Married                                     | 191 | (54.6)|
| Residence                                   |     |      |
| Buraydah                                    | 142 | (40.6)|
| Unaizah                                     | 123 | (35.1)|
| Al-Ras                                      | 85  | (24.3)|
| Know someone having MSL                    |     |      |
| No                                          | 268 | (76.6)|
| Yes                                         | 82  | (23.4)|
| Sources of information on MS               |     |      |
| 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)    |         |
| Age group (in years)  |                 |         |
| 20-                   | 110 (69.6)      | 48 (30.4) | 0.62 |
| 30-                   | 80 (65.0)       | 43 (35.0) |       |
| 40-57                 | 49 (71.0)       | 20 (29.0) |       |
| Gender                |                 |         |
| Male                  | 71 (78.0)       | 20 (22.0) | 0.02 |
| Female                | 168 (64.9)      | 91 (35.1) |       |
| Education level       |                 |         |
| Secondary and less    | 47 (69.1)       | 21 (30.9) | 0.87 |
| High and above        | 192 (68.1)      | 90 (31.9) |       |
| Employment            |                 |         |
| Employee              | 145 (70.0)      | 62 (30.0) | 0.39 |
| Un-employed           | 94 (65.7)       | 49 (34.3) |       |
| Marital status        |                 |         |
| 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)    |         |
| Sources of information about MS       |                 |         |
| 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*                               | 35 (71.4)       | 14 (28.6) | 0.61 |
| Knowing someone having MS             |                 |         |
| 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.\(^{19}\)

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\(^{17}\) 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.\(^{20,22}\)

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.\(^{20}\)

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,\(^{17}\) who reported a similar percentage of 61\%, and was higher than that reported by Amer et al,\(^{20}\) 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.\(^{23}\)

This finding is in line with Hudaif et al\(^{17}\) and better than that of Amer et al.\(^{20}\) In the present study, 38.6\% of participants answered that MS affects more women than men, as also reported by Hudaif et al\(^{17}\) and Amer et al.\(^{20}\) The Multiple Sclerosis International Federation reported that women and young adults are commonly affected by MS.\(^{24}\) 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.\(^{25,26}\)

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\(^{17}\) and Al-Taif, KSA studies.\(^{20}\) There is considerable evidence that vitamin D deficiency may increase susceptibility to MS.\(^{27}\) Vitamin D deficiency is present in 28–80\% of Saudi adults. On the other hand, vitamin D supplementation can eliminate disability.\(^{22}\) In addition, adolescent obesity and smoking are considered factors that increase the risk of susceptibility for MS.\(^{28}\)

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.\(^{29}\)

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\(^{17}\) and Amer et al.\(^{20}\)

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,\(^{17}\) 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.\(^{15}\) 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.\(^{16}\)

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. 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. and Amer at al., 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.

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.

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, 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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