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ORIGINAL ARTICLE

The assessment of knowledge level among the patient, family, and patients diagnosed with multiple sclerosis

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ABSTRACT

Objective: This study aimed to assess the knowledge level among the patients' families and the patients diagnosed with multiple sclerosis.

Methods: A cross-sectional study was carried out recruiting a convenient sample of 316 patients and family members. Data were collected using a demographic questionnaire and the Multiple Sclerosis Knowledge Questionnaire. Data were collected through online means via Google Forms.

Results: The findings revealed moderate knowledge among the majority of both patients (44.3%) and family members (45.6%). However, mean knowledge scores showed that family members were more knowledgeable (74.3%) than the patients (63.2%). Among patients, significant differences in knowledge scores were observed across their education level ($p < 0.001$), age (p-value = 0.02), and income level (p-value = 0.05). Among family members, significant differences in knowledge scores were observed across their education level ($p < 0.001$) and income level (p-value = 0.03). Family members were more knowledgeable about diagnostic methods, the nature of the disease, and treatment options, compared to patients.

Conclusion: The moderate knowledge among the participants highlighted the need for targeted educational programs designed to fill the participants' knowledge deficits detected in this study to improve disease management.

Keywords: Assessment, knowledge level, patient, family members, multiple sclerosis.

Introduction

Multiple sclerosis (MS) is specifically an autoimmune disease that attacks the central nervous system (CNS), where nerves are protected by a substance called the myelin sheath. The consequences interfere with the firing of electrical signals along the nerve cells, thus manifesting neurological effects [1]. MS relapses are worsening attacks followed by a stabilization of symptoms for a while, although patients and their disease's severity can be quite different. Some signs might include tiredness, slurred speech, weakness in leg muscles, loss of sensation in the limbs or face, blurriness, memory loss, and bowel control problems, among others [2]. MS tends to occur in young people, usually in the age group of 20–40 years, and the condition is more common among women than men [3].

This disease affects people globally, with statistics showing that close to 2.8 million people globally are suffering from MS [3]. It differs geographically, with the highest incidences being more common in the areas that are further from the Equator in Europe, North America, and Oceania. However, the prevalence rates have been reported to be comparatively lower in tropical areas, including the sub-Saharan Africa region [4].

The rates are particularly high in high-income countries, including Canada, the United States of America, and the northern part of Europe, with incidence rates higher

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than 200 per 100,000 population [3]. These geographical differences seem to imply that both genetic and environmental factors have important roles to play in the development of the disease [5].

The incidence of MS in Saudi Arabia is increasing at a gradual rate, as a study conducted at a national level suggested that the rate is 40.4/100,000 for the general population and 61.95/100,000 for Saudi residents [6]. These increased cases signify that MS has increasingly become a major public health concern in the region. MS in Saudi Arabia also has some similarities to global trends, and there is a higher prevalence rate among women, and most of them had the relapsing-remitting type of the disease [6,7]. This increased prevalence might be due to factors such as heredity, deficiency in many essential nutrients such as vitamin D, and lifestyle changes that are seen in urban society.

Therefore, knowledge concerning this disease is essential for better management of the condition. The patients, as well as their families, need to have considerable knowledge regarding the disease, its manifestations, and the available management regimes to be able to offer the patients the best quality of life [8]. Studies across countries indicated that patients' knowledge about the disease affects episodes of symptoms, ability to follow up on physicians' advice, and mechanisms of handling psychological aspects of MS. Moreover the level of awareness plays an important role in diagnosing MS during its early stages that are important in limiting the intensity of the disease and potential damages [9].

Although knowledge about MS has increased in many areas globally, there is still a lack of information concerning the disease among various populations. A Saudi Arabia-based cross-sectional study revealed that despite having a moderate to high level of knowledge regarding some aspects of MS, the patients were deficient in their knowledge regarding the causes or risk factors of the disease, its genetic predisposition, and diagnostic processes [7].

Notably, 80% of the information that MS patients used came from social media, and few sources stemmed from healthcare practitioners. This brings out the importance of systematic public health information delivery strategies that would help combat myths and nurture informed knowledge [7,8].

While there have been numerous studies conducted on awareness of MSc, the majority of them were carried out with patients [8,10] only with little information given on awareness among the families. This presented a critical oversight because families are usually the people who stand with the patient, taking the role of a caregiver, besides performing some physical functions for the patient [11,12]. Family members need to gain more knowledge about the illness to provide appropriate care to the patient, identify signs of steroid inflammation, and help the patient manage the difficulties associated with the condition. Therefore, this study assessed knowledge levels among the patients' families and patients diagnosed with MS.

Subjects and Methods

This study adopted a cross-sectional research design to determine levels of knowledge among both family members and patients with MS. The design was considered ideal and enabled the study to establish a snapshot of the knowledge levels at a single point in time, thus allowing a comprehensive understanding of current knowledge among the study participants.

The study included both patients diagnosed with MS and their family members. A convenience sampling method was used to recruit participants in the study. A convenient sample of 316 patients and family members was included. The sample size was determined using an online software for sample size, using a response distribution rate of 50%, a 0.05 margin of error, and a confidence level of 0.95% [13]. The eligibility criteria for both patients and family members required them to be aged ≥18 years. The study excluded patients with unconfirmed MS diagnoses. Dr. Soliman Fakeeh Hospital June 2023 - April 2024.

Patients were identified from patient records, and their contacts were retrieved. The researcher contacted the patients, who also facilitated the recruitment of their family members. Additionally, social media platforms were used to recruit family members into the study. Data collection was conducted via online means, and questionnaires were distributed using Google Forms. To enhance data integrity, various measures were put in place. The participants were required to provide their valid email addresses to Google Forms to prevent response duplication. The forms were also accompanied by instructions emphasizing the significance of accurate responses, honesty, and the aim of the study was stated clearly. Consent to participation was voluntary, and the responses were treated confidentially.

A structured questionnaire, comprised of two parts, was used during data collection. The sociodemographic part and the Multiple Sclerosis Knowledge Questionnaire (MSKQ-25). The sociodemographic part was used to determine the age, gender, marital status, education level, employment status, and income level. The MSKQ-25 was used to assess participants' knowledge of MS. It comprised of 25 items assessing knowledge in dimensions of the nature of the MS disease, prevalence and predisposing factors, causation, and genetic factors, diagnostic methods and procedures, and types and treatment. The items had 3–5 possible responses, and one point was allocated for a correct response. The total score ranged from 0 to 25 [14].

The reliability of the instrument was established with a coefficient of 0.76, suggesting good reliability. For interpretation of the findings, the knowledge levels were categorized into three categories: low knowledge level

(0%–50%), moderate knowledge level (51%–80%), and high knowledge level (81%–100%).

The data were analyzed using the Statistical Package for Social Sciences (SPSS) software version 27. Both descriptive and inferential statistics were applied for data analysis. Sociodemographic and baseline knowledge levels were analyzed descriptively using means, frequencies, percentages, and standard deviations. Pearson's Correlation analysis was used to determine the significant relationships between knowledge and demographics. A $p < 0.05$ was considered statistically significant.

Results

A total of 316 participants completed the questionnaire. Of these, 158 patients were diagnosed with MS, and 158 were family members. The age range of participants spanned from 18 to 75 years. The mean age for patients was 38.5 ± 12.3 years, while for family members, it was 34.5 ± 10.1 years. This indicated that, on average, family members were slightly younger than patients. Of the 158 patients, 98 (62.1%) were females. Similarly, among the 158 family members, 93 (58.9%) were females. The overall distribution showed 191 females (60.4%) and 125 males (39.6%) across both groups, indicating that a higher proportion of females participated in the study. Among the patients, only 80 (50.6%) of participants were married. In contrast, family members had a higher proportion of married individuals, with 109 (69.0%) married. Education level was relatively high among both groups. Among patients, 39 (24.7%) had obtained postgraduate education. While among family members 48 (30.4%) had completed postgraduate education. The employment status for both groups was quite similar, with 75.9% of participants employed. Income levels were categorized into three groups: low, medium, and high. Among patients, 50 (31.6%) had a low income (less than U.S. $2,000 per month). Among family members, 48 (30.4%) had a low income (Table 1).

The mean knowledge score for patients was 63.2% (SD = 13.5%), while the mean knowledge score for family members was 74.3% (SD = 10.2%). Overall, the results showed that both patients (44.3%) and family members (45.6%) had moderate knowledge levels of MS. However, family members showed significantly higher knowledge compared to patients, indicating that family members might be more exposed to MS or interested in knowing more about MS compared to patients (Table 2).

Using the MSKQ-25 to assess knowledge in dimensions of the nature of the MS disease, prevalence and predisposing factors, causation and genetic factors, diagnostic methods and procedures, and types and treatment, the results revealed the following significant insights. The results showed that family members had a better knowledge level in the nature of the MS

Table 1. *Demographic characteristics of participants.*

Demographic variable	Patients *n* = 158 (%)	Family members *n* = 158 (%)	Total *n* = 316 (%)
Age (Mean ± SD)	38.5 ± 12.3	34.5 ± 10.1	36.5 ± 11.7
Gender			
Male	60 (37.9)	65 (41.1)	125 (39.6)
Female	98 (62.1)	93 (58.9)	191 (60.4)
Marital status			
Married	80 (50.6)	109 (69.0)	189 (59.8)
Single	50 (31.6)	41 (26.0)	91 (28.8)
Divorced	18 (11.4)	8 (5.1)	26 (8.2)
Widowed	10 (6.3)	0 (0.0)	10 (3.2)
Education level			
High school	30 (19.0)	19 (12.0)	49 (15.5)
Undergraduate	89 (56.3)	91 (57.6)	180 (57.0)
Postgraduate	39 (24.7)	48 (30.4)	87 (27.5)
Employment status			
Employed	120 (75.9)	120 (75.9)	240 (75.9)
Unemployed	38 (24.1)	38 (24.1)	76 (24.1)
Income level			
Low	50 (31.6)	48 (30.4)	98 (31.0)
Medium	80 (50.6)	86 (54.4)	166 (52.5)
High	28 (17.7)	24 (15.2)	52 (16.5)

Table 2. *Knowledge level categorization among the participants.*

Knowledge Level	Patients *n* = 158 (%)	Family Members *n* = 158 (%)	Total *n* = 316 (%)
Low knowledge (0%–50%)	65 (41.1)	46 (29.1)	111 (35.0)
Moderate knowledge (51%–80%)	70 (44.3)	72 (45.6)	142 (45.0)
High knowledge (81%–100%)	23 (14.6)	40 (25.3)	63 (20.0)
Mean knowledge score	63.2 (SD = 13.5)	74.3 (SD = 10.2)	68.7 (SD = 12.8)

Table 3. *Knowledge by dimensions for patients and family members.*

Category	Items	Patients (%)	Family Members (%)
Nature of the disease	Organs involved in MS	85	92
	CNS composition	80	90
	Impact of MS on life expectancy	60	75
	MS is an immune disease	70	80
	MS is a contagious disease	75	82
	Myelin/axon damage	78	85
	Myelin function	80	88
Prevalence and predisposing factors	Prevalence of MS worldwide	70	80
	Age of onset	85	90
	The ratio of sex in MS prevalence	65	75
	Pregnancy's impact on MS	50	65
Causation and genetic factors	MS etiology	65	80
	Transmission of MS to offspring	60	70
	Transmission of MS to other family members	58	68
Diagnostic methods and procedures	Used tests to diagnose MS	70	80
	MRI role in MS diagnosis	79	85
	Gadolinium injections' role during MRI	65	75
	MRI role in disease follow-up	72	80
	Definite diagnosis of MS	60	72
	Role of lumbar puncture	68	78
	Frequency of lumbar puncture	65	72
Types and treatment	Definition of remittent MS	65	75
	Benign MS	55	70
	Curative treatment	50	65
	Types of MS disease targeted by current therapies	60	72

disease dimension compared to patients. However, both participants showed high knowledge about the role of myelin, with above 80% understanding its significance. The lowest knowledge level was seen regarding the effects of MS on life expectancy among both patients and family members, with 75% of family members as well as 60% of patients providing correct answers.

The results showed that both patients and family members provided correct answers about the age at which MS is likely to occur, with 85% and 90%, respectively. Low understanding was observed in terms of MS prevalence and the related impact of pregnancy on MS. Moderate understanding was observed, where family members (70%) and patients (60%) understood that MS can be transmitted to offspring. The least well-understood concept was the transmission of MS to other family members, which was correct for 58% of patients and 68% of family members. Family members generally had a better understanding of diagnostic procedures, especially regarding the role of MRI in MS diagnosis (85% of family members *vs.* 79% of patients). The knowledge of MS types was relatively low for both groups, especially regarding benign MS and the lack of curative treatments. Only 50% of patients and 65% of family members answered correctly regarding curative treatments (Table 3).

Table 4. *Correlation analysis of the participants' demographics with the knowledge level.*

Patients		
Variable	***R*-value**	***p*-value**
Age	-0.25	0.02
Gender (Male = 1, Female = 2)	0.08	0.42
Education level	0.34	<0.001
Income level	0.18	0.05
Family members		
Variable	***R*-value**	***p*-value**
Age	-0.12	0.15
Gender (Male = 1, Female = 2)	0.05	0.60
Education level	0.29	<0.001
Income level	0.20	0.03

For patients, a significant negative correlation was found between age and knowledge level ($r = -0.25$, p-value = 0.02), indicating that younger participants tended to have higher knowledge about MS. Education level showed a positive correlation with knowledge ($r = 0.34$, $p < 0.001$), meaning that patients with higher levels of education had better knowledge of MS. Additionally, a weak positive correlation between income level and knowledge (r = 0.18, p-value = 0.05) suggested that those with higher incomes tended to have a slightly higher level of knowledge. For family members, education level also showed a significant positive correlation with knowledge ($r = 0.29$, $p < 0.001$). The income level was positively correlated with knowledge (r = 0.20, p-value = 0.03) (Table 4).

Discussion

The research findings revealed essential insights into the knowledge levels, knowledge across various dimensions, as well as the factors associated with the knowledge of the participants. Generally, the findings revealed that both patients and family members had moderate knowledge regarding MS. However, family members had better knowledge (74.3%) compared to patients (63.2%). For instance, a study in Saudi Arabia, conducted during COVID-19, also reported moderate knowledge of MS in patients [15]. Similar findings were reported among MS patients in Turkey [16]. On the contrary, high knowledge of MS was reported among patients in a recent study in Lebanon [8].

Moreover, regarding knowledge of MS among the family members, the current findings corroborate with previous studies highlighting low to moderate knowledge levels among family members of MS patients [9,17,18]. The difference between knowledge among patients and family members suggested a significant trend, where family members without MS have an active and keen interest toward understanding the disease; this might be due to their roles of caregiving as well as concern for the well-being of their patients. This concurs with other studies that show that caregivers of patients with chronic diseases are more inclined to learn more to support their families [12,19,20]. Such findings suggested the need to provide educational support to the patients, as they might not proactively look for information, despite their illness.

The results showed a knowledge deficit across different dimensions of MS knowledge. In the knowledge about treatment, patients and family members had contrasting understandings of treatment conditions. For instance, family members had better awareness of the illness, diagnosis process, and available cures. This might indicate that they were more readily exposed to the disease and its treatment through doctors' visits, treatment talks, or directly experiencing how the disease impacts patients. Still, the findings observed several knowledge gaps among the family members, including the understanding of the relationship between MS and life expectancy and the effect of the disease. These were indicated by the response rates, which were low in these areas from both groups, hence a lack of widespread education on these issues that would require healthcare personnel to focus more when educating their patients, as well as the family members [8].

Regarding the knowledge of MS in the four domains of knowledge, the setting was characterized by gaps of understanding, especially regarding causes and genetics, as well as the treatment of MS by both patients and family members. Thus, while both groups revealed a fair amount of knowledge about the heritability of the disease, including its transmissibility to children, they continue to contain misconceptions about the transmissibility to other family members. This implies that although the two groups have some level of awareness towards MS, there is still limited and insufficient knowledge about the genetic aspect of the disease. This is in line with a previous study, which revealed that patients in Saudi Arabia had less knowledge of the genetic role of MS transmission [21]. Another study among the public in Libya showed they had low MS awareness, including the nature of its transmission [9]. This lack of adequate knowledge about MS etiology can result in to delay in diagnosis and treatment, thus negatively affecting the prognosis and quality of life of MS patients [22].

Similarly, the knowledge about the types of MS and currently available treatment was better but had fewer gaps in some areas. Both groups lacked information that there is no cure for MS, and only a portion of the family members and patients knew the treatment available for various types of MS. This raises the need for better disclosure on treatment and disease and more emphasis on palliative care and the need to manage diseases to avoid some of its complications.

The findings of this study further revealed that the knowledge scores are higher among patients with higher education and incomes, indicating that people who are more educated and financially capable can afford to acquire more knowledge.

This supports the notion that education is key to MS awareness, where persons who have attained higher levels of education are more likely to have access to information, such as online, health care, and support groups [9,21]. On the other hand, patients with lower education and income levels had low levels of knowledge, and the offer could be further hampered by their inability to seek or receive proper information or professional advice. This all points to the potential need for more equitable distribution of more sophisticated healthcare educational programs for those communities or groups that are still at a low educational level in their educational distribution or system.

The findings through correlation analysis further highlighted the factors associated with the knowledge of the participants. The level of knowledge regarding MS was inversely related to age, meaning patients with this illness were more knowledgeable at a younger age. This might be due to younger patients being proactive by seeking information or consultations with doctors, groups, or other patients, whereas the elderly might lack the energy or mental or physical abilities to go through the process because of the disease.

The results of the analysis were also significant for family members: education and income were positively associated with knowledge in the group, which meant that knowledge receivers of better education and higher income had more information sources available to them. The findings of the current study on the relationship between education levels are incongruent with a previous study, which established that the knowledge of family members was not affected by their education levels [9,23]. However, the present findings about family members are congruent with a previous study, where a significant association between income level and knowledge was established [17].

Overall, this study revealed that patients and family members had moderate knowledge about MS, even though family members have slightly better awareness than patients themselves. Therefore, the results highlighted the need for enhancing educational interventions on MS for both patients and families. It is therefore important for health professionals to understand the influence of factors such as age, education, and income on knowledge and to utilize this understanding when developing an educational program. Such efforts would be beneficial not only in terms of raising the quality of care and support for people with MS but also in providing helpful information to family members to make informed decisions that would foster the well-being of individuals with MS.

The main limitations of this study include the collection of data from a single healthcare setting in Saudi Arabia, therefore, the findings might not be generalized to patients with MS from other hospitals in Saudi Arabia. Data was collected using online-self-reported surveys, thus there may be reporting bias.

Conclusion

The findings of this study are important in presenting a view on the knowledge levels of patients with MS and members of their families. While moderate knowledge levels were reported among the participants, family members showed a better understanding in most cases compared to the patients in diagnostic methods, the nature of the disease, and treatment options. The study also established that awareness level depends on education and income level, where individuals with higher education and income levels have a better understanding. Targeted educational programs designed to fill the perceived knowledge deficits detected in this study could go a long way toward helping both MS patients and family members and could enhance the quality of life of those afflicted by MS.

List of abbreviations

MS	Multiple sclerosis
CNS	central nervous system
MSKQ-25	Multiple Sclerosis Knowledge Questionnaire
SPSS	Statistical Package for Social Sciences

Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

Consent to participate

Informed consent was obtained from all the participants.

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Ethical approval

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