

Evaluation of the Knowledge, Source of Information and Quality of Life among Multiple Sclerosis Patients in Saudi Arabia

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Abstract: **objective:** the aim of the present study is to examine the awareness and knowledge of people with multiple sclerosis (MS) toward their illness and their source of information, and the quality of life across gender, age, and symptom severity. **Method:** Cross-sectional study used by using a self – administered questionnaire. **Setting and Participants:** The sample was collected from patients Registered in “Arfaa society” and their followers on social media, 143 participants were qualified for the study. **Results:** General knowledge about MS among patients were unexpectedly high, and the primary source of information was obtained from the internet. The only health education provider in hospitals were doctors, yet one-third of participant’s complaints was about difficulties in communicating with their doctors during their visits. None of the patients have had a health education specialist to educate them about the disease and nature of relapses. The quality of life was relatively high throughout all participants, with only 7% of them with a very low quality of life. The lower the knowledge about MS among patients, the lower the quality of life they receive. **Conclusions:** Patient information and counseling need to be included in the management plan for Multiple Sclerosis (MS) patients, through health education specialists, especially at early stages of disease for the management of the disease relapses.

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1. Introduction

Multiple sclerosis (MS) is the most common autoimmune disease affecting the central nervous system (CNS). It is a demyelinating disease of the central nervous system, which leads to impaired cognitive, motor and or sensory functions (NIH Medline Plus, 2016). The range and severity of symptoms may vary greatly from individual to individual, but the symptoms typically include impaired mobility and balance, fatigue, bladder and bowel difficulties, sexual dysfunction, depressed mood and cognitive difficulties. MS can cause impairment in various areas of an individual's life, influencing family roles, employment, quality of life, daily functioning, and it affects adults during their most productive years (G. Mancardi, 2013; Bevan & Steadman, 2015).

The estimated 2,500,000 people in the world have multiple sclerosis (Multiple Sclerosis Trust, 2015). Prevalence of MS in Saudi Arabia is 40/100,000 in 2008; researchers suggest an increase in incidence and prevalence in the Middle East (Al-Hashel, Besterman, & Wolfson, 2008).

It has been suggested that education and information on symptom management and treatment options can provide a sense of empowerment over the

course of the disease, and provide people with the tools that permit them to make informed decisions regarding their own well-being, this sense of patient empowerment is thought to play an integral role in the successful management of MS (Rieckmann et al., 2015; Saleh et al., 2014; Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014).

The Internet is increasingly prominent as a source of health information for people with multiple sclerosis (MS). But there has been a little exploration of the needs, experiences and preferences of people with MS for integrating treatment information into decision making, in the context of searching on the Internet (Synnot et al., 2016). Yet still, it is important that people with MS have access to education pertaining to MS to allow them to self-manage their illness and maintain a good quality of life. For that Quality of life (QOL) is becoming an increasingly important factor in the measurement of disease impact as well as an outcome measure in clinical trials (Buhse, Banker, & Clement, 2014).

Thus, the aim of the present study is to examine the awareness and knowledge of people with MS toward their illness and their source of information,

and the quality of life across gender, age, and symptom severity.

The significance of the study: Not enough studies have been done to measure the knowledge, source of information and the quality of life in Saudi Arabia, so we choose to measure this situation scene it's unclear. The findings of this study will contribute to identifying the characteristics of patients with multiple sclerosis, determine how much knowledge that multiple sclerosis (MS) patients have about their illness across the kingdom of Saudi Arabia, and to determine the source of information that are most used and what sources are in a greater need. Also to study the quality of life in patients with multiple sclerosis (MS). In addition, the role of the illness in employment. Our findings will be presented to Arfaa society as an appreciation for their support in the dissemination of the questionnaire, and to those who are interested in this subject.

2. Subjects and methods

According to the nature of the data and used approach in this cross-sectional study, along with the time availabilities; a questionnaire was sought to be the most appropriate instrument for use. And a survey tool from google called "google drive" was adapted for the online questionnaire. A total of (44) questions were presented to the group of patients who joined the survey.

The sample was collected from patients Registered in "Arfaa society" and their followers on social media. The survey remained available for almost 3 weeks collecting data. With a total response of 165 participants. The stipulation before filling in the questionnaire was, to be multiple sclerosis patients and to be living in Saudi Arabia. Yet, responses came from across the regions in addition to some Neighboring countries (Egypt, Jordan, UAE, Kuwait and Tunis...etc.) but had been excluded from the results. Remaining 143 participants qualified for the study.

The study instrument: After reviewing previous literatures related to the study's topic, a modified questionnaire about the use of the Internet as a source of health information was drawn from a previous study (Lima-Pereira, Bermúdez-Tamayo, & Jasienska, 2012), while a modified structured, validated self-report questionnaire drawn from the National Multiple Sclerosis society (MSQOL)-54 have been used as the study's instrument for the quality of life section (Vickrey, 1995). The results were analyzed using Excel and SPSS software programs.

3. Results:

Table 1 demonstrate socio-demographic characteristics of studied MS patient, it was found that the highest percentage of the studied MS patients aged

26 – 30 years (36.4%) and the lowest percentage of them belonged to the age group 56 – 60 years (0.7%). Nearly half of the sample were married (51.7%), while single were 43.4%. Regarding economical state, 41.3% of the participants had income from 5,000 to 10,000 riyals / month, while 7.7% had no income. 65% of the participants had a bachelor degree, while 8.4% were pre-secondary. Regarding Duration of the disease, 48.3% of the participants had MS more than a year to 5 years, while 9.1% year and less.

Table 1: Socio-demographic characteristics of the studied multiple sclerosis patients.

	N= 143	%
Sex		
Male	43	30
Female	100	70
Marital status		
Single	62	43.4
Married	74	51.7
Divorcee	5	3.5
Widower	2	1.4
Age group (years)		
15-30	70	48.9
31-45	57	39.8
46-60	11	7.6
The scientific degree		
Pre-secondary	12	8.4
Secondary	29	20.3
Bachelor degree	93	65
Higher degree	9	6.3
Occupation		
Student	14	9.8
Employee	60	42
Unemployed	69	48.3
Income		
No income	11	7.7
Less than 5,000 Riyals	30	21
From 5,000 to 10,000 Riyals	59	41.3
More than 10,000 Riyals	43	30.1
Housing type		
Renter home	52	36.4
Owned home	91	63.6
Duration of the disease		
Year and less	13	9.1
More than a year to 5 years	69	48.3

The knowledge level and the evaluation of the quality of life was divided into 4 levels; ideal, high, moderate and low. The table 2 shows that 68% of the participants had an ideal level of awareness as they answered basic general information about MS which given to them in the questioner and 30.8% had a high level, while just 0.7% of the participants had a low level of awareness. While the quality of life shows that

35% of the participant had a high level of quality of life, 31% had a moderate level and 24.5 % had a low level. Figure 1 shows that search engines like google and yahoo are the most used sources of information.

The table 3 reveals that there is a clear relationship between quality of life and patients' knowledge where more knowledge the participants have the more quality of life they get. Table 4 demonstrates that the most of the participants 63% complained about not having any health care provider to communicate with about health problems. While 33% complained about difficulties communicating with their doctor. And only 3% complained about difficulties communicating with their nurse.

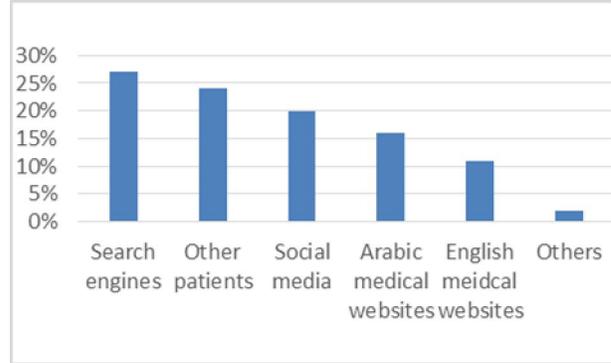


Figure 1: Distribution of studied subjects according to the most used source of information about multiple sclerosis.

Table 2: Distribution of studied subjects according to their knowledge and quality of life scores.

	Ideal		High		Moderate		Low	
	N	%	N	%	N	%	N	%
knowledge	97	67.8	44	30.8	1	0.7	1	0.7
Quality of life	13	9.1	50	35	45	31.5	35	24.5

Table 3: Distribution of subjects according to the relationship between their total knowledge score and their quality of life score.

		Quality of life				Total
		Ideal	High	Moderate	Low	
Knowledge level	Ideal	11	37	29	20	97
	High	2	13	15	14	44
	Moderate	0	0	0	1	1
	Low	0	0	1	0	1
Total		13	50	45	35	143

Table 4: Distribution of the studied subjects according to the relationship between the source of information and the level of satisfaction.

		Difficulties in communication with healthcare providers						Total	
		Yes		No		Sometimes			
		N	%	N	%	N	%	N	%
Health care providers as a source of information	Physicians	21	33.3	31	77.5	30	75	82	57.3
	Nurses	2	3.2	0	0	0	0	2	1.4
	No one	40	63.5	9	22.5	10	25	59	41.3
Total		63	100	40	100	40	100	143	100

4. Discussion:

The epidemiology of MS is rapidly changing in many parts of the world, based on the Kurtzke classification, the Arabian Gulf Region is located in a low-risk zone for MS (Bohlega et al., 2013), however (Yaqub & Daif, 1988) published a paper about MS in Saudi Arabia, stating that there are indications of increasing incidence of MS in Saudi Arabia. They noted that the symptomatology of MS and the site of lesions are similar to that seen in the West, but the course and evolution might be different.

Based on the study results, patients had an ideal level of awareness as they answered basic general

information about MS which given to them in the questioner this may be due to high level of education, (65%) of patients had a bachelor degree. These findings are supported by a previous study by (Abolfazli et al., 2014) which indicated that Level of education was significantly associated with knowledge (P=0.0010); the higher level of education leads to more knowledge of participants.

Furthermore, (74.5%) of patients had a quality of life between moderate to high and who well-educated had a high quality of life (Table 2 and 3), this enforces the relationship between the level of knowledge, education and quality of life. This finding is supported

by (Bishop, Frain, Espinosa, & Stenhoff, 2009) as they concluded that being well-known about multiple sclerosis (MS) and its treatment is associated with a number of positive clinical and psychosocial outcomes, including higher levels of quality of life and personal control, better coping and adjustment after diagnosis, and reduced dependence on health providers.

The study indicated that the most source of information used was the internet, and that proved by another study (Marrie, Salter, Tyry, Fox, & Cutter, 2013) which indicated that although physicians remain the most trusted source of health information for people with MS, the Internet is the first source of health information for most of them.

The findings of this study revealed that patients' complaint complained about not having any health care provider to communicate with about health problems and the difficulty of communicating with their doctor. A study (Heesen, Kasper, Segal, Köpke, & Mühlhauser, 2004) stated that the Shared decision-making is the ideal model of patient-physician communication especially in chronic diseases and a previous study (Saleh et al., 2014) revealed that the Saudi patients preferred shared decision-making approach.

Conclusion

The results of the study revealed that in spite the education about multiple sclerosis (MS) in hospitals was relatively low, the general knowledge about MS among patients was unexpectedly high and the primary source of information was obtained from the research engines on the internet.

The only health education provider in hospitals were doctors, yet, one-third of participant's complaints was about difficulties in communicating with their doctors during their visits and the quality of life was relatively high between all participants and the degree of it is associated with patients awareness about their disease.

Recommendation

Patient information and counseling need to be included in the management plan for Multiple Sclerosis (MS) patients for empowering patients, through health education specialists, especially at early stages of disease for the management of the disease relapses. As a result of increasing search the internet, information can be misleading or inaccurate, to limit these issues, an updated reliable source of information in Arabic should be provided by experts. Received emotional support from family, friends, support groups and healthcare providers strongly influence perspectives of disease and treatment.

Declaration of conflicting interests

None declared

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