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Original Research Article

Awareness of the Saudi community toward multiple sclerosis in Al-Madinah Al- Munawarrah, Saudi Arabia

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ABSTRACT

Background: Multiple sclerosis (MS) is an inflammatory neurodegenerative disease affecting the central nervous system (CNS); pathophysiological concepts revealed that exposure to some infectious agents during childhood and genetics involvement played a role. Data reported that females were more affected by MS than males due to genetic predisposition. Recent epidemiological data indicated a higher prevalence of MS in the Arabian Gulf region, with increasing incidence in the Kingdom of Saudi Arabia (KSA). Knowledge about MS shall aid in better management, diagnosis and treatment. This study aimed to assess the level of awareness about MS among participants in Al Madinah Al Munawarrah, KSA.

Methods: This was a cross-sectional non-interventional observational survey questionnaire among 381 participants in Al Madinah.

Results: The majority of participants were female aged more than 20 years old and high graded; 66.4% of the participants reported good awareness about MS, and 68% reported that MS impact the central nervous system, causing more illness among females aged between 20-39 years.

Regarding the risk factors towards MS, Family history of MS and personal history of autoimmune diseases were on top of the list among the participants in relation to risk factors MS, with 43.3% and 38.1%, respectively.

Conclusions: In summary, our study shed light on the lack of knowledge about MS among the adult population in Al Madinah AL Munawarrah, KSA. A better understanding of MS shall contribute towards better diagnosing and management.

Keywords: KSA, MS, Awareness, Risk factors, Management

INTRODUCTION

The Immune response is the body's ability to stay safe by affording protection against harmful agents and involves lines of defence against most microbes as well as a specialized and precise response to a particular offender.[1] While the immune system protects the individual against threats, an exaggerated immune response often generates a reaction against self-antigens leading to autoimmunity. Also, the immune system cannot defend against all threats. So, autoimmunity refers to an defect in the body's normal development such that the immune system mounts an attack against its cells.[2] The nerves system is a complex network that facilitates an organism to interact with its surroundings. Sensory complex detect environmental stimuli, and motor complex provide

skeletal, cardiac, and smooth muscle control.[2] The nervous system can be divided into the peripheral and central nervous systems (PNS and CNS, respectively). The central nervous system (defined as the brain and spinal cord) is usually considered to have seven essential parts: the spinal cord, the medulla, the pons, the cerebellum, the midbrain, the diencephalon, and the cerebral hemispheres Multiple sclerosis (MS) is a chronic, degenerative disease of the CNS that is caused by an immune-mediated inflammatory process.[3] This process results in the demyelination of white matter in the brain and spinal cord. Symptoms vary depending on lesion location.[4] Clinical symptoms characterized by acute relapses typically first develop in young adults, and a gradually progressive course ensues with permanent disability in 10 to 15 years.[5] The prevalence of MS is around 33/100000 patients; another analysis has shown that 2.8 million have been diagnosed with MS. Based on that data, less than 1% of the population has MS.[6]

MS is caused by your immune system mistakenly attacking the brain and nerves. It is unclear why this happens, but it may be a combination of genetic and environmental factors.[7,8] The pathogenesis of MS includes the inflammation of the white and grey matter tissues in the CNS due to focal immune cell infiltration and their cytokines which all are the incipient cause of damage in MS.[9] Prevalence of MS in the Gulf region is marked as a low-risk zone; however, recent data have shown a marked increase in the prevalence of MS, nearly 31–55 MS per 100,0000 individuals.[10] From 2015 to 2018, the first nationwide multicenter MS registry was initiated in KSA, mainly to describe the current epidemiology, disease patterns, and clinical characteristics of MS in KSA.[11] The data reported a high rampancy of MS in KSA, which is alarming and warrants immediate public health action. A local study showed that the projected prevalence of MS was estimated at 40.40/100,000 total population putting KSA above the low-risk zone as per Kurtzke classification.[12] The Global Burden of Disease (GBD) 2016 MS Collaborators (2019) estimated that there are 2.2 million persons with MS worldwide and that 0.04% of all DALYs are due to MS.[13] The economic burden of MS is enormous; the estimated total economic burden was $85.4 billion, with a direct medical cost of $63.3 billion and indirect and nonmedical costs of $22.1 billion.[14] Depressive spectrum disorders are pretty high in patients diagnosed with MS. The point prevalence rates for major depressive syndromes in patients with MS visiting outpatient clinics were 14%, and the lifetime risk for major depressive disorder in the MS population may be as high as 50%.[15] A study in KSA reported that 95.6% of the sample surveyed had depressive symptoms.[16] Another source of difficulty in MS care is a lack of knowledge and understanding about the nature of the disease. There is no effective cure for MS, but information and understanding can reduce ambiguity and bridge the gap between the sufferer and the general population. Improving the level of knowledge is crucial and essential for diagnosing and providing help and support to people living with MS.

Objectives

The objective of this study was to evaluate the awareness of Saudi Arabian citizens in the Al- Madinah Al-Munawarrah region, Saudi Arabia, on multiple sclerosis (MS).

METHODS

This was a cross-sectional non-interventional disease area study conducted in the Al-Madinah Al-Munawarrah region, Saudi Arabia. The study period was between December 2021 to September 2022.

Study design and study type

A cross-sectional study among the public living in Al-Madinah Al-Munawara in the western region of Saudi Arabia. The study was conducted using a self-administration, pre-designed and validated electronic questionnaire.

Sample size

The sample size was calculated using EPI InfoTM 717. We used a 95% confidence interval and 5% margin of error, and 30% prevalence of awareness (6) 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.

Data source and study population

We have collected data via interactions with the public in several places across Al-Madinah Al Munawarrah; we have included Saudi national male and female adults older than 18 years old, either single or married. Exclusion criteria represented all single and married Saudi males and females who live out of Al-Madinah Al-Munawarrah; other exclusion criteria were employed as a health-related professional or study at any health college or a patient diagnosed with MS.

The participants were interviewed randomly in different public areas in Al-Madinah Al- Munawarrah, including shopping malls, coffee shops, social clubs, and supermarkets, using a convenience non-probability sample. A sum of 381 participants was enrolled in our study.

The questionnaires contained 8 Arabic close-ended questions and were divided into 3 sections: (1) sociodemographic characteristics include age in years, gender, education level, employment, and marital status, (2) wellsprings of data on MS, like the web or online entertainment; family, companions, or neighbours; medical care labourers; or different sources (training programs on TV or radio, and MS data flyers, leaflets, or posters) and (3) knowledge of MS.

Endpoint

The primary endpoint of our study was to estimate the degree of awareness among public participants across Al-Madinah Al-Munawarrah city concerning MS.

Ethical approval

The official permission was approved by the Al-Rayan Research Ethics Committee (HA-03-M-122). Participation was voluntary and online written informed consent from all the participants after describing the aim of the study. Privacy and confidentiality were assured.

Statistical analysis

We have performed a qualitative analysis of the data. This is a descriptive study, and as such, no statistical testing will be conducted. The summary of statistics for patient demographics, clinical characteristics, and the wellspring of knowledge and awareness towards MS have been analyzed. We used BM SPSS 26 for data analysis. Summary statistics for continuous variables will include the number of observations, mean, standard deviation, median, first and third quartiles, minimum, and maximum. Summary statistics for categorical data will include the number of observations, counts and percentages.

RESULTS

Baseline characteristics

In our study, 381 participants have participated in our cross-sectional study; half were aged between 18-25 years, the majority were female (73.8%), and almost 80% were at a high educational level, half of the participants were married, while one-third of the sample (36.5%) were students. Most of the participants were from Al-Madinah (60.4%), as per Table 1.

General awareness of MS

Across the 381 participants, several questions were offered to the participants to check their level of awareness about MS; 71.4% have shared being unaware relative or friend complaining of MS, two-thirds of the participants (66.4%) reported awareness about MS disease, and same as two- thirds of participants augmented the correct body system (central nervous system) which is related to MS. However, 40% of participants did not know if MS was more common based on gender or in the specific aged group Table 2. Participants should also understand the infectious root of MS if it is transmitted from one person to another (89.2%). However, more than 50% of the participants were unaware that cold or hot weather could impact the symptoms and variety of MS.

Table 1: Baseline characteristics (n=381).

Variables	%
Age (in years)	
19-29	50.4
30-40	11.5
41-51	38.1
Sex	
Male	28.9
Female	73.8
Educational level	
Primary	0.8
Middle	1.0
Secondary	18.6
High level	79.5
Employment status	
Student	36.5
Employed	41.5
Un-employed	22.0
Marital status	
Single	46.5
Engaged	1.8
Married	51.7
Residence	
Madinah	60.4
Jeddah	13.1
Riyadh	3
Other	23.4

General awareness about risk factors for MS

In our study, we assessed the level of awareness regarding the different risk factors associated with MS; 9 inputted options were offered to the 381 participants. All were asked to select the top-rated risk factors related to MS; family history of MS and personal history of autoimmune diseases were on top of the list among the participants in relation to the risk factors for MS with 43.3% and 38.1%, respectively, on the other side elevated levels of growth hormone. Obesity was the least interlinked risk factor for MS among 5.8 and 9.2% of the participants, respectively. On the other hand, more than one-third of the participants were not aware of any risk factors for MS (36.7%), as per Table 3.

Worrying drivers after diagnosis of MS

Feeling worried after diagnosing with MS was one of the questionnaires shared among the participating

participants; we measured the level of attitude of participants once they knew that being diagnosed with MS, more than one-third of participants (40%) shall feel isolated from the community one-quarter of participants (27%) will fear death, one out of five of participants reported fear of disease spreading and only 12% referred to the worrying of treatment cost Table 4.

Table 2: General awareness of MS.

General awareness	
Do you know someone who has MS (relative, friends)?	
Yes	28.6
No	71.4
Have you ever heard of a disease termed MS?	
Yes	66.4
No	33.6
Which system is affected by multiple sclerosis?	
Central nervous system	65.6
Musculoskeletal system	8.9
Respiratory system	1.6
Circulatory system	1.3
I do not know	22.6
Which age group is affected by multiple sclerosis?	
0-19 y	4.2
20-39 y	28.3
40-60 y	19
Above 60 y	7.3
I do not know	40.9
Who is affected more by multiple sclerosis?	
Equal in both	19.4
More in male	12.3
More in femal	28.6
I do not know	39.6
What is the cause of multiple sclerosis?	
Atherosclerosis	8.9
Immunodeficiency	20.7
Meningoencephalitis	9.7
Unknown	14.4
Evil eye	3.9
I do not know	42.3
Can you catch MS disease from someone else?	
Yes	10.2
No	89.8
Is there a relationship between living in hot or areas and having MS symptoms or complication?	
Yes	22.3
No	21.3
I do not know	56.4

Table 3: General awareness about risk factors for MS.

Risk factors	N (%)
Vitamin D deficiency	31.8
Personal history of autoimmune diseases	43.3
Hypertenstion	11
High level of growth hormone	5.8
Virus	11.3
Obesity	9.2
Sedentary lifestyle	11.0
I do not know	36.7

Table 4: Worrying driver after diagnosis with MS.

Factors	N (%)
Fear of death	27
Fear of disease spread to family	21
Cost of treatment	12
Isolation from the society	40

Touchpoints after diagnosing with MS

Identifying the first touch point after diagnosis with MS shall aid us in identifying better ways to management of

patients with MS; across the 381 participants, 73% shared that physician would be the first touch point after diagnosis with MS, 18% to family members, while less than 10% of the participants would refer to no one or a friend as per Table 5.

Table 5: Participant's opinion towards first touch point after diagnosis with MS.

Variables	N (%)
Physician	73
Family	18
Friends	3
No one	6

DISCUSSION

Multiple sclerosis is a debilitating inflammatory illness affecting the central nervous system. Greater disease knowledge and education lead to greater advantages from early detection and intervention.[17] According to the World Health Organization's (WHO) Atlas of MS, the prevalence of MS has increased significantly in recent years. The estimated global prevalence of MS is 30 per 100,000, with 2.1 million diagnosed cases in the same year.[18]

Patients may present late due to a lack of understanding about disease signs, missing out on the benefits of early treatments. Public awareness of the condition is vital for early detection and improving patients' quality of life.[19] It is challenging to treat and interact with patients when they lack knowledge, which can severely impact their mental and physical health.[17] We need more MS education to help people with the disease and lessen the disease's burden.

In this study, we published results from 381 individuals from Al Madinah Al Munawarrah; two-thirds of participants claimed MS awareness, which contradicted prior studies in Saudi Arabia among adults. A study conducted in Riyadh with 226 residents to assess MS knowledge found that 30.3 percent of respondents knew and firmly understood MS.[19] A community-based study with 715 participants in Al-Taif, KSA, found that 26 percent had adequate understanding.[20] On the other side, the current study's good knowledge prevalence is substantially higher than Majmaah's, which was 12.7 percent average/good knowledge. Public awareness of MS is generally low, and this lack of knowledge delays early diagnosis and treatment.[21]

Across all participants, 28.6 percent reported a higher infection rate with MS among females than males, which was consistent with the findings of Amer et al.[20] According to the Multiple Sclerosis International Federation, women and young adults are the most typically affected by MS. Furthermore, 28.3 percent of participants claimed that age groups between 20 and 39 years were more likely to develop MS, which was comparable with the worldwide association's recommended average age of onset of MS of 30 years.[22]

Patients with a family history of MS and recurring autoimmune illnesses were the top two stated risk factors for MS by more than one-third of participants. This result was consistent with other local investigations, except for vitamin D deficiency, which was observed more frequently in other studies, confirming substantial evidence that vitamin D deficiency may enhance susceptibility to MS.[20,23] In our survey, just 9.2 percent of participants thought vitamin D insufficiency was one of the risk factors contributing to the occurrence of MS.

There were some limitations to our study, a uncenter study with a small participants number, and it was a self-reported questionnaire.

CONCLUSION

Our study has revealed the presence of a significant knowledge gap towards understanding, diagnosing and treating MS; this shall contribute towards more challenges in managing MS patients, increasing self-awareness of MS can aid in management, 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.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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