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Assessment of Multiple Sclerosis Patients' awareness and knowledge about their illness in KSA: A cross-sectional study

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ORIGINAL ARTICLE

Assessment of Multiple Sclerosis Patients' awareness and knowledge about their illness in KSA: A crosssectional study

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Abstract

Objectives: Multiple Sclerosis (MS) is prevalent worldwide and commonly elicits neurological impairment. Knowledge and awareness assist in better managing the illness. Evaluating the level of knowledge and awareness among MS students is crucial to implementing an effective educational campaign.

Aim: to assess how well-informed MS patients are about their condition.

Methods: We conducted this study among MS patients in KSA. We collected data via a pre-designed questionnaire, which included sociodemographic data, disease course status, the participants' MS information sources, and possible associated risk factors. We employed a validated MS knowledge questionnaire (MSKQ-25) to assess patients' awareness of their illness.

Results: Of the 343 participants, 56.6% were female, and 38.5% were in the 26–35 age range. Most participants (62.7%) get their information about MS via social media. There is a statistically significant difference (P = 0.000) between knowledge level and age, educational status, and course of the disease. The participants have a good knowledge level (>70%) about the nature of the disease, its course, and treatment options. A moderate level of knowledge (50–70%) was noted about the MS diagnostic modalities and procedures, and low knowledge (<50%) about the disease prevalence, causation, and predisposing factors.

Conclusions: Most of the participants have a good knowledge level (>70%) about many aspects of the MS but are still unaware of others or have a low level of knowledge (<50%). So, it is better to implement awareness-raising educational programs by healthcare workers for MS patients to improve their knowledge level about their illness.

Keywords: Multiple Sclerosis, knowledge, MSKQ-25, KSA

1. Introduction

ultiple sclerosis (MS) is a diverse

LVI demyelinating and neurodegenerative illness that involves the central nervous system and has varying presentations, courses, and prognosis. ¹ MS incidence is increasing and becoming more prevalent worldwide in both developed and developing countries .² An estimated 2.8 million individuals worldwide suffer from MS, which is considered a primary cause of disability, particularly among young adults .³ Al-Jumah and Abumelha ⁴ conducted a national study in Saudi Arabia, finding an overall MS prevalence of 40.40/100,000 for the general population and 61.95/100,000 for Saudi residents. This indicates a significant increase in MS prevalence, classifying the kingdom as a low-risk zone according to the Kurtzke classification .⁵

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Unfortunately, we still don't know exactly what causes MS or how it starts. However, factors like location, genetic alleles, sex, low blood vitamin D levels, smoking, UVB radiation exposure, childhood obesity, parental closeness, and Epstein-Barr virus infection are known to play a major role .6,7 Multiple sclerosis's journey begins with being at risk and continues through the asymptomatic, prodromal, and symptomatic stages of the disease. When an individual complains of a clinically isolated syndromewhich can be either mono- or poly-symptomatic depending on the site and extent of the lesion(s)-MS is typically considered .8 Common neurological symptoms include changes in mood, numbness, weakness, exhaustion, discomfort, bladder dysfunction, loss of coordination and balance, and visual impairment .8 Relapses in MS typically happen sub-acutely, lasting hours to days before plateauing and then slowly improving. With decreased recurring inflammatory activity, both main and secondary progressive MS disease courses show increasing clinical impairment .9

Multiple sclerosis may have evidential consequences for affected persons, their families, and the community since it often occurs during a very productive period of life when people are beginning families and establishing professions. The expanding arsenal of disease-modifying treatments ¹⁰ presents opportunities to lessen impairment and improve the survival of MS patients .¹¹ Nevertheless, there is currently no effective treatment and little knowledge about what causes the illness.

There is an ongoing, pressing need for highquality epidemiological data to enhance our understanding of the risk factors for illness across the world and support advocacy initiatives and health policies aimed at addressing the specific requirements of individuals with MS .3 Contextspecific data about the target population's knowledge, awareness, and perception is crucial for the successful implementation of any health promotion program. However, there needs to be more data about MS patients' knowledge and awareness of their illness in Saudi Arabia. Therefore, our research aimed to assess the level of knowledge and awareness that MS patients have regarding their illness and estimate the risk factors that are associated with it.

2. Subjects and Methods

2.1. The study's design and participants:

The MS patients at KSA participated in this cross-sectional study from January 2023 to May 2023. The study enrolled patients with a provisional MS diagnosis who were under 18 years old and willing to participate. We obtained consent from each participant at the start of the questionnaire. We kept the participants' responses private and confidential. The institutional review board of the continuous medical education committee King Fahad Hospital at (KFH/IRB20112022/3) approved the study. We used the Richard Geiger equation to determine the minimal sample size, ensuring a 95% confidence level and 80% power .¹² We calculated it based on the estimated number of MS patients in Saudi Arabia, 40.40/100,000 for the general population .⁵ We determined that a minimum sample size of 345 was adequate for our study, and ultimately, we obtained a final sample size of 343.

2.2. Tools and measurements:

We distributed a semi-structured questionnaire electronically to MS patients. The questionnaire includes three sections: the first part includes sociodemographic data (age, sex, employment, marital status, and educational level); the second part asks about disease course status and its possible associated risk factors (family history, smoking, obesity, vitamin D deficiency, and childhood infection); and the third part includes items that assess patients knowledge about MS.

We used the MS knowledge questionnaire (MSKQ-25) to assess patients' knowledge about MS. We obtained permission from the corresponding author to use his questionnaire .¹³ Experts proficient in both English and Arabic translated the MSKQ-25 into Arabic before its distribution. A previous study assessed the questionnaire's content validity, internal consistency (Kuder-Richardson-20 Eq. 0.76), and validity, and the results were positive .¹³

The questionnaire entails 25 items about MS. Every item has three to five multiple-choice responses for each question. There was an exception to question number 3, which was asking about the disease's prevalence in Italy (Q3), and it has been replaced by another question asking about the estimated prevalence in Saudi Arabia. Each correct response earned one point. As a result, zero is the lowest possible score, and 25 is the greatest. 2.3. Statistical analysis:

We exported the data to Microsoft Excel 2019. We analyzed the raw data using IBM Statistical Package for Social Sciences (SPSS) software version 26. The statistical test listed below was done. We measured the qualitative variables using frequencies and percentages and the quantitative variables using the measure of central tendency. In the analysis of variance, the Chi-square test and the Mann-Whitney U test were utilized. The confidence intervals were 95% CI with a margin of error of 5%; all p values less than 0.05 were considered statistically significant.

3. Results

The participant's level of knowledge about multiple sclerosis is based on their demographic data.

Table 1. Demographic data of the studied patients with different levels of knowledge about Multiple Sclerosis

VARIABLE	%	MSKQ SCORE < 5 0%	MSKQ SCORE 50% TO ≤ 70%	MSKQ SCORE > 70%	P- VALUE					
		n = 123	n = 198	n = 22						
SEX	1	(33.770)	(37.770)	(0.470)						
MALE	149	61 (49.6%)	81	7 (31.8%)	164					
WINTEL	(43.4%)	01 (49.0%)	(40.9%)	7 (51.070)	.104					
FEMALE	194	62 (50.4%)	117	15 (68.2%)						
	(56.6%)		(59.1%)							
AGE GROUPS										
18-25	67	13 (10.6%)	40	14 (63.6%)	.000**					
	(19.5%)		(20.2%)							
26-35	132	53 (43.1%)	79	0 (0.0%)						
	(38.5%)		(39.9%)							
36–45	116	41 (33.3%)	67	8 (36.4%)						
	(33.8%)		(33.8%)							
> 45	28	16 (13.0%)	12	0 (0.0%)						
	(8.2%)		(6.1%)							
EDUCATIONAL	LEVEL	10 (0 1)	0	0. (0. 0)						
PRIMARY		10 (8.1%)	0	0 (0.0%)	.000**					
OF COMPARY	(2.9%)	48 (20.00/)	(0.0%)	7 (21.90/)						
SECONDARY	98	48 (39.0%)	43	/ (31.8%)						
UNIVEDOUTV	(28.0%)	(5) (5) (0)	(21.7%)	15 (69.20)						
UNIVERSITY	233	65 (52.8%)	155	15 (08.2%)						
(68.5%) (78.3%)										
MARITAL STAT	150	78 (62 404)	74	7 (21 804)	000**					
MARKIED	(16 104)	78 (03.4%)	(27.4%)	7 (31.6%)	.000**					
SINCLE	(40.4%)	30 (24.4%)	104	15 (68 2%)						
SINGLE	(13, 1%)	30 (24.470)	(52.5%)	15 (08.270)						
DIVORCED	30	10 (8 1%)	20	0 (0.0%)						
DIVORCED	(8 7%)	10 (0.170)	(10.1%)	0 (0.070)						
WIDOW	5	5 (4 1%)	0	0 (0.0%)						
1112011	(1.5%)	5 (4.170)	(0.0%)	0 (0.070)						
EMPLOYMENT	(1.570)		(0.070)							
WORKING	154	54 (43 9%)	93	7 (31.8%)	414					
	(44.9%)	- (()	(47.0%)	. (221070)						
NOT	189	69 (56.1%)	105	15 (68.2%)						
WORKING	(55.1%)		(53.0%)							
DISEASE STATUS										
RELAPSING	270	101 (82.1%)	147	22 (100%)	.010**					
	(78.7%)		(74.2%)	. ,						
CONTINUOUS	73	22 (17.9%)	51	0 (0.0%)						
	(21.3%)		(25.8%)							
** Indic	nated a	highly	signific	ant corr	elation					

** Indicated a highly significant correlation (p<0.01)



Figure 1. The possible predisposing factors for Multiple sclerosis

We received 365 responses from patients with multiple sclerosis. However, we only used 343 responses in the final analysis, as we deleted 22 responses due to their failure to meet our study eligibility criteria. As shown in Table 1, the participants were 194 (56.6%) females and 149 (43.4%) males, with a mean age of 34.26 ± 8.48 . The participants were educated at the university level (68.5%), unemployed (55.1%), married (46.4%), and had a relapsing disease course (78.7%). There is no statistically significant difference between males and females regarding their level of knowledge about MS. However, there is a significant association between MS knowledge and factors such as age, educational level, marital status, and the course of the disease. Table 1. Regarding the possible associated risk factors, vitamin D deficiency is the only possible predisposing factor, with a high percentage among participants 211 (61.5%), as shown in Fig. 1. The majority of participants (62.7%) learned about MS through social media and the Internet, followed by friends and relatives (27.1%). Healthcare workers (10.2%) provided the least amount of information.

Table 2. Score of correct knowledge among the studied patients

Q		MSKQ SCORE < 50 %	MSKQ SCORE 50% TO≤ 70%	MSKQ SCORE > 70 %	CORREC T ANSWER S	<i>P</i> - VALU E	LEVEL OF AWARENES S AND KNOWLED			
NIAT		n = 123	<i>n</i> = 198	<i>n</i> = 22	n = 343		GE			
NAT 1	URE OF THE DISEAS	E 107 (87.0%)	191(86.5	22 (100%)	320	.003**	High			
	MS	(· · · · · · · · · · · · · · · · · · ·	%)		(93.3%)		6			
2	CNS composition	93 (75.6%)	186(93.9 %)	22 (100%)	301(87.8 %)	.000**	High			
4	Impact of MS on life expectancy	74 (60.2%)	132 (66.7%)	22 (100%)	228 (66.5%)	.001**	high			
5	MS as immune disease	33 (26.8%)	149 (75.3%)	16 (72.7%)	198 (57.7%)	.000**	High			
6	MS as a contagious disease	20 (16.3%)	30 (15.2%)	18(81.8%)	68 (19.8%)	.000**	Low			
10	Myelin/axon damage	0 (0.0%)	20 (10.1%)	5 (22.7%)	25 (7.3%)	.000**	Low			
13	Myelin function	120 (97.6%)	198 (100%)	22 (100%)	340 (99.1%)	.079	High			
PRE	DISPOSING FACTORS	S AND PREVAI	LENCE		, ,					
3	Prevalence of MS in Saudi Arabia	44 (35.8%)	93 (47.0%)	19 (86.4%)	156 (45.5%)	.000	Moderate			
11	Age of onset	28 (22.8%)	70 (35.4%)	9 (40.9%)	107 (31.2%)	.036**	Low			
12	Ratio of sex in MS prevalence	83 (67.5%)	159 (80.3%)	22 (100%)	264 (77%)	.000**	High			
23	Pregnancy impact on MS	8 (6.5%)	36 (18.2%)	10 (45.5%)	54 (15.7%)	.000**	Low			
CAU	SATION AND GENET	TIC FACTOR								
7	MS etiology	2 (1.6%)	16 (8.1%)	6 (27.3%)	24 (7.0%)	.000**	Low			
8	Transmission of MS to offspring	15 (12.2%)	11 (5.6%)	17 (77.3%)	43 (12.5%)	.000**	Low			
9	Transmission of MS to other family member	52 (42.3%)	139 (70.2%)	20 (90.9%)	211 (61.5%)	.000**	High			
DIA	GNOSTIC PROCEDUR	RES AND METH	IODS							
14	Used tests to diagnose MS	72 (58.5%)	170 (85.9%)	22 (100%)	264 (77.0%)	.000**	High			
15	MRI role in MS diagnosis	40 (32.5%)	122 (61.6%)	18 (81.8%)	180 (52.5%)	.000**	Moderate			
16	Gadolinium injections' role during MRI	41 (33.3%)	144 (72.7%)	18 (81.8%)	203 (59.2%)	.000**	Moderate			
17	MRI role on disease follow-up	24 (19.5%)	38 (19.2%)	6 (27.3%)	68 (19.8%)	.689	Low			
18	Role of lumbar	8 (6.5%)	42 (21.2%)	0 (0.0%)	50 (14.6%)	.000**	Low			
19	Frequency of lumbar puncture	89 (72.4%)	192	22 (100%)	303 (88,3%)	.000**	High			
20	Definite diagnosis of MS	36 (29.3%)	104 (52.5%)	22 (100%)	162 (47.2%)	.000**	Moderate			
COU	COURSE AND TREATMENT									
21	Definition of remittent	32 (26.0%)	106 (53.5%)	19 (86.4%)	157 (45.8%)	.000**	Moderate			
22	Benign MS	68 (55.3%)	171 (86.4%)	12 (54.5%)	251 (73.2%)	.000**	High			
24	Curative treatment	72 (58.5%)	181	22 (100%)	275	.000**	High			
25	Types of MS disease targeted by current therapies	92 (74.8%)	193 (97.5%)	22 (100%)	307 (89.5%)	.000**	High			

The level of participants' knowledge regarding each MSKQ-25 guestionnaire item was assessed.14 categorized the responses into three groups: the first group included participants whose MSKQ-25 score was less than 50%, the second group included participants whose MSKQ-25 score ranged from 50% to 70%, and the third group included participants whose MSKQ-25 score was less than 70%. There were 123 (35.9%) participants categorized in the second group, 198 (57.7%) in the first group, and 22 (6.4%) in the third group. The average MSKQ score was $13.29 \pm$ 2.92. The lowest score was 7 (5%), and the highest score was 21 (0.6%) out of 25. As shown in Table 2, there is a high level of knowledge with regard to the disease's nature (1-13) and its treatment modalities (21-25). The questions Q1, Q13, and Q25 received the most accurate responses. Q7 and Q10 were the least likely to receive successful answers. There is a high level of knowledge regarding the nature of the disease; 320 (93.3%) of the participants knew the organs involved in the disease, 340 (99.1%) knew the myelin function, and 198 (57.7%) knew that it is a disease of the immune system. However, there is a lack of knowledge about myelin and axon damage. Only 25 people (7.3%) and 19.8% understand that myelin and axon damage is not a contagious illness.

The prevalence and predisposing factors of MS are not well known to the participants, as only 15.7% know that MS has an impact on pregnancy, and 31.2% know about the age of the onset of the disease. Nearly half the participants (45.5%) know the prevalence of MS in Saudi Arabia. Also, many of them need more knowledge about the disease's causation and genetic factors; only 7.0% knew about MS etiology. About 77.0 percent knew the tests used for MS diagnosis, but only 14.6% knew the role of the lumbar puncture in the diagnosis, and 19.8% knew about the role of MRI in the follow-up. Most of the participants have a high level of knowledge about the course of the disease and its treatment options.

4. Discussion

The findings of this study contribute to our understanding of the knowledge and awareness landscape among MS patients in KSA. While participants demonstrated commendable understanding in certain domains, notable knowledge gaps were evident, aligning with similar observations in the region. For instance, the study by [Al-Jumah and Abumelha]. on the prevalence of MS in Saudi Arabia highlighted the disease's rising impact.

Prevalence rates of 40.40/100,000 for the general population and 61.95/100,000 for Saudi citizens were recorded. This indicates a significant rise, surpassing the low-risk zone classification, according to .⁵ Herein, we noted that the prevalence of good MS knowledge among MS patients is in agreement with other Saudi studies, such as that conducted by ¹³ on the general population of the Al-Qassium region and ¹⁵ in the Rivadh region, which found that 30.3% of respondents were aware of and had a good understanding of MS. On the other hand, the current study's prevalence of good knowledge is substantially higher than that of Majmaah, which was 12.7% average/good knowledge. Still, the target group was the general population .¹⁶

The study's participants, much like those in other regions, exhibited strong awareness of certain aspects of MS, such as the nature of the disease and available treatment modalities .¹³ However, similar to the observations made by ¹⁴, critical gaps persist, particularly concerning disease prevalence, genetic factors, and specific diagnostic procedures. The participants' reliance on social media and the Internet as primary sources of information echoes trends observed in other studies 16. While digital platforms offer unprecedented opportunities for disseminating health-related knowledge, there is a need for caution. Ensuring the accuracy and reliability of information on these platforms is crucial to preventing the spread of misinformation. A significant aspect of believing in transparent information is reliance on authentic sources ¹⁷, like the recommendation of the ¹⁸ study that proved written materials may be a successful, low-cost, and simple-to-implement technique for improving popular comprehension of an ailment or its treatment, particularly for the patients and their relatives.

The influence of sociodemographic factors on MS knowledge aligns with broader trends identified in studies worldwide. Age, educational level, marital status, and disease course emerged as significant determinants of awareness, consistent with findings from diverse cultural contexts ^{13, 14}. Tailoring educational interventions to these demographic characteristics could enhance their effectiveness.

Drawing parallels with international studies, our findings emphasize the universal challenge of addressing knowledge gaps in MS patient communities. Bridging these gaps is essential not only for improving patient understanding but also for informing advocacy efforts and shaping health policies. As we navigate the evolving landscape of MS, collaborative efforts between healthcare providers, policymakers, and patient communities are imperative to foster a wellinformed and empowered MS population in Saudi Arabia.

Despite the limitations inherent in any population survey study, such as the reliance on self-reported data and the potential for recall bias, the insights gained from this research are invaluable. They provide a foundation for developing targeted health promotion programs that address the identified knowledge gaps. Integrating these findings into comprehensive strategies could not only enhance the understanding of MS among patients but also contribute to broader advocacy initiatives and health policies. As we navigate the evolving landscape of MS, bridging these knowledge gaps is paramount for fostering a well-informed and empowered MS community in Saudi Arabia.

5. Conclusion

Most of the participants have a good knowledge level (>70%) about many aspects of the MS but are still unaware of others or have a low level of knowledge (<50%). So, it is better to implement awareness-raising educational programs by healthcare workers for MS patients to improve their knowledge level about their illness.

Disclosure

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