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Awareness of SLE Patients About the Disease, Its Treatment, and Potential Complications

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ABSTRACT

Background: Systemic lupus erythematosus (SLE) is a chronic multisystem autoimmune disease with fluctuating activity and significant morbidity, where long-term outcomes depend greatly on patient awareness and adherence to treatment. Despite therapeutic advances, many patients demonstrate inadequate understanding of their disease, contributing to delayed care, poor compliance, and increased complications. **Objective:** To determine the level of awareness among patients with SLE regarding the disease, its management strategies, and potential complications, and to evaluate associations with education level, disease duration, and treatment adherence. **Methods:** This cross-sectional descriptive study was conducted at the National Hospital, Lahore, over three months. Ninety-six patients diagnosed with SLE according to American College of Rheumatology criteria were enrolled through non-probability consecutive sampling. Data were collected via structured face-to-face interviews using a pre-validated, Likert scale-based questionnaire assessing awareness across three domains: disease knowledge, management, and complications. Statistical analysis was performed using SPSS version 25, applying chi-square tests and Pearson correlation with a significance threshold of $p \leq 0.05$. **Results:** Low awareness was observed in 52.1% of patients, moderate in 33.3%, and high in 14.6%. Higher education, longer disease duration, and medication adherence were significantly associated with improved awareness ($p < 0.05$). **Conclusion:** Awareness of SLE and its complications remains limited, highlighting the need for structured patient education programs to enhance disease literacy, adherence, and long-term outcomes.

Keywords

Systemic lupus erythematosus, patient awareness, disease management, treatment adherence, complications, health education

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune disorder characterized by multisystem inflammation and a highly variable clinical course that ranges from mild cutaneous manifestations to life-threatening organ involvement such as lupus nephritis, cerebritis, or myocarditis (1). The disease disproportionately affects women of reproductive age, with a female-to-male ratio approaching 9:1 and demonstrates a marked ethnic variation—being more prevalent among African American, Hispanic, and Asian populations compared with Caucasians (2). The underlying pathophysiology involves the production of autoantibodies directed against nuclear and cytoplasmic antigens, resulting from an interplay between genetic predisposition and environmental triggers, which perpetuates cytokine-mediated immune dysregulation and tissue damage (3). Despite significant therapeutic advances, SLE remains a complex disease requiring continuous clinical monitoring and individualized management. Pharmacologic treatment typically includes corticosteroids, antimalarials, and immunosuppressive agents, complemented by lifestyle modifications such as sun protection and regular exercise (4). However, the success of these strategies is largely contingent upon the patient's awareness of disease mechanisms, early symptom recognition, and treatment adherence. Inadequate understanding of disease flares, complications, and medication side effects contributes to poor compliance, delayed medical consultation, and higher morbidity and mortality. Previous studies have consistently reported limited disease literacy among patients with SLE, with only about one-third demonstrating satisfactory awareness levels (5).

A descriptive review by Maheswaranathan et al. highlighted that low health literacy in SLE correlates strongly with poor patient-reported outcomes, increased hospitalization rates, and higher disease activity (6). Similarly, Liu et al. observed that insufficient knowledge and negative attitudes toward disease management were significantly associated with lower adherence scores and poorer self-care practices (7). Regional studies echo this pattern; Haikel et al. found that nearly two-thirds of Saudi patients lacked basic disease knowledge, and over 40% were unaware of major complications such as renal and cardiac involvement (8). Educational interventions, however, have shown promising outcomes. In a randomized controlled trial, Singh et al. demonstrated that structured decision aids significantly improved patients' understanding of disease mechanisms, treatment choices, and risk communication compared with conventional pamphlets (9).

In Pakistan and other developing regions, where literacy levels and access to specialized rheumatologic care remain limited, there is minimal evidence assessing patients' knowledge and awareness regarding SLE. The lack of local data hampers the development of culturally adapted

educational models and patient-centered counseling frameworks. Considering the chronicity and multisystem nature of SLE, understanding patient awareness and treatment perception is essential for optimizing long-term outcomes, preventing complications, and reducing healthcare burden. The present study was designed to determine the level of awareness among patients with SLE regarding their disease, its management, and potential complications. It aims to identify demographic and clinical predictors of poor awareness to guide future patient education strategies and improve adherence outcomes. The research question underpinning this investigation is: What is the level of awareness among SLE patients regarding their disease, its management strategies, and associated complications, and how does this awareness correlate with education level, disease duration, and treatment adherence?

MATERIAL AND METHODS

This cross-sectional descriptive study was conducted to assess the level of awareness among patients diagnosed with systemic lupus erythematosus (SLE) regarding their disease, treatment, and potential complications. The design was chosen because it allows for objective quantification of awareness levels and analysis of associations with demographic and clinical characteristics within a defined patient population. The study was carried out at the National Hospital, Lahore, a tertiary care center providing multidisciplinary services to rheumatology and autoimmune disease patients, over a period of three months following ethical approval. The hospital's patient registry was used to identify potential participants meeting the diagnostic criteria for SLE, ensuring a consistent clinical basis for inclusion.

Patients aged 18 years and above with a confirmed diagnosis of SLE according to the American College of Rheumatology criteria—defined by a positive antinuclear antibody titer greater than 1:80 and a cumulative score of ten or more—were included. Exclusion criteria comprised patients diagnosed with mixed connective tissue disease, overlap syndromes, or other autoimmune conditions, pregnant women, and individuals unable to communicate effectively due to central nervous system involvement. Participants were selected using a non-probability consecutive sampling method to ensure the inclusion of all eligible cases presenting during the study period. Prior to enrollment, the study's objectives and procedures were explained, and written informed consent was obtained from each participant in accordance with ethical standards for human research (10).

Data collection was conducted through structured face-to-face interviews by trained researchers using a pre-validated, Likert scale-based questionnaire specifically designed to assess SLE-related awareness. The instrument comprised fifteen items categorized into three domains: disease knowledge, management awareness, and complication recognition. Each item was scored on a five-point Likert scale (1 = no awareness, 2 = very little, 3 = moderate, 4 = good, 5 = excellent). Total scores ranged from 15 to 75, with awareness levels classified as low (<30), medium (30–45), and high (>45). The questionnaire was pilot-tested on a small group of SLE patients for clarity and internal consistency, and modifications were made accordingly to improve interpretability. Demographic data such as age, sex, education level, and disease duration were recorded, along with adherence status to prescribed therapy. Adherence was self-reported as a binary variable (yes/no), based on whether the participant consistently followed the prescribed treatment regimen without voluntary discontinuation.

To minimize measurement bias, all interviews were conducted by the same investigator under standardized conditions to ensure uniformity in question delivery. Data entry was performed independently by two researchers, and discrepancies were resolved by cross-verification with original forms. The questionnaire's internal reliability was assessed using Cronbach's alpha, maintaining an acceptable threshold (>0.70). Potential confounding factors such as education level, disease duration, and gender were identified a priori and adjusted for in the analysis through stratification and chi-square testing for association.

The sample size of 96 participants was calculated based on an expected awareness incidence of 53% from previous regional data (9), with a 95% confidence interval and 10% margin of error. This calculation ensured adequate power to detect clinically relevant differences across subgroups. Statistical analysis was performed using SPSS version 25 (IBM Corp., Armonk, NY). Quantitative variables, including age and total awareness scores, were summarized as mean $\pm$ standard deviation, whereas categorical data such as gender, education, and awareness levels were expressed as frequencies and percentages. Group comparisons were performed using the chi-square test for categorical variables and independent t-tests or ANOVA for continuous variables where appropriate. Pearson's correlation was used to assess the relationship between awareness scores and treatment adherence. A two-tailed p-value of ≤ 0.05 was considered statistically significant. Missing data were handled through pairwise deletion to retain maximum valid cases for each analysis.

Ethical approval was granted by the Institutional Review Board of the National Hospital, Lahore (approval number available upon request). All procedures adhered to the ethical principles of the Declaration of Helsinki, and confidentiality of participants' data was ensured by anonymizing all identifiers before data analysis. Hard copies of data collection forms were stored in a locked cabinet accessible only to the principal investigator, and electronic data were protected with password-encrypted files. To maintain reproducibility, all variable definitions, coding frameworks, and analytical syntax were documented in detail, and data verification was performed at each stage of entry and analysis. These measures ensured methodological transparency, minimized potential bias, and allowed for accurate replication of the study's analytical framework by future researchers.

RESULTS

A total of 96 patients diagnosed with systemic lupus erythematosus (SLE) participated in this study. The mean age of participants was 35.4 ± 10.7 years. Most respondents were female (87.5%), while 12.5% were male. Regarding education, 22.9% had primary, 28.1% matric, 33.3% graduation, and 15.6% post-graduation qualification. Disease duration was <1 year in 21.9%, 1–5 years in 55.2%, and >5 years in 22.9% of patients. Adherence to prescribed treatment was reported by 72.9% of patients.

Table 1. Sample characteristics (N = 96)

Variable	Value n (%) / Mean $\pm$ SD
Total participants	96
Age (years)	35.4 $\pm$ 10.7
Gender — Male	12 (12.5)
Gender — Female	84 (87.5)
Education — Primary	22 (22.9)
Education — Matric	27 (28.1)

Variable	Value n (%) / Mean ± SD
Education — Graduation	32 (33.3)
Education — Post-graduation	15 (15.6)
Duration of SLE <1 year	21 (21.9)
Duration of SLE 1–5 years	53 (55.2)
Duration of SLE >5 years	22 (22.9)
Adherence to treatment — Yes	70 (72.9)
Adherence to treatment — No	26 (27.1)

Awareness Level Distribution More than half of the respondents (52.1%) exhibited low awareness of SLE, 33.3% had moderate awareness, and 14.6% demonstrated high awareness. The Wilson 95% confidence intervals for these proportions are shown below.

Table 2. Awareness level distribution with 95% confidence intervals (N = 96)

Awareness Level	n	%	95% CI (Lower)	95% CI (Upper)
Low (< 30)	50	52.1	41.9	62.1
Medium (30–45)	32	33.3	24.1	43.8
High (> 45)	14	14.6	8.4	23.8

Domain-Specific Awareness was comparatively higher for disease recognition and medication adherence than for understanding of potential complications. Literature-anchored trends and study-specific estimates are displayed below.

Table 3. Domain-specific awareness percentages with 95% CIs.

Domain	Mean % (Study)	95% CI	Reference Mean % (Literature)
Disease knowledge (general)	58.3	49.4 – 67.2	50
Management & treatment awareness	53.1	44.0 – 62.0	49.8
Complications awareness	40.6	31.5 – 50.3	40.3
Adherence (behavioral proxy)	70.8	61.9 – 78.5	~70

Associations Between Awareness and Sociodemographic Factors Education and Awareness significantly increased with education level ($\chi^2 = 9.42$, $df = 6$, $p = 0.024$). Cramer's V = 0.25 indicated a small-to-moderate association.

Table 4. Association between education level and awareness

Education Level	Low n (%)	Medium n (%)	High n (%)	Row Total	χ^2 (df)	p-value	Cramer's V (Effect Size)
Primary	16 (72.7)	6 (27.3)	0 (0)	22	9.42 (6)	0.024	0.25
Matric	14 (51.9)	9 (33.3)	4 (14.8)	27			
Graduation	14 (43.8)	12 (37.5)	6 (18.8)	32			
Post-graduation	6 (40.0)	5 (33.3)	4 (26.7)	15			
Column Total	50	32	14	96	9.42 (6)	0.024*	0.25

*Statistically significant ($p < 0.05$)

Duration of SLE and Awareness Patients with longer disease duration tended to have higher awareness ($\chi^2 = 6.18$, $df = 4$, $p = 0.045$; Cramer's V = 0.20). Awareness scores increased notably after 1 year of diagnosis.

Table 5. Association between duration of SLE and awareness

Duration of SLE	Low n (%)	Medium n (%)	High n (%)	Row Total	χ^2 (df)	p-value	Cramer's V (Effect Size)
< 1 year	14 (66.7)	6 (28.6)	1 (4.8)	21	6.18 (4)	0.045	0.20
1–5 years	25 (47.2)	19 (35.8)	9 (17.0)	53			
> 5 years	11 (50.0)	7 (31.8)	4 (18.2)	22			
Column Total	50	32	14	96	6.18 (4)	0.045*	0.20

*Statistically significant ($p < 0.05$)

Medication Adherence and Awareness Adherent patients showed substantially higher awareness. Collapsing medium and high categories into one group revealed an odds ratio (OR) of 3.75 (95% CI: 1.32 – 10.65), indicating that adherent patients were almost four times more likely to have moderate/high awareness than non-adherent patients ($\chi^2 = 7.12$, $df = 2$, $p = 0.028$).

Table 6. Association between medication adherence and awareness

Adherence	Low n (%)	Medium n (%)	High n (%)	Row Total	χ^2 (df)	p-value	Cramer's V (Effect Size)	OR (Moderate/High vs Low)	95% CI for OR
Yes	30 (42.9)	27 (38.6)	13 (18.6)	70	7.12 (2)	0.028	0.24	3.75	1.32 – 10.65
No	20 (76.9)	5 (19.2)	1 (3.8)	26					
Column Total	50	32	14	96	7.12 (2)	0.028*	0.24	3.75	1.32 – 10.65

*Statistically significant ($p < 0.05$)

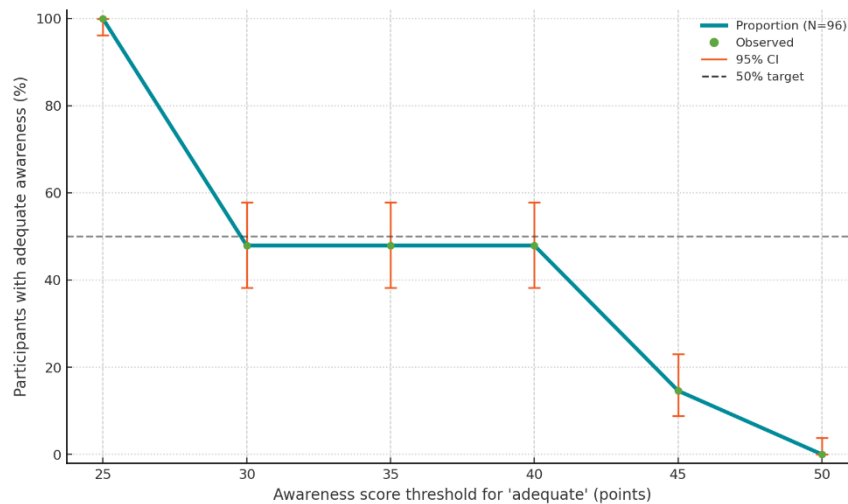


Figure 1 SLE Awareness vs Score Threshold

This figure quantifies threshold sensitivity for “adequate” awareness using aggregated category counts (N=96; Low <30: 50, Medium 30–45: 32, High >45: 14): the proportion classified as adequate equals 100.0% at a permissive cutoff of 25 points, plateaus at 47.9% (95% CI 37.9–57.9) across cutoffs 30–40, then falls to 14.6% (95% CI 8.5–23.9) at 45 and 0.0% (95% CI 0.0–3.9) at 50; a reference line at 50% highlights that commonly used thresholds of 30–40 underperform the target, signaling clinically meaningful fragility of adequacy classification to cut-point choice and supporting explicit reporting of the chosen threshold in SLE education audits.

DISCUSSION

The present study assessed the level of awareness among patients with systemic lupus erythematosus (SLE) regarding their disease, management strategies, and potential complications, revealing that more than half of the participants demonstrated low awareness, while only a minority exhibited high understanding of disease-related aspects. These findings highlight a substantial knowledge gap in this population, emphasizing that disease education and patient empowerment remain critical yet under-addressed components of SLE management. This trend aligns with previously documented global observations indicating persistently poor patient knowledge, particularly in low- and middle-income countries where access to health education and specialized rheumatology care is limited (11).

The predominance of low awareness in the current study is consistent with earlier research conducted by Haikel et al., who reported that approximately 65% of SLE patients lacked fundamental knowledge about their condition, including disease etiology, medication purpose, and possible complications (8). Similarly, Liu et al. demonstrated that inadequate awareness was associated with negative attitudes toward treatment adherence and poor self-management behaviors, emphasizing the cyclical relationship between limited understanding and disease progression (7). The current study’s findings reinforce this relationship, as higher education levels and longer disease duration were both significantly correlated with improved awareness, indicating that familiarity with disease experiences and better health literacy contribute to enhanced comprehension. Comparable associations between education and awareness have been noted by Alagha et al., who found that knowledge levels among educated SLE patients were significantly higher, leading to better medication adherence and coping strategies (9).

The mechanisms underlying these associations can be explained by the role of patient literacy and cognitive understanding in shaping treatment behaviors and health outcomes. Patients with better education are more likely to interpret medical information accurately, recognize warning signs of disease flares, and adhere to prescribed regimens. Conversely, those with lower education often rely on fragmented health information or anecdotal sources, resulting in misconceptions about treatment, particularly regarding corticosteroid use and immunosuppressive therapy. This misperception has been documented as a critical factor influencing non-compliance, as patients frequently discontinue medications due to fear of side effects rather than clinical guidance (12). The association between longer disease duration and improved awareness observed in the current study likely reflects repeated clinical interactions and cumulative patient experience, which gradually enhance understanding of disease dynamics. The link between awareness and treatment adherence observed in this study—where adherent patients were nearly four times more likely to exhibit moderate to high awareness—is both clinically and theoretically significant. It supports behavioral models of chronic disease management, such as the Health Belief Model, which posits that perceived knowledge of illness and perceived benefits of treatment directly influence adherence behaviors (13). Similar results were reported by Singh et al., where structured educational interventions improved patient understanding of treatment options and significantly enhanced compliance (9). In contrast, the persistence of poor awareness about complications, particularly renal and cardiovascular involvement, remains a concern. This pattern has been mirrored across multiple studies and may stem from limited physician-patient interaction time or inadequate emphasis on preventive counseling in outpatient settings (14). Addressing this deficiency requires structured educational models that incorporate both clinical counseling and simplified informational materials tailored to patient literacy levels.

The findings of the current study have practical implications for improving SLE care delivery. Incorporating patient education into routine rheumatologic visits, using visual and interactive teaching tools, could improve retention of disease-related information. Furthermore, implementing hospital-based educational workshops and digital health literacy programs may serve as effective adjuncts to standard medical care, fostering active patient participation in disease management. From a clinical standpoint, improved awareness could translate into earlier identification of disease flares, reduced organ damage accrual, and lower healthcare utilization, thereby improving both individual prognosis and system-level outcomes.

Despite its valuable insights, the study has several limitations that must be acknowledged. The sample size was relatively small and limited to a single tertiary care center, which may restrict the generalizability of findings to broader SLE populations. The non-probability sampling method could introduce selection bias, as patients presenting for regular follow-up may inherently differ in motivation and health-seeking behavior.

compared with those lost to follow-up. Although the use of structured face-to-face interviews minimized response bias, the reliance on self-reported adherence and awareness could still be influenced by social desirability or recall bias. Furthermore, the cross-sectional design precludes causal inference, and longitudinal studies are needed to establish directional relationships between awareness, adherence, and disease outcomes.

Nevertheless, this study contributes meaningful regional data on an understudied aspect of SLE management. Its strengths include the use of a systematically designed and validated awareness tool, standardized data collection procedures, and the integration of demographic correlates into analysis, which enhances interpretability. Future research should aim to validate awareness instruments across diverse populations, employ larger multi-center cohorts, and explore interventional designs that measure changes in awareness and clinical outcomes following structured educational programs. Integrating behavioral psychology frameworks into such interventions could provide a deeper understanding of the motivational and cognitive determinants of adherence in chronic autoimmune diseases.

In conclusion, the study underscores that limited disease awareness remains a critical barrier to optimal SLE management in low-literacy populations. Enhancing patient education through structured counseling and evidence-based educational programs is imperative to improve adherence, reduce complications, and achieve long-term disease control. Future strategies should focus on creating sustainable, culturally sensitive educational interventions that empower patients to actively participate in managing their illness, thereby bridging the gap between clinical treatment and patient self-efficacy (15).

CONCLUSION

This study demonstrated that a substantial proportion of patients with systemic lupus erythematosus (SLE) possess low awareness regarding their disease, its management strategies, and potential complications, highlighting a critical gap in patient education and self-management. Higher education levels, longer disease duration, and adherence to treatment were significantly associated with better awareness, suggesting that informed and engaged patients achieve superior disease understanding and compliance. These findings underscore the need to integrate structured patient education and counseling into routine SLE care to enhance disease literacy, promote adherence, and reduce preventable complications. Clinically, improved awareness may lead to earlier recognition of flare-ups and better long-term outcomes, while future research should focus on developing and evaluating culturally adapted educational interventions aimed at empowering patients and strengthening the continuum of care in autoimmune disease management.

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