Original Article

Diagnostic Delays and Clinical Presentation of Systemic Lupus Erythematosus: A Single-centre Study in the Eastern Region

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Abstract

Background: Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with diverse clinical features that cause delayed diagnosis. This research investigates SLE patient clinical features as well as elements that may extend the time needed for proper diagnosis. **Objective:** Our primary goal in this study is to assess patient characteristics and clinical situation at disease onset and its influence on the time of diagnosis. **Materials and Methods:** This retrospective cross-sectional study was conducted at King Fahd Hospital of the University in Khobar, Saudi Arabia. The study included adult SLE patients diagnosed according to the European League Against Rheumatism and the American College of Rheumatology 2019 criteria. **Results:** This study included 109 patients, with the majority being female (n = 103, 94.5%) and Saudi nationals (n = 101, 92.7%). The most common initial symptom was synovitis or tenderness in at least two joints (n = 41, 37.6%), followed by fever and acute cutaneous lupus (n = 12, 11.0% each). The median time from symptom onset to the first physician visit (Lag 1) was 3 weeks, while the mean time from the first physician visit to rheumatology consultation (Lag 2) was 44.15 weeks. A significant proportion of patients (n = 36, 33.0%) consulted five or more physicians before receiving a confirmed diagnosis. Laboratory findings showed low C3 levels in 40 patients (36.7%), low C4 in 31 patients (28.4%) and positive anti-dsDNA in 29 patients (26.6%). **Conclusion:** In this study, diagnosis of SLE is delayed because of physician misdiagnosis and unnecessary referral periods. The two key steps needed to shorten diagnostic delays include better physician awareness and better patient referral systems.

Keywords: Autoimmune disease, clinical presentation, diagnostic delay, lupus, rheumatology

Introduction

Systemic lupus erythematosus (SLE) is a multifaceted autoimmune disorder characterised by a chronic relapsing-remitting course. Its onset results from a combination of genetic predisposition, immunological, hormonal and environmental factors, with a strong tendency to affect women of childbearing age. It can present as a range of diseases, from mild to severe and potentially life-threatening, leading to organ damage. Early signs of SLE are often variable and non-specific, resembling other health conditions, which can delay diagnosis. Because of its heterogeneous and often non-specific presentation, SLE can be difficult to recognise early in routine clinical practice.

Patients with symptoms may delay seeking primary care, and even when they do, the diagnosis might be missed, resulting in delayed referrals to secondary care. In both primary and secondary care, symptoms may be wrongly attributed to other conditions, like rheumatoid arthritis, further delaying the correct diagnosis. Reducing these delays could lead to earlier diagnosis and treatment, improving patient outcomes and lowering healthcare costs. SLE has no cure, and the disease places a heavy burden on both patients and caregivers.[1,2] These patient- and system-related factors contribute to diagnostic delay, which may lead to preventable organ damage, poorer quality of life and higher healthcare costs.

Several international studies have quantified these delays and described typical initial manifestations. According to an online survey conducted in the UK that included 121 patients, 70% were initially misdiagnosed with another condition, and 59% received treatment for the incorrect diagnosis. Fatigue was the

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most disabling symptom, affecting 79% of patients on a daily basis.[3] A cross-sectional analysis in Germany found that the average time from the onset of symptoms to diagnosis was 47 months, with joint involvement (40.5%) being the most frequently reported initial symptom.[4]

In Saudi Arabia, a recent multicentre observational study identified a substantial delay between the first medical visit and referral to a rheumatologist ('Lag 2'), underscoring system-level barriers to timely diagnosis. However, this study did not include centres from the Eastern Province, the largest province by area and the third most populous, and did not explore in detail how the speciality of the first physician or distinct lag periods influence diagnostic delay.[5]

Despite these international and local data, the Eastern Province remains underrepresented, and there is limited evidence on patient- and system-related factors associated with specific diagnostic lag periods in SLE. Therefore, this study aimed to describe the sociodemographic, clinical and immunological characteristics of adult SLE patients attending a tertiary hospital in the Eastern Province of Saudi Arabia and to quantify diagnostic delay across defined lag periods and identify patient- and system-related factors associated with prolonged delay.

Materials and Methods

This retrospective, hospital-based cross-sectional study, supplemented by a structured telephone survey, was conducted over 8 months at the Rheumatology Clinic of King Fahd Hospital of the University, Khobar, Saudi Arabia. All adult patients with a confirmed diagnosis of SLE according to the 2019 American College of Rheumatology/European League Against Rheumatism criteria who attended the rheumatology clinic during the study period were screened for eligibility (120 patients). Patients who declined participation, did not complete the questionnaire, had incomplete core medical records, failed to provide informed consent or were younger than 18 years at follow-up were excluded (11 patients). After applying these criteria, 109 patients were included in the final analysis. To reduce selection bias, we attempted to include all consecutive eligible patients seen during the study period.

The minimum required sample size was estimated using the single-proportion formula $n=Z^2\ p(1-p)/d^2$, assuming a prevalence of prolonged diagnostic lag of 34.3% based on a similar study, a 95% confidence level (Z=1.96) and an absolute precision of 10%. This yielded a required sample size of 83 patients. To allow for incomplete records and non-response, we aimed to include at least 100 patients and ultimately analysed 109 SLE patients, exceeding the calculated minimum. Convenience sampling was applied, and data were obtained through review of electronic medical records supplemented by structured phone interviews to minimise recall bias.

The primary outcome (dependent variable) was diagnostic delay, expressed as four lag times: Lag 1 (symptom onset to first physician encounter), Lag 2 (first physician encounter to first rheumatology consultation), Lag 3 (first rheumatology visit to SLE diagnosis) and Lag 4 (SLE diagnosis to treatment initiation). The secondary outcomes included the number of physicians seen before reaching a final diagnosis. Independent (predictor) variables included sociodemographic characteristics (age, sex, marital status, nationality, ethnicity, education level and geographical area), clinical presentation (age at first symptom, first symptom type and speciality of the first physician encountered) and immunological/laboratory parameters (complement levels, autoantibodies and markers of renal involvement).

The structured phone interviews were used solely to complete or clarify historical information (e.g. timing of symptom onset and first medical contact) for the cross-sectional dataset; no prospective follow-up or longitudinal measurements were performed. Collected variables included demographic and clinical data, age at first presentation, initial symptoms, diagnostic lag intervals (these intervals were categorised as follows: Lag 1 – from symptom onset to the first physician encounter; Lag 2 – from the first physician encounter to the first rheumatology consultation; Lag 3 – from the first rheumatology visit to SLE diagnosis; and Lag 4 – from SLE diagnosis to treatment initiation), speciality of the first physician encountered, number of physicians consulted before diagnosis, pregnancy morbidity as the first presentation and immunological domains (antiphospholipid antibodies, complement proteins and specific autoantibodies such as anti-dsDNA and anti-Sm).

Data were entered into Microsoft Excel and analysed using IBM SPSS Statistics version 27.0.1 (Armonk, NY, USA: IBM Corp.). Descriptive statistics summarised demographic and clinical characteristics. Categorical variables were compared using Chi-square tests or Fisher's exact test when expected cell counts were <5. For continuous variables, independent *t*-tests or one-way ANOVA were used when data were approximately normally distributed, whereas non-parametric tests (Mann–Whitney U for two groups and Kruskal–Wallis for more than two groups) were applied for skewed variables such as diagnostic lag times. Logistic regression was used to explore predictors of diagnostic delay, with $P < 0.05$ considered statistically significant. Results were presented using tables and graphical displays, including bar charts. Laboratory and immunological variables were analysed using an available-case approach. For each specific test (e.g. anti-dsDNA, anti-Sm and antiphospholipid antibodies), patients without a recorded result were coded as 'not done' in descriptive tables and were excluded from any analyses involving that variable. No statistical imputation was performed for missing data.

Results

Demographic characteristics of systemic lupus erythematosus patients in the Eastern Province

The study included 109 participants with a mean age of 40.04 years (standard deviation [SD] = 11.03). The majority

were female (*N* = 103, 94.5%). Most participants were Saudi nationals (*N* = 101, 92.7%). In terms of marital status, 64 individuals (58.7%) were married. Ethnically, most participants were Arab (*N* = 106, 97.2%). Regarding education, the majority had a diploma or university degree (*N* = 68, 62.4%). Participants resided in various geographical areas, with the highest proportions from Al-Khobar Governorate (*N* = 43, 39.4%), Dammam Governorate (*N* = 27, 24.8%) and Qatif Governorate (*N* = 17, 15.6%). The vast majority of participants resided in urban areas (*N* = 105, 96.3%), while only 4 (3.7%) lived in rural areas [Table 1].

Clinical presentation and diagnostic delay in systemic lupus erythematosus patients

The average age at which patients first experienced symptoms was 25.62 years (SD = 9.66), with the most common initial symptom being synovitis or tenderness in at least two joints (*N* = 41, 37.6%). One patient presented with pregnancy morbidity (eclampsia/pre-eclampsia) as their first symptom. For diagnostic delay, Lag 1 (symptom onset to first physician visit) had a mean of 16.34 weeks (SD = 71.47) and a median of 3.00 weeks (interquartile range [IQR]: 1.00–8.00). Lag 2 (first physician visit to rheumatology consultation) had a mean of 44.15 weeks (SD = 113.93). Lag 3 and Lag 4 showed mean delays of 6.50 weeks (SD = 15.69) and 4.23 weeks (SD = 16.01), respectively. Before reaching a final diagnosis, 7 patients (6.4%) saw only one physician, 25 (22.9%) saw two, 28 (25.7%) saw three, 13 (11.9%) saw four and 36 (33.0%) consulted five or more physicians. The average age at the time of SLE diagnosis was 26.85 years (SD = 9.85) [Table 2]. The distribution of initial clinical manifestations is illustrated in Figure 1.

Immunological and laboratory findings in systemic lupus erythematosus patients

Among antiphospholipid antibodies, anticardiolipin immunoglobulin G (IgG) (>40 GPL) was absent in 69 patients (63.3%) and present in 18 (16.5%). Similarly, anti-β2GP1 IgG (>40 units) was absent in 67 patients (61.5%) and present in 20 (18.3%). Lupus anticoagulant was present in 12 (11.0%). Complement protein abnormalities were identified in 40 patients (36.7%) with reduced C3 levels, while 67 patients (61.5%) had normal C3. Reduced C4 levels were observed in 31 patients (28.4%). Anti-dsDNA antibodies were present in 29 patients (26.6%). Among those with anti-dsDNA positivity (*N* = 18), the mean initial reading was 413.86 (SD = 359.19). Anti-Sm antibodies were present in 15 patients (13.8%), and antinuclear antibodies were detected in 55 patients (50.5%) with a mean first reading of 1018.05 (SD = 468.44) in 41 of the cases.

Anti-SSA antibodies were found in 22 patients (20.2%), whereas anti-SSB antibodies were present in only 4 patients (3.7%). Regarding renal involvement, microalbuminuria was present in 27 patients (24.8%), haematuria was observed in 26 patients (23.9%), while pyuria was detected in 42 (38.5%). Cast formation was present in 5 patients (4.6%) [Table 3].

Table 1: Demographic characteristics of systemic lupus erythematosus patients in the Eastern Province

	n (%)
Age, mean±SD	40.04±11.03
Gender	
Female	103 (94.5)
Male	6 (5.5)
Marital status	
Divorced	10 (9.2)
Married	64 (58.7)
Single	34 (31.2)
Widowed	1 (0.9)
Nationality	
Non-Saudi	8 (7.3)
Saudi	101 (92.7)
Ethnicity	
African	1 (0.9)
Arab	106 (97.2)
Asian	1 (0.9)
Other	1 (0.9)
Ethnicity – Other (*n*=1)	
Indian	1 (100.0)
If previous answer is others, what is the patient ethnicity	
Indian	1 (100.0)
Educational level	
Elementary school	2 (1.8)
High school	24 (22.0)
Intermediate school	9 (8.3)
Postgraduate	3 (2.8)
Illiterate	3 (2.8)
Diploma/university	68 (62.4)
Geographical area	
Al-Khobar Governorate	43 (39.4)
Dammam Governorate	27 (24.8)
Qatif Governorate	17 (15.6)
Al-Ahsa Governorate	13 (11.9)
Jubail Governorate	2 (1.8)
Hafar Al-Batin Governorate	1 (0.9)
Al-Nairyah Governorate	1 (0.9)
Other	5 (4.6)
If previous answer was other, what is the patient geographical living area (*n*=5)	
Riyadh	1 (20.0)
Najran	1 (20.0)
Bahrain	1 (20.0)
Al-Qassim	1 (20.0)
Al-Baha	1 (20.0)
What is the type of the geographical living area	
Rural	4 (3.7)
Urban	105 (96.3)

SD: Standard deviation

Factors influencing the delay from symptom onset to first physician visit in systemic lupus erythematosus patients

The median time from symptom onset to the first physician visit was slightly longer in females (3.00 weeks, IQR: 1.00–8.00) compared to males (1.00 week, IQR: 0.00–4.00), though this

Table 2: Clinical presentation and diagnostic delay in systemic lupus erythematosus patients

	n (%)
Age at first presentation appeared (Input by years), mean±SD	25.62±9.66
What was the first symptom of the disease	
Synovitis or tenderness in at least 2 joints	41 (37.6)
Fever	12 (11.0)
Acute cutaneous lupus	12 (11.0)
Non-scarring alopecia	10 (9.2)
Subacute cutaneous or discoid lupus	8 (7.3)
Low platelet count (thrombocytopenia)	5 (4.6)
Nephrotic range proteinuria in more than 500 mg/24 h	4 (3.7)
Seizure	1 (0.9)
Others	16 (14.7)
If the previous answer is others, what was the first symptom of the disease (*n*=16)	
Fatigue	4 (25.0)
Lower limb oedema	2 (12.5)
Skin peeling and general fatigue	1 (6.3)
Raynaud's syndrome	1 (6.3)
Rash on foot	1 (6.3)
Lower limb and facial oedema	1 (6.3)
Haematuria	1 (6.3)
DVT	1 (6.3)
Dizziness	1 (6.3)
Dimple in the face	1 (6.3)
Bruises	1 (6.3)
Bluish discoloration of hands (PE)	1 (6.3)
Pregnancy morbidity as first presentation (*n*=1)	
Eclampsia/pre-eclampsia	1 (100.0)
Lag 1: First appearance of the symptom to the first physician visit (input by weeks), mean±SD	16.34±71.47
What was the speciality of the first doctor encountered	
Emergency	40 (36.7)
Primary health care	19 (17.4)
Internal medicine	15 (13.8)
Dermatology	15 (13.8)
Orthopaedics	7 (6.4)
Family medicine	4 (3.7)
Rheumatology	3 (2.8)
Paediatrics	3 (2.8)
Obstetrics and gynaecology	1 (0.9)
Neurology	1 (0.9)
Haematology	1 (0.9)
Lag 2: first physician encounter until you were seen by a rheumatologist (Input by weeks), mean±SD	44.15±113.93
Lag 3: first visit to a rheumatologist to SLE diagnosis (Input by weeks), mean±SD	6.50±15.69
Lag 4: SLE diagnosis to the initiation of treatment (Input by weeks), mean±SD	4.23±16.01
Number of physicians seen before reaching the final diagnosis	
One	7 (6.4)
Two	25 (22.9)
Three	28 (25.7)
Four	13 (11.9)
Five or more	36 (33.0)
What was the patient age at the time of confirming the diagnosis (input by years), mean±SD	26.85±9.85

SLE: Systemic lupus erythematosus, SD: Standard deviation, DVT: Deep vein thrombosis

difference was not statistically significant ($P = 0.124$). Marital status did not significantly affect the delay. Nationality also showed no significant difference. Educational level did not significantly impact the delay. Geographic location showed variation but was not statistically significant ($P = 0.789$). Notably, patients from Jubail had a longer median delay of 8.00 weeks (IQR: 4.00–12.00). Rural residents had a shorter median delay (1.00 week, IQR: 1.00–2.00) compared to urban residents (4.00 weeks, IQR: 1.00–8.00), though this was not statistically significant ($P = 0.193$). Regarding the first symptom of the disease, the delay varied but was not statistically significant ($P = 0.711$). Patients with synovitis or tenderness in at least two joints and fever had a median delay of 3.00 weeks (IQR: 1.00–8.00), while those with acute cutaneous lupus had a longer delay of 3.00 weeks (IQR: 1.00–14.00). Patients with non-scarring alopecia experienced a median delay of 4.00 weeks (IQR: 3.00–12.00), while those with subacute cutaneous or discoid lupus had a shorter delay of 1.50 weeks (IQR: 1.00–4.00). The shortest delay was observed in patients with seizures [Table 4].

Speciality of first physician encountered and its impact on delay to rheumatology consultation

The median time from the first physician encounter to being seen by a rheumatologist varied significantly depending on the speciality of the initial doctor ($P < 0.001$) [Table 5]. Patients who first consulted a rheumatologist had no delay. The shortest delay was observed in patients who initially saw a neurologist (1.00 week) followed by those who visited an emergency physician (3.50 weeks, IQR: 1.00–8.00). The longest delays were seen in patients who initially visited paediatricians (48.00 weeks, IQR: 12.00–144.00) and obstetrics and gynaecology (32.00 weeks). These findings indicate that the speciality of the first physician significantly influences the time taken to reach a rheumatologist. The frequency of each initial physician speciality is shown in Figure 2.

Association between initial physician speciality and number of physicians seen before systemic lupus erythematosus diagnosis

The number of physicians seen before reaching a final diagnosis varied based on the speciality of the first doctor encountered, though the association was not statistically significant ($P = 0.122$). Among patients who first consulted a dermatologist, 40.0% ($N = 6$) required five or more physicians before diagnosis. Similarly, those who initially visited emergency physicians followed a comparable pattern.

Table 3: Immunological and Laboratory findings in systemic lupus erythematosus

Patients	*n* (%)
Antiphospholipid antibody domain: Anticardiolipin IgG >40 GPL	
Absent	69 (63.3)
Not done for the patient	22 (20.2)
Present	18 (16.5)
Antiphospholipid antibody domain: Anti-ß2GP1 IgG >40 units	
Absent	67 (61.5)
Not done for the patient	22 (20.2)
Present	20 (18.3)
Antiphospholipid antibody domain: Lupus anticoagulant	
Absent	58 (53.2)
Not done for the patient	39 (35.8)
Present	12 (11.0)
Complement proteins domain: Low C3	
Absent	67 (61.5)
Not done for the patient	2 (1.8)
Present	40 (36.7)
Complement proteins domain: Low C4	
Absent	76 (69.7)
Not done for the patient	2 (1.8)
Present	31 (28.4)
Anti-dsDNA antibody	
Absent	59 (54.1)
Not done for the patient	21 (19.3)
Present	29 (26.6)
If an anti-dsDNA antibody was present, what was its first reading (*n*=18), mean±SD	413.86±359.19
Anti-Sm antibody	
Absent	45 (41.3)
Not done for the patient	49 (45.0)
Present	15 (13.8)
ANA	
Absent	23 (21.1)
Not done for the patient	31 (28.4)
Present	55 (50.5)
If an antinuclear antibody was present, what was its first reading (*n*=41), mean±SD	1018.05±468.44
Antibodies to RNP	
Absent	34 (31.2)
Not done for the patient	62 (56.9)
Present	13 (11.9)
Absent	45 (41.3)
Anti-SSA	
Not done for the patient	42 (38.5)
Present	22 (20.2)
Anti-SSB	
Absent	62 (56.9)
Not done for the patient	43 (39.4)
Present	4 (3.7)
Microalbumin in urine	
Absent	59 (54.1)
Not done for the patient	23 (21.1)
Present	27 (24.8)
Active urinary segment (haematuria)	
Absent	83 (76.1)
Present	26 (23.9)
Active urinary segment (pyuria)	
Absent	67 (61.5)
Present	42 (38.5)
Active urinary segment (cast)	
Absent	104 (95.4)
Present	5 (4.6)

Contd...

Table 3: Contd...

ANA: Antinuclear antibody, RNP: Ribonucleoprotein, Anti-SSA: Anti-Sjögren's syndrome-related antigen A autoantibodies, Anti-SSB: Anti-Sjögren's syndrome type B antibodies, IgG: Immunoglobulin G, SD: Standard deviation

Patients who started with family medicine showed a different trend, with 75.0% reaching a diagnosis after two physicians. Patients first seen by internal medicine physicians were more evenly distributed, with 33.3% seeing three doctors, 26.7% seeing two and 26.7% requiring five or more. Patients who first visited primary healthcare providers showed greater variation, with 42.1% requiring five or more physicians, 26.3% seeing four and 21.1% seeing three. Interestingly, among those who initially consulted a rheumatologist, 66.7% reached a diagnosis after just one physician, while 33.3% required three [Table 6].

Discussion

The results of this study revealed important information about SLE symptoms and diagnostic delays across the Eastern Province of Saudi Arabia. In our cohort, the main delay was in Lag 2 (from first physician visit to rheumatology consultation), with a mean of 44.15 weeks. Direct comparison with other studies is challenging because many report total time from symptom onset to diagnosis rather than separating individual lag periods. For example, Ziade *et al*. described a median delay of around 18 months from symptom onset to diagnosis for chronic inflammatory rheumatic diseases across eight Arab countries, combining both patient- and system-related delays.[6] Our data, therefore, could not be interpreted as 'shorter' or 'longer' than theirs on a numerical basis, but both studies highlight substantial health system delays before patients reach a rheumatologist. Similarly, the Saudi multicentre study by Karremah *et al*. decomposed delay into four lags and also identified Lag 2 as the predominant bottleneck, with most patients experiencing a delay between first medical contact and rheumatology referral.[5] Our findings from the Eastern Province were consistent with this pattern, reinforcing that referral delay is a key modifiable target in the Saudi context.

In the German LuLa cohort, Kernder *et al*. reported a mean duration of 47 months from symptom onset to SLE diagnosis.[4] This 'total delay' includes both the time before first medical contact and subsequent health system delay. By contrast, our primary outcome was Lag 2, a physician-to-specialist interval

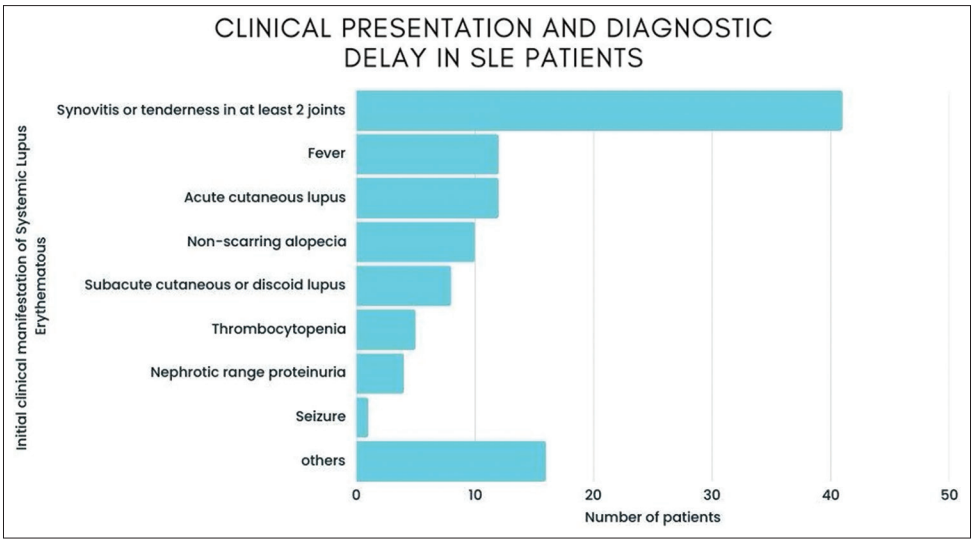

Figure 1: Distribution of the initial clinical manifestations of systemic lupus erythematosus among 109 patients

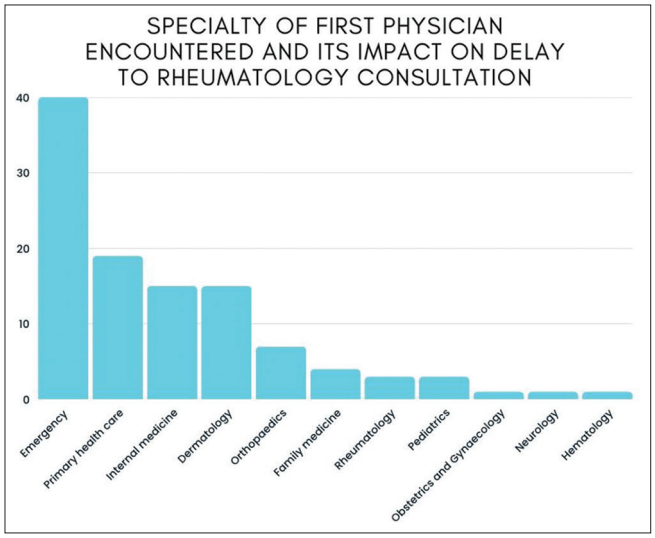

Figure 2: Number of patients ($N = 109$) according to the speciality of the first physician consulted for systemic lupus erythematosus-related symptoms

within a single tertiary care centre. Because the time frames and denominators differ, only qualitative comparison is appropriate: Both cohorts show that prolonged diagnostic delay remains common and is associated with worse outcomes, but absolute durations are not directly comparable. Moreover, our single-centre tertiary cohort in the Eastern Province differs from large national registries and online survey samples in terms of disease severity, access patterns and healthcare organisation, which further limits strict numerical comparison. This suggests that regional disparities across different areas play a role in diagnostic efficiency, influenced by differences in physician awareness, healthcare accessibility and referral systems.[7,8]

Consistent with our Results, in which synovitis or tenderness in at least two joints was the most frequent first manifestation, joint involvement has also been the leading presenting symptom in other Saudi and international cohorts.[5,9,10] Yet, despite these well-recognised patterns, early musculoskeletal and cutaneous complaints are often misattributed to more common conditions such as viral or rheumatoid arthritis, delaying rheumatology referral.[2,11]

A crucial finding was the marked variation in Lag 2 according to the speciality of the first physician. Patients initially assessed by paediatricians, obstetricians and gynaecologists, internists, dermatologists or orthopaedic surgeons experienced the longest median delays and were more likely to consult multiple physicians before diagnosis, whereas those first seen by rheumatologists had virtually no delay. Emergency physicians were the first point of contact for over one-third of patients, underscoring that many SLE cases present with acute complaints in front-line settings where autoimmune disease patterns may not be readily recognised. This pattern mirrors prior Saudi multicentre data showing that initial assessment by non-rheumatologists is associated with misdiagnosis and late referral[5,12] and highlights the need for clear referral algorithms and rheumatology triage clinics, particularly in emergency and primary care services.[13,14]

The median age at disease onset was 25.62 years, with a mean diagnostic age of 26.85 years, aligning with previous reports where SLE predominantly affects young adults, particularly women of childbearing age.[15] The female-to-male ratio (94.5% female) also aligns with findings of a recent study, where the female-to-male ratio for SLE is reported to be as high as 13:1, indicating a significant predominance of women among affected individuals.[16] However, our study's findings further emphasise that despite the well-characterised demographic and clinical patterns, significant delays persist in obtaining a confirmed diagnosis, raising concerns about underdiagnosis or misclassification in primary care settings.

Our study further evaluated the immunological and laboratory markers associated with SLE. Low C3 levels (36.7%), low

Table 4: Factors influencing the delay from symptom onset to first physician visit in systemic lupus erythematosus patients

Lag 1: First appearance of the symptom to the first physician visit (Input by Weeks)			
	Median	**IQR**	***P***
Gender			
Female	3.00	1.00–8.00	0.124
Male	1.00	0.00–4.00	
Marital status			
Divorced	2.00	1.00–8.00	0.963
Married	3.00	1.00–8.00	
Single	4.00	1.00–8.00	
Widowed	2.00	2.00–2.00	
Nationality			
Non-Saudi	2.00	0.00–4.50	0.315
Saudi	3.00	1.00–8.00	
Ethnicity			
African	5.00	5.00–5.00	0.461
Arab	3.00	1.00–8.00	
Asian	3.00	3.00–3.00	
Other	0.00	0.00–0.00	
Educational level			
Diploma/University	4.00	1.00–8.00	0.859
Elementary school	1.50	1.00–2.00	
High school	2.00	1.00–6.00	
Illiterate	2.00	1.00–8.00	
Intermediate school	4.00	0.00–16.00	
Postgraduate	1.00	1.0048.00	
Geographical area			
Al-Khobar Governorate	3.00	1.00–8.00	0.7890
Dammam Governorate	3.00	1.00–8.00	
Qatif Governorate	4.00	1.00–12.00	
Al-Ahsa Governorate	2.00	1.00–4.00	
Jubail Governorate	8.00	4.00–12.00	
Hafar Al-Batin Governorate	1.00	1.00–1.00	
Al-Nuairyah Governorate	4.00	4.00–4.00	
Other	4.00	2.00–8.00	
If previous answer was other what is the patient geographical living area (*n*=5)			
Riyadh	48.00	48.00–48.00	0.344
Najran	8.00	8.00–8.00	
Bahrain	2.00	2.00–2.00	
Al-Qassim	4.00	4.00–4.00	
Al-Baha	0.00	0.00–0.00	
What is the type of the geographical living area			
Rural	1.00	1.00–2.00	0.193
Urban	4.00	1.00–8.00	
What was the first symptom of the disease			
Synovitis or tenderness in at least 2 joints	3.00	1.00–8.00	0.711
Fever	3.00	1.00–8.00	
Acute cutaneous lupus	3.00	1.00–14.00	
Non-scarring alopecia	4.00	3.00–12.00	
Subacute cutaneous or discoid lupus	1.50	1.00–4.00	
Low platelet count (thrombocytopenia)	3.00	0.00–4.00	
Nephrotic range proteinuria in more than 500 mg/24 h	2.00	1.00–5.00	
Seizure	0.00	0.00–0.00	
Others	4.00	0.50–12.00	

*P<0.05, Significant, [K]Independent Samples Kruskal–Wallis test, [U]Independent Samples Mann–Whitney U-test. IQR: Interquartile range

C4 levels (28.4%) and positive anti-dsDNA (26.6%) were common findings, which mirror the immunological patterns, as also described in a Spanish cohort.[17] Antiphospholipid antibodies were identified in a significant number of patients (anticardiolipin IgG: 16.5%, lupus anticoagulant: 11.0%), suggesting a considerable risk for thrombotic complications, similar to findings from a study, which also noted a strong association between diagnostic delays and disease-related morbidity.[14]

One of the most concerning aspects of our findings is the high number of physicians consulted before reaching a diagnosis. 33% of patients visited five or more physicians before being diagnosed. The study identified a lack of disease awareness among primary care physicians, leading to diagnostic delays.[18] These findings suggest a systemic failure in recognising early signs of SLE, resulting in excessive referrals and unnecessary delays that could contribute to worsening disease outcomes.

Our findings also highlight that diagnostic delays are associated with increased organ damage, as evidenced by the presence of nephrotic range proteinuria (3.7%) and thrombocytopenia (4.6%) at initial presentation. This is consistent with a study, which found that patients with delays beyond 12 months were more likely to develop irreversible organ damage, particularly neuropsychiatric and thrombotic complications.[19] The median time to treatment initiation (4.23 weeks) following diagnosis in our cohort was relatively short, suggesting that once SLE was diagnosed, timely intervention was possible. However, the pre-diagnosis delay remains the main contributor to increased morbidity.

While most participants were from urban areas (96.3%), we observed that patients from smaller cities, such as Jubail and Hafar Al-Batin, experienced significantly longer delays compared to those in Khobar and Dammam. A recent study found that rural residents, particularly those without access to specialised care, experienced longer diagnostic delays, reinforcing that accessibility to rheumatologists is a determinant of early diagnosis.[20] Although geographical differences in delay were not statistically significant and numbers per governorate were small, the longer lags in some areas may reflect differences in access to rheumatology services and referral pathways between major cities and outlying regions. These findings indicate the need for improved healthcare infrastructure and outreach programmes to address disparities in SLE diagnosis based on patient residence.

Overall, the short Lag 1, the prolonged Lag 2 and the high number of physicians consulted indicate that diagnostic delay in this cohort is driven primarily by physician- and system-related rather than patient-related factors. This aligns with Saudi and international data showing limited SLE awareness among non-specialists, misattribution of early

Table 5: Speciality of first physician encountered and its impact on delay to rheumatology consultation

Lag 2: first physician encounter until you were seen by a rheumatologist (Input by weeks)			
What was the speciality of the first doctor encountered	**Median**	**IQR**	***P**
Dermatology	12.00	4.00–96.00	<0.001
Emergency	3.50	1.00–8.00	
Family medicine	8.00	3.00–12.00	
Haematology	12.00	12.00–12.00	
Internal medicine	24.00	8.00–240.00	
Neurology	1.00	1.00–1.00	
Obstetrics and gynaecology	32.00	32.00–32.00	
Orthopaedics	4.00	4.00–12.00	
Paediatrics	48.00	12.00–144.00	
Primary health care	12.00	4.00–48.00	
Rheumatology	0.00	0.00–0.00	

*P<0.05, Significant, [K]Independent samples Kruskal–Wallis test.
IQR: Interquartile range

Table 6: Association between initial physician speciality and number of physicians seen before systemic lupus erythematosus diagnosis

What was the speciality of the first doctor encountered	Number of physicians seen before reaching the final diagnosis										*P
	One		Two		Three		Four		Five or more		
	n	Row %	*n*	Row %	*n*	Row %	*n*	Row %	*n*	Row %	
Dermatology	1	6.7	4	26.7	3	20.0	1	6.7	6	40.0	0.122
Emergency	1	2.5	8	20.0	1	25.0	6	15.0	1	37.5	
Family medicine					0				5		
Haematology	0	0.0	3	75.0	1	25.0	0	0.0	0	0.0	
Internal medicine	0	0.0	1	100.0	0	0.0	0	0.0	0	0.0	
Neurology	1	6.7	4	26.7	5	33.3	1	6.7	4	26.7	
Obstetrics and Gynaecology	0	0.0	0	0.0	0	0.0	0	0.0	1	100.0	
Orthopaedics	0	0.0	0	0.0	0	0.0	0	0.0	1	100.0	
Paediatrics	1	14.3	2	28.6	3	42.9	0	0.0	1	14.3	
Primary health care	0	0.0	2	66.7	1	33.3	0	0.0	0	0.0	
Rheumatology	1	5.3	1	5.3	4	21.1	5	26.3	8	42.1	

*P<0.05, significant. [C]Pearson's Chi-square test or Fisher's exact test (when expected cell counts were <5)

features to more common conditions and uncertainty about when to refer to rheumatology.[2,3,5,7,9,14,18]

Conclusion

This study shows that many patients with SLE experience delays in getting diagnosed, especially between their first doctor visit and seeing a rheumatologist. Joint pain was the most common early symptom, but many patients had to see multiple doctors before getting the right diagnosis. Emergency doctors were often the first point of contact, but delays were longer when patients first saw dermatologists or internists. These findings highlight the need for better awareness among doctors and clearer referral pathways.

Application

The findings of this study emphasise the need for interventions to reduce diagnostic delays in SLE. Medical education programmes should focus on improving awareness among non-specialist physicians, particularly in primary care, emergency medicine and dermatology, where the longest delays were observed. Standardised referral pathways should be established to facilitate early rheumatology consultation, reducing unnecessary specialist visits and improving time to diagnosis. Given the regional disparities in diagnostic delays, future research should explore the role of healthcare accessibility, particularly in rural areas, and evaluate telemedicine initiatives as a potential solution. Public health campaigns aimed at educating patients on early SLE symptoms may also help reduce delays by encouraging timely medical consultations.

Practically, our findings support targeted educational programmes for primary care, emergency, dermatology, internal medicine and obstetrics/gynaecology physicians to improve recognition of early SLE 'red flags' and appropriate use of autoantibody testing. Implementing simple, standardised referral criteria and electronic referral pathways to rheumatology clinics may shorten Lag 2 and reduce the number of physicians consulted before diagnosis. In settings with limited rheumatology coverage, tele-rheumatology triage or joint clinics could further streamline access to specialist assessment.

Limitations and recommendations

Several limitations should be acknowledged. The retrospective cross-sectional design relied on medical records and patient recall, which made the study susceptible to recall bias which in turn distorted the accuracy of recorded diagnostic delays. Although we attempted to include all consecutive eligible patients, the use of convenience sampling at a single tertiary hospital may introduce selection bias and limit the generalisability of our findings to the broader SLE population in Saudi Arabia. The evaluation of diagnostic delays factored in multiple variables, but our analysis did not thoroughly explore the effects of socioeconomic status together with healthcare literacy as well as healthcare provider experience. Our study performed research at a single hospital facility which could reduce its ability to measure diagnostic delays across multiple healthcare facilities throughout Saudi Arabia. Future research could include a larger sample size that is representative of a larger population. Furthermore, having a prospective study would reduce recall bias and help in obtaining precise data from the patient at the time of presentation and diagnosis. In our cohort, we observed markers of organ involvement at presentation (e.g. nephrotic-range proteinuria and thrombocytopenia), but the study was not powered to formally quantify the association between specific lag periods and subsequent complications. Thus, any link between diagnostic delay and organ damage in our data should be interpreted as hypothesis-generating. Some laboratory variables (e.g. anti-Sm and antiphospholipid antibodies) were missing for a substantial proportion of patients; these were handled using an available-case approach without imputation, which may have introduced information bias and reduced power for some analyses. Finally, non-response to telephone interviews may have led to under-representation of patients with more severe disease or limited access to care. Future research should focus on improving early diagnosis, expanding access to rheumatologists and evaluating the impact of delayed diagnosis on patient outcomes.

Ethical approval

The authors stated that the project was approved by the Institutional Review Board.

Data availability

Data supporting the findings of this study are available from the corresponding author upon reasonable request.

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Conflicts of interest

There are no conflicts of interest.

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