International Journal of Advances in Medicine
Alrashdi MN et al. Int J Adv Med. 2021 Sep;8(9):1253-1260
http://www.ijmedicine.com
pISSN 2349-3925 | eISSN 2349-3933
DOI: https://dx.doi.org/10.18203/2349-3933.ijam20213197

Original Research Article

Population awareness about systemic lupus erythematosus in the Al-Qassim region, Saudi Arabia

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Received: 17 July 2021
Accepted: 06 August 2021

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ABSTRACT

Background: The objective was to evaluate the level of awareness regarding systemic lupus erythematosus (SLE) among the general population in the Al-Qassim region, Kingdom of Saudi Arabia (KSA).
Methods: This was a cross-sectional study carried out between March and April 2021 and conducted among the general population at Al-Qassim region, KSA. A valid pre-tested electronic questionnaire was distributed through social media among the targeted population that included socio-demographic characteristics and questionnaires measuring awareness, attitude and their belief about SLE. All statistical analyses were performed using SPSS version 26.
Results: A total of 377 participants were enrolled. The most common age group was more than 40 years old (39%), with slightly females (52.5%) than males. The prevalence of participants who had heard about SLE was 52.5%. Of those who have heard about SLE, a poor level of awareness was detected among 69.2% of participants, while 30.8% were at a good level. Factors associated with an increased level of awareness were having diagnosed been with SLE and those who indicated their doctor as their sources of SLE information.
Conclusions: The awareness of the general population in the Al-Qassim region regarding SLE was insufficient. Obtaining SLE information from their doctor and having been diagnosed with SLE are associated with better awareness. We propose that awareness campaigns should be promoted.

Keywords: Systemic lupus erythematosus, Awareness, Kingdom of Saudi Arabia, Al-Qassim

INTRODUCTION

SLE is an autoimmune disease in which the immune system attacks its own tissues with unclear aetiology.[1] It can affect variable organs and tissues including skin, joints, brain, lungs, kidneys and blood vessels, producing a variety of presenting symptoms and complaints.[2] Also, the diagnosis of SLE is affected by it is chronicity, which is also characterized by periods of remission and relapse that might delay in diagnosis.[3] According to the presentation of symptoms of SLE, patients may have mild disease that can be treated with medications, whereas others can have a life threatening disease. This is why early diagnosis and treatment are important to avoid the progression of severe disease and difficulties in social life, which may negatively impact patients' quality of life.[2-5] The prevalence of SLE in the Al-Qassim region is estimated to be 19.28 per 100,000 populations in the local study.[6] We believe that increasing social awareness about various diseases symptoms might accelerate diagnosis and treatment, leading to a positive outcome. Awareness of different populations in multiple studies addressing the public awareness about SLE has been evaluated, showing

poor awareness.[7,8] Awareness and knowledge of the Saudi population regarding SLE was investigated in three studies that each conclude that more than 50% of the targeted participants did not know about SLE.[9-11] Nevertheless, studies addressing SLE awareness are still lacking in some regions including Al-Qassim. This study aimed to estimate the awareness of SLE among the general population in the Al-Qassim region, KSA.

METHODS

This study was a cross-sectional study conducted between March and April 2021 among the general population at Al-Qassim, KSA. Prior to starting the study, ethical approval was obtained from Qassim local research committee (QREC). After taking permission, a valid pre-tested electronic questionnaire used by Haikel et al in their study (awareness of systemic lupus erythematosus among primary health care patients in Riyadh, Saudi Arabia) was used for this study. It was distributed through social media among the targeted participants and included socio-demographic characteristics and general awareness, attitude and their belief about SLE.[11]

The awareness of the population toward SLE was assessed using 15 questions, where the correct answers had been identified, marked and coded as 1, while the incorrect answers had been coded as 0. The overall score for the awareness had been achieved by adding all 15 questions. A score range from 0 to 15 had been generated, which indicated that the higher the score, the higher the awareness toward SLE. By using 50% of the maximum score as a cutoff point to determine the level of awareness, participants were classified as poor level by the score range of 0 to 7 points, while above 7 points were considered as good awareness.

The study setting was the Al-Qassim region of KSA. We included participants who were currently living in Al-Qassim, aged above 18 years old, mentally competent and voluntary accept to complete all the questions asked in the questionnaire. The questionnaire was translated to clear the Arabic language. Two research experts revised the questionnaire and a pilot study was conducted with ten participants to confirm and verify the instrument's validity. The sample size was calculated by the Openepi website. Categorical variables were presented using numbers and percentages, while continuous variables were presented using mean, standard deviation and median (interquartile range). The association between the score of awareness in relation to the socio-demographic characteristics of the participants had been calculated using the Mann Whitney U test and the Kruskal Wallis test. Statistical collinearities were performed using the Shapiro Wilk test. The awareness score follows the abnormal distribution. Thus, non-parametric tests were applied. $P<0.05$ was considered statistically significant. The data analyses were performed using the statistical package for social sciences, version 26 (SPSS, Armonk, NY: IBM Corp.).

Ethical considerations

We obtained ethical approval from QREC. The permission was obtained electronically after explaining the research problem and aim of the study on the first page. The participants were informed about the purpose of the research and provided consent prior to completing the questionnaire. Ethical considerations also were taken to ensure the confidentiality and privacy of the collected data. The research followed the Declaration of Helsinki.

RESULTS

We enrolled 377 participants to measure their awareness regarding SLE. Table 1 presents the socio-demographic characteristics of participants. The most common age group was more than 40 years old (39%), slightly more than half were female (52.5%) and nearly 60% were working. With regards to marital status, 62.1% were married and nearly two-thirds (65%) were college level or below. Furthermore, more than one-third (36.6%) had one or fewer dependents. The prevalence of participants who have heard about SLE was 52.5%. When compared to those who have information about SLE, all socio-demographic characteristics of participants did not show a significant relationship with having heard about SLE, including age group in years (p=0.217), gender (p=0.098), occupational status (p=0.078), marital status (p=0.210), educational level (p=0.113) and the number of dependents (p=0.304).

Out of 377 participants, only 4% were diagnosed with SLE, while the rest were non-SLE (96%) (Figure 1). On the other hand, 21.2% of the participants knew that their colleagues had been diagnosed with SLE, 19.2% indicated their relatives have it and 6.1% indicated that their family member had been diagnosed with SLE as displayed in Figure 2. Also, it was found that the most commonly known sources of SLE information were a friend or colleague (53.5%), followed by internet/online sources (43.9%) and the doctor (17.2%), while the radio was the least (4.5%) as showed in Figure 3.

Table 2 assessed participants' awareness toward SLE. The assessment was based on participants who had heard about SLE (N=198); those who had not heard about the disease were excluded from the analyses. We found that 58.6% of respondents believed that SLE was not contagious; however, only 17.2% were sure that SLE was fatal. Furthermore, nearly half of them (48%) knew that SLE was an autoimmune disease and (51%) were sure that it was most common in females. Similarly, one-third (33.8%) believed that SLE affected any part/organ in the body and 22.2% indicated that kidney, blood, heart, eyes, liver, skin, joints, lungs were the most affected organs. Likewise, 23.7% indicated that rash, alopecia, joint pain, hematuria and photosensitivity were the most common symptoms associated with SLE. Moreover, 30% believed that SLE cannot be diagnosed with single blood, while (20.7%) and (21.2%) were sure that SLE cannot be

prevented and cannot be treated. Also, 38.4% did not agree that SLE had few complications. The most mentioned treatment of SLE was combinations of medications (20.7%), followed by steroids (18.7%), chemotherapy (3%) and malaria medications (1.5%). Conversely, nearly 20% believe that SLE disease affected the fertility of men and women, whereas 22.7% knew that SLE caused fetal abnormalities or recurrent abortion in the affected women. Also, most of them (86.9%) agreed that awareness about SLE should be promoted. Based on 15 awareness items, the overall median awareness score was (5.00, IQR: 6.0, mean: 5.37). Figure 4 depicts the level of awareness toward SLE. It can be observed that nearly 70% were classified into poor awareness, while the rest (30.8%) were classified into a good level.

When measuring the differences in the awareness score in regard to the socio-demographic characteristics of participants, we found that the median awareness score of those who indicated their doctor as their sources of SLE information was statistically significantly higher than those with other sources (Z=-5.494; p<0.001) (Table 3). We also found that the median awareness score of those who had been diagnosed with SLE was statistically significantly higher (Z=-3.521; p<0.001). Other socio-demographic characteristics of participants were not significantly different across the groups (p>0.05).

Table 1: Socio-demographic characteristics of participants.

Study variables	Overall N (%) (N=377)	Heard of SLE		P value
		Yes; N (%) (N=198)	No; N (%) (N=179)	
Age group (in years)				
18-30	136 (36.1)	79 (39.9)	57 (31.8)	0.217
31-40	94 (24.9)	44 (22.2)	50 (27.9)	
>40	147 (39.0)	75 (37.9)	72 (40.2)	
Gender				
Male	179 (47.5)	86 (43.4)	93 (52.0)	0.098
Female	198 (52.5)	112 (56.6)	86 (48.0)	
Occupational status				
Unemployed	161 (42.7)	93 (47.0)	68 (38.0)	0.078
Employed	216 (57.3)	105 (53.0)	111 (62.0)	
Marital status				
Unmarried	143 (37.9)	81 (40.9)	62 (34.6)	0.210
Married	234 (62.1)	117 (59.1)	117 (65.4)	
Educational level				
College level or below	245 (65.0)	136 (68.7)	109 (60.9)	0.113
Bachelor's degree or higher	132 (35.0)	62 (31.3)	70 (39.1)	
Number of dependents				
0-1	138 (36.6)	67 (33.8)	71 (39.7)	0.304
2-5	117 (31.0)	68 (34.3)	49 (27.4)	
>5	122 (32.4)	63 (31.8)	59 (33.0)	

Table 2: Assessment of awareness towards SLE.

Awareness questions	N (%)
Is SLE contagious?	
Yes	8 (04.0)
No*	116 (58.6)
I don't know	74 (37.4)
Is SLE fatal	
Yes*	34 (17.2)
No	78 (39.4)
I don't know	86 (43.4)
SLE is an autoimmune disease which means	
There is no cause (the body fights itself)*	95 (48.0)
There are tumors	19 (09.6)
It is heredity	84 (42.4)

Continued.

Awareness questions	N (%)
Dose SLE mostly affect females?	
Yes*	101 (51.0)
No	14 (07.1)
I don't know	83 (41.9)
Does SLE affect any part/organ in the body?	
Yes*	67 (33.8)
No	33 (16.7)
I don't know	98 (49.5)
What organs can be affected by SLE?†	
Kidney	30 (15.2)
Blood	38 (19.2)
Heart	11 (05.6)
Eyes	9 (04.5)
Liver	29 (14.6)
Skin	60 (30.3)
Joints	33 (16.7)
Lungs	17 (08.6)
All of the above*	44 (22.2)
I don't know	61 (30.8)
Symptoms of SLE†	
Rash	73 (36.9)
Alopecia	53 (26.8)
Joint pain	45 (22.7)
Hematuria	13 (06.6)
Photosensitivity	29 (14.6)
Don't know	50 (25.3)
All of the above*	47 (23.7)
Others	62 (31.3)
SLE can be diagnosed with a single blood test	
Yes	51 (25.8)
No*	59 (29.8)
Don't know	88 (44.4)
SLE can be prevented	
Yes	38 (19.2)
No*	41 (20.7)
Don't know	119 (60.1)
SLE is a treatable disease	
Yes	85 (42.9)
No*	42 (21.2)
Don't know	71 (35.9)
SLE is an illness with few complications	
Yes	28 (14.1)
No*	76 (38.4)
Don't know	94 (47.5)
Treatment of SLE	
Chemotherapy*	6 (03.0)
Steroids*	37 (18.7)
Malaria medications*	03 (01.5)
Combination of the above medications*	41 (20.7)
Others	06 (03.0)
Don't know	105 (53.0)
Can SLE disease affect the fertility of men and women?	
Yes*	38 (19.2)

Continued.

Awareness questions	N (%)
No	48 (24.2)
Don't know	112 (56.6)
SLE cause fetal abnormalities or recurrent abortions in the affected mother	
Yes*	45 (22.7)
No	35 (17.7)
Don't know	118 (59.6)
Should awareness of SLE be promoted?	
Yes*	172 (86.9)
No	6 (03.0)
Don't know	20 (10.1)
Total awareness score	
Mean±SD	5.37±3.68
Median (IQR)	5.00 (6.00)

*Indicates correct answer; †variable with multiple response answer.

Table 3: Association between awareness score and the socio-demographic characteristics of participants.

Factors	Awareness total score (15); median (IQR)	Z/H test	P value
Age group (in years)[a]			
18-30	5.00 (6.00)	H=5.731	0.057
31-40	3.50 (7.00)		
>40	4.00 (5.00)		
Gender[b]			
Male	5.00 (6.00)	Z=-0.105	0.916
Female	4.50 (5.00)		
Occupational status[b]			
Unemployed	5.00 (6.00)	Z=-1.540	0.124
Employed	4.00 (6.00)		
Marital status[b]			
Unmarried	5.00 (5.50)	Z=-1.361	0.174
Married	4.00 (5.50)		
Educational level[b]			
College level or below	5.00 (5.00)	Z=-0.109	0.913
Bachelor's degree or higher	4.50 (7.25)		
Number of dependents[a]			
0-1	6.00 (7.00)	H=1.091	0.296
2-5	4.00 (5.00)		
>5	4.00 (4.00)		
Sources of SLE information[b] †			
Doctor	10.0 (5.75)	Z=-5.494	<0.001**
Internet/online sources	5.00 (6.00)	Z=-0.709	0.479
TV	5.00 (5.00)	Z=-0.134	0.893
Radio	5.00 (4.50)	Z=-0.642	0.521
Friend or colleague	4.00 (4.25)	Z=-1.832	0.067
Newspaper and magazine	5.50 (9.00)	Z=-1.078	0.281
Diagnosed with SLE[b]			
Yes	11.0 (3.50)	Z=-3.521	<0.001**
No	4.50 (6.00)		

†variable with multiple response answer; [a]pvalue has been calculated using the Kruskal Wallis test; [b]p value has been calculated using the Mann Whitney U test; **significant at p<0.05 level.

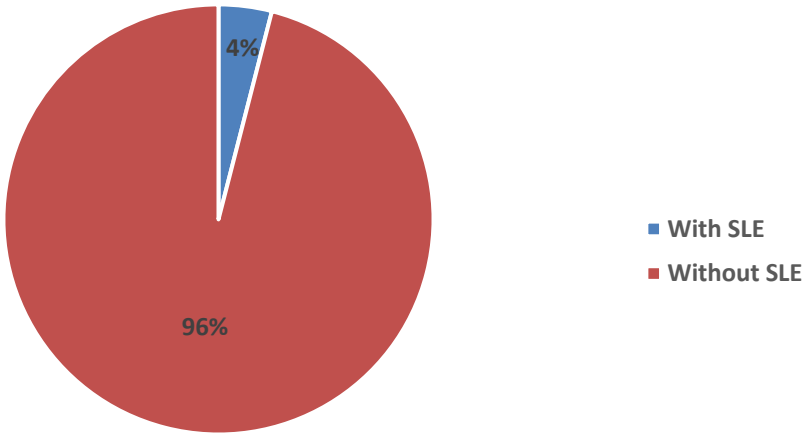

Figure 1: Prevalence of patients who had been diagnosed with SLE.

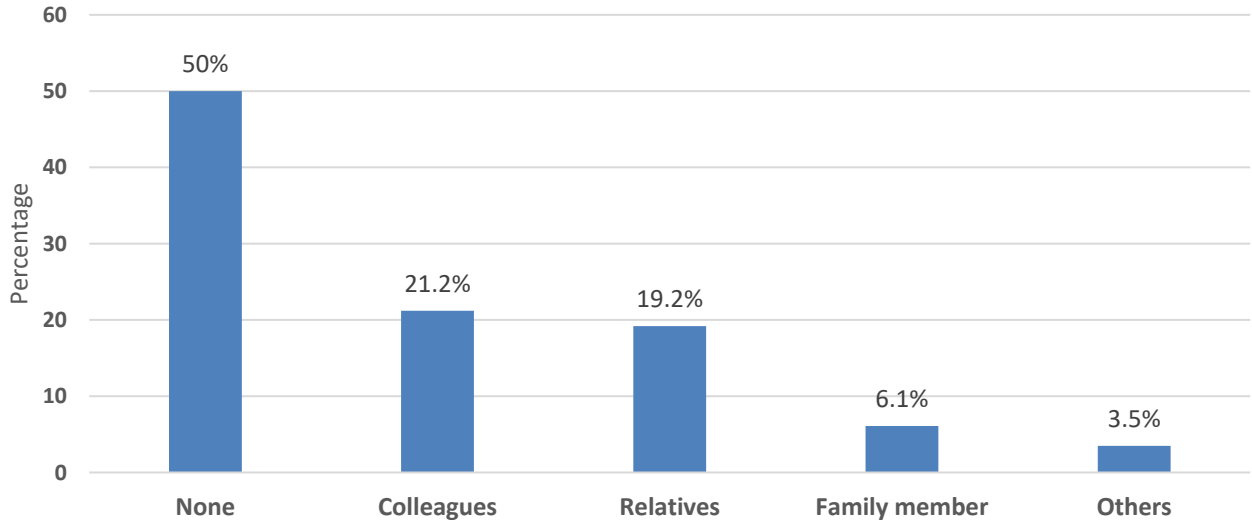

Figure 2: Knowledge of anyone who had been diagnosed with SLE.

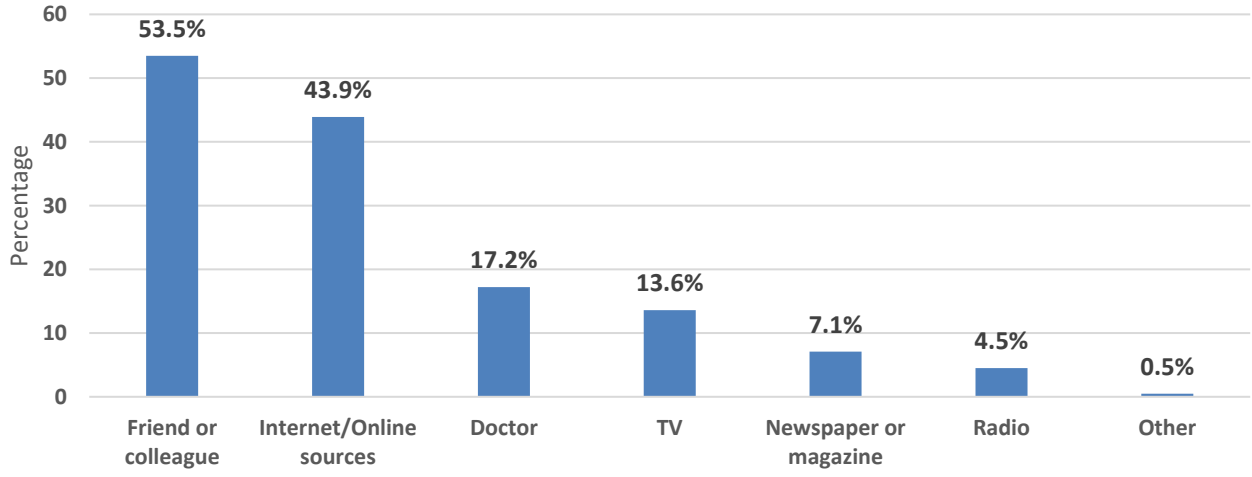

Figure 3: Sources of SLE information.

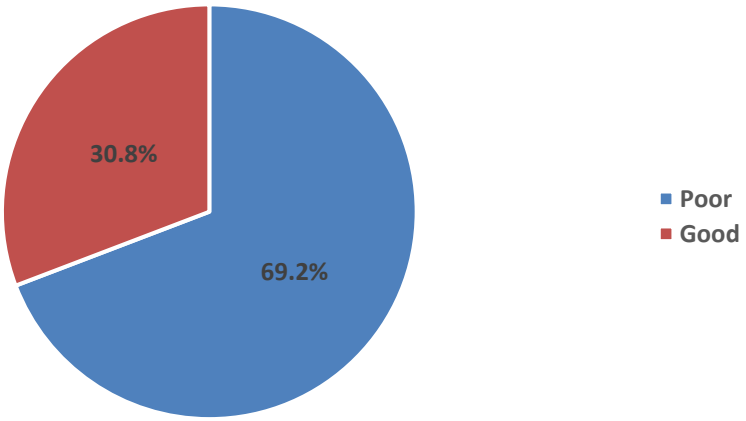

Figure 4: Level of awareness toward SLE.

DISCUSSION

This study sought to determine the general population's level of awareness regarding SLE in the Al-Qassim region, KSA. In this study, the level of awareness among the general public was inadequate. Out of 15 awareness items, the mean score was (5.37) and based on the given criteria, 69.2% were classified into poor awareness level and only 30.8% were classified as good. These findings are similar to those of a study done in the Aseer region, Saudi Arabia, in which more than 60% of the respondents were considered as having poor knowledge of SLE and only 39.3% had good knowledge.[12] Another study that measured the level of knowledge of female students regarding SLE showed that the knowledge level of the students was suboptimal.[9] Only 29% of the students demonstrated good knowledge and the rest had poor knowledge (71%); in addition, the study informed that students who knew someone with SLE had better knowledge score than those without knowledge of anyone with SLE.[9] Also, a study conducted in Riyadh reported that knowing a person who had been diagnosed with SLE was observed to have better awareness than the others.[11]

In our study, receiving SLE information from the doctor and having been diagnosed with SLE was associated with a significantly better awareness score ($p<0.05$). On the other hand, Assiri et al indicated that the factors associated with increased knowledge about SLE were younger participants, gender, nationality and profession.[12] In our study, the differences in the awareness score of age group, gender, occupational status and educational level did not show significant differences across the groups ($p>0.05$), which were not consistent with previous reports.

Moreover, we noted that 52.5% of the respondents had heard about SLE. Of those who had heard about it, nearly 60% of them knew it was contagious and 48% were sure that it was an autoimmune disease, however, their knowledge that SLE can be fatal was poor as only 17.2% knew about it. Multiple studies suggested that students, patients or the general population had a similar level of information about SLE varying from (40% to 1%).[9-13] Apparently, Assiri et al have reported that the general population in the Aseer region, Saudi Arabia, demonstrated better awareness that SLE was an autoimmune disease as nearly 70% of them were sure about it and most (61.2%) of them were aware that it was a life threatening disease.[12] Similarly, our study revealed that 51% of the study population were aware that SLE affects females more than males, with 33% indicating that it could affect multiple organs including kidney, blood, heart, eyes, liver skin, joints and lungs. These findings were consistent with the papers done in Saudi Arabia and in Egypt.[10-14]

It can be further observed that the awareness level of the respondents that SLE was unpreventable and untreatable were poor. Only 20.7% and 21.2% were aware of this scenario. In a similar tempo, Harbi et al noted that 29% and 27.5% of the general public in Dammam city, Saudi Arabia believed that SLE cannot be prevented and cannot be treated.[10] On the other hand, as reported by AlKhalaf et al students exhibited better information about it, as 65% and 66%, respectively were sure that SLE was a unpreventable and untreatable disease.[14] Conversely, our participants responded that the most common symptoms associated with SLE were rash (36.9%), alopecia (26.8%) and joint pain (22.7%), which was consistent with the papers conducted in Saudi Arabia, Egypt, India and the Philippines.[11,12,15,16] Likewise, it had been suggested that steroids were the most common treatment available for SLE.[16] In our study, although 18.7% indicated that steroid was one of the treatment methods for SLE, 20.7% of the subjects stated that a combination of medication was more effective than any other single medication.[9-11,16]

In our further investigations, (29.8%) of the respondents disagreed that SLE can be diagnosed by a single blood test. Omair et al had reported that history and examination were the methods to diagnose SLE, while Assir et al reported that blood test, physical examination and medical history were ways to detect SLE disease.[9,12]

It was important to note that the respondents in this study had relied on their SLE information toward friend and colleague (53.5%), followed by internet or online resources (43.9%) and only 17.2% indicated their doctor. This finding was similar to those reported by Haikel et al.[11] These authors reported that primary health care patients obtained their SLE information from internet/online materials as well as friends and relatives, while in a report of Omair et al female students were reliant on books, newspapers and magazines to obtain necessary information about SLE.[9]

Limitations

This study was limited for specific populations of Al-Qassim region in KSA. Therefore, it might not reflect the real result of whole population in the kingdom. We believed that rarity of SLE also had negative effect on people interest of this disease. Also, recall bias was possible.

CONCLUSION

This study shows that the awareness of the general population in the Al-Qassim region regarding SLE is insufficient. We believe that the lacking frequent public awareness activities have contributed to the poor population awareness in our region. Aiming to early disease detection, we propose that awareness campaigns should be increased.

ACKNOWLEDGEMENTS

Researchers would like to thank the deanship of scientific research, Qassim university for funding publication of this project. Also we thank American manuscript editors (www.americanmanuscripteditors.com) for English language editing.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Alrashdi MN, Alrasheedi SM, Almasaud AK, Almosaiteer SA, Alhindi HA, Alharbi YM, et al. Population awareness about systemic lupus erythematosus in the Al-Qassim region, Saudi Arabia. Int J Adv Med 2021;8:1253-60.