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The level of Systemic Lupus Erythematosus awareness and its barriers, Qassim, Saudi Arabia

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ABSTRACT

Systemic Lupus Erythematosus (SLE) is a multi systemic multi factorial autoimmune disease. Organ's damage and failure may occur during life time. Severe SLE presentations may lead to life threatening complications even at younger age. Therefore, general populations need to increase their awareness about SLE to reduce SLE complications. The purpose of this study to assess the levels of SLE awareness and the barriers that affect the SLE awareness among Qassim University members, Saudi Arabia, 2022. The items of the questionnaire used in this study includes socio demographic characteristics, source of SLE information, knowledge about the symptoms and treatment of SLE, assessment about the awareness toward SLE and barriers to SLE awareness. Sample size that has been collected during this study was 206 participants. The overall mean awareness score was 3.08 out of 10 points with a poor awareness level compromising of 82.3% while only 17.7% had good awareness. Factors associated with increased awareness were being a female or being a medical student, etc.

Keywords: Systemic Lupus Erythematosus, SLE, Awareness, knowledge, barriers**.**

1. INTRODUCTION

The Systemic Lupus Erythematosus (SLE), also known as lupus, is a multi systemic autoimmune disease attacks different body's organs, with a wide spectrum of variable serological and clinical presentations, such as skin, joints, renal, cardiopulmonary or hematological involvements (Bin Haikel and Al Tulaihi, 2018; Alkhalaf et al., 2018; Moriarty et al., 2003). The SLE may affect all age groups, with most affected age group of patients between 14 up to 44 years and the females are likely to be affected more than males and there was modest increased risk with familial history (Chakravarty et al., 2007; Pons-Estel et al., 2010; Petri et al., 2002). The SLE prevalence is estimated to be

between 20 and 150 cases per 100,000, with more predominance among African American/Hispanic ethnic groups (Izmirlyet al., 2021; Danchenko et al., 2006; Peschken and Esdaile, 1999; Petri et al., 2002). The exact SLE etiology is not fully known, but it is likely to be multi factorial in nature (Rees et al., 2017; Khan et al., 2017; Strand et al., 2013; Heller et al., 2007). The prevalence, frequency, extent and severity of clinical presentations and laboratory findings, seems to be influenced by many factors including environmental, microbial, social factors, as well as geography and ethnicity elements. In few patients whom they may have severe manifestations, organs involvement and failure may follow in the disease course (Tan et al., 1982; Stein et al., 1986). In order to prevent or at least reduce the devastating complications and enhance the quality of people's lives, the general population must raise awareness of SLE in order to encourage early medical advice seeking and early suitable management (Cervera et al., 1993; Jacobsen et al., 1998; Gudmundsson et al., 1990). The purpose of this study is to assess the levels of SLE awareness and the barriers among Qassim University members, Saudi Arabia 2022.

2. SUBJECTS AND METHODOLOGY

This is a quantitative cross-sectional study conducted among Qassim University members, Qassim region, Saudi Arabia 2022. After the approval from institutional review board (IRB) committee in Qassim region, a questionnaire was distributed among the targeted participants through online distribution, using non probability sampling technique. Sample size was calculated manually using "Epi InfoTM". The inclusion criteria include participant with age of 18 years or more and being a Qassim University member (Staff and student). The sample size enrolled on this study was of 206 participants. The questionnaire includes socio demographic characteristics (i.e., age, gender, professions, educational background, living area, etc.) questions about source of SLE information, knowledge about the symptoms and treatment of SLE, assessment about the SLE awareness level and its barriers. We conducted a pilot study with ten participants to verify and confirm the questionnaire validity and were included the final analysis and illustrated in chart 1.

Categorical variables were presented as numbers and percentages while continuous variables were summarized as means and standard deviation. The awareness toward SLE has been assessed using 10 questions where the correct answers had been identified and have been coded with 1 while the incorrect answer had been coded with 0. A score ranging from 0 to 10 has been generated, with the higher the score, the greater the awareness level of SLE. The overall awareness score was calculated by adding all 10 items. Participants were divided into two groups based on awareness score, such that participants were considered as having poor awareness if the score was 60% or below and good awareness if the score was above 60% of the total awareness score. The awareness score was compared to the socio demographic characteristics of the patients by using Mann Whitney Z test. Normality tests were conducted using Shapiro Wilk, Kolmogorov and Smirnov tests. The awareness score follows the abnormal distribution. Thus, non parametric tests were applied. Two tailed analysis with $p<0.05$ was used as the cutoff for statistical significance. All data analyses were performed using the statistical package for social sciences, version 26 (SPSS, Armonk, NY: IBM Corp, USA).

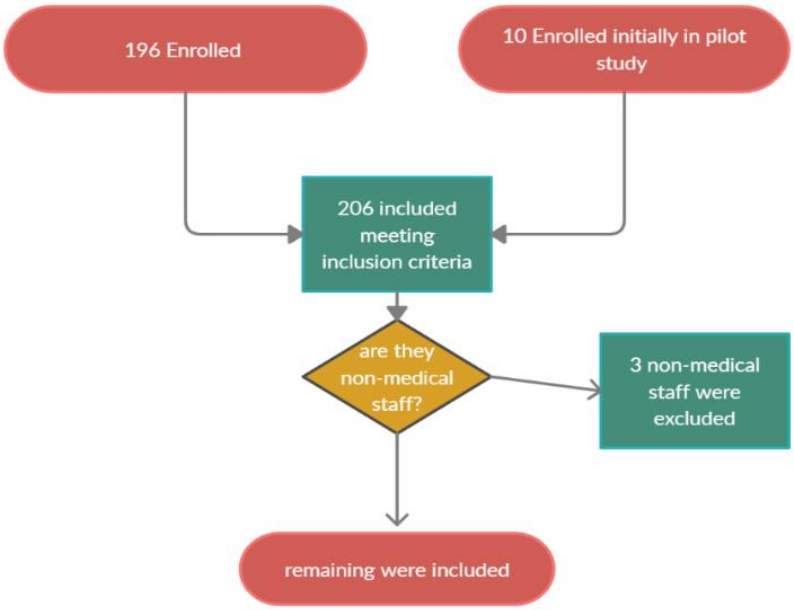

Chart 1 Consort chart

3. RESULTS

The socio demographics of participants are presented in Table 1. The most dominant age group was 18–25 years (94.1%) with more than half being males (53.7%). Nearly two thirds (64.5%) were nonmedical students and 54.2% had higher education. The proportion of respondents who have heard about SLE was 62.6%. The majority (79.8%) did not know someone with SLE with only 3.9% knowing a colleague with SLE.

Table 1 Socio-demographic characteristics of participants

Study Data	No (%)
Age group	
<18 years	02(01.0%)
18-25 years	191(94.1%)
26-30 years	05(02.5%)
31-35 years	03(01.5%)
41-45 years	01(0.50%)
>60 years	01(0.50%)
Gender	
Male	109(53.7%)
Female	94(46.3%)
Professions	
Non medical student	131(64.5%)
Medical student	69(34.0%)
Non medical staff	03(01.5%)
Educational background	
Higher education	110(54.2%)
Non higher education	93(45.8%)
Heard or read of Systemic Lupus Erythematosus	
Yes	127(62.6%)
No	76(37.4%)
Diagnosed with SLE	
Yes	02(01.0%)
No	201(99.0%)
Knowledge of anyone who has SLE	
Family member	04(02.0%)
Relatives	07(03.4%)
Colleague	08(03.9%)
None	162(79.8)
Others	22(10.8%)

In Figure 1, the commonly mentioned source of SLE information was the internet/social media (53.2%), followed by friends or colleagues (23.2%) and doctors (17.7%)

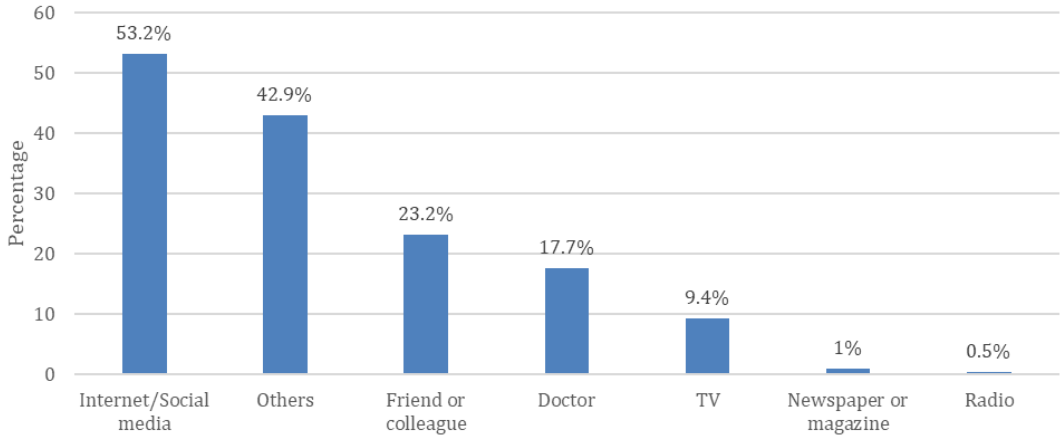

Figure 1 Source of SLE information

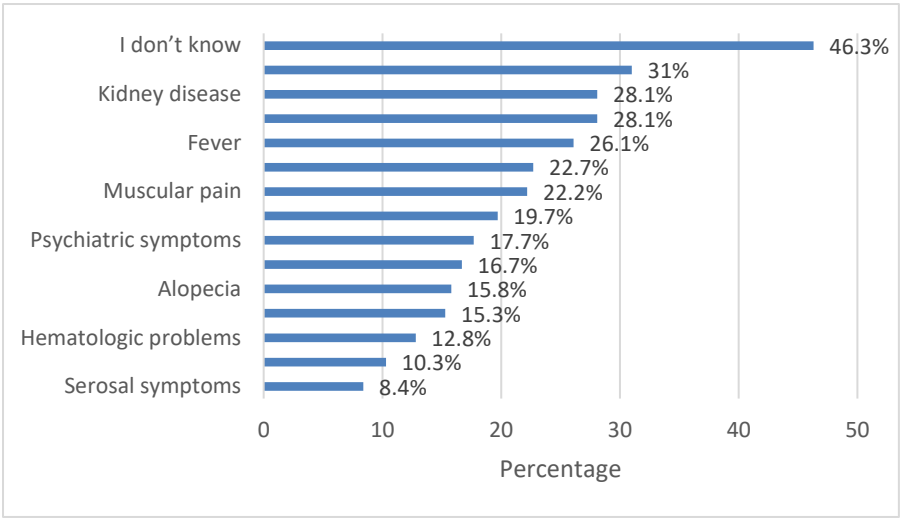

Figure 2 Symptoms of SLE

In Figure 2, according to multiple response answers from the question related to symptoms of SLE, it was revealed that the participants were aware that the most common symptoms associated with SLE were rash (31%), kidney disease (28.1%) and joint pain (28.1%).

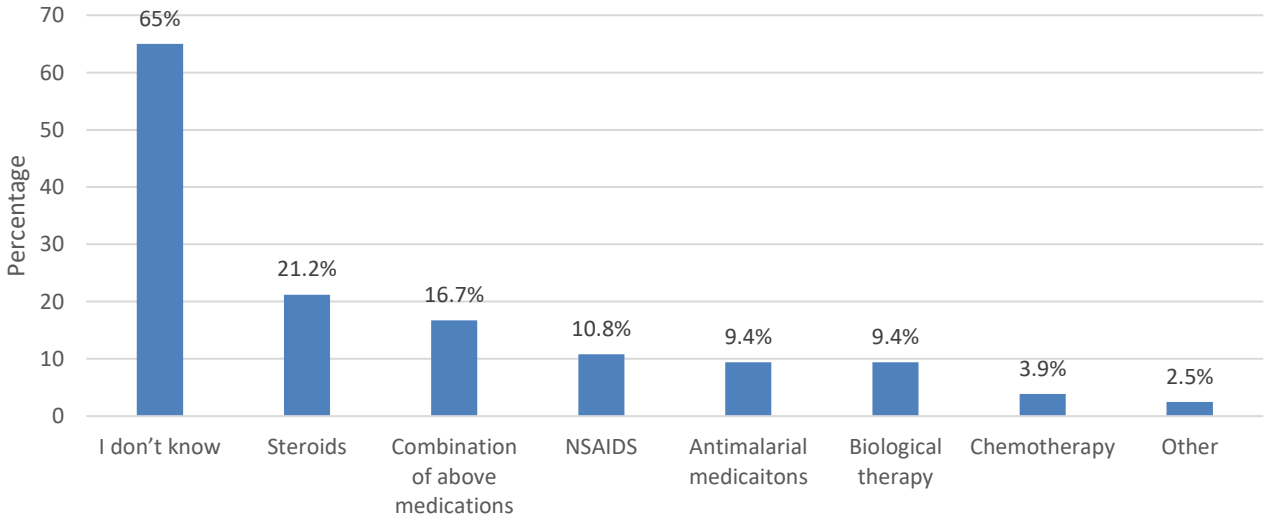

Figure 3 Treatment of SLE

In Table 2, 48.3% were aware that the SLE affects body organs. Only 19.2% were correct that SLE affects females than males and only 14.3% were aware that SLE is fatal. Also, only 18.2% were correct that SLE cannot be diagnosed by a single blood test and only 17.7% knew that SLE can be prevented. The proportion of respondents who knew that SLE is a treatable disease was 30.5%. The 31.5% of respondents were correct that SLE have many complications. Nearly 80% of the respondents believed that the awareness of SLE should be promoted while 40.4% were sure that SLE affects a patient's social life. Only 7.9% of the respondents believe that the prognosis of SLE patients was good. Based on the above awareness statement, the mean awareness level score was 3.08 (SD 2.33) with poor and good awareness levels were found among 82.3% and 17.7%, respectively. In Figure3, it was observed that the most commonly known treatment of SLE was steroids (21.2%), followed by a combination of medications (16.7%) and NSAIDs (10.8%).

Table 2 Assessment about the awareness toward SLE

Awareness question	No. (%)
Does SLE affect body organs?	
Yes *	98(48.3%)
No	01(0.50%)
I don't know	104(51%)
Does SLE mostly affect males?	
Yes	09(04.4%)
No *	39(19.2%)
I don't know	155(76%)
SLE is fatal?	
Yes *	29(14.3%)
No	31(15.3%)
I don't know	143(70%)
SLE can be diagnosed with a single blood test?	
Yes	13(06.4%)
No *	37(18.2%)
I don't know	153(75%)
SLE can be prevented?	
Yes *	36(17.7%)
No	26(12.8%)
I don't know	141(69%)
SLE is a treatable disease?	
Yes *	62(30.5%)
No	29(14.3%)
I don't know	112(55%)
SLE is an illness with few complications?	
Yes	08(03.9%)
No *	64(31.5%)
I don't know	131(64%)
Should awareness of SLE be promoted?	
Yes *	162(79%)
No	01(0.50%)
I don't know	40(19.7%)
Does dose SLE affect a patient's social life?	
Yes *	82(40.4%)
No	09(04.4%)
I don't know	112(55%)
What is the prognosis of an SLE patient?	

Good *	16(07.9%)
Poor	78(38.4%)
I don't know	109(53%)
Total awareness score (mean± SD)	3.08 ±2.33
Level of awareness	
Poor	167(82%)
Good	36(17.7%)

** Indicates correct answer*

The assessment of barriers to SLE awareness was given in Table 3. It can be observed that the most common statement associated with the barrier to SLE awareness was "Too many other things to worry about" (56.7%), followed by "Too scared to go and see the doctor" (51.7%) and "Afraid of the results" (50.7%) while "Healthcare providers are not trustworthy" was the least common barrier (9.4%).

Table 3 Assessment of barriers to SLE awareness

Barrier's statement	Yes (%)
Too many other things to worry about	115(56.7%)
Too scared to go and see the doctor	105(51.7%)
Afraid of the results	103(50.7%)
Health care providers didn't try to increase awareness about SLE	101(49.8%)
Lacks confidence talking about symptoms	86(42.4%)
Family reliance on folk medicine and not visiting the doctor	78(38.4%)
Too busy to make time to search about SLE	57(28.1%)
Find it difficult to make an appointment with a doctor	52(25.6%)
Find the doctor difficult to talk to	52(25.6%)
Too embarrassed to go and see the doctor	50(24.6%)
Finance problem to search about SLE	47(23.2%)
Worried about wasting the time of the doctor	29(14.3%)
Language barrier/ problem while searching about SLE	25(12.3%)
Health care providers are not trustworthy	19(09.4%)

When measuring the association between the awareness score and the socio demographic characteristics of participants, it was found that a higher awareness score was more associated with being females ($Z=5.335$; $p<0.001$), being a medical student ($Z=6.001$; $p<0.001$), those who have heard or read of SLE ($Z=9.513$; $p<0.001$) and those with sources of SLE information such as a doctor

(Z=4.942; p<0.001), internet/social media (Z=4.918; p<0.001), TV (Z=2.133; p=0.033) and friend or colleague (Z=3.332; p=0.001) (see Table 4).

Table 4 Association between the awareness level score and the Socio-demographic characteristics

Factor	Awareness Score (10) Mean ± SD	Z test	P value§
Gender			
Male	2.30 ± 2.26	5.335	<0.001 **
Female	3.98 ± 2.09		
Professions †			
Non medical student	2.33 ± 2.14	6.001	<0.001 **
Medical student	4.46 ± 2.08		
Educational background			
Higher education	3.06 ± 2.44	0.203	0.839
Non higher education	3.09 ± 2.21		
Heard or read of Systemic Lupus Erythematosus			
Yes	4.26 ± 1.93	9.513	<0.001 **
No	1.11 ± 1.45		
Source of SLE information *			
Doctor	4.89 ± 2.07	4.942	<0.001**
Internet/social media	3.82 ± 2.25	4.918	<0.001 **
TV	4.16 ± 1.92	2.133	0.033 **
Friend and colleague	4.11 ± 2.28	3.332	0.001 **

** Variable with multiple response answers.† There were 3 non medical staff who were excluded from the analysis*
*§ P-value was determined by utilizing the Mann Whitney Z-test. ** Significant p-value at p<0.05 level.*

4. DISCUSSION

The objective of the present study is to evaluate the awareness of Qassim University members regarding SLE. 82.3% of the respondents were classified as having poor awareness and only 17.7% had good awareness level (mean score: 3.08; SD 2.33, out of 10 points). Several papers reported a poor level of awareness and misconception about SLE (Omair et al., 2015; Asiri et al., 2020). A study that conducted showed a better understanding of the disease SLE. 39.3% of the general population demonstrated good knowledge towards SLE treatment methods and 41.7% had good knowledge about SLE symptoms (Asiri et al., 2020). Data in our study suggested that females exhibited better awareness levels than their male counterparts. This is in contrast to findings of the lately compared study, where male participants showed good knowledge than females.

The lack of awareness stemmed from the poor understanding of the clinical manifestation of SLE. For example, only 19.2% of our students knew that SLE more commonly affects women than men their knowledge that SLE can be fatal was poor, as only 14.3% were aware of it and a considerable proportion of respondents have no knowledge about it (70.4%). Our results also revealed that although 30.5% were aware that SLE can be treated, however, only 17.7% knew that it can be prevented while the majorities (69.5%) do not know anything about it. There were similar findings reported by earlier study that was done in Abha (Bin Haikel

and Al Tulaihi, 2018). Another study conducted in Dammam, Saudi Arabia (Alharbi et al., 2018), indicated that 69% of the general public have no idea if the SLE is fatal and although 32% knew that SLE is more common among women.

The students showed better knowledge with some domains. For instance, 62.6% stated that they have heard or read about SLE, 48% of the students were confident that SLE affects body organs and it is an illness with many complications, 31.5%, with 40.4% believing that it affects more with patient social life. This is almost consistent witha study done in India, Afiqah et al., (2017) findings suggest that the majority (62.9%) knew something about the disease, however, 83% placed SLE as a life-threatening disease.

Study suggests that knowing someone with SLE could have a positive effect on awareness level. Similar findings of the study done in Abha (Bin Haikel and Al Tulaihi, 2018) as a significant gap between those who knew a patient with SLE and those who did not know anyone. In our study, approximately 21.2% of the campus members knew someone with SLE and the most common of them was colleagues (3.9%) or family members (3.4%). Moreover, searching information from different sources could positively influence knowledge. In our study, the most often used information source was the internet/social media (53.2%), followed by friends or colleagues (23.2%) and doctors (17.7%).

According to the knowledge of our students, the most frequent symptom associated with SLE was rash (31%), followed by kidney disease (28.1%) and joint pain (28.1%), fever (26.1%) and photosensitivity (22.7%). Other symptoms mentioned were muscular pain (22.2%), neurological symptoms (19.7%), psychiatric symptoms (17.7%), antibodies (16.7%), alopecia (15.8%) and hematologic problems (12.8%). Few students also mentioned thrombosis (10.3%) and serosal symptoms (8.4%). The study done in Abha indicated that rash, alopecia, joint pain and photosensitivity were the most frequent symptom connected to SLE, while in study done in Riyadh (Omair et al., 2015) hair loss (56.1%), loss of energy (38.6%) and anemia (34.5%) were the most commonly indicated symptoms of SLE.

According to publications related to medications used in SLE, chemotherapy and steroids were the most prominent treatment method for SLE (Omair et al., 2015; Afiqah et al., 2017). This is also true in our study, according to our students, steroids (21.2%), combination of medications (16.7%) and NSAIDs (10.8%) are likely to be the disease's most effective therapeutic actions. Another hallmark finding of our study was about the barriers to SLE awareness. According to our data, “Too many other things to worry about” (56.7%) was the main leading barrier to SLE awareness, next was “afraid to visit the doctor” (51.7%), “Afraid of the results” (50.7%), “not getting enough information from healthcare providers” (49.8%), being “not confident to talk about it” (42.4%). These barriers if not addressed could have a significant effect on population awareness and we may not be able to achieve the desired level of awareness among the study population.

5. CONCLUSION

This study has shown that the level of awareness was poor among Qassim university members. Female medical students showed more awareness of SLE than the rest of the university population. There is a need to address the huge gap in awareness. Such gaps can be narrowed if barriers to SLE awareness were addressed. General understanding regarding SLE symptoms and complications could be one of the first steps to achieving better outcomes in awareness. The present study highlighted the importance of awareness among the population and although it is not a contagious disease, it may lead to a worst-case scenario such as kidney failure, stroke and premature death if being neglected. Further studies are deemed necessary to minimize the barriers towards general awareness of SLE that might lead to better overall outcome of the disease.

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Ethical approval

The study was approved by the Medical Ethics Committee of Qassim University. Ethical approval code: 21-06-07.

Author's contributions

Introduction/literature review: Alkhdairi, Almithn, Alnawfal.

Methods: Alkhdairi, Alharbi, Alotaieq.

Data collection/analysis: Alkhdairi, Alotaieq, Alharkan, Alsaeed.

Discussion/conclusion: Alkhdairi, Alharbi, Alrasheedi S, Alrasheedi M, Aljameeli.

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Conflict of interest
The authors declare that there is no conflict of interests.

Data and materials availability
All data sets collected during this study are available upon reasonable request from the corresponding author.

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