



Evaluation of pregnancy planning and contraceptive methods in patients with systemic lupus erythematosus

Özlem Karakaş¹, Dudu Çelik Tam², Pınar Akyüz Dağlı³, Bahar Özdemir Ulusoy⁴, Berkan Armağan², Şükran Erten⁵

¹Kırıkkale University Faculty of Medicine, Department of Internal Medicine, Division of Rheumatology, Kırıkkale, Türkiye

²Ankara Bilkent City Hospital, Clinic of Rheumatology, Ankara, Türkiye

³University of Health Sciences Türkiye, Gülhane Training and Research Hospital, Clinic of Rheumatology, Ankara, Türkiye

⁴University of Health Sciences Türkiye, Ankara Gaziler Physical Therapy and Rehabilitation Training and Research Hospital, Clinic of Rheumatology, Ankara, Türkiye

⁵Ankara Yıldırım Beyazıt University Faculty of Medicine, Ankara Bilkent City Hospital, Department of Rheumatology, Ankara, Türkiye

Cite this article as: Karakaş Ö, Çelik Tam D, Akyüz Dağlı P, Özdemir Ulusoy B, Armağan B, Erten Ş. Evaluation of pregnancy planning and contraceptive methods in patients with systemic lupus erythematosus. Gulhane Med J. [Epub Ahead of Print]

Date submitted:

19.09.2024

Date accepted:

19.03.2025

Epub:

21.05.2025

Corresponding Author:

Özlem Karakaş, M.D., Kırıkkale University Faculty of Medicine, Department of Internal Medicine, Division of Rheumatology, Kırıkkale, Türkiye
ozlem01us@yahoo.com

ORCID:

orcid.org/0000-0002-3031-3353

Keywords: SLE, pregnancy planning, contraception

ABSTRACT

Aims: Women's educational background plays a crucial role in family planning, chronic disease management, and treatment adherence. Chronic diseases and the use of rheumatological medications can raise various concerns, influencing family planning decisions. This study aimed to evaluate pregnancy-related status, contraceptive methods, and factors contributing to pregnancy-related concerns in female patients with systemic lupus erythematosus (SLE) and to compare these findings based on educational levels.

Methods: This cross-sectional study included women aged 18-49 diagnosed with SLE based on the 2019 European Alliance of Associations for Rheumatology/American College of Rheumatology classification criteria. Participants were eligible if they were planning a pregnancy, currently pregnant, or had a prior pregnancy history. Patients with overlapping autoimmune diseases or those unwilling to participate were excluded. The primary outcome was the assessment of pregnancy-related concerns and contraceptive methods. Data were collected through structured interviews and analyzed using statistical tests to compare groups based on educational levels.

Results: A total of 71 female patients were included, with a median age of 42 years [interquartile range (IQR): 36-48], and the majority were married (75.3%). The median disease duration was 9 years (IQR: 5-14). Only 25.0% of the patients consulted their physician before planning a pregnancy, and 37.1% used contraception. The most commonly used contraception methods were condoms (17.8%), intrauterine devices (14.5%), and oral contraceptives (4.8%). The most common concern was the belief that medications could harm the baby (32.7%). No significant differences were observed in primary outcomes when comparing educational levels ($p>0.05$).

Conclusions: This study highlights low rates of preconception counseling and contraceptive use among female SLE patients, as well as prevalent concerns regarding pregnancy-related risks.

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that characterized by a wide range of clinical manifestations, from mild symptoms to life-threatening organ involvement. The clinical onset of SLE in genetically predisposed individuals results from the interaction of environmental, immunological, and hormonal factors. Since the disease frequently affects women of childbearing age, fertility and pregnancy-related issues are a significant part of SLE management (1). Advances in diagnostic and therapeutic approaches have led to significant improvements in the clinical management of the disease, with enhanced survival rates among patients. With enhanced life expectancy and quality of life, individuals with SLE are expressing a growing desire to marry and have children, posing important clinical challenges for healthcare providers (2).

Hormonal changes during pregnancy can trigger SLE flare-ups. Additionally, factors such as pre-existing organ damage, autoantibodies, and treatment medications may significantly impact maternal and fetal health (3). Various clinical studies have demonstrated that pregnancy-related complications—including recurrent miscarriages, preterm birth, fetal death, congenital heart block, and intrauterine growth restriction—occur at significantly higher rates in women with SLE compared to women without the disease (4-6).

Effective pregnancy planning and management in SLE patients require a comprehensive, multi-phase approach, including preconception counseling, disease monitoring and treatment during pregnancy, management of complications, fetal monitoring, breastfeeding, postpartum follow-up, and newborn care (2). Additionally, factors such as education level and access to healthcare services also influence pregnancy decisions and treatment adherence. A study evaluating factors affecting women's access to healthcare services in Türkiye highlighted that demographic characteristics such as women's education levels, employment status, and number of children are significant determinants of healthcare accessibility (7). According to the 2023 data from the Turkish Statistical Institute, 44% of women in Türkiye have completed high school and higher education (8). Another study in Türkiye demonstrated that education level influences healthcare service utilization, with higher education levels being associated with fewer children and improved child survival rates (9).

Despite these findings, no previous studies in Türkiye have specifically examined the perspectives of women with SLE on pregnancy. This study aims to assess the pregnancy-related status of female SLE patients, their contraceptive methods, and the factors contributing to pregnancy-related concerns. Additionally, we aim to compare these findings based on the patients' educational levels to evaluate the perspectives of women with SLE-on-pregnancy.

Methods

Study design and patient selection

This study was conducted using a cross-sectional design. Female patients aged 18 and older, diagnosed with SLE and followed at the Rheumatology Clinic of Ankara Bilkent City Hospital, were evaluated. Among them, 71 patients who agreed to participate were included in the study after face-to-face interviews. Since our study was retrospective, informed consent forms were not obtained from participants.

The inclusion criteria consisted of women aged 18-49 diagnosed with SLE met one or more of the following conditions: planning to become pregnant at any point in their lives, currently pregnant or having a history of pregnancy. Exclusion criteria included patients who did not meet the 2019 European Alliance of Associations for Rheumatology/American College of Rheumatology classification criteria for SLE (10), those with an additional autoimmune disease (e.g., overlap syndromes, Sjogren's syndrome, scleroderma, inflammatory myositis), individuals under 18 years old, and those unwilling to complete the survey.

The Clinical Research Ethics Committee of Ankara Bilkent City Hospital approved the study (decision number: E1-23-3567, date: 10.05.2023) and conducted in accordance with the ethical standards of the 1964 Declaration of Helsinki and its later amendments.

Data collection

Demographic and clinical data

Demographic characteristics including age, marital status, and educational level were recorded. Information regarding planned and unplanned pregnancies, preconception counseling, decision-making in pregnancy, and contraceptive methods [e.g., condom, oral contraceptives, intrauterine devices (IUDs)] was collected. The withdrawal method was not considered a form of contraception.

Assessment of pregnancy-related concerns

To assess pregnancy-related concerns among female SLE patients, all participants were asked the following eight questions:

1. Fear of being unable to care for the child,
2. Belief that rheumatologic medications would harm the baby,
3. Concern that the disease could be passed on to the baby,
4. Belief that SLE may lead to early death in the patient,
5. Doctor's opposition to pregnancy due to the rheumatologic condition,
6. Previous experiences of pregnancy loss(es),
7. Previous complications during pregnancy,
8. Fear disease flare-ups during and after pregnancy.

Given that educational level may influence pregnancy planning, patients were categorized based on their educational background. For analysis, they were divided into two groups: those with primary education or less (Group 1, n=36) and those with high school education or higher (Group 2, n=35).

Outcomes

The primary outcome was the assessment of pregnancy-related concerns, contraceptive methods, and the factors contributing to these concerns. The secondary outcome was to evaluate the perspectives of women with SLE on pregnancy by comparing these findings based on the patients' educational levels.

Statistical Analysis

Data were analyzed using the Statistical Package for the Social Sciences for Windows, version 22.0 (IBM Corp., Armonk, NY, USA). The normality of continuous variables was evaluated using the Shapiro-Wilk test and visually through plots and histograms. Continuous variables were presented either as median (minimum-maximum) or mean±standard deviation (SD), according to normality. Categorical variables were compared between groups using the Pearson Chi-squared test. Independent-samples t and Mann-Whitney U tests were used for the comparison of continuous variables, as appropriate. A p-value of less than 0.05 was considered statistically significant.

Results

Demographic characteristics

A total of 71 female patients were included, with a median age of 42 years (range: 19-69). The median disease duration was 9 years (range: 0-28). There were 20 postmenopausal patients. Among them, 15 (75.0%) were diagnosed with SLE after completing all their pregnancies. Two patients (10.0%) were diagnosed with SLE without ever having been pregnant. Of the patients, 75.3% were married, and 11.7% were divorced.

Pregnancy and contraception patterns

The median number of pregnancies was 3 (range: 0-11), with a median of 2 planned pregnancies (range: 0-8). The median number of live births was 2 (range: 0-6). When evaluating who primarily initiated the desire to become pregnant, it was found that in 60.0% of the patients, the decision to become pregnant was initiated by the patient herself, while in 11.1% of cases, the decision was initiated by the partner. In 26.7% of the patients, pregnancy was planned through a mutual decision between the patient and partner. The rate of consulting a physician to plan pregnancy was found to be 25.0%. The overall rate of contraception use was determined to be 37.1%. Among the contraceptive methods used, condoms were the most common at 17.8%, followed by IUDs at 14.5% and oral contraceptives at 4.8%. The

oral contraceptives used are often preparations containing combined estradiol and progesterone.

Educational status and pregnancy outcomes

SLE patients were compared in two groups based on their educational level. Group 1 included patients with primary education or less, and Group 2 included patients with high school education or higher. Among the patients, 44.2% (n=36) had completed primary education (8 years), 26% (n=20) had completed high school, and 19.5% (n=15) were university graduates. The baseline characteristics of these two groups are presented in Table 1. Group 1 patients had a higher mean age (SD) and median [interquartile range (IQR)] disease duration compared to Group 2 [48.1 (9.3) vs. 38.3 (10.1) years, $p<0.001$, and 12 (8) vs. 8 (9) years, $p=0.01$, respectively]. In terms of marital status, 91.7% of Group 1 patients were married, compared to 64.1% of Group 2 patients ($p=0.003$). The median (IQR) number of pregnancies and the median (IQR) number of planned pregnancies was higher in Group 1 than in Group 2 [3 (1) vs. 2 (3), $p<0.001$, and 2.5 (2) vs. 1 (2), $p=0.013$, respectively]. There was no significant difference between the groups in terms of who made the decision to become pregnant. However, pregnancy initiated by the partner and family was more common in Group 1, while more patients in Group 2 made the decision independently. There were no significant differences between the groups in terms of consulting a physician before planning a pregnancy, the use of contraception, or the type of contraception used.

When evaluating the responses to the eight questions assessing the concerns of female SLE patients about pregnancy and having children, the most common concern was the belief that rheumatologic medications might harm the baby (32.7%). Other concerns included fear of a disease flare-up during and after pregnancy (20.4%), the fear of being unable to care for the child (16.3%), the concern that the disease would be passed on to the baby (16.3%), the doctor's opposition to pregnancy due to the rheumatologic condition (14.3%), previous complications during pregnancy (14.3%), the belief that the disease may lead to early death in the patient (12.2%), and previous experiences of pregnancy loss(es) (12.2%). When comparing the two educational groups, no significant differences were found regarding these concerns (Figure 1).

Discussion

In the study, 60% of female patients with SLE expressed the desire to become pregnant. The rate of consulting a physician to plan pregnancy before conception was 25.0%, and the rate of contraception use was 37.1%. When stratified by educational level, no significant differences were observed in terms of who initiated the desire for pregnancy, consultation rates for preconception planning, or contraception use. Regarding

Table 1. Comparison of demographic and pregnancy characteristics in systemic lupus erythematosus patients based on educational level

	Primary education or below, n=36	High school or above, n=35	p-value
Age, years, mean±SD	48.1±9.3	38.3±10.1	<0.001
Disease duration, years, median (IQR)	12 (8)	8 (9)	0.010
Marital status, n (%)			
- Married	33 (91.7)	22 (63.0)	0.003
- Divorced	3 (8.3)	5 (14.2)	
- Single	0	8 (22.8)	
Number of pregnancies, median (IQR)	3 (1)	2 (3)	<0.001
Number of planned pregnancies, median (IQR)	2.5 (2)	1 (2)	0.013
Who decided on the pregnancy, n (%)			
- Patient	13 (36.1)	14 (40.0)	0.501
- Partner	4 (11.1)	1 (2.8)	
- Joint decision (patient and partner)	6 (16.6)	6 (17.2)	
- Family	1 (2.7)	0	
Planned pregnancy with consultation from physician before pregnancy, n (%)	6 (16.6)	6 (17.2)	0.738
Use of any contraceptive method, n (%)	11 (30.5)	12 (34.3)	0.394

SD: Standard deviation, IQR: Interquartile range

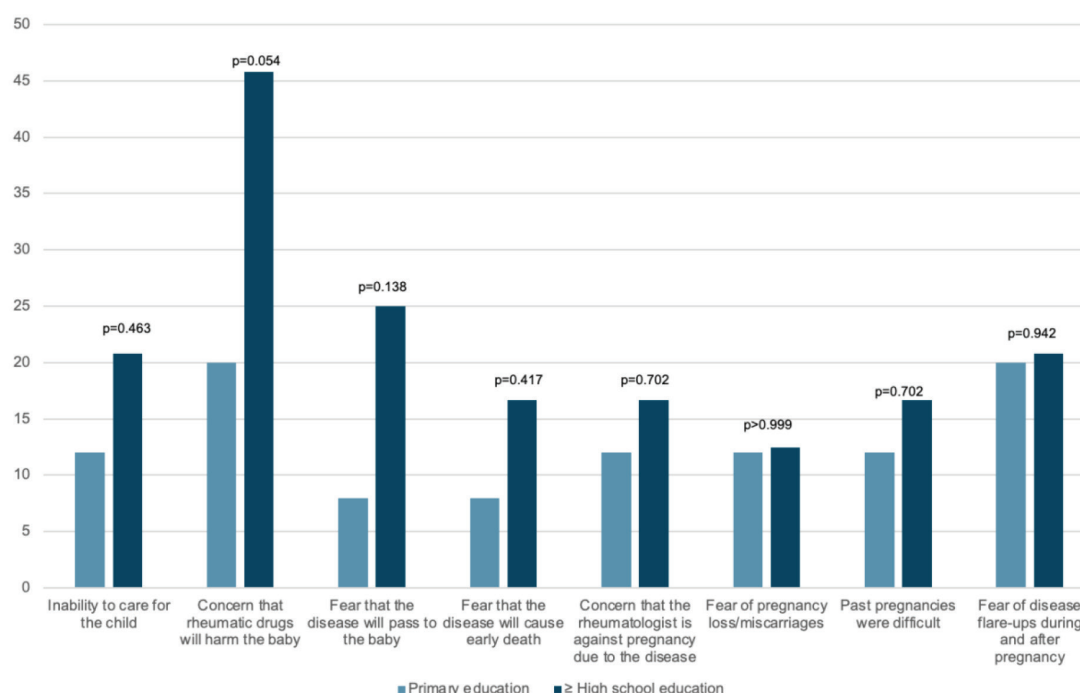


Figure 1. Comparison of the reasons that negatively affect pregnancy desire in women with systemic lupus erythematosus according to educational status

pregnancy-related concerns, more than one-third of the patients expressed worry about the potential teratogenic effects of rheumatologic medications, and one-fifth were concerned about disease flare-ups during or after pregnancy.

As SLE commonly affects women of reproductive age, it is crucial that patients receive proper information about pregnancy planning and disease management before, during, and after

pregnancy. However, there is limited research on this topic both in our country and globally. In our study, we found that 60% of women with SLE made the decision to become pregnant themselves. Upon reviewing the literature, we could not find any study that specifically evaluated the role of family or partner influence versus personal decision-making regarding pregnancy in SLE patients. Studies have shown that SLE patients tend to

have smaller families with fewer children (11,12). In this study, the median number of live births was two. Education can influence family relationships and decisions about childbirth. Higher education and longer schooling often lead to later marriages, delayed childbearing, and smaller family sizes (13,14). In the study, we observed that patients with lower education levels had more children; however, these patients were, on average, 10 years older than those with higher education levels, making direct comparisons challenging.

Despite the importance of pregnancy timing for SLE patients, there has been a lack of focus on contraceptive counseling and recommendations, leading to the underuse of effective contraceptive methods in this patient population (12). In the study, 37.1% of patients used some form of contraception. A separate study conducted in Türkiye with 113 SLE patients found that 20.3% of patients did not use any contraceptive method (15). The most commonly used contraceptive method among our patients was condoms (17.8%). A similar study in the literature also showed that condoms were the most preferred contraceptive method among SLE patients (16). SLE patients, especially during periods of high disease activity, should receive contraceptive counseling to prevent unplanned pregnancies and manage teratogenic drug use. IUDs can be recommended to all patients unless there is a gynecological contraindication. The safety of combined (estrogen plus progestin) and progestin-only contraceptives has been demonstrated in randomized controlled trials for SLE patients who are negative for antiphospholipid antibodies (aPL) (17). However, combined hormonal contraceptives should not be recommended for women whose tests were positive for aPL antibodies. Progestin-only methods (e.g., pills, subcutaneous depot injections) may be suitable for these women, though their use should be evaluated in light of the associated thrombosis risk. Estrogen therapy may be considered for the management of persistent gynecological issues that cannot be managed otherwise. While copper IUDs can be used in all patients, levonorgestrel-releasing IUDs should be considered only if the benefits (e.g., reducing menstrual bleeding in patients who are using an anticoagulant) outweigh the risks of thrombosis. In our study, only one patient reported using a hormonal IUD.

Preconception pregnancy planning is critically important for both maternal and fetal health in women with SLE (18,19). Family planning should be discussed as early as possible after the diagnosis of the disease. This approach allows most women to have healthy and successful pregnancies while ensuring timely measures are taken to reduce the risks of adverse maternal and/or fetal outcomes (18). The best pregnancy outcome will be achieved in patients who are in remission for 6 months before conception (20). Patients at high risk due to disease flare-ups should postpone pregnancy until the disease is well-controlled (21).

Given that pregnancy rates among SLE patients have increased in recent years, healthcare providers must pay greater attention to pregnancy management (19). A study reveals that the majority of SLE patients received preconception counseling in a non-multidisciplinary approach, and 16% of those ultimately decided not to pursue pregnancy (22). Another study from the United States revealed that over 60% of women with any rheumatologic disease did not receive documented pregnancy planning counseling (23). While there are no similar studies specifically focused on SLE, we found that only 25% of our patients consulted their physician for pre-pregnancy planning, and there were no differences between education levels in this regard. Based on the results of our study, family planning should be regularly addressed as part of the management of SLE, beginning as early as possible, ideally shortly after diagnosis, through a multidisciplinary approach.

The disease course and treatment modalities required for SLE can affect patients' personal relationships and decisions about having children. Factors that may influence patients' concerns about pregnancy and childbearing include disease activity, the belief that medications used during the disease course may harm the pregnancy process or baby, recurrent pregnancy losses, and previous pregnancy complications (1,24). One-third of childless women with SLE attribute their lack of children to the disease (22). The responses to the questions we asked our patients are consistent with the concerns reported in the literature. The most common concerns were that rheumatologic medications could harm the baby and that the disease might flare up during or after pregnancy. There were no statistically significant differences between education groups regarding any of the questions. However, the concern that rheumatologic medications could harm the baby, approaching statistical significance ($p=0.054$), was more common among those with higher education levels. This suggests that increasing the level of education may bring different concerns to the fore.

There are several limitations of this study. The most significant factors are a small sample size and the lack of assessment of disease activity, organ damage, or treatment regimens. Additionally, the study was conducted at a single center, which may limit the representation of different socioeconomic groups compared to multicenter studies involving university and private hospitals.

Assessing risk factors for adverse maternal and fetal outcomes in pregnant women with SLE is crucial for preconception counseling and the implementation of appropriate preventive strategies and patient-specific monitoring plans during pregnancy.

Conclusion

This study found that the desire for pregnancy was mostly initiated by the patients themselves. However, the

rates of preconception counseling and contraceptive use were low. There were no significant differences between education groups in these aspects. Providing information about pregnancy to SLE patients as early as possible after diagnosis may increase the use of effective contraception and lead to more planned pregnancies. Additionally, educating patients about the rheumatologic medications used during pregnancy and breastfeeding and discussing the risk of disease flare-ups were among the key concerns raised by our patients. Increasing awareness and providing family planning information to SLE patients, particularly through rheumatology and gynecology specialists, should be a priority in the preconception period.

Ethics

Ethics Committee Approval: The Clinical Research Ethics Committee of Ankara Bilkent City Hospital approved the study (decision number: E1-23-3567, date: 10.05.2023).

Informed Consent: Retrospective study.

Footnotes

Authorship Contributions

Surgical and Medical Practices: B.A., Ş.E., Concept: Ö.K., P.A.D., B.A., Design: Ö.K., D.Ç.T., B.A., Data Collection or Processing: Ö.K., B.Ö.U., Analysis or Interpretation: B.A., Ş.E., Literature Search: D.Ç.T., B.Ö.U., Ş.E., Writing: Ö.K., P.A.D.

Conflict of Interest: The authors declared no conflict of interest.

Financial Disclosure: The authors declared that this study received no financial support.

References

1. Saulescu IC, Opris-Belinski D, Balanescu AR, Pavel B, Gica N, Panaitescu AM. Preparing for pregnancy in women with systemic lupus erythematosus-a multidisciplinary approach. *Medicina (Kaunas)*. 2022;58(10):1371.
2. Tian X, Zhao J, Song Y, Wang Q, Li M, Liu J, et al. 2022 Chinese guideline for the management of pregnancy and reproduction in systemic lupus erythematosus. *Rheumatol Immunol Res*. 2023;4(3):115-138.
3. Chinese rheumatology association; National clinical research center for dermatologic and immunologic diseases; Chinese systemic lupus erythematosus treatment and research group. [2020 Chinese guidelines for the diagnosis and treatment of systemic lupus erythematosus]. *Zhonghua Nei Ke Za Zhi*. 2020;59(3):172-185.
4. Wu J, Ma J, Bao C, Di W, Zhang WH. Pregnancy outcomes among Chinese women with and without systemic lupus erythematosus: a retrospective cohort study. *BMJ Open*. 2018;8(4):e020909.
5. Wang Z, Li M, Ye Z, Li C, Li Z, Li X, et al. Long-term outcomes of patients with systemic lupus erythematosus: a multicenter cohort study from CSTAR registry. *Rheumatol Immunol Res*. 2021;2(3):195-202.
6. Yang Y, Zhou Y, Zhang X, Huang C, Liu L, Zhao J, et al. Risk and protective factors of disease flare during pregnancy in systemic lupus erythematosus: a systematic review and meta-analysis. *Clin Rheumatol*. 2025;44(3):887-899.
7. Gözümlü P. Turkish women's employment: challenges and opportunities. *BERSAD*. 2024;2(1):109-125.
8. Türkiye İstatistik Kurumu. Ulusal Eğitim İstatistikleri, 2022. 2023.
9. Ekizer A. Health sociology and its historical development. *Journal of Selçuk Health*. 2020;1(1):1-12.
10. Aringer M, Costenbader K, Daikh D, Brinks R, Mosca M, Ramsey-Goldman R, et al. 2019 European League Against Rheumatism/American College of Rheumatology Classification Criteria for Systemic Lupus Erythematosus. *Arthritis Rheumatol*. 2019;71(9):1400-1412.
11. Bermas BL, Sammaritano LR. Fertility and pregnancy in rheumatoid arthritis and systemic lupus erythematosus. *Fertil Res Pract*. 2015;1:13.
12. Clowse ME, 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 (Hoboken)*. 2012;64(5):668-674.
13. Götmark F, Andersson M. Human fertility in relation to education, economy, religion, contraception, and family planning programs. *BMC Public Health*. 2020;20(1):265.
14. George A, Wong-Pack A, Peschken CA, Silverman E, Pineau C, Smith CD, et al. Influence of education on disease activity and damage in systemic lupus erythematosus: data from the 1000 Canadian faces of lupus. *Arthritis Care Res (Hoboken)*. 2017;69(1):124-132.
15. Dalkilic E, Tufan AN, Oksuz MF, Sahbazlar M, Coskun BN, Seniz N, et al. Comparing female-based contraceptive methods in patients with systemic lupus erythematosus, rheumatoid arthritis and a healthy population. *Int J Rheum Dis*. 2014;17(6):653-657.
16. 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.
17. Petri M, Kim MY, Kalunian KC, Grossman J, Hahn BH, Sammaritano LR, et al. Combined oral contraceptives in women with systemic lupus erythematosus. *N Engl J Med*. 2005;353(24):2550-2558.
18. Andreoli L, Bertias GK, Agmon-Levin N, Brown S, Cervera R, Costedoat-Chalumeau N, et al. EULAR recommendations for women's health and the management of family planning, assisted reproduction, pregnancy and menopause in patients with systemic lupus erythematosus and/or antiphospholipid syndrome. *Ann Rheum Dis*. 2017;76(3):476-485.
19. Teng YKO, Bredewold EOW, Rabelink TJ, Huizinga TWJ, Eikenboom HCJ, Limper M, et al. An evidence-based approach to pre-pregnancy counselling for patients with systemic lupus erythematosus. *Rheumatology (Oxford)*. 2018;57(10):1707-1720.

20. Petri M. Pregnancy and systemic lupus erythematosus. *Best Pract Res Clin Obstet Gynaecol.* 2020;64:24-30.
21. Bikdeli A, Li D, Malide M, Nouri M, Sun H, Yang Q, et al. Studying pregnancy outcome risk in patients with systemic lupus erythematosus based on cluster analysis. *Biomed Res Int.* 2023;2023:3668689.
22. Blomjous BS, Johanna I P V, Zijlstra E, Cramer K, Voskuyl AE, Bultink AIEM. Desire to have children and preferences regarding to pre-pregnancy counselling in women with SLE. *Rheumatology (Oxford).* 2021;60(6):2706-2713.
23. Wolfgang T, Anstett S, Arabelovic S. Improvement of pregnancy counselling and contraception counselling and documentation in a single rheumatology academic practice: a quality improvement project. *BMJ Open Qual.* 2022;11(4):e001871.
24. Mok CC, Wong RW. Pregnancy in systemic lupus erythematosus. *Postgrad Med J.* 2001;77(905):157-165.