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Patient Perspectives on Reproductive Health in Systemic Lupus Erythematosus: Exploring Disease Manifestations, Quality of Life, and the Role of Social Support

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Introduction/Aim: Systemic Lupus Erythematosus (SLE) is an autoimmune condition that can cause a wide range of clinical symptoms, resulting in a substantial burden on its patients. This study examines how disease symptoms, quality of life, and social support affect SLE patients' reproductive health perspectives.

Methods: This cross-sectional study included all consecutive female SLE patients at a single-provider rheumatology clinic. Sixty-six patients provided data from September 2023 to March 2024. MSPSS, SLEDAI and WHOQOL-BREF scores were used to test patients perceived social support, disease activity and quality of life, respectively.

Results: The mean age of the study population was 39.62 ± 15.40 years. Constitutional symptoms were the most common disease manifestations (85.8%), followed by mucocutaneous and musculoskeletal symptoms (83.3% each). The mean SLEDAI score was 7.95 ± 9.29. Among previously married patients, 53.0% (n =35) had at least one child, and 81.0% of them experienced at least one pregnancy-related complication. Notably, 69.2% of patients were uncertain about the impact of SLE on fertility, and 91.0% had never received reproductive health counseling. Patients who were consulted by their Obstetrics and Gynecology (OBGYNs) doctors had significantly higher WHOQOL-BREF physical health (32.1 vs 10.3, P-value =0.036) and higher psychological health scores (63.2 vs 35.1, P-value =0.012).

Conclusion: SLE profoundly influences patients' physical, psychological, and social well-being, with a notable impact on reproductive health. Collaboration among OBGYNs and Rheumatologists to create a culturally sensitive method to address common misconceptions about SLE and infertility is needed.

Keywords: SLE, reproductive health, fertility, female

Introduction

Systemic lupus erythematosus (SLE) is an autoimmune relapsing-remitting multisystem disease primarily affecting women of childbearing age.[1] Its manifestations are a result of interactions between environmental, immune and genetic factors, resulting in autoantibodies that cause a spectrum of organ damage.[2] The disease has a range of clinical manifestations with varying severity that commonly involves the cutaneous, pulmonary, cardiovascular, renal and hematological organ systems.[3] The global incidence of SLE is 5.14 (1.4 to 15.13) per 100,000 person-years, with a worldwide prevalence of 43.7 (15.87 to 108.92) per 100,000 persons.[4] In the Arab world, prevalence ranges between 19 and 103 per 100,000.[5,6] While no studies have specifically investigated the prevalence of SLE in Jordan, an observational study by Adwan et al reported data on 275 SLE patients seen at two tertiary centers over two years.[7] SLE has a substantial burden on patients, as the long-term and unpredictable course of SLE disrupts many aspects of daily life, including patients' ability to perform their normal daily activities properly, leading to direct and indirect financial losses and decreasing the overall quality of life. The health-related quality of life of SLE patients has been consistently reported to be lower than the general population.[8,9]

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Given its disproportionate impact on women of childbearing age, SLE poses unique challenges to reproductive health. The challenges facing women with SLE begin prior to conception, where SLE affects both fecundity and fertility.[10] The rates of secondary infertility are higher among women with SLE due to factors such as irregular menses caused by disease flares and reduced fertility related to renal disease.[8] Additionally, cytotoxic drugs used to treat SLE, such as cyclophosphamide, decrease the ovarian reserve and may cause premature ovarian failure.[11] In the case of a successful conception, an increasing rate of adverse pregnancy outcomes poses a challenge to both patients and physicians. SLE results in increasing complications for the mother due to a higher risk and frequency of preeclampsia, hypothyroidism, infections and strokes. Moreover, it also has adverse fetal outcomes, resulting in higher levels of intrauterine growth restriction, preterm births and mortality.[12] The outcomes and complications of the pregnancy can be predicted by the level of disease.[13] According to Mobini et al, inadequate contraception and family planning for women with SLE can potentially increase the rates of pregnancy complications.[14] All these factors make family planning an essential component of the care that should be offered to women with SLE.

Limited research exists on patients' perspectives regarding fertility and pregnancy outcomes among individuals with SLE in the Arab world. This study aims to address this gap by exploring pregnancy outcomes and patients' views and attitudes on reproductive health topics, focusing on the relationship between disease manifestations, quality of life, and the influence of social support. A deeper understanding of patient-reported experiences is critical to designing culturally appropriate interventions, yet remains underexplored in Arab populations.

Methods

Study Design

This study is an observational cross-sectional study that enrolled all sequential female patients with SLE who attended a single-provider rheumatology clinic at Jordan University Hospital, a tertiary care teaching hospital in Amman, the capital of Jordan, between September 2023 and December 2024. This study was approved by the ethics committee of the University of Jordan Hospital (10/2023/30525), and all participants signed an informed consent form before participating in the study. The study protocol was in concordance with the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) checklist,[15] and complied with published guidelines.[16]

Inclusions and Exclusions Criteria

The study enrolled all consecutive female patients aged 18 years or older who met the 2019 EULAR/ACR Classification Criteria for SLE.[17] Enrollment concluded after six months when no new patients presented for clinic visits. Patients were excluded if they were younger than 18 years or declined participation, often due to time constraints, as completing the questionnaire required an additional 30 minutes following their routine clinic visit.

Demographic and Clinical Data Collection

A structured questionnaire was designed and used to collect patients' demographic and clinical data, including socio-demographic profile, educational status, occupation, duration of the disease, presence of any systemic illness or comorbid conditions, history of any drug intake, smoking, past medical history, and past surgical history. In addition, reproductive health data, including age at menarche, period regularity and obstetric history, including the number of pregnancies with their outcomes and complications. The electronic medical records were used to collect patients' medications and antibody profiles.

Measurement of SLE Disease Activity, Quality of Life and Perceived Social Support

SLE disease activity was measured using the *Systemic Lupus Erythematosus Disease Activity Index* SLEDAI.[18] The World Health Organization Quality of Life instrument (WHOQOL) and the Multidimensional Scale of Perceived Social Supports (MSPSS) were used to assess patients' quality of life and perceived social support, respectively. WHOQOL assesses patients' perceptions of their quality of life across physical, psychological, social, and environmental domains, allowing the practitioners to understand the holistic impact of diseases or treatments on patient well-being.[19] MSPSS provides insights into a patient's perception of social support, which can be pivotal in understanding recovery dynamics, especially in chronic diseases or post-surgical scenarios.[20]

Statistical Analysis

The data analysis was performed using IBM-SPSS v27. Demographic data, laboratory values, organ involvement, WHOQOL-BREF, MSPSS, and SLESAI scores were reported as counts and percentages or means and standard deviation. The association between variables and patients' perception of the effect of SLE on reproductive health was tested using Chi-square, Fischer-Exact test or *T*-test as appropriate.

Results

Demographics of the Participants

A total of 66 females with SLE participated in this study. The mean age was 39.6 ±15.4. Regarding educational level, 50% of participants (N=33) had school-level education, 48.5% of participants (N=32) had college-level education, and only 1.5% of participants (N=1) were illiterate. In terms of employment, 51.5% were employed, of whom 22.7% (N=15) had white-collar jobs. Only two patients (3.0%) smoked cigarettes, and nine patients (13.6%) smoked Hookah. The most common comorbidity was osteoporosis, present in 27.3% of participants, followed by Diabetes mellitus (DM) and thyroid disease, each present in 12.1% of participants (N=8). Most patients (84.4%, N=54) used calcium and vitamin D supplements (Table 1).

Table 1 Demographics and Baseline Characteristics of the Patients

Variable	Count (Percentage)	Mean (SD)
Age (Years)		39.62 (15.40)
Age at onset of SLE		28.46 (12.05)
Educational level		
College	32 (48.5)	
School	33 (50)	
Illiterate	1 (1.5)	
Occupation		
Retired	8 (12.1)	
Unemployed	32 (48.5)	
White collar	15 (22.7)	
Student	11 (16.7)	
Marital status		
Married	39 (59.1)	
Single	24 (36.4)	
Divorced	3 (4.5)	
Smokers		
Cigarettes	2 (3.0)	
Hooka	9 (13.6)	
Not smokers	55 (83.4)	

(*Continued*)

Table 1 (Continued).

Variable	Count (Percentage)	Mean (SD)
Family history of SLE		
Yes	16 (25.8)	
NO	46 (74.2)	
Ophthalmologic	8 (12.1)	
Comorbidities		
Osteoporosis	18 (27.3)	
DM	8 (12.1)	
Thyroid disease	8 (12.1)	
Cancer	5 (7.6)	
DVT	6 (9.1)	
Other medications		
Hypertension medications	26 (40.5)	
Diabetes Mellitus medications	10 (15.6)	
Thyroid drugs	7 (10.9)	
Dyslipidemia medications	9 (14.1)	
Bisphosphonate	15 (23.2)	
PPI and H2 blockers	43 (67.2)	
Calcium and Vitamin D	54 (84.4)	

Abbreviations: SD, Standard Deviation; GI, Gastrointestinal; DM, Diabetes mellitus; OCP, Oral contraceptive pills; IUD, Intrauterine device; DVT, Deep Vein Thrombosis; PPI, Proton Pump Inhibitor.

Clinical Manifestations of SLE

The manifestations of SLE varied among the patients: 84.8% (N=56) reported constitutional symptoms, 83.3% (N=55) had mucocutaneous involvement, and an identical proportion (83.3%, N=55) experienced musculoskeletal manifestations. However, these did not necessarily occur in the same individuals. Additionally, vascular involvement was observed in 50% of patients, and 36.4% of patients (N=24) had renal involvement (Figure 1). Sixteen patients (25.8%) had a family history of SLE. The mean SLEDAI score of patients was 7.95± 9.29.

Regarding the antibodies profile, the majority of patients were positive for cardiolipin IgG (51.6%, N=33). On the other hand, only thirteen patients (20.3%) and twenty-six patients (40.6%) were positive for SS-A and DS-DNA antibodies, respectively.

Hydroxychloroquine was used by fifty-two patients (81.3%), which was the most prescribed drug in our study population, followed by corticosteroids, which was used by forty-seven patients (73.4%) (Table 2).

Reproductive History of the Participants

Of the participants, thirty-nine (59.1%) were married, twenty-four (36.4%) were single, and three (5.0%) were divorced. Thirty-five patients (53.0%) had 1 or more children. The mean number of gravity was 5.05 ±2.62 times, and parity was 3.63 ±1.83 children. Regarding delivery methods, eighteen patients had only vaginal deliveries (27.2%), six patients had only cesarean deliveries (9.1%), and eleven patients had both (16.7%). Most patients were not using contraceptive

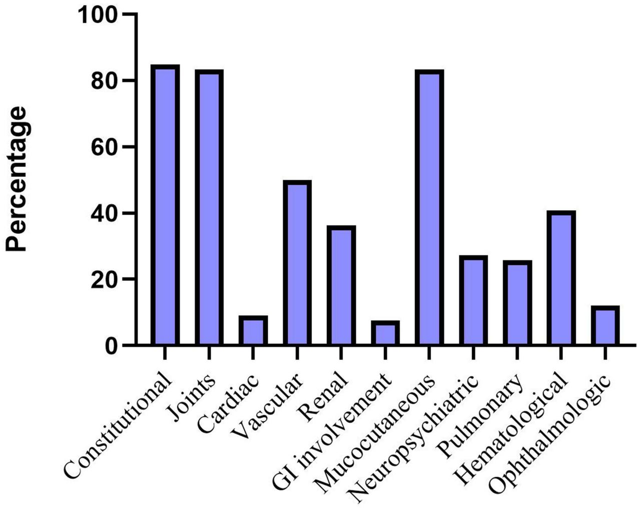

Figure 1 SLE manifestations among the study sample.

methods (22.7%, N=15). However, among patients who were using contraceptive methods, IUDs were the most used (10.7%, N=7).

Among patients who were married before, thirty-five patients (83.3%) had at least one pregnancy-related complication. During their pregnancies, 66.7% of patients (N=28) reported maternal-related pregnancy complications, and 76.2% of patients (N=32) reported fetal-related pregnancy complications. Miscarriage occurred at least once in twenty-four patients (57.1%). Pregnancy complications were reported in 47.6% of first pregnancies, 50.0% of second pregnancies, and 54.8% of subsequent pregnancies. Table 3 describes patients' reproductive health and pregnancy-related complications.

Table 2 Disease Features and Quality of Life Measures in Systemic Lupus Erythematosus Patients

Variable	Count (Percentage)	Mean (SD)
SLE medications		
Corticosteroids	47 (73.4)	
Mycophenolate	25 (39.1)	
Hydroxychloroquine	52 (81.3)	
Tacrolimus	7 (10.9)	
Azathioprine	23 (25.9)	
Methotrexate	6 (9.4)	
Leflunomide	1 (1.6)	
Cyclosporine	1 (1.6)	
Antibodies		
RNP	8 (12.5)	
Rheumatoid factor	4 (6.3)	
DS DNA	26 (40.6)	
Lupus anticoagulant	32 (50.0)	
Cardiolipin IgG	33 (51.6)	

(*Continued*)

Table 2 (Continued).

Variable	**Count (Percentage)**	**Mean (SD)**
Cardiolipin IgM	18 (28.1)	
Beta-2 Glycoprotein	12 (18.8)	
SS-A	13 (20.3)	
SS-B	4 (6.3)	
Anti-Smith	4 (6.3)	
Anti citrullinated peptide	1 (1.6)	
Histone	6 (9.4)	
Low C4	8 (12.5)	
Low C3	17 (26.6)	
MSPSS		67.27 (12.30)
SLEDAI		7.95 (9.29)
WHOQOL-BREF		
Physical		15.15 (21.80)
Psychological		40.34 (22.66)
Environmental		30.08 (5.90)
Social		72.35 (22.32)

Abbreviations: MSPSS, Multidimensional Scale of Perceived Social Support; SLEDAI, Systemic Lupus Erythematosus Disease Activity Index; WHOQOL-BREF, World Health Organization Quality of Life Brief Version.

Quality of Life and Perceived Social Support Measures Among the Participants

Patients' perceived social support was assessed using MSPSS; the mean score of participants was 67.27 ±12.3. When patients' perceived social support was categorized according to MSPSS, Four patients (6.1%) were in the low category, twenty-five (37.9%) were in the moderate, and thirty-seven (56.1%) were in the high category. Regarding the quality of life as measured by the WHOQOL-BREF, the mean scores in the physical health domain were 15.15 ±21.8, in the psychological health domain 40.34 ±22.66, in the environmental health domain 30.08 ±5.90 and in the social health domain 72.35 ±22.32 (Table 2).

Patients' Perspectives on Reproductive Health and Associated Influencing Factors

Forty-five patients (69.2%) were unsure whether SLE affects fertility, twelve patients (18.5%) thought it does not alter fertility, and eight patients believed SLE decreases fertility. Only six patients (9.0%) had previously received counseling on reproductive health and family planning from their obstetrics and gynecology doctor, while thirty patients (45.5%) had not been counseled. Patients were asked about their preferences for reproductive health counseling; regarding the timing of these consultations, 10.6% (N=7) preferred to receive counseling immediately after their SLE diagnosis, 7.6% (N=5) preferred to be consulted once their disease was under control, and 4.5% (N=3) were not interested in receiving such consultations. Regarding preferences for the consultation setting and the presence of others, 12.2% of patients (N=8) preferred to be consulted alone. Only four participants (6.1%) expressed a preference for having someone else present, such as their husband (4.5%, N=3) or mother (1.5%, N=1). Additionally, 18.2% of patients (N=12) indicated a preference for being consulted by a rheumatologist (Table 4).

Table 3 Reproductive Health of Data of The Patients

Variable	**Count (%)**	**Mean (SD)**
Age at menarche		13.75 (1.60)
Age at menopause		46.85 (5.72)
Having children		
Yes	35 (53.0)	
No	7 (10.6)	
Single	24 (36.4)	
Gravity(times)		5.05 (2.62)
Parity(child)		3.63 (1.83)
Delivery method		
Vaginal	18 (27.2)	
Cesarean section	6 (9.1)	
Both	11 (16.7)	
Not applicable	31 (47.0)	
Contraception		
OCP	1 (1.5)	
Barrier methods	1 (1.5)	
IUD	7 (10.7)	
Coitus interruptus	2 (3.0)	
None	15 (22.7)	
Not applicable	40 (60.6)	
Ever had pregnancy-related complications	35 (83.3)	
Maternal-related complications	28 (66.7)	
During first pregnancy	20 (47.6)	
During second pregnancy	21 (50.0)	
During other pregnancies	23 (54.8)	
Fetal-related complications	32 (76.2)	
During first pregnancy	25 (59.5)	
During second pregnancy	26 (61.9)	
During other pregnancies	24 (57.1)	
Miscarriages		
Yes	24 (57.1)	
No	18 (42.9)	

Abbreviations: OCP, Oral Contraceptive Pills; IUD, Intrauterine Device.

Table 4 Patients' Perspectives on Reproductive Health and Counseling in SLE

Variable	Count (Number)	Percentage (%)
Preferred consult time to discuss reproductive health and family planning		
Immediately after diagnosis	7	10.6
After the disease was controlled	5	7.6
Not interested	3	4.5
Not applicable	51	77.3
Have been consulted by Obgyn?		
Yes	6	9.0
No	30	45.5
Not applicable	30	45.5
How does SLE affect Fertility?	24	80
I do not know	45	69.2
Decrease fertility	8	12.3
Does not change fertility	12	18.5
Was a previous pregnancy outcome led to the decision not to have children?		
Yes	2	3.2
No	36	58.1
Unmarried	24	38.7
How do you prefer being consulted about SLE?		
Alone	8	12.2
Not interested	8	12.2
No preference	3	4.5
With my mother	1	1.5
With husband	3	4.5
Does not apply	43	65.1
Which doctor do you prefer to consult?		
Rheumatology	12	18.2
Obgyn	1	1.5
GP	1	1.5
Not interested	8	12.1
Does not apply	44	66.7

Abbreviations: Obgyn, Obstetrics and Gynecology; SLE, Systemic lupus erythematosus; GP, General practitioner.

Patients were asked if a previous pregnancy outcome influenced their decision not to have children. Only 3.2% of patients (N=2) agreed, while 58.1% (N=36) reported that their previous pregnancy outcome did not impact their decision (Table 4).

Influence of Perceived Social Support and Quality of Life on Patients' Perceptions of Reproductive Health in SLE

Regarding patients' perception of how SLE affects fertility, patients who think SLE decreases fertility had significantly lower WHOQOL-BREF social health scores (55.21 ±28.15) compared to patients who were unsure (71.85 ±22.07) and those who believe it does not negatively impact fertility (86.11 ±8.21) (P-value =0.008). Similarly, patients who think SLE decreases fertility had lower MSPSS scores (59.25 ±13.75) compared to patients who were unsure (66.84 ±12.78) and who think it does not affect fertility (73.08 ±6.88) (P-value =0.049). On the other hand, neither the age, age at the onset of SLE, age at menarche or menopause were significantly associated with patients' perceptions of reproductive health (Table 5). None of the medications were associated with patients on patients' perspectives on reproductive health.

Patients who were consulted by their Obstetrics and Gynecology doctor had significantly higher WHOQOL-BREF physical health scores (32.1 vs 10.3) (P-value =0.036) and higher psychological health scores (63.2 vs 35.1) (P-value =0.012). In addition, patients who preferred to be consulted by physicians had higher scores in the physical health domain compared to patients who were not interested in receiving such consultation (24.7 vs 5.4) (P-value =0.48). MSPSS scores were not significantly different between patients who received a prior reproductive health consultation

Table 5 Differences in Demographics, Clinical Manifestations, Disease Activity, Quality of Life, and Social Support Based on Patients' Perceptions of SLE's Impact on Reproductive Health

Variables	**"Unsure" N=45**	**Decrease Fertility N=8**	**Does not Change Fertility N=12**	**P-value**
Age	38.12 (16.31)	39.13 (7.95)	48.92 (12.34)	0.091
Age at onset of SLE	27.26 (11.93)	32.00 (10.35)	31.33 (13.53)	0.419
Age at menarche	13.76 (1.59)	14.00 (1.77)	13.67 (1.614)	0.900
Age at menopause	47.78 (4.18)	42.33 (7.23)	47.50 (6.61)	0.350
Thyroid disease	2 (4.4)	3 (37.5)	2 (16.7)	**0.002**
Cancer	2 (4.4)	0 (0)	3 (25)	0.061
Osteoporosis	10 (22.2)	3 (37.5)	5 (41.7)	0.452
Miscarriages	14 (58.3)	5 (62.5)	5 (55.5)	0.958
Joint involvement	40 (88.9)	4 (50)	11 (91.7)	**0.005**
Mucocutaneous involvement	36 (80)	7 (87.5)	7 (58.3)	0.082
Constitutional symptoms	38 (84.4)	7 (87.5)	11 (91.7)	0.108
Kidney involvement	19 (42.2)	2 (25)	3 (25)	0.502
Pregnancy complication	36 (80.0)	7 (87.5)	9 (75.0)	0.722
Delivery method				**0.038**
Vaginal only	9 (42.9)	2 (33.3)	3 (50)	
CS only	3 (14.2)	3 (50)	0 (0)	
Both	9 (42.9)	1 (16.7)	3 (50)	
Age (Years)	37.71 (16.25)	39.13 (7.95)	48.92 (12.34)	0.075
Age at first pregnancy (Years)	21.22 (3.42)	25.29 (4.71)	23.22 (3.93)	0.065

(*Continued*)

Table 5 (Continued).

Variables	"Unsure" N=45	Decrease Fertility N=8	Does not Change Fertility N=12	P-value
WHOQOL-BREF				
Physical	14.37 (21.38)	13.84 (31.62)	15.48 (13.31)	9.83
Psychological	38.89 (22.26)	29.17 (25.56)	51.74 (19.1)	0.075
Social	71.85 (22.07)	55.21 (28.15)	86.11 (8.21)	**0.008**
Environmental	29.40 (6.42)	28.88 (4.82)	33.00 (3.41)	0.147
MSPSS	66.84 (12.78)	59.25 (13.75)	73.08 (6.88)	**0.049**
SLEDAI	8.79 (10.28)	9.50 (7.19)	5.33 (5.98)	0.514

Note: Bold Significant at (P <0.05).

Abbreviations: SLE, Systemic Lupus Erythematosus; CS, Cesarean Section; MSPSS, Multidimensional Scale of Perceived Social Support; SLEDAI, Systemic Lupus Erythematosus Disease Activity Index; WHOQOL-BREF, World Health Organization Quality of Life Brief Version; CS, Cesarean section.

compared to those who did not (67.5 vs 63.2) and between patients who prefer to be consulted by a doctor compared to patients who are not interested in consultation (65.7 vs 69.8).

Discussion

This cross-sectional study explores the demographics and organ manifestations of Jordanian females diagnosed with SLE while also examining social support, quality of life, and patients' perspectives on reproductive health and their experience and knowledge regarding the effects of SLE on their fertility and pregnancy outcomes.

Our findings showed that 98.5% of study participants had at least school-level education, which reflects the very high literacy rates in Jordan.[21] SLE patients are known to face a substantial burden of decreased productivity.[22] This observation was evident in our study, where none of the patients were in demanding jobs, and 60.1% of patients were either unemployed or retired. Similar to the marriage rates in Jordan,[23] 59.1% of study participants were married. Even though these numbers mean that SLE does not affect the likelihood of getting married due to its latter presentation among the Jordanian population,[7] It does not reflect the marital satisfaction of these patients compared to individuals without the disease. Smoking cessation should be considered a cornerstone in SLE treatment because of its effects on the disease activity and treatment response.[24] Among our study participants, 16.6% of patients were smokers, 3% were cigarette smokers, and 13.6% were Hooka smokers.

Even though the prevalence of joint involvement (83.3%), renal involvement (36.4%) and constitutional symptoms (84%) in our study were consistent with previous reports from Jordan,[7] the prevalence of neuropsychiatric (27.3%) and pulmonary involvement (25.8%) were considerably higher compared to the same study[7] and other reports in the world.[25] The higher rate of organ involvement observed in our study was reflected in the SLEDAI score in our sample (7.95 ±9.29), which, when compared to other studies, is considerably elevated.[26,27] Due to the underlying etiology of the disease and the effects of certain medications, especially steroids, patients with SLE are at an increased risk of developing osteoporosis.[28] In our study, 27.3% of participants were diagnosed with osteoporosis, making it the most common comorbidity observed among our study population. Compared to the normal population in the Middle East and other areas of the world, the average WHOQOL-BREF scores in our study were lower in the physical health domain (15.5 ±21.8), psychological health (40.3 ±22.7) and environmental health (30.1 ±22.3) while the social health scores where comparable to other studies (72.4 ±22.3).[29,30] The elevated social health scores can be attributed to the fact that patients with chronic illness need stronger social networks, which can make coping with the disease easier.[31] Low physical and psychological health scores demonstrate the effect of SLE on daily functioning and psychological well-being, highlighting the need for mental and physical recreational health services for patients.

It is well-established that SLE is associated with worse pregnancy-related outcomes.[32,33] However, the SLE patients included in our study had an average of 3.63 ± 1.83 children per woman, which is higher than previous reports[32,33] and above the national average for Jordan. This discrepancy may be explained by the fact that a significant proportion of these patients were diagnosed after completing their families or reaching the end of their childbearing years. SLE is highly associated with fetal loss, where almost one out of five pregnancies end with miscarriage.[34] Among the 42 patients who had been married previously, 24 patients (57.1%) had experienced at least one miscarriage. The rate of Cesarean section among SLE patients varies between 40–60%.[35,36] In our study, among the 35 patients who experienced pregnancies complicated by SLE, 17 (48.6%) had at least one cesarean section, which is comparable to the studies mentioned earlier.

Low levels of knowledge regarding the effects of SLE on reproductive health and fertility were observed in our study population. Only 8% of patients thought that SLE decreases fertility, whereas the rest thought it either does not change it (18.5%) or did not know whether SLE affects their fertility or not (69.2%). A greater proportion of women in Blomjous et al's study in the Netherlands believed that SLE decreases fertility[37] compared to our sample despite the higher educational level of our sample. This divergent observation may be attributed to the fact that our patients were younger and had less experience with the disease compared to Blomjous et al's study population and a potential denial observed in our patients -even though it was not assessed directly- which may reduce their perception of the disease's impact on their reproductive health.[38] Among the 22 married patients of reproductive age who are planning to have more children, 36.4% were unwilling to discuss their reproductive health and fertility with their physicians. This observation highlights the possibility that some patients may be in denial about the impact of the disease on their reproductive health. Strong family connections and support are usually the norm among the Jordanian community.[39] However, our findings contrast with this pattern, as only four patients expressed a preference for discussing their SLE in the presence of a family member, which may stem from concerns about judgment or embarrassment, as well as the possibility that having companions present could compromise patients' autonomy and privacy when addressing sensitive topics.[40] While our study was not designed to explore the underlying motivations for this preference, prior regional research has highlighted the role of chronic illness stigma.[41] Another explanation of the low level of knowledge regarding how SLE affects fertility is the fact that only 9% of our study participants were consulted before by their OBGYN regarding the effect of their disease on fertility.

A high proportion of patients had high perceived social support (56.1%) and moderate perceived social support (37.9%). Our findings of high perceived social support among our population of SLE are higher than other studies in different populations in different areas of the world.[42,43] Patients who believed that SLE does not change fertility and those who did not know had higher MSPSS scores and higher social-health scores using WHOQOL-BREF compared with patients who thought it decreased fertility, an observation that may be attributed to the fact that infertile women are often stigmatized by their communities and families[44,45] leading to decreased social support for patients whose families are aware of their infertility or higher risk of infertility. Patients who prefer to be consulted by physicians had higher physical health scores compared to patients who are not interested in consultation (24.7 vs 5.4). This may be attributed to the fact that patients, due to their unfavorable disease outcomes and poor physical health, believe that seeking a doctor's help will not change the course of their condition.[46]

The advantages of this study include its being the first in the region to describe the perception of SLE patients toward how the disease affects their reproductive health and their attitudes toward it. It is also considered the first study in Jordan to utilize quality of life and social support measures in assessing patients with SLE. Another advantage of this study is it was conducted in a tertiary hospital in the capital of Jordan, Amman, to which patients from across the country are referred.

Our study has some limitations. The cross-sectional study design used in this study does not allow dynamic monitoring of how patients' perspectives, attitudes, quality of life and social support change with time. Also, the relatively small sample size in our study is considered a limitation, which can lead to missed significant associations between variables.

Conclusions

Despite the high levels of education, a lack of knowledge about the effects of SLE on reproductive health was noted, with a significant portion of patients unwilling to discuss fertility issues with their doctors. A need for targeted educational interventions tailored for SLE patients to enhance patients' understanding of their disease, particularly its impact on fertility and pregnancy outcomes, is of paramount importance. Additionally, a need for collaboration among OBGYNs and Rheumatologists to create a culturally sensitive method to address common misconceptions

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about SLE and infertility is needed. Future research with a larger sample size and longitudinal design is recommended to investigate further the perception and attitudes of SLE females regarding how the disease affects their fertility.

Abbreviations

ACR, American College of Rheumatology; CI, Confidence Interval; COSMIN, Consensus-based Standards for the selection of health status Measurement Instruments; DM, Diabetes Mellitus; DS-DNA, Double-Stranded Deoxyribonucleic Acid; EULAR, European Alliance of Associations for Rheumatology; IBM-SPSS, International Business Machines - Statistical Package for the Social Sciences; IUD, Intrauterine Device; MSPSS, Multidimensional Scale of Perceived Social Support; OBGYN, Obstetrics and Gynecology; OR, Odds Ratio; SLE, Systemic Lupus Erythematosus; SLEDAI, Systemic Lupus Erythematosus Disease Activity Index; SS-A, Sjogren's Syndrome-related Antigen A; WHOQOL, World Health Organization Quality of Life; WHOQOL-BREF, World Health Organization Quality of Life - Brief Version.

Data Sharing Statement

Data will be available upon reasonable request from the corresponding author.

Ethics Approval and Consent to Participate

Jordan University Hospital approved the study, and IRB approval number was (10/2023/30525). All procedures followed the ethical standards of the institutional research committee and adhered to the principles of the World Medical Association Declaration of Helsinki. Informed consent was obtained.

Consent to Participate

Written consent was obtained from all participants.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare no conflicts of interest in this work.

References

1. Justiz Vaillant AA, Goyal A, Varacallo M. Systemic lupus erythematosus. In: *StatPearls*. StatPearls Publishing; 2024.
2. Karrar S, Cunninghame Graham DS. Review: abnormal B cell development in systemic lupus erythematosus: what the genetics tell us. *Arthritis Rheumatol*. 2018;70(4):496–507. doi:10.1002/art.40396
3. Ameer MA, Chaudhry H, Mushtaq J, et al. An overview of Systemic Lupus Erythematosus (SLE) pathogenesis, classification, and management. *Cureus*. 2022. doi:10.7759/cureus.30330
4. Tian J, Zhang D, Yao X, Huang Y, Lu Q. Global epidemiology of systemic lupus erythematosus: a comprehensive systematic analysis and modelling study. *Ann Rheum Dis*. 2023;82(3):351–356. doi:10.1136/ard-2022-223035
5. Al-Arfaj AS, Al-Balla SR, Al-Dalaan AN, et al. Prevalence of systemic lupus erythematosus in central Saudi Arabia. *Saudi Med J*. 2002;23(1):87–89.

6. Al Dhanhani AM, Agarwal M, Othman YS, Bakoush O. Incidence and prevalence of systemic lupus erythematosus among the native Arab population in UAE. *Lupus*. 2017;26(6):664–669. doi:10.1177/0961203316678677
7. Adwan MH, Qasem U, Atawnah Saed Y, et al. Insights into systemic lupus erythematosus: a retrospective observational study of clinical features, autoantibodies, and gender-related differences. *Rheumatol Int*. 2024;44(7):1255–1263. doi:10.1007/s00296-024-05592-7
8. Alarcón GS, McGwin G, Uribe A, et al. Systemic lupus erythematosus in a multiethnic lupus cohort (LUMINA). XVII. Predictors of self-reported health-related quality of life early in the disease course. *Arthritis Rheum*. 2004;51(3):465–474. doi:10.1002/art.20409
9. Rinaldi S, Doria A, Salaffi F, et al. Health-related quality of life in Italian patients with systemic lupus erythematosus. I. Relationship between physical and mental dimension and impact of age. *Rheumatology*. 2004;43(12):1574–1579. doi:10.1093/rheumatology/keh397
10. Dao KH, Bermas BL. Systemic lupus erythematosus management in pregnancy. *IJWH*. 2022;14:199–211. doi:10.2147/IJWH.S282604
11. Andreoli L, Chighizola CB, Iaccarino L, et al. Immunology of pregnancy and reproductive health in autoimmune rheumatic diseases. Update from the 11th International Conference on Reproduction, Pregnancy and Rheumatic Diseases. *Autoimmun Rev*. 2023;22(3):103259. doi:10.1016/j.autrev.2022.103259
12. Sangah AB, Jabeen S, Hunde MZ, Devi S, Mumtaz H, Shaikh SS. Maternal and fetal outcomes of SLE in pregnancy: a literature review. *J Obstetrics Gynaecol*. 2023;43(1):2205513. doi:10.1080/01443615.2023.2205513
13. Larosa M, Le Guern V, Guettrot-Imbert G, et al. Evaluation of lupus anticoagulant, damage, and remission as predictors of pregnancy complications in systemic lupus erythematosus: the French GR2 study. *Rheumatology*. 2022;61(9):3657–3666. doi:10.1093/rheumatology/keab943
14. Mobini M, Mohammadpour RA, Salehi Y, Niksolat F. Contraceptive prevalence and consulting service in women with systemic lupus erythematosus: a cross-sectional study. *Ethiop J Health Sci*. 2021;31(2):293–298. doi:10.4314/ejhs.v31i2.12
15. Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Qual Life Res*. 2010;19(4):539–549. doi:10.1007/s11136-010-9606-8
16. Zimba O, Gasparyan AY. Designing, conducting, and reporting survey studies: a primer for researchers. *J Korean Med Sci*. 2023;38(48):e403. doi:10.3346/jkms.2023.38.e403
17. Aringer M, Costenbader K, Daikh D, et al. 2019 European League Against Rheumatism/American College of Rheumatology classification criteria for systemic lupus erythematosus. *Ann Rheum Dis*. 2019;78(9):1151–1159. doi:10.1136/annrheumdis-2018-214819
18. Petri M, Kim MY, Kalunian KC, et al. Combined oral contraceptives in women with systemic lupus erythematosus. *N Engl J Med*. 2005;353(24):2550–2558. doi:10.1056/NEJMoa051135
19. The Whoqol Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med*. 1998;28(3):551–558. doi:10.1017/S0033291798006667
20. Fekih-Romdhane F, Fawaz M, Hallit R, Sawma T, Obeid S, Hallit S. Psychometric properties of an Arabic translation of the multidimensional social support scale (MSPSS) in a community sample of adults. *BMC Psychiatry*. 2023;23(1):432. doi:10.1186/s12888-023-04937-z
21. Education Policy Data Center, National Education Profile 2018: Jordan [Internet]. Available from: https://www.epdc.org/sites/default/files/documents/EPDC_NEP_2018_Jordan.pdf. Accessed September 18, 2024.
22. Gordon C, Isenberg D, Lerstrøm K, et al. The substantial burden of systemic lupus erythematosus on the productivity and careers of patients: a European patient-driven online survey. *Rheumatology*. 2013;52(12):2292–2301. doi:10.1093/rheumatology/ket300
23. Oracle. Marriage and divorce. Department of Statistics. Available from: https://dosweb.dos.gov.jo/ar/population/marriage-and-divorce/. Accessed September 18, 2024.
24. Parisis D, Bernier C, Chasset F, Arnaud L. Impact of tobacco smoking upon disease risk, activity and therapeutic response in systemic lupus erythematosus: a systematic review and meta-analysis. *Autoimmunity Rev*. 2019;18(11):102393. doi:10.1016/j.autrev.2019.102393
25. Borchers AT, Naguwa SM, Shoenfeld Y, Gershwin ME. The geoepidemiology of systemic lupus erythematosus. *Autoimmunity Rev*. 2010;9(5):A277–A287. doi:10.1016/j.autrev.2009.12.008
26. Speyer CB, Li D, Guan H, et al. Comparison of an administrative algorithm for SLE disease severity to clinical SLE Disease Activity Index scores. *Rheumatol Int*. 2020;40(2):257–261. doi:10.1007/s00296-019-04477-4
27. Lai NS, Lu MC, Chang HH, et al. A comparison of the correlation of systemic lupus erythematosus disease activity index 2000 (SLEDAI-2K) and Systemic Lupus Erythematosus Disease Activity Score (SLE-DAS) with health-related quality of life. *J Clin Med*. 2021;10(10):2137. doi:10.3390/jcm10102137
28. Lee C, Ramsey-Goldman R. Osteoporosis in systemic lupus erythematosus mechanisms. *Rheum Dis Clin North Am*. 2005;31(2):363–385. doi:10.1016/j.rdc.2005.01.004
29. West EC, Williams LJ, Stuart AL, Pasco JA. Quality of life in south-eastern Australia: normative values for the WHOQOL-BREF in a population-based sample of adults. *BMJ Open*. 2023;13(12):e073556. doi:10.1136/bmjopen-2023-073556
30. Tahoun MM, Ismail HM, Fiidow OA, et al. Quality of life among the Arab population two years after COVID-19 pandemic. *BMC Public Health*. 2023;23(1):1–13. doi:10.1186/s12889-023-16171-z
31. Bae SC, Hashimoto H, Karlson EW, Liang MH, Daltroy LH. Variable effects of social support by race, economic status, and disease activity in systemic lupus erythematosus. *J Rheumatol*. 2001;28(6):1245–1251.
32. Roussou E, Weerakoon A, Iacovou C, Ahmed K. Ethnic differences in the number of miscarriages, number of children, perceived family support and the impact of the disease on daily living in patients with systemic lupus erythematosus. *Clin Rheumatol*. 2013;32(8):1223–1228. doi:10.1007/s10067-013-2234-2
33. Clowse MEB, Chakravarty E, Costenbader KH, Chambers C, Michaud K. Effects of infertility, pregnancy loss, and patient concerns on family size of women with rheumatoid arthritis and systemic lupus erythematosus. *Arthritis Care Res*. 2012;64(5):668–674. doi:10.1002/acr.21593
34. Clark CA, Spitzer KA, Laskin CA. Decrease in pregnancy loss rates in patients with systemic lupus erythematosus over a 40-year period. *J Rheumatol*. 2005;32(9):1709–1712.
35. Li J, Li Z, Yu L, Su J. Maternal and neonatal outcomes of pregnancy complicated with Systemic Lupus Erythematosus. *Food Sci Technol*. 2021;42:e56921. doi:10.1590/fst.56921
36. Eudy AM, Jayasundara M, Haroun T, Neil L, James AH, Clowse MEB. Reasons for cesarean and medically indicated deliveries in pregnancies in women with systemic lupus erythematosus. *Lupus*. 2018;27(3):351–356. doi:10.1177/0961203317720525
37. Blomjous BS, Johanna IPDV, Zijlstra E, Cramer K, Voskuyl AE, Bultink AIEM. Desire to have children and preferences regarding to pre-pregnancy counselling in women with SLE. *Rheumatology*. 2021;60(6):2706–2713. doi:10.1093/rheumatology/keaa684

38. Williams AR, Olfson M, Galanter M. Assessing and improving clinical insight among patients "in denial". *JAMA Psychiatry*. 2015;72(4):303–304. doi:10.1001/jamapsychiatry.2014.2684
39. Zeilani RS, Abdalrahim MS, Hamash K, Albusoul RM. The experience of family support among patients newly diagnosed with cancer in Jordan. *Eur J Oncol Nurs*. 2022;60:102173. doi:10.1016/j.ejon.2022.102173
40. Pino M, Land V. How companions speak on patients' behalf without undermining their autonomy: findings from a conversation analytic study of palliative care consultations. *Sociol Health Illness*. 2022;44(2):395–415. doi:10.1111/1467-9566.13427
41. Alananzeh I, Lord H, Fernandez R. Social support for Arab people with chronic conditions: a scoping review. *Clin Nurs Res*. 2021;30(4):380–391. doi:10.1177/1054773820932262
42. Aizuddin AN, Mohamed M, Gopal S, Mohd Miskam H, Idris I. Social support among Systemic Lupus Erythematosus (SLE) patient in Malaysia. *Southeast Asia Psychology Journal*. 2023;11:122–138.
43. Elwardany S, Mohammed F, Abd-Almageed A, Hassan G. Comparative study for pattern of social support among systemic lupus erythematous patients' at out-patient clinics, Assiut University Hospital. *Am J Nurs Res*. 2018;6:500–506. doi:10.12691/ajnr-6-6-18
44. Ergin RN, Polat A, Kars B, Öztekin D, Sofuoğlu K, Çalışkan E. Social stigma and familial attitudes related to infertility. *Turk J Obstet Gynecol*. 2018;15(1):46–49. doi:10.4274/tjod.04307
45. Obeidat HM, Hamlan AM, Callister LC. Missing motherhood: Jordanian women′s experiences with infertility. *Adv Psychiatr*. 2014;2014(1):241075. doi:10.1155/2014/241075
46. Taber JM, Leyva B, Persoskie A. Why do people avoid medical care? A qualitative study using national data. *J Gen Intern Med*. 2015;30(3):290–297. doi:10.1007/s11606-014-3089-1