



The Extent of Knowledge in Patient with Systemic Lupus Erythromatosis (SLE) and Lupus Nephritis

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ABSTRACT

Systemic Lupus Erythematosus (SLE) is an autoimmune disease that affects multiple systems in the human body. Previous studies have found that Asian patients are more susceptible to this disease and the Quality of Life (QoL) after SLE is hugely impacted by an individual's knowledge, awareness and perception of the disease. This study aims to assess the knowledge of SLE among patients with this disease and also to help provide materials and resources to maximize the understanding and improve the QoL. The study included 199 patients with SLE participated in this quantitative awareness study conducted in a single study center at the Abdulaziz University Hospital. A questionnaire to assess the knowledge of SLE was given to patients and the data were analyzed with SPSS 20.0. Results showed that most of the participants of the study were well educated and had good knowledge about the nature and awareness of SLE and there was also a statistically significant relationship in the age and duration between the two nationalities of the test subjects. Based on the analysis, it can be concluded that a physician can play a major role in increasing the knowledge and the awareness of an individual in relation to SLE and its renal complications.

KEYWORDS :

Introduction

Systemic Lupus Erythematosus (SLE) is an autoimmune disease in which the body's immune system attacks the host and it can involve multiple organs. The symptoms of the disease can range from mild to severe and in some cases may even prove to be fatal. The disease is pervasive and can occur at most crucial times in the lives of young adults such as at the time of getting married, career changes, or even at the time of starting a family. Patients with SLE may thus be psychologically affected and have social issues as well.

Prevalence studies found Asians are 2 to 3 times more likely than the Caucasians to have SLE^[1-8]. It was also reported that the severity of SLE is higher in the Asian population in the SLE Disease Activity Index (SLEDAI). High severity index was also associated with an increased susceptibility to renal involvement^[9]. There are several cohort studies that have been conducted across various ethnicities that have depicted that Asians have a higher predilection for SLE especially in the aspects of acquiring renal disease, disease activity, and organ damage^[4,10-12].

Quality of life (QoL) or Health related Quality of Life (HRQoL) refers to what extent a disease impacts a person's daily functioning of life with respect to psychological well being, physical well being, as well as social aspects of their life. As the pressure on healthcare services have begun to increase, the need to measure the impact of management of diseases by healthcare providers on patient's well being have become the prime focus. The measure of HRQoL in conjunction with clinical parameters of the disease helps assess the patient's responsiveness towards treatment while also assessing the extent of damage by the disease^[13].

Many researchers have depicted that the QoL of the patient post management for SLE is largely dependent on the patient's knowledge, awareness and perception of the disease. It has also been depicted that in more recent times, the prognosis and mortality rates of the patient's with SLE have improved. While

understanding the disease is an important factor to the management aspects, understanding the patients themselves can lead to effective management of the disease. Additionally, research has indicated there is always existent miscommunication between the patient and the treating physician which also attributes to a lower quality of care. It has therefore been deemed necessary that the educational materials provided to the patients along with the instructions in simple language need to be addressed. The present study has therefore been conducted to assess the level of knowledge of SLE and lupus nephritis in patient with diagnosis of SLE or its complication. Also, to provide correct resources to the patient and minimize the lack of information among SLE patients about the disease and how it impacts their life^[14].

Methodology

The study is a quantitative awareness study conducted on 199 patients diagnosed with SLE and have been followed in the clinic at Abdul Aziz University Hospital, making this a single center study. Data collection is carried out with the use of self-administered questionnaire which was meant to evaluate the extent of the awareness on management of SLE and its renal complications. While conducting the questionnaire, medical specialist was available to answer patient's questions and to provide them with educational resources. Statistical analysis was carried out using the SPSS 20.0 software. The following statistical analysis was enumerated in the data: frequency distribution, binary logistic regression, independent sample t test and two sample z test. Demographic information of the patients was analyzed through frequency distribution. The association between the educational status of the patients and their knowledge on SLE was calculated by binary logistic regression. Age and duration of disease were compared between Saudi and non-Saudi SLE patients using the independent sample t test. Finally, both nationality patients' perceptions in relation to the causes of deterioration of kidney function were compared through two sample z test. The statistical significant was considered as 5 percent level ($p < 0.05$).

Ethical approval was obtained from the institutional review board committee at King Abdulaziz University.

Results

In this research, total of 200 patients was participated. Among the SLE patients, 168 belonged to Saudi nationality and 31 belonged to the non-Saudi nationality. One SLE patient was not included in the analysis, because the patient's nationality was not provided.

The prevalence rate of SLE was high among the females in Saudi and non-Saudi patients. Also, most of the SLE patients of Saudi and non-Saudi completed college level education and 30 percent of Saudi patients and 39 percent of non-Saudi patients completed high school level education while a minimum number of both nationality patients completed primary and elementary level of education. The majority of the Saudi patients were single (48%) followed by, 40 percent were married and the least number of patients were widows and divorced. But, married patients (52%) mostly participated from the non-Saudi nationality while unmarried were 42 percent. 58 percent of Saudi patients and 77 percent of the non-Saudi patients were unemployed. It is inferred that most of the both nationality patients were homemakers. Further, the majority of the Saudi patients lived in middle (34%) geographical region while non-Saudi patients lived in the west (71%) geographical region (Figure 1).

Association between the educational status of SLE patients and their knowledge on the disease is presented in table 1. As per the 5 percent level of significance ($p < 0.05$), SLE patients who completed high school and college level education, possessed the sufficient knowledge on SLE flares ups and downs due to exposure to sunlight. However, there was no statistically significant association noticed between the SLE patients who completed primary and elementary level education, and knowledge on the disease.

Table 2 depicts the SLE patients' knowledge about their disease in general. On the basis of the findings, it is concluded that a maximum number of both nationality patients had the sufficient knowledge on SLE disease; i.e., the disease affects many organs. Especially, 95 percent of Saudi patients and 93 percent of non-Saudi patients knew that SLE affects kidneys' function. However, the patients did not know causes of the disease. Only 36 percent of Saudi patients and 35 percent of non-Saudi patients knew causes of the disease such as environmental and genetic causes. Also, the majority of the Saudi and non-Saudi patients ascertained that the disease could be controlled and SLE patients could get marriage and have children.

Knowledge about the complications of SLE disease especially renal complication is presented in table 3. The findings revealed that the majority of the Saudi and non-Saudi patients had the knowledge of renal complications of SLE such as hematuria or proteinuria, high blood pressure and high creatinine and the knowledge of initial symptoms of kidney impairment such as back pain, asymptomatic, limb edema and SOB. Finally, a maximum number of both nationality patients pointed out that dialysis was not only the treatment of renal failure. However, an alternative treatment for kidney failure is kidney transplantation.

Discussion

The prevalence of the SLE was found to be high among females of both Saudi and non-Saudi population as in the previous studies^[6,15,16]. This is consistent with the evidence that Asian and African population show a two-three times increased risk to SLE^[17-22]. Also, most of the SLE patients of Saudi and non-Saudi completed college level education while a smaller number of Saudi patients and 39 percent of non-Saudi patients completed high school level education while a minimum number of both nationality patients who have a primary and elementary level of education which is also similar to the findings of Hearsh-Holmes et al.^[23].

However, the average age for the Saudi and Non-Saudi patients with SLE was found to be significantly different. For Saudi patients, the

average age was 32 while for the Non-Saudi patients, the average age was 35. Meanwhile, there was no statistical difference noticed between the Saudi and non-Saudi SLE patients on the basis of their disease duration (both reported 7 years mean) which is again along the same lines of one particular Saudi Arabian study^[24].

As for the renal complications, most of the participants were aware of complications such as hematuria or proteinuria, high blood pressure and high creatinine (kidney impairment) along with knowing the initial symptoms that indicate kidney impairment. Most of the participants mentioned the fact that dialysis was not the only treatment for renal failure and that renal transplant may be considered. This finding would imply that the participants do exercise some amount of knowledge over the disease especially related to the complications and management aspects of the disease. Hearsh-Holmes et al.^[23] in this regard stated that patient's capability to read education material plays an important role in patients' knowledge of SLE. Another study Davis et al.^[25] too iterates the same and states that the educational material requires a readability level of 11th- 14th grade. In this study, SLE patients who completed high school and college level education, possessed sufficient knowledge on SLE and that it flares up and down due to exposure to sunlight which can be considered as further evidence to those offered by Hearsh-Holmes et al.^[23] as well as Davis et al.^[25].

When it comes to the deterioration of renal functions, it was observed that most of the Saudi patients believed that the reason for deterioration of renal functions was not having regular follow up with treating physician while Non-Saudi patients believed that the reason was non adherence to the prescribed treatment. The implication of the finding here is that non-adherence as well as lack of knowledge can be considered factors that contribute to the development of renal complications in SLE. Adherence to medication is a common issue in any disease area with the prevalence of non-adherence in SLE being reported at 3-76%^[26].

Majority of the Saudi patients had acquired disease awareness from the internet and social media while non-Saudi patients getting awareness from doctors. Similarly, a maximum number of Saudi patients wanted to know how to manage the disease while non-Saudi patients wanted to know the symptoms of the disease. It was found that the patients of Saudi and Non-Saudi origin had significantly different opinions on how much a person can understand about SLE. This was applied for patients gaining awareness of the nature of SLE from doctors during consultation and from other resources. It was also shown that a person's intention to acquire knowledge and learn more about the disease also had a significant impact on gaining awareness. This is in line with a study conducted by Zirkzee et al.^[27] who state that patients prefer to have certain measures initiated for their care and management. These measures include standardizes assessment on a yearly basis, yearly inventory, contacting care providers such as nurses through the internet, and a comprehensive medical course.

However, only a small number from both the population were aware of the causes of SLE (environmental and genetic). A majority also stated that SLE cannot be treated but managed and that they could get married and have children. It can therefore be inferred that while patients do possess adequate knowledge on the management of the disease, several were unaware as to the causes. Patients are therefore especially in need for more education and awareness in the clinic, specifically in the first visit.^[28]

Conclusion

Based on the findings of the present study, it can be concluded that both patients of Saudi and Non-Saudi origin were well educated and had reasonable knowledge about SLE and renal complications. A physician can play a major role in the education of the patient and in inciting awareness of each individual patient, as the physician will discuss not only the nature of the disease in general, but also the individual patients case history. Especially in the first clinic visit,

health provider may provide the patients with educational pamphlets regarding the nature of the disease and its possible complication. Also, they may provide patients with trusted resources available in the web. In this regard, miscommunication between the doctor and the patient could be stemmed. Further, a better understanding of the disease by the patient can also lead to a better health related quality of life to the patient.

List of Tables

Table 1 : Association between educational status of SLE patients and their knowledge about 'disease flares ups and downs due to exposure to sunlight'.

	p-value	Odds ratio	95% C.I. for EXP(B)	
			Lower	Upper
Primary	0.99	3230949731.98	0.00	-
Elementary	0.09	10.00	0.67	149.04
High school	0.01*	29.50	2.18	399.30
College and above	0.02*	20.60	1.71	247.64
Constant	0.57	0.50		

*p<0.05

Dependent variable: Knowledge on SLE flares ups and downs due to exposure to sunlight

Table 2 : SLE patients' knowledge about their disease

	Saudi n (%)	Non-Saudi
SLE affects many organs in the body including the kidneys		
Yes	160 (95.2)	29 (93.5)
No	2 (1.2)	-
I don't know	6 (3.6)	2 (6.5)
Total	168 (100.0)	31 (100.0)
The causes of SLE		
Environmental and genetic causes	61 (36.3)	11 (35.5)
No causes	71 (42.3)	11 (35.5)
I don't know	36 (21.4)	9 (29.0)
Total	168 (100.0)	31 (100.0)
Can SLE be treated?		
It could be controlled	155 (92.3)	23 (74.2)
No	4 (2.4)	2 (6.5)
I don't know	9 (5.4)	6 (19.4)
Total	168 (100.0)	31 (100.0)
Can SLE patients get married and have children		
Yes	154 (91.7)	25 (80.6)
No	2 (1.2)	1 (3.2)
I don't know	12 (7.1)	5 (16.1)
Total	168 (100.0)	31 (100.0)

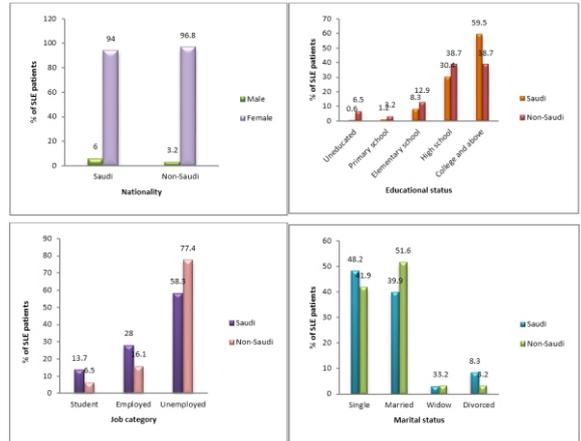
Table 3 : SLE patients' knowledge about renal complications of SLE

	Saudi n (%)	Non-Saudi
The primary symptoms of kidney diseases caused by SLE		
Hematuria or proteinuria	69 (41.1)	8 (25.8)
High BP	3 (1.8)	1 (3.2)
High Cr	30 (17.9)	4 (12.9)
All of the above	63 (37.5)	10 (32.3)
I don't know	3 (1.8)	8 (25.8)
Total	168 (100.0)	31 (100.0)
The initial symptoms of renal impairment		
Back pain	8 (4.8)	1 (3.2)
Limb edema and SOB	19 (11.3)	4 (12.9)
Asymptomatic	83 (49.4)	8 (25.8)
All of the above	52 (31.0)	10 (32.3)
I don't know	6 (3.6)	8 (25.8)
Total	168 (100.0)	31 (100.0)

Which of this information are not true about renal failure		
Renal failure can be avoided	15 (8.9)	8 (25.8)
Can be treated with medications	51 (30.4)	6 (19.4)
Renal failure patients' needs dialysis	76 (45.2)	8 (25.8)
Nothing forms the above	18 (10.7)	4 (12.9)
I don't know	8 (4.8)	5 (16.1)
Total	168 (100.0)	31 (100.0)

List of Figures

Figure : Demographic details



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