

Assessment of knowledge and awareness regarding systemic lupus erythematosus among the population in Taif, Saudi Arabia

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Author Affiliation:

¹Professor of Internal Medicine & Rheumatology Taif University (TU), Kingdom of Saudi Arabia

²Medical student, Taif University (TU), Kingdom of Saudi Arabia

³Medical intern, Taif University (TU), Kingdom of Saudi Arabia

Corresponding author

Medical student, Taif University (TU), Kingdom of Saudi Arabia
Email: rami334360@gmail.com

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Jamal Abdullah Albishri¹, Moayyad Fateh Alotbi², Rami Faleh Algethami^{2✉}, Amani Hassan Alrumaym², Abdulelah Mosherf Albaradi³

ABSTRACT

Objectives: Our study aimed to assess the awareness and knowledge of systemic lupus erythematosus (SLE) in Taif, Saudi Arabia among the Taif city population. **Subjects and methods:** A cross-sectional study was started in July 2021 in Taif city on a representative sample of 450 participants. The data collection tool was an online questionnaire, which consisted of sociodemographic data and questions regarding knowledge and awareness of systemic lupus. **Results:** We were able to collect data from 450 participants in response to our questionnaire. Regarding knowledge about SLE, 81.1% of the participants reported that they had heard about SLE mainly from a friend or their colleagues and the Internet. Furthermore, we found that skin was the main organ known by participants to be affected by SLE (43.1%) followed by joints (29.3%), and 52.9 % of participants could identify rash as a symptom of SLE, followed by joint pain (37.3%) and alopecia (17.6%). In general, 5.6% of the participants were able to answer more than 60% of questions correctly, and those of a young age, who were male, and who were more educated had previous knowledge about SLE or diagnoses of SLE and thus showed a higher level of awareness. **Conclusion:** This study revealed that knowledge about SLE among participants was insufficient, especially among the less educated, and there are many misconceptions about basic information regarding this serious disease, which requires public health education.

Keywords: Autoimmune diseases, SLE, Taif city

1. INTRODUCTION

Lupus, which is also known as systemic lupus erythematosus (SLE), is an autoimmune disease in which the body's immune system destroys healthy tissue in many parts of the body (Alharbi et al., 2018). Symptoms differ from person to person and can be mild to severe. Painful and swollen joints, fever,



chest discomfort, hair loss, mouth ulcers, swollen lymph nodes, tiredness, and a red rash on the face are all typical symptoms. There are also periods of disease, (flare-ups), and phases of remission, when there are minimal symptoms (Lionaki & Boletis, 2020; Sciascia et al., 2018). In all age and ethnic groups, women are more affected by SLE than men. Women of reproductive age (15-45) are most vulnerable with a 9-to-1 female-to-male ratio (bin Haikel & al Tulaihi, 2018). The etiology of SLE is considered to be a mix of genetic, environmental, and hormonal factors. SLE, on the other hand, has a complicated pathophysiology that is still unclear (Pan et al., 2020). The highest prevalence of SLE has been found in North America at 241 per 100,000 people, while the lowest has been found in South Africa at 0.3 per 100,000 people each year (Rees et al., 2017). The majority of respondents in studies conducted in Al-Dammam, Al-Hasa in 2018 and Riyadh in 2019 had no clear understanding of SLE symptoms, treatment, or consequences (Alharbi et al., 2018; bin Haikel & al Tulaihi, 2018; Alkhalaf et al., 2018). Increased SLE awareness will aid in identifying the condition sooner and developing a clear plan to manage it; thus, we conducted this study. Our study aimed to assess the awareness and knowledge of SLE in Taif among the Taif city population.

2. METHODOLOGY

A quantitative, observational, cross-sectional study was conducted in Taif city, Saudi Arabia, during the period from 1st July to 30th September, 2021, and assessed the level of knowledge about systemic lupus erythematosus among Taif city population. Male and female ≥18 years were enrolled in the study. People who did not give the consent and health care workers were excluded. In total, 450 participants' males and females who live in Taif city were joined in our research via random sampling. An electronic-based, modified, self-contained questionnaire composed of two parts. The first part contains demographic information, such as gender, age, marital status and residency. The second part gathered data on the participant's knowledge regarding systemic lupus erythematosus.

Data was analysed using The Statistical Package of Social Science Software (SPSS) program version 22 (IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.) For statistical analysis Frequency and percent were used for categorical variables, while the mean and standard deviation were calculated for ongoing variables. Chi test and t test were used to assess the relation between different variables. A P value of < 0.05 was considered statistically significant. Official approvals were obtained from the Research Ethics Committee of Taif University with number (42-178). During the research activities, each studied participant was informed about the study objectives with a stress on the confidentiality of collected data and obtaining consents from the subjects to participate in the study.

3. RESULTS

In this study, we were able to collect data from 450 participants in response to our questionnaire. Most of participants were between 18 and 32 years old (69.6%), and most were women (71.1%). Regarding marital status, 56.9% of them reported being single and 38.7% were married. Moreover, about half of the participants were students at college (56.4%), while 21.1% were graduated; thus, 35.8% reported being students at the time of the study. Regarding knowledge about SLE, 81.1% of the participants reported that they had heard about SLE (Table 1).

		Count	Column N %
Age	18–32	313	69.6%
	33–50	81	18.0%
	>50	56	12.4%
Gender	Male	130	28.9%
	Female	320	71.1%
Marital status	Single	256	56.9%
	Married	174	38.7%
	Widowed	2	0.4%
	Divorced	18	4.0%
Education	Primary school	6	1.3%
	Middle school	4	0.9%
	level High school	77	17.1%

	College	254	56.4%
	Graduated	95	21.1%
	Post-graduation studies	14	3.1%
Occupation	Student	161	35.8%
	Housewife	69	15.3%
	Employed	99	22.0%
	Unemployed	75	16.7%
	Retired	46	10.2%
Have you ever heard of the term "systemic lupus erythematosus"?	Yes	365	81.1%
	No	85	18.9%
N= Number of participants, N% percentage of the participants			

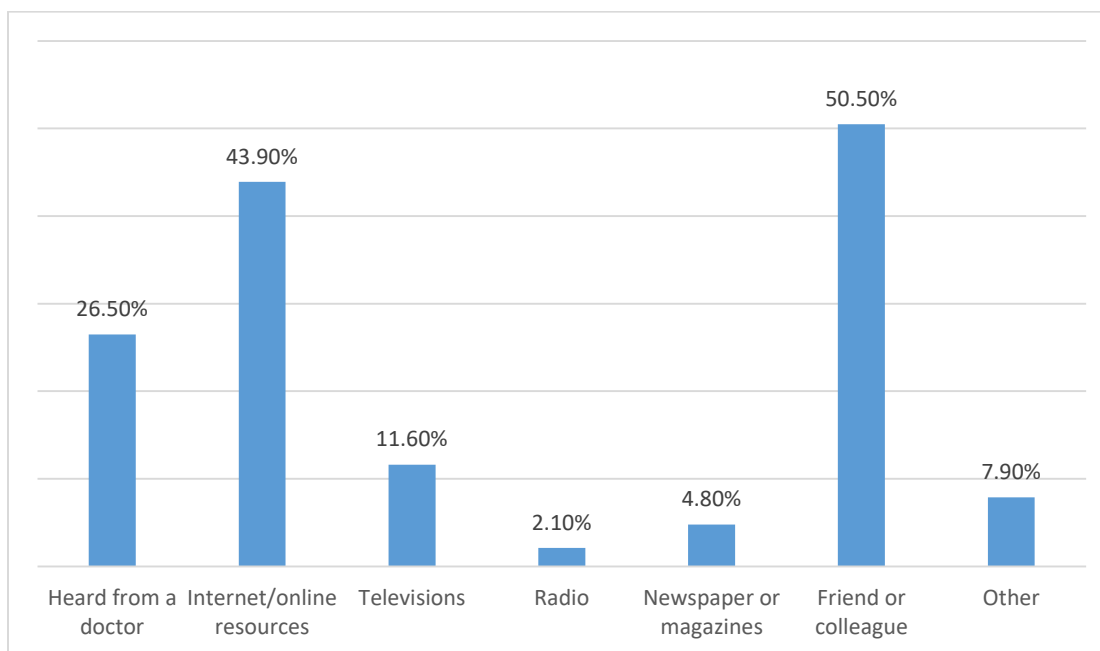


Figure 1 The source of knowledge as reported by participants

Regarding the source of knowledge reported by participants, 50.5% of participants indicated that they had obtained knowledge from a friend or their colleagues, while 43.9% reported knowledge from the Internet or online resources, and only 26.5% received knowledge from their doctors (Figure 1). Among the sample, the prevalence of SLE, as reported by the participants, was 2%, while 34.2% of them indicated knowing another person diagnosed with SLE, including 18% were their colleagues, 11.1% were relatives, and 2.9% were family members (Table 2).

		N	N %
Have you been diagnosed with systemic lupus erythematosus?	Yes	9	2.0%
	No	441	98.0%
Do you know anyone who has systemic lupus erythematosus?	Family member	13	2.9%
	Relatives	50	11.1%
	Colleague	81	18.0%

	No one	296	65.8%
	Others	10	2.2%
N= Number of participants, N% percentage of the participants			

In Table 3, we show the responses of participants regarding knowledge about SLE. As shown in Table 3, 49.8% of the participants had knowledge that SLE is not contagious, while only 27.6% of them did not think that SLE could be fatal. Moreover, 43.6% correctly knew that SLE has no known cause, where only the body attacks itself, and 39.8% knew that SLE affects more women than men. Moreover, 83.6% of participants thought that SLE could be diagnosed using a single lab test, and 85.6% thought that SLE is a preventable and treatable disease. Furthermore, 82.7% of the participants thought that SLE has few complications, and only 18.4% knew the treatments for SLE, including the use of a combination of chemotherapy, steroids, and malaria medications. Moreover, 12.9% knew that SLE could affect the fertility of men and women, and 21.8% knew that SLE could cause fetal abnormalities or recurrent abortions in the affected mother.

Table 3 Responses of participants toward knowledge about SLE.

	False/I do not know		True	
	N	N %	N	N %
Is systemic lupus erythematosus contagious?	226	50.2%	224	49.8%
Is systemic lupus erythematosus fatal?	326	72.4%	124	27.6%
Systemic lupus erythematosus is an autoimmune disease, which means: There is no cause (the body fights itself)*	254	56.4%	196	43.6%
Does systemic lupus erythematosus mostly affect females?	271	60.2%	179	39.8%
Does systemic lupus erythematosus affect any organ/part in the body?	277	61.6%	173	38.4%
Systemic lupus erythematosus can be diagnosed with a single blood test	376	83.6%	74	16.4%
Systemic lupus erythematosus can be prevented	385	85.6%	65	14.4%
Systemic lupus erythematosus is a treatable disease.	385	85.6%	65	14.4%
Systemic lupus erythematosus is an illness with few complications	372	82.7%	78	17.3%
The treatment of SLE is (Combination of above medications)*	367	81.6%	83	18.4%
Can lupus erythematosus disease affect the fertility of men and women?	392	87.1%	58	12.9%
Systemic lupus erythematosus causes fetal abnormalities or recurrent abortions in the affected mother.	352	78.2%	98	21.8%
N= Number of participants, N% percentage of the participants.				
* multi-choice question with provided correct answer				

Furthermore, we found that skin was the main organ known by participants to be affected by SLE (43.1%), followed by the joints (29.3%) and blood (26.2%), while 36% of the sample reported that they had no knowledge of the organs affected by SLE. Moreover, 52.9% of the participants could identify rash as a symptom of SLE, followed by joint pain (37.3%) and alopecia (17.6%) (Table 4).

Table 4 The knowledge of participants about affected organ and symptoms of SLE

		N	N%
What organs can be affected by systemic lupus erythematosus?	Kidney	115	25.6%
	Blood	118	26.2%
	Heart	61	13.6%

	Eyes	71	15.8%
	Liver	53	11.8%
	Skin	194	43.1%
	Joints	132	29.3%
	Lungs	59	13.1%
	Don't know	162	36.0%
The following are symptoms of systemic lupus erythematosus.	Rash	238	52.9%
	Alopecia	79	17.6%
	Joint pain	168	37.3%
	Haematuria	61	13.6%
	Photosensitivity	69	15.3%
	Don't know	141	31.3%
N= Number of participants, N% percentage of the participants			

After analyzing the answers, we found that the mean score was 29 with a standard deviation of 26.5, where 15.6% of participants could answer more than 60% of the questions correctly and were considered aware. Regarding awareness, we found that the age of the participants had a significant impact on their level of awareness in which the level of awareness was significantly higher in the younger participants (17.3% in the 18–32 age group compared with 7.1% in the >50 age group, $P=0.004$). Moreover, we found that males showed significantly higher level of awareness compared with females ($P=0.002$), and those who were single were more aware of the condition than those who were married ($P=0.015$). Furthermore, participants who indicated that they had heard about SLE had higher levels of awareness (18.6%) compared with others who did not hear about SLE before (2.4%) ($P=0.000$). Finally, of the patients who had been diagnosed with SLE, 44.4% were aware of the disease, whereas only 15% of SLE-free participants were aware of SLE (Table 5).

Table 5 The relation between demographic factors of participants and their level of awareness

		Level of awareness				P-value
		Aware		Unaware		
		N	N %	N	N %	
Age	18–32	54	17.3%	259	82.7%	0.004*
	33–50	12	14.8%	69	85.2%	
	>50	4	7.1%	52	92.9%	
Gender	Male	23	17.7%	107	82.3%	0.002*
	Female	47	14.7%	273	85.3%	
Marital status	Single	52	20.3%	204	79.7%	0.015*
	Married	16	9.2%	158	90.8%	
	Widowed	0	0.0%	2	100.0%	
	Divorced	2	11.1%	16	88.9%	
Education	Primary school	0	0.0%	6	100.0%	0.069
	Middle school	0	0.0%	4	100.0%	
	High school	13	16.9%	64	83.1%	
	College	49	19.3%	205	80.7%	
	Graduated	7	7.4%	88	92.6%	
	Post-graduation studies	1	7.1%	13	92.9%	
Occupation	Student	48	29.8%	113	70.2%	0.000*
	Housewife	7	10.1%	62	89.9%	
	Employed	10	10.1%	89	89.9%	
	Unemployed	4	5.3%	71	94.7%	
	Retired	1	2.2%	45	97.8%	

Have you ever heard of the term “systemic lupus erythematosus”?	Yes	68	18.6%	297	81.4%	0.000*
	No	2	2.4%	83	97.6%	
Have you been diagnosed with systemic lupus erythematosus?	Yes	4	44.4%	5	55.6%	0.016*
	No	66	15.0%	375	85.0%	
N= Number of participants, N% percentage of the participants						
* Person X ² test, significant at p value <0.05						

4. DISCUSSION

This is a cross-sectional study that was conducted in Taif, KSA. Building awareness regarding SLE is essential to promote early diagnosis and treatment and to ensure that people with SLE are aware of the support and resources available to help them in the management of the disease (Alkhalaf et al., 2018). This study aimed to understand the knowledge regarding SLE among the general population of Taif, KSA.

In our study, most participants (81.1%) reported that they had heard of the term SLE, and 65% did not know anyone that had SLE, while the prevalence of SLE among our sample was 2%. In a cross-sectional study conducted in Riyadh region, Saudi Arabia, among 400 participants, 56.8% reported that they had heard of the term SLE, while most of them did not know anyone that had SLE, and the prevalence of SLE was 14.5% (bin Haikel & al Tulaihi, 2018). Moreover, in another study conducted in Al Dammam, Saudi Arabia, of 240 participants, the authors reported that the majority of the participants (54%) never heard about SLE (Alharbi et al., 2018), while a similar study was carried among six hundred and thirty participants at King Saud University, and the results showed that 40% had heard of the term SLE before (Omair et al., 2015). Moreover, in our study, the main source of knowledge as reported by the participants were friends and the Internet, which is similar to the results, reported by another study conducted in Al Riyadh (bin Haikel & al Tulaihi, 2018). This indicates the significant role of the Internet in providing knowledge, especially for teenagers, and the deficient role of physicians in increasing knowledge of some conditions, such as SLE.

Regarding participant awareness of SLE, we found that 49.8% of them knew that SLE is not contagious, while only 27.6% did not think that SLE could be fatal, whereas in the Dammam study, 69% of the participants did not know whether the disease is fatal or not (Alharbi et al., 2018), and in the study from Al- Riyadh, the majority did not know that SLE is not contagious (48.2%) but may be fatal (43.5%) (Bin Haikel & al Tulaihi, 2018) moreover, 43.6% correctly recognized that SLE has no known cause, where only the body attacks itself, and 39.8% knew that SLE affects females more than males. Similar results have been reported by other studies (Alharbi et al., 2018; bin Haikel & al Tulaihi, 2018; Omair et al., 2015).

Patients with SLE may manifest different symptoms. However, the main symptoms experienced by individuals suffering from SLE include rash, arthritis, and fatigue (Kuhn et al., 2015; Manson & Rahman, 2006). Regarding symptoms, we reported that 52.9% of the participants could identify rash as a symptom of SLE, followed by joint pain (37.3%) and alopecia (17.6%), whereas 31.3% of them did not know the symptoms of SLE. Similar to our findings, Haikel et al., (2018) reported that a large number of patients were not aware of the main symptoms of SLE (28.5%). In addition, another study found that the majority of participants were unaware of SLE symptoms (63%), while the main symptoms reported by the participants included rashes and alopecia at 6.7% and 6.3%, respectively (Alharbi et al., 2018). Omair et al., (2015) found that when participants were asked about SLE symptoms, most of the participants (56.1%) chose hair loss, while only 10.5% chose lung problems, and 26.3% of participants chose depression as a symptom of SLE. Other participants believed that the symptoms of SLE were anemia (34.5%), weight loss, headache (28.4%), reproductive problems (21.2%), mouth sores (21.2%), loss of energy (38.6%), heart problems (16.2%), and kidney problems (13.4%).

Although SLE is a life-threatening disease, it can still be managed and treated if properly diagnosed. Regarding treatment methods for patients with SLE, only 18.4% knew the treatment for SLE, including the use of a combination of chemotherapy, steroids, and malaria medications. In Riyadh, another study reported that 40.5% do not know if SLE can be prevented, although the majority believed that the disease can be cured (41.2%). Then, 26% of participants believed that the SLE treatment was chemotherapy, 19.3% reported antimalarial drugs, and 18.2% reported steroids (bin Haikel & al Tulaihi, 2018). In Dammam, another study found that 39.5% of respondents believe that SLE is a preventable disease, while 29% of respondents believe that SLE is a disease that cannot be prevented. Then, 35% agreed that it is treatable, while 37.5% did not know if it can be cured or not (Alharbi et al., 2018). Additionally, as a treatment modality, the study reported that 14.5% of participants believed that SLE is treated with

chemotherapy, 14% participants believed that SLE could be treated with steroids, 10% responded that it could be treated with multivitamin supplementation, 7% of participants answered that it could be treated with a combination of the previous medications, but most 52% answered "I don't know" (Alharbi et al., 2018).

In our study, 39.8% knew that SLE affects more women than males, and 82.7% of the participants thought that SLE has few complications. In Riyadh, another study found that the majority of participants were unaware of the complications of SLE (40.2%), and 44% were not aware that SLE can affect fertility in men and women, even though they knew that SLE causes fetal abnormalities or repeated miscarriages. In the affected mother (50.3%) (Bin Haikel & al Tulaihi, 2018), diagnosis is based on a variety of signs and symptoms combined with laboratory tests, including blood, urine, and sometimes a biopsy, to rule out additional diseases. In our study, most participants were unaware of the major laboratory tests for SLE, which is in agreement with another study that reported that 41.5% were not aware of the major laboratory tests for SLE (bin Haikel & al Tulaihi, 2018).

In general, we found that almost 20% of participants were aware of SLE and its characteristics, which is a low percentage. In India, a study was conducted in 2017 among the general population to assess their awareness and knowledge of SLE, and they found that the majority of participants had insufficient knowledge of its status as a rare disease occurring in the population (Nurul & Gheena, 2017). This result indicates the need for campaigns to increase the awareness of the population about SLE and its symptoms, which will result in early diagnosis of SLE and thus more appropriate treatment.

Regarding the relationship between the knowledge level and demographic variables, our study found that the highest level of knowledge was among younger participants (< 32 years old) compared to the elderly (17.3% vs. 7.1%) with a statistical significance ($P < 0.004$). Regarding gender, 17.7% of the male participants had a better level of knowledge compared to 14.7% of the women, with a statistically significant difference ($P < 0.002$). Another study reported, in contrast to our results, that SLE awareness by gender was not statistically significant ($P = 0.304$), but there was a statistically significant difference according to educational level. Participants with a secondary education were more aware than those with a lower level of education (primary and secondary) ($P = 0.023$), which is in contrast to our results (bin Haikel & al Tulaihi, 2018).

Limitations of the study

This study had some limitations. One of these limitations was that it depended on the study tool of a self-reported questionnaire, which could cause some personal bias in which some participants may not be honest when completing the questionnaire, leading to misleading results. Moreover, another limitation is the online method for distributing the questionnaire, which may lead to some sampling bias toward younger participants, who are more familiar with using these applications. Finally, the study was conducted in the region of Taif; therefore, we could not generalize the results for the entire Kingdom. Thus, we recommend using the same questionnaire in different regions of the Kingdom to enable generalization of the results.

5. CONCLUSION AND RECOMMENDATIONS

This study revealed that knowledge about SLE among the participants was insufficient, especially among the less educated, and there are many misconceptions about the basic information regarding this serious disease that require public health education using various methods, including social networks. A comprehensive national study is proposed to explore the public knowledge about SLE.

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Informed consent

Informed consent was obtained from all participants included in the study.

Author Contributions

All the authors contributed evenly with regards to data collecting, analysis, drafting and proofreading the final draft.

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Conflict of Interest

The authors declare that there are no conflicts of interests.

Data and materials availability

All data associated with this study are presented in the paper. Further inquiries can be directed to the corresponding author.

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