ORIGINAL RESEARCH

Assessment of Knowledge and Awareness Regarding Systemic Lupus Erythematosus among the General Population: A Cross-Sectional Study

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ABSTRACT

Aim: To assess the awareness and knowledge regarding systemic lupus erythematosus (SLE) among the general population and to identify demographic factors associated with awareness levels.

Material and Methods: This community-based, cross-sectional observational study was conducted in urban and semi-urban areas, enrolling 200 adult participants through multistage random sampling. Data were collected using a pre-validated, semi-structured questionnaire covering demographics, knowledge of SLE symptoms and complications, and sources of information. Face-to-face interviews were conducted, and data were analyzed using SPSS version 25.0. Associations between awareness and demographic factors were assessed using the chi-square test, with a significance threshold of p<0.05. **Results:** Out of 200 participants, 39.00% were aged 18–30 years and 54.00% were females. Only 38.00% of participants had heard of SLE, and detailed knowledge was limited, with just 24.00% recognizing it as an autoimmune disease and 18.00% aware of its common symptoms. Healthcare professionals (36.84%) and internet/social media (28.95%) were major information sources. Awareness was significantly associated with younger age (p=0.021), higher education (p<0.001), and middle to high socioeconomic status (p=0.002). Among participants aware of SLE, 50.00% had poor knowledge, 34.21% had moderate knowledge, and only 15.79% demonstrated good knowledge.

Conclusion: Awareness and knowledge about systemic lupus erythematosus remain low in the general population, with significant gaps in understanding of disease manifestations and complications. Demographic factors such as younger age, higher education, and better socioeconomic status were positively associated with awareness. Strengthening public health education through healthcare providers and digital media is critical to improve community-level awareness.

Keywords: Systemic lupus erythematosus, Awareness, Knowledge, Population study, Health education

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INTRODUCTION

The human immune system is a highly intricate network of cells, tissues, and organs that work collectively to defend the body against pathogens and maintain homeostasis. It is designed to recognize and eliminate foreign invaders while distinguishing them from the body's own healthy tissues. However, when the immune system malfunctions, it can mistakenly target the body's own cells, resulting in a range of autoimmune disorders. Among these, systemic lupus erythematosus (SLE) stands out due to its complex clinical manifestations, unpredictable course, and significant impact on quality of life.¹

Systemic lupus erythematosus is a chronic autoimmune disease characterized by the production of autoantibodies that target multiple organ systems, including the skin, joints, kidneys, heart, and nervous system. The disease can range from mild to life-threatening and exhibits a broad spectrum of symptoms, making it challenging to diagnose and manage. SLE predominantly affects women of reproductive age, though it can occur in both genders and across all age groups and ethnicities. Its heterogeneous nature and overlapping symptoms with other conditions often result in delayed diagnosis and treatment, underscoring the need for greater public awareness.²

Autoimmunity arises from a failure of the immune system to maintain self-tolerance, leading to an aberrant immune response against the body's own tissues. This breach in immune regulation is influenced by a complex interplay of genetic predisposition, environmental triggers, hormonal factors, and epigenetic modifications. In the context of SLE, genetic susceptibility plays a significant role, with variations in genes related to immune function contributing to disease development. Studies have identified numerous genetic loci associated with SLE, suggesting that individuals carrying certain genetic variants have a heightened risk of developing the disease. Moreover, familial aggregation of lupus cases points to a strong hereditary component.³

Beyond genetic factors, epigenetic mechanisms such as DNA methylation, histone modifications, and non-coding RNAs also influence the pathogenesis of SLE. Epigenetic alterations can modulate gene expression without changing the underlying DNA sequence, thereby affecting promoting immune cell function and autoimmunity. Environmental exposures, such as ultraviolet (UV) light, infections, certain medications, and smoking, can induce epigenetic changes that trigger or exacerbate SLE in genetically susceptible individuals. These insights into the molecular underpinnings of SLE have opened new avenues for research and therapeutic interventions.⁴

Despite advancements in understanding the biological basis of SLE, public awareness about the disease remains limited. Many individuals are unfamiliar with its symptoms, risk factors, and potential severity. Common misconceptions and lack of knowledge often lead to delayed medical consultation and diagnosis, resulting in worse clinical outcomes. Early recognition and timely

intervention are critical in SLE management to prevent organ damage and improve prognosis. Public education campaigns, patient advocacy initiatives, and community-based outreach programs are essential to bridge the knowledge gap and empower individuals to seek early medical attention.⁵

The clinical presentation of SLE is remarkably diverse, earning it the moniker "the great imitator." Patients may present with fatigue, joint pain, skin rashes, photosensitivity, fever, and serositis, among other symptoms. The presence of antinuclear antibodies (ANA) is a hallmark laboratory finding, although it is not specific to lupus. Organ-specific manifestations, such as lupus nephritis, neuropsychiatric lupus, and hematologic abnormalities, significantly contribute to morbidity and mortality. The disease course is characterized by periods of flares and remissions, necessitating long-term and individualized monitoring treatment strategies.6

Current therapeutic approaches for SLE focus on controlling disease activity, preventing flares, and minimizing organ damage. Treatment regimens often include non-steroidal antiinflammatory drugs (NSAIDs), antimalarials like hydroxychloroquine, corticosteroids, immunosuppressive agents, and biologics targeting specific immune pathways. However, treatment outcomes vary widely among patients, and long-term medication use can lead to adverse effects. Therefore, increasing public understanding of the importance of medication adherence, regular follow-up, and lifestyle modifications is crucial for optimal disease management.^{7,8}

Research efforts continue to uncover novel biomarkers for early diagnosis, disease monitoring, and therapeutic targeting. Advances in genomic, proteomic, and epigenetic technologies have enhanced our comprehension of SLE pathophysiology, offering hope for more personalized and effective treatments in the future. Nevertheless. these scientific developments must be paralleled by increased population-level education to ensure that individuals can recognize early warning signs and access appropriate healthcare resources.⁴

SLE disproportionately affects certain populations, particularly women of African, Asian, and Hispanic descent, who tend to experience more severe disease manifestations and poorer outcomes. Socioeconomic disparities, limited access to healthcare, and cultural beliefs

further compound the burden of SLE in these communities. Addressing these inequities requires culturally sensitive awareness campaigns and targeted public health initiatives that consider the unique needs of diverse populations.

AIM AND OBJECTIVES Aim of the Study

The aim of this study was to assess the level of awareness and knowledge regarding systemic lupus erythematosus (SLE) among the general population in a selected region and to identify factors influencing awareness.

Objectives of the Study

- 1. To determine the proportion of the general population who have heard of systemic lupus erythematosus (SLE).
- 2. To assess the level of knowledge about the causes, symptoms, risk factors, complications, and management of SLE among those aware of the disease.
- 3. To identify the primary sources of information through which the public learns about SLE.
- 4. To evaluate the association between sociodemographic factors (age, gender, education, socioeconomic status) and the level of awareness and knowledge about SLE.
- 5. To highlight the need for public health initiatives aimed at improving awareness and understanding of SLE.

MATERIAL AND METHODS

Study Design: This was a community-based, cross-sectional observational study conducted to assess the knowledge and awareness of systemic lupus erythematosus (SLE) among the general population.

Study Population: The study included adult participants aged 18 years and above from urban and semi-urban regions of the city. A total of 200 adults were enrolled through a multistage random sampling method to ensure representation across various socioeconomic backgrounds.

Study Place: Participants were recruited from public locations such as marketplaces, community centres, educational institutions, and outpatient departments of Department of General Medicine, ShriRamkrishna Institute of Medical Sciences & Sanaka Hospitals, Durgapur, West Bengal, Indiain the study area.

Study Period: The study was conducted over a periodone year and seven months from June 2023 to November 2024.

Ethical Considerations

Prior to initiation, ethical approval was obtained from the Institutional Ethics Committee. Written informed consent was collected from all participants before enrollment. Confidentiality of participant information was maintained throughout the study.

Inclusion Criteria

- Adults aged 18 years and above.
- Residents living in the study area for at least the past 6 months.
- Willingness to participate and provide informed consent.
- Ability to comprehend and respond to the questionnaire.

Exclusion Criteria

- Individuals previously diagnosed with systemic lupus erythematosus (SLE).
- Medical professionals or students from health-related fields (to avoid bias).
- Individuals with cognitive impairments hindering questionnaire completion.
- Participants who refused or withdrew consent during the study.

Study Procedure

A pre-validated, semi-structured questionnaire was used as the data collection tool. The questionnaire consisted of three sections:

- Section A: Demographic details (age, gender, education, occupation, socioeconomic status).
- Section B: Knowledge and awareness regarding SLE, including symptoms, risk factors, complications, and treatment options.
- Section C: Sources of information about SLE (e.g., healthcare professionals, media, internet, social networks).

The questionnaire was initially developed in English and translated into the local language using forward and backward translation to maintain consistency. Trained investigators administered the questionnaire through face-toface interviews lasting approximately 15–20 minutes to ensure clarity and completeness.

Outcome Measures

The primary outcome was the level of knowledge and awarenessregarding SLE among the general population, assessed through responses to the questionnaire.

Statistical Analysis

Collected data were entered into Microsoft Excel and analyzed using Statistical Package for the Social Sciences (SPSS) version 26.0. Descriptive statistics such as frequencies, percentages,

means, and standard deviations were calculated. Associations between awareness levels and demographic variables were assessed using the chi-square test, with a p-value < 0.05 considered statistically significant.

RESULTS

Variable	Number	Percentage (%)
Age Group (Years)		
18–30 years	78	39.00
31–45 years	64	32.00
46–60 years	40	20.00
>60 years	18	9.00
Gender		
Male	92	46.00
Female	108	54.00
Education Level		
Illiterate	24	12.00
Up to Primary	52	26.00
Secondary/Higher Secondary	76	38.00
Graduate and Above	48	24.00
Socioeconomic Status		
Low	58	29.00
Middle	110	55.00
High	32	16.00

Table 1: Demographic Characteristics of Participants (n = 200)

Table 1 show that a total of 200 participants were included in the study. The majority of participants (39.00%) were in the 18–30 years age group, followed by 32.00% between 31–45 years, 20.00% between 46–60 years, and 9.00% above 60 years of age. Regarding gender distribution, females constituted a slightly higher proportion (54.00%) compared to males (46.00%). The education levels varied, with 38.00% having attained secondary or higher secondary education, 26.00% up to primary education, 24.00% being graduates or above, and 12.00% being illiterate. Most participants belonged to the middle socioeconomic class (55.00%), followed by the low socioeconomic group (29.00%) and high socioeconomic status (16.00%).

Table 2: Awareness about Systemic Lupus Erythematosus (SLE)				
Awareness Parameter	Number	Percentage (%)		
Heard about SLE	76	38.00		
Not heard about SLE	124	62.00		
Knowledge of SLE being an autoimmune disease	48	24.00		
Awareness of common symptoms (joint pain, rash)	36	18.00		
Awareness of serious complications (kidney/CNS)	22	11.00		

 Table 2: Awareness about Systemic Lupus Erythematosus (SLE)

Table 2 shows that out of the 200 participants, only 76 individuals (38.00%) had heard about systemic lupus erythematosus (SLE), whereas the majority (62.00%) were unaware of the disease. When asked about specific knowledge, 48 participants (24.00%) recognized SLE as an autoimmune disorder. Awareness about common symptoms, such as joint pain and skin rash, was observed in 36 participants (18.00%). Knowledge about serious complications, including kidney involvement and central nervous system manifestations, was the least common, identified by only 22 participants (11.00%).

Source of Information	Number	Percentage (%)
Healthcare Professionals	28	36.84
Internet/Social Media	22	28.95
Television/Newspapers	16	21.05
Friends/Relatives	10	13.16

Table 3: Sources of Information about SLE among Those Aware (n = 76)

Table 3 shows that a total of 200 participants were included in the study. The majority of participants (39.00%) were in the 18–30 years age group, followed by 32.00% between 31–45 years, 20.00% between 46–60 years, and 9.00% above 60 years of age. Regarding gender distribution, females constituted a slightly higher proportion (54.00%) compared to males (46.00%). The education levels varied, with 38.00% having attained secondary or higher secondary education, 26.00% up to primary education, 24.00% being graduates or above, and 12.00% being illiterate. Most participants belonged to the middle socioeconomic class (55.00%), followed by the low socioeconomic group (29.00%) and high socioeconomic status (16.00%).

Among the 76 participants who were aware of SLE, the most common source of information was healthcare professionals, reported by 28 individuals (36.84%). The internet and social media platforms were the next most common sources, accounting for 22 participants (28.95%). Traditional media sources such as television and newspapers contributed to the awareness of 16 participants (21.05%), while friends and relatives were the source for 10 participants (13.16%).

Demographic	Category	Aware	Percentage	Not	Percentage	p-value
Parameter		(n=76)	(%)	aware	(%)	
				(n=124)		
Age Group	18–30 years	36	47.37	42	33.87	0.021
(in year)	31–45 years	24	31.58	40	32.26	
	46–60 years	10	13.16	30	24.19	
	>60 years	6	7.89	12	9.68	
Gender	Male	30	39.47	62	50.00	0.128
	Female	46	60.53	62	50.00	
Education	Illiterate	2	2.63	22	17.74	< 0.001
Level	Up to Primary	10	13.16	42	33.87	
	Secondary/Higher	36	47.37	40	32.26	
	Secondary					
	Graduate and	28	36.84	20	16.13	
	Above					
Socioeconomic	Low	12	15.79	46	37.10	0.002
Status	Middle	46	60.53	64	51.61	
	High	18	23.68	14	11.29	

 Table 4: Association between Demographic Parameters and Awareness about SLE (n = 200)

Table 4 and figure I, show that analysis of the association between demographic factors and awareness revealed statistically significant results for age, education level. and socioeconomic status. Awareness was significantly higher among participants aged 18-30 years (47.37%) compared to older age groups (p = 0.021). Gender was not significantly associated with awareness (p =0.128), although a higher proportion of females were aware (60.53%) compared to males (39.47%). Education level showed a highly significant association (p < 0.001), with awareness notably higher among participants who had completed secondary/higher secondary (47.37%) and graduate and above education (36.84%) compared to those who were illiterate or only up to primary education. Socioeconomic status was also significantly associated with awareness (p = 0.002), with participants from middle (60.53%) and high (23.68%) socioeconomic classes showing greater awareness compared to those from low socioeconomic backgrounds.



 Table 5: Knowledge Score among Participants Aware of SLE (n = 76)

Knowledge Level	Number	Percentage (%)
Poor (Score 0–3/10)	38	50.00
Moderate (Score 4–6/10)	26	34.21
Good (Score 7–10/10)	12	15.79

Table 5, show that among the 76 participants who had heard about SLE, the level of detailed knowledge varied considerably. Half of the aware participants (50.00%) scored poorly (0–3 out of 10) on the knowledge assessment. A moderate level of knowledge (score 4–6/10) was observed in 26 participants (34.21%), while only 12 participants (15.79%) demonstrated good knowledge (score 7–10/10) about SLE.

DISCUSSION

In the present study, the majority of participants (39.00%) belonged to the 18–30 years age group, followed by 32.00% in the 31-45 years category, with a slight female predominance (54.00%). This demographic trend is comparable to the study by Alrashdi et al 2021, where a large proportion (43.0%) of participants were under 30 years of age and 57.0% were females.¹⁰ Similarly, Asiri et al 2020 reported a youthful cohort with 48.6% females.¹¹ The educational status in our study revealed that 38.00% had completed secondary/higher secondary education and 24.00% were graduates, indicating a moderately educated sample, which is similar to Alharbi et al 2018, where 40.7% of respondents had a university degree.¹² A majority (55.00%) of participants in the current study belonged to the middle socioeconomic class, consistent with findings by Omair et al 2015, who noted that awareness levels were higher in middle-class populations.¹³

Regarding awareness about systemic lupus erythematosus, our study found that only 38.00% of participants had heard of SLE. This is in line with Alharbi et al 2018, who observed a 35.0% awareness rate among the public in Al-Dammam.¹² In contrast, Omair et al 2015 reported a slightly higher awareness of 46.0% among female university students, highlighting that educational setting influences awareness. Specific knowledge in our study was low: only correctly identified SLE as an 24.00% autoimmune disease, 18.00% were aware of joint pain and rash as symptoms, and a mere 11.00% knew about serious complications like kidney and CNS involvement.¹³ Comparatively, Haikel et al 2019 reported that 30.0% recognized SLE as an autoimmune disorder, indicating slightly better disease understanding among primary healthcare patients than in our broader community sample.¹⁴ When sources of information were assessed,

healthcare professionals emerged as the most frequent source in our study (36.84%), followed by media internet/social (28.95%),television/newspapers (21.05%),and friends/relatives (13.16%). AlKhalaf et al 2018 found that 34.2% of participants received information through physicians, and 29.7% through internet sources, closely mirroring our results.¹⁵Similarly, Alrashdi et al 2021 emphasized the growing role of internet-based

platforms for health education among the younger population, corroborating our findings.¹⁰ Analysis of the association between demographic parameters and awareness revealed that younger age, higher education, and higher socioeconomic status were significantly associated with greater awareness. Participants aged 18-30 years were more aware (47.37%, p=0.021), matching observations by Shelbie et al 2016, who highlighted that younger individuals with greater exposure to educational material scored higher in lupus knowledge assessments.¹⁶ Education level was a strong predictor of awareness in our study (p<0.001), with graduates and those with secondary education showing significantly higher knowledge — a finding echoed by Moriarty et al 2003, who demonstrated that higher educational attainment correlated with earlier diagnosis and better disease recognition in Portugal.¹⁷ Socioeconomic status also influenced awareness significantly (p=0.002) in our study, similar to the findings of Saman et al 2020, where higher income groups showed superior awareness about rheumatic diseases including SLE.¹⁸

Regarding knowledge scores among those aware of SLE, 50.00% in our study had poor knowledge (0–3/10), 34.21% had moderate knowledge (4–6/10), and only 15.79% had good knowledge (7–10/10). These results are quite similar to those reported by Zaaba et al 2017, where 53.0% of participants had poor knowledge, and only 17.0% exhibited good knowledge.¹⁹ Additionally, Gulay et al 2011 noted that poor disease knowledge adversely impacted outcomes among patients with juvenile SLE, further reinforcing the need for better public education campaigns.²⁰

LIMITATIONS OF THE STUDY

- **Cross-sectional Design:** As this was a cross-sectional study, it only provides a snapshot of knowledge and awareness at a single point in time. Causal relationships could not be established.
- Self-reported Responses: Data were collected through face-to-face interviews based on self-reported answers, which might have introduced response bias or social desirability bias.
- Limited Geographical Area: The study was confined to selected urban and semiurban areas of a single city, which may limit the generalizability of the findings to

broader populations, especially rural regions.

- **Sample Size:** Although 200 participants were included, a larger sample size could have enhanced the statistical power and precision of the findings.
- Exclusion of Healthcare Professionals: Excluding medical professionals and health sciences students was necessary to avoid bias, but it also means the study cannot comment on awareness levels among people more likely to influence public knowledge.
- **Potential Information Gaps:** Despite translation efforts, some nuanced understanding of SLE-related questions might have been lost, affecting the accuracy of responses.

CONCLUSION

This community-based, cross-sectional study highlights a substantial lack of awareness and knowledge regarding systemic lupus erythematosus (SLE) among the general population. Only 38% of participants had heard of SLE, and among those, detailed knowledge about the disease, its symptoms, complications, and management was generally poor. Awareness was significantly associated with younger age groups, higher education levels, and better socioeconomic status.

Healthcare professionals emerged as the most trusted source of information, followed by internet and social media platforms. These findings underscore an urgent need for targeted public health education programs aimed at increasing awareness of autoimmune diseases like SLE, particularly among older; less educated, and lowers socioeconomic groups. Improved awareness could lead to earlier recognition of symptoms, prompt medical consultation, and better disease outcomes.

Future studies with larger, more diverse samples across different geographic regions and longitudinal designs are recommended to further explore and address the gaps in public awareness about SLE.

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