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ORIGINAL RESEARCH

Thoughts on Fertility and Pregnancy in Patients with Systemic Lupus Erythematosus*

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ABSTRACT

The aim of the study was to investigate the thoughts of women with systemic lupus erythematosus (SLE) on fertility and pregnancy and to compare the data obtained with those of rheumatoid arthritis (RA) patients with different pregnancy outcomes and healthy individuals (HC). The study included 100 SLE patients, 100 RA patients and 103 HC. The study data were collected using a questionnaire that included sociodemographic characteristics, disease characteristics, pregnancy history, and thoughts about pregnancy and fertility. Percentage, chi-square, Mann-Whitney U and Kruskal-Wallis analyses were performed using SPSS. The rates of miscarriage ($p<0.001$) and stillbirth ($p=0.004$) were higher in SLE patients. It was found that 66% of SLE patients were informed about pregnancy and its risks, 47% became pregnant after the disease, and the rates were significantly higher than RA patients ($p<0.001$). It was found that 31% of SLE patients had a desire to have children (RA=22% and HC=24.3%), 37% used contraception, and most of them used the withdrawal method. The proportion of SLE patients who primarily wanted a child was significantly higher than in the RA and HC groups ($p=0.024$). As a result, most SLE patients were concerned about pregnancy and its risks, and the proportion of those who wanted a new child was higher than in the other groups. The idea of pregnancy should be questioned in SLE patients from the time of diagnosis, and education and follow-up should be provided to plan for a healthy pregnancy outcome.

Keywords: Systemic lupus erythematosus. Woman. Pregnancy. Patient Education.

Sistemik Lupus Eritematozus Hastası Kadınların Doğurganlık ve Gebelik Hakkındaki Düşünceleri

ÖZET

Çalışmanın amacı, sistemik lupus eritematozus (SLE) hastası kadınların doğurganlık ve gebelik hakkındaki düşüncelerini araştırmak ve elde edilen verileri, farklı gebelik sonuçları olan romatoid artrit (RA) hastaları ve sağlıklı bireyler ile karşılaştırmaktı. Çalışmaya 100 SLE hastası, 100 RA hastası ve 103 sağlıklı birey dahil edildi. Çalışma verileri, sosyodemografik özellikler, hastalık özellikleri, gebelik öyküsü ve gebelik ve doğurganlık hakkındaki düşünceleri içeren bir anket kullanılarak toplandı. Yüzde, ki-kare, Mann-Whitney U ve Kruskal-Wallis analizleri SPSS kullanılarak yapıldı. Düşük ($p=0,004$) ve ölü doğum ($p=0,004$) oranları SLE hastalarında daha yüksekti. SLE hastalarının %66'sının hamilelik ve riskleri hakkında bilgilendirildiği, %47'sinin hastalık sonrası hamile kaldığı ve bu oranların RA hastalarına göre anlamlı olarak daha yüksek olduğu ($p=0,001$) saptandı. SLE hastalarının %31'inin çocuk sahibi olma isteği olduğu (RA=%22 ve HC=%24,3), %37'sinin doğum kontrolü kullandığı ve çoğunun geri çekme yöntemini kullandığı saptandı. Öncelikle çocuk isteyen SLE hastalarının oranı, RA ve HC gruplarına göre anlamlı olarak daha yüksekti ($p=0,024$). Sonuç olarak, çoğu SLE hastası hamilelik ve riskleri konusunda endişeliydi ve yeni bir çocuk isteyenlerin oranı diğer gruplara göre daha yüksekti. SLE hastalarında hamilelik fikri tanı konulduğu andan itibaren sorgulanmalı ve sağlıklı bir hamilelik sonucu için eğitim ve takip sağlanmalıdır.

Anahtar Kelimeler: Sistemik lupus eritematozus. Kadın. Gebelik. Hasta Eğitimi.

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Systemic lupus erythematosus (SLE) is a chronic, multisystemic autoimmune disease characterized by a tendency to exacerbate with varying severity and course[1,2]. Although fertility is not affected in SLE, it has been reported that during pregnancy there may be an increased risk of disease exacerbation and unfavorable maternal/fetal outcomes[3,4]. Increased disease activity is the most crucial factor that increases the risk of maternal/fetal morbidity in patients with SLE, and many factors such as the presence of antiphospholipid antibodies, lupus nephritis, low serum complement, thrombocytopenia, moderate to high-dose glucocorticoid use, hypertension, and unplanned pregnancy have been associated with unfavorable pregnancy outcomes[3,5-7]. To ensure the best pregnancy outcomes, it is therefore recommended to delay conception until the disease is in remission and to be in an inactive disease state for at least six months prior to pregnancy[5].

Pregnancy is common in women with rheumatic diseases such as SLE and rheumatoid arthritis (RA), which occur in women of childbearing age. The effects of the disease on pregnancy and its consequences are different in SLE and RA. In contrast to SLE, RA shows improvement during pregnancy, and when disease activity is assessed using objective measures, about half of patients show improvement[3]. During pregnancy, in addition to the disease and exacerbations, there are also risks associated with medications used to treat rheumatologic diseases. By switching to compatible medications during pregnancy planning, it may be possible to achieve disease control and improve maternal/fetal outcomes by reducing both disease exacerbations and medication risks[8]. These findings suggest that it is important to educate women with SLE who are planning a pregnancy about the benefits and risks of taking certain medications during pregnancy[5]. Despite this, women of childbearing age with SLE are reported to receive inadequate reproductive health counseling[1,9]. The use of effective contraception is essential for timely pregnancy planning. However, when comparing SLE patients with HC, data on contraceptive use is also limited[1]. To reduce the risk of adverse maternal/fetal outcomes, family planning should be discussed with the patient and her partner as early as possible after the diagnosis of SLE. Accordingly, pre-pregnancy counseling is very important to ensure optimal pregnancy outcomes through careful risk stratification that takes into account disease activity, organ involvement, autoantibody profile, medication use and previous pregnancy outcomes[5].

Having a child is a special and sensitive topic, but for parents with these chronic diseases it is even more so. In SLE patients, it is important to manage the potential problems for both mother and child during pregnancy. As soon as a woman with the disease starts thinking about pregnancy, she should inform her doctor and take the necessary precautions for her health and that of her child. However, in order to do this, she must be informed about the issue, understand the importance of the issue, and accept this condition brought on by the disease and the disease. Acceptance of the disease allows the individual to better adapt to the limitations caused by the disease and to experience less psychological distress[10]. There are numerous studies on treatment management during pregnancy, follow-up before pregnancy, pregnancy outcomes and contraceptive use[6,11-15]. However, one study was found in which the pregnancy thoughts of SLE patients were investigated[16] and one in which the pregnancy outcomes were comparatively examined[1]. Furthermore, considering that the thoughts and behaviors of individuals about pregnancy can be affected by cultural differences, it is thought that the results of studies conducted in different societies will make important contributions to the literature. Our study was conducted to examine the thoughts of women with SLE about fertility and pregnancy, and to compare the obtained data with data obtained from rheumatoid arthritis (RA) patients with different pregnancy courses and healthy individuals (HC).

Materials and Methods

This descriptive cross-sectional study was conducted in the rheumatology clinic of a university hospital. Since clinical follow-up is recommended for SLE patients at least every 3 months in the clinic, the data collection period of the study was determined as three months. In the sample calculation based on the known universe for SLE patients, the sample size was calculated as 99 with an 80% confidence level and 5% margin of error. In addition, in the power analysis performed using the study data of Galappatthy et al. (2017); the sample size was found to be 94 with an 80% confidence level and 5% margin of error. It was aimed to have a similar number of participants in the three groups, and it was planned to include at least 100 participants in each group.

Participants of the study

The study was conducted with individuals who met the inclusion criteria and voluntarily agreed to participate in the study. The study data were collected from individuals defined as SLE (n=100) according to the SLICC 2012 criteria (17), RA (n=100) according to the ACR/EULAR 2010 Rheumatoid Arthritis Classification Criteria (18), and HC without any disease (n=103). The inclusion criteria for the study were determined as (x) presented to the rheumatology outpatient clinic within a three-month period between

the data collection dates, (xx) having been diagnosed with the disease for at least 6 months (for SLE and RA patients), (xxx) being of childbearing age (18-49 years old) and (ix) illiteracy. The HC group included the patient's relatives who had no know health problems and came to the rheumatology outpatient clinic with the patient. People with other chronic diseases and communication problems due to different languages were excluded from the study. In the study, patients with RA in whom the course and outcome of pregnancy differed between SLE and HC were considered as a control group.

Data collection

The data of the study were collected using the "Patient Information Form" and "Healthy Individual Information Form" prepared by the researchers. Data from SLE and RA patients were collected using the Patient Information Form, while data from HC were collected using the Healthy Individual Information Form. Participants in the study were asked to complete the questionnaires, and each questionnaire took approximately 15 minutes to complete.

Patient information form

The form, consisting of a total of 25 questions, asked for data on sociodemographic characteristics (age, education level, marital status, place of residence, economic status), disease characteristics (disease duration, disease activity, status of being informed about pregnancy and status of requesting information, pregnancy history after the disease) and pregnancy characteristics (menstrual pattern, pregnancy history, status of pregnancy desire, status of contraceptive method use). In addition, patients were asked to give their opinion on 7 sentences related to pregnancy with "agree, disagree, no opinion". Disease activity was categorized as active/inactive by the rheumatologist conducting the patient interview, based on the patient's current clinical condition. Pregnancy-related data were obtained based on the patient's own reports.

Healthy individual information form

The form, consisting of a total of 16 questions, was used to collect data on socio-demographic characteristics (age, education, marital status, place of residence, economic status) and pregnancy characteristics (menstrual patterns, pregnancy history, pregnancy desire, use of contraceptive methods). In addition, they were asked to give their opinion on 2 sentences about pregnancy with "agree, disagree, no opinion".

Statistical analysis

When analyzing the data, a normality analysis was performed with the Kolmogorov-Smirnov test using SPSS version 29.0.2.0. As the data did not show a normal distribution, percentages and median values (minimum - maximum) were given. Chi-square was used to analyze categorical variables, Student's t-test, Mann Whitney U (MWU) and Kruskal Wallis (KW) analyzes were performed to analyze continuous variables. In the study, a $p<0.05$ was considered significant.

Ethical considerations

Before starting the study, approval was obtained from Bursa Uludağ University Clinical Research Ethics Committee (date: 2018-02-20 and number: 2018-4/21). In addition, informed consent was obtained by explaining to the subjects what type of study it was, that they would not be harmed and that they could withdraw from the study at any time.

Results

The mean age of the SLE patients included in the study was 35.71±5.98 years, and 81% of them were married. When comparing the socio-demographic characteristics of RA patients and HC group who were included in the study as a control group, it was found that there was a difference in age ($p=0.006$) and educational status ($p<0.001$). It was found that the difference in terms of age was due to the RA group, while the difference in terms of educational status was due to the HC group (Table I).

Table I. Sociodemographic characteristics

	SLE		RA		HC		p
	n	%	n	%	n	%	
Age, years (mean±SD)	35.71±5.98		37.22±6.95*		34.53±7.29		KW=10.260 p=0.006
Level of education							
Primary school	25	25.0	35	35.0	14	13.6	
Middle school	20	20.0	22	22.0	9	8.7	χ^2=36.023
High school	32	32.0	18	18.0	26	25.2	p=<0.001
University	23	23.0	25	25.0	54	52.4	
Marital status							
Married	81	81.0	82	82.0	83	80.6	χ^2=7.718
Single	19	19.0	18	18.0	20	19.4	p=0.102
Place of residence							
Province	75	75.0	67	67.0	78	75.7	χ^2=7.878
District	21	21.0	26	26.0	14	13.6	p=0.096
Village	4	4.0	7	7.0	11	10.7	
Economic status							
Income less than expenses	28	28.0	26	26.0	36	35.0	χ^2=2.659
Income equal to expenses	69	69.0	70	70.0	65	63.1	p=0.616
Income more than expenses	3	3.0	4	4.0	2	1.9	
Total	**100**	**100.0**	**100**	**100.0**	**103**	**100.0**	

χ^2= Chi-square, KW=Kruskal-Wallis

When analyzing the distribution of fertility characteristics (Table II), 75% of SLE patients reported that their menstrual cycle was "regular" and 76% reported a pregnancy in the past. The median number of pregnancies was 2 (1-6), and a significant difference was found compared to the other groups,

which was due to lower scores in the HC (p=0.013). Of the SLE patients with a history of pregnancy, 39.5% reported miscarriages, 14.5% reported stillbirths and 7.9% reported preterm births. The rate of miscarriages (p<0.001) and stillbirths (p=0.004) was higher in SLE patients. While 20% of SLE patients reported that they had an obstacle to pregnancy, 45% of these patients reported that the obstacle was the disease (p=0.043). It was determined that 36% of SLE patients used contraception, and the method used was withdrawal at 37.8%. It was determined that 31% of SLE patients wanted pregnancy and there was no difference with the other groups (p=0.317).

Table II. Fertility characteristics

		SLE		RA		HC		Statistical analysis
		n	%	n	%	n	%	
Menstrual cycle	Regular	75	75.0	75	75.0	79	76.7	χ^2=0.560
	Irregular	20	20.0	19	19.0	18	17.5	p=0.967
	Menopause	5	5.0	7	7.0	6	5.8	
Pregnancy history	Yes	76	76.0	76	76.0	70	68.0	χ^2=2.243
	No	24	28.0	24	28.0	33	32.0	p=0.326
Number of pregnancies, median (min-max)		2 (1-6)		2 (1-8)		* 2 (1-4)		KW=8.681 **0.013**
Miscarriage		1 (1-4)		1 (1-2)		1 (1-2)		
Yes		30	39.5	13	17.1	9	12.9	χ^2=16.964
No		46	60.5	63	82.9	61	87.1	p**<0.001**
Premature birth		1 (1-2)		1 (1-1)		1		
Yes		6	7.9	2	2.6	1	1.4	X^2=4.518
No		70	92.1	74	97.4	69	98.6	p=0.104
Still birth		* 1 (1-3)		1 (1-2)		1		
Yes		11	14.5	3	3.9	1	1.4	X^2=11.290
No		65	85.5	73	96.1	69	98.6	p=**0.004**
Number of children, median (min-max)		2 (1-3)		**2 (1-3)**		2 (1-3)		KW=4.331 **0.014**
Number of children	1	29	42.6	**23**	**30.3**	28	40.6	
	2	32	47.1	**39**	**51.3**	40	58.0	χ^2=12.596
	3 and above	7	10.3	**14**	**18.4**	1	1.4	**0.013**
A condition that prevents pregnancy	Yes	20	20.0	17	17.0	10	9.7	χ^2=4.104
	No	80	80.0	83	83.0	93	90.3	**0.043**
A condition that prevents pregnancy								
Disease		9	45.0	4	23.5	-	-	χ^2=9.443
Menopause		9	45.0	11	64.7	8	80.0	0.051
Other		2	10.0	2	11.8	2	20.0	
Using a contraceptive method	Yes	36	36.0	28	28.0	37	35.6	χ^2=1.911
	No	64	64.0	72	72.0	66	64.1	0.385
Used contraceptive method								
Condom		11	29.7	8	27.6	18	48.6	
Withdrawal		14	37.8	18	62.1	10	27.0	χ^2=19.436
Intrauterine device		7	18.9	3	10.3	9	24.3	**0.003**
Tubal ligation		5	13.5	-	-	-	-	
Wanting pregnancy	Yes	31	31.0	22	22.0	25	24.3	χ^2=2.295
	No	69	69.0	78	78.0	78	75.7	0.317
Wanting pregnancy in the family	Yes	31	31.0	34	34.0	41	39.8	χ^2=1.793
	No	69	69.0	66	66.0	62	60.2	0.408

χ^2=Chi-square, KW=Kruskal Wallis

The mean disease duration of SLE patients was 10.43±5.47 years, 35% of patients described their disease as active and 29% reported systemic involvement (Table III). It was found that 47% of SLE patients were pregnant after disease diagnosis and that 28% of the 82 pregnancies after disease ended in miscarriage and 7.4% in stillbirth. When comparing these rates with those of RA patients, a significant difference was found (p=0.047). It was found that 66% of SLE patients were informed about pregnancy and its risks and 66% of them requested information about pregnancy during the disease. These rates were significantly higher compared to RA patients (p<0.001). However, 87.5% of the 88 patients who received information were patients who requested information, while the proportion of patients who did not request information but received information was only 9.8% (χ^2=120.679 and p<0.001).

Table III. Disease characteristics

	SLE		RA		Statistical analysis
	n	%	n	%	
Duration of disease, *years* (mean±SD)	10.41±5.44		9.09±6.82		t=1.510 0.066
Disease activity					
Active	35	35.0	42	42.0	χ^2=1.035
Inactive	65	65.0	58	58.0	0.383
Health team providing information about pregnancy					
Yes	66	66.0	22	22.0	χ^2=39.286
No	34	34.0	78	78.0	**<0.001**
Request for information about pregnancy during disease					
Yes	66	66.0	22	22.0	χ^2=39.286
No	34	34.0	78	78.0	**<0.001**
Pregnancy after disease	1 (1 - 6)		1 (1 - 3)		
Yes	47	47.0	19	19.0	χ^2=17.730
No	53	53.0	81	81.0	**<0.001**
Pregnancy outcome					
Live birth	53	64.6	21	84.0	
Miscarriage	23	28.0	4	16.0	χ^2=3.931
Stillbirth	6	7.4	-	-	**0.047**
Total	82	100.0	25	100.0	

χ^2=Chi-square, t=Student t test

When analyzing the distribution of opinions on pregnancy by group (Table IV), the agreement rates for the statements "Pregnancy has a negative effect on my disease" (p=0.002), "My disease has a negative effect on the baby's health" (p=0.011) and "My disease is an obstacle to pregnancy" (p<0.001) were significantly higher among SLE patients (p<0.05). The agreement rates for the statement "I can give birth to a healthy baby" were significantly different in all three

groups (p<0.001), with the difference between SLE and RA also being significant (χ^2=8.697, p=0.013). The degree of agreement with the statement "I want a baby more than anything else" was also significantly different in the three groups (p=0.024), and the difference between SLE and RA was significant in pairwise analyzes (χ^2=4.373 p=0.038).

Table IV. Thoughts about pregnancy

	SLE n	SLE %	RA n	RA %	HC n	HC %	Statistical analysis
My illness has no effect on pregnancy.							
Agree	24	24.0	20	20.0	*		χ^2=4.326
Disagree	48	48.0	38	38.0			0.115
No idea	28	28.0	42	42.0			
Pregnancy has a negative effect on my illness.							
Agree	58	58.0	33	33.0	*		χ^2=12.682
Disagree	20	20.0	30	30.0			0.002
No idea	22	22.0	37	37.0			
My illness has a negative effect on the baby's health.							
Agree	55	55.0	34	34.0	*		χ^2=9.090
Disagree	16	16.0	26	26.0			0.011
No idea	29	29.0	40	40.0			
The medicines I use are harmful to the baby.							
Agree	60	60.0	55	55.0	*		χ^2=0.900
Disagree	10	10.0	14	14.0			0.637
No idea	30	30.0	31	31.0			
My illness is an obstacle to pregnancy							
Agree	47	47.0	21	21.0	*		χ^2=15.073
Disagree	30	30.0	44	44.0			<0.001
No idea	23	23.0	35	35.0			
I can give birth to a healthy baby.							
Agree	39	39.0	22	22.0	65	63.1	χ^2=38.770
Disagree	33	33.0	33	33.0	14	13.6	<0.001
No idea	28	28.0	45	45.0	24	23.3	
I want a baby more than anything else.	38	38.0	27	27.0	19	18.4	χ^2=11.225
Agree	47	47.0	48	48.0	59	57.3	0.024
Disagree	15	15.0	25	25.0	25	24.3	
No idea							

* Healthy individuals were not asked. χ^2=Chi-square

Discussion and Conclusion

Pregnancy in SLE patients is considered high risk due to the adverse effects of the disease and treatments[5]. Therefore, the EULAR working group has developed recommendations for the management of SLE patients seeking pregnancy, including pre-conception counseling and risk stratification[19]. The most critical issue in the management of SLE pregnancies is the integration of pre-conception counseling into outpatient care. Preconception counseling is important for planning the pregnancy and ensuring low disease activity prior to conception to ensure the best pregnancy outcome and minimize the risk of exacerbation during pregnancy[4]. However, there are studies showing that low disease activity during pregnancy in SLE patients increases significantly after delivery, especially in the first six months[6,15,20]. Therefore, to be able to speak of a successful pregnancy outcome, it is recommended to control disease activity throughout pregnancy as well as to perform close follow-up in the postpartum period and during lactation to reduce the risk of maternal morbidity[6,11,20].

If pregnancy is planned, most women with SLE can successfully conceive and measures can be taken to reduce the risk of adverse maternal/fetal outcomes[2,12]. In women with inactive, mild or moderate disease at the time of conception, 80% of pregnancies are without complications[8,21]. In women with SLE, compared to HC; the rate of preeclampsia is at least three times higher, preterm birth is two to three times more common, the risk of low birth weight is two times higher, and these complications are reported to be strongly associated with more active SLE[8]. However, 32.7% of SLE patients with low disease activity experienced an exacerbation of the disease during pregnancy, 17.3% had pre-eclampsia, 20% had fetal loss and 17.8% had a preterm birth[5]. Galappatthy et al (2017) found no significant difference between the number of pregnancies (79, 80 and 85 respectively) in 38 SLE patients, 38 RA patients and women without chronic disease (p>0.05). Of the pregnancies that occurred after SLE diagnosis, 80% were unplanned pregnancies, and the pregnancy rate after diagnosis was significantly higher in SLE (25%) than in RA (10%) (p<0.05). Fetal losses, preterm births and low birth weight were significantly higher in SLE patients than in RA patients and individuals without chronic disease (p<0.05)[1]. In our study, no difference was found in the number of pregnancies between RA and SLE patients, but the number of pregnancies after the disease was higher in SLE patients (47%) (p<0.001). Among SLE patients with a history of pregnancy, 39.5% had a history of miscarriage (p<0.001), 14.5% had a history of stillbirth (p=0.004), and 7.9% had a history of preterm birth (p=0.104). It was found that the rates of miscarriage and stillbirth were significantly higher in SLE patients. Of the 82 pregnancies that occurred after the disease in SLE patients, 28% had a miscarriage and 7.4% ended in stillbirth. When comparing these rates with those of RA patients, the difference was significantly higher (p=0.047). However, the number of living children was significantly higher in RA patients. This result is probably due to the higher average age of RA patients.

Maintaining adequate contraception in SLE patients is an important aspect of health care. When effective contraception is used in patients with SLE, it will be possible to prevent pregnancy complications, including maternal mortality, premature birth, and fetal abnormalities due to teratogenic exposure. However, studies suggest that an inadequate proportion of SLE patients receive contraceptive counseling, which may result in patients not adequately understanding their contraceptive choices[22]. The guidelines emphasize that recommendations for effective contraception should be individualized to prevent drug-induced fetal abnormalities due to increased adverse pregnancy outcomes and teratogenic therapies. However, key recommendations include the use of long-acting reversible contraceptives such as intrauterine devices in patients at high risk of thrombosis or with active SLE and the avoidance of estrogen-containing contraceptives[3,22,23]. In the study by Galappatthy et al. (2017), the use of modern contraceptive methods was significantly lower in SLE patients compared to RA patients and healthy individuals of the same age (25.6%, 33% vs. 56.4%; $p<0.01$)[1]. In the study conducted by Dalkılıç et al. (2014), it was found that 20.3% of SLE patients used contraceptive methods, with the most commonly used methods being withdrawal (36%) and condom (28.3%)[14]. Mobini et al. (2021) found that 74.4% of SLE patients used contraceptive methods in the past three months, with the most common contraceptive method being withdrawal, followed by other permanent methods and barrier methods[23]. Similar to these results, 36% of SLE patients in our study reported using contraceptive methods, and the most frequently mentioned contraceptive methods were withdrawal and condoms. While there was a difference between the groups in terms of methods used, it was striking that tubal ligation, which is an effective and permanent method, was only reported by SLE patients. Prevention of unplanned pregnancies in SLE patients depends on the reliability of the contraceptive method used, and the risk of failure with the withdrawal method is quite high[14,23]. Again, the annual failure rate for the most commonly used condoms is reported to be around 13%. In a follow-up study conducted by Sims et al. using a web-based patient education and follow-up system, it was found that those who became pregnant despite not thinking about pregnancy did not use an effective method, while none of the women who used an effective contraceptive method became pregnant[13]. Therefore, it is believed that educating SLE patients about the use of correct and reliable contraceptive methods is as important as educating them about pregnancy and its risks.

Unplanned pregnancies in women with SLE can have serious consequences for mother and child[23]. Unplanned pregnancies in SLE women have been reported to occur primarily in those who do not actively engage in family planning or contraception during active disease or while taking teratogenic medications[21]. While this suggests that SLE patients are not well counseled, measures such as appropriate preconception counseling, medication adjustment, strict disease control prior to pregnancy, and intensive monitoring during and after pregnancy are essential for optimal pregnancy outcomes[2,3,5,20]. Blomjous et al. (2021) found that SLE patients preferred to receive information about pregnancy from a healthcare professional (rheumatologist and/or gynecologist) (81%) and with their partner (69%) immediately after SLE diagnosis (53%)[16]. Brites et al. (2021) reported that 64.8% of women with SLE had received reproductive health information and 80.6% had received counseling on contraceptive methods. The striking finding of the study was that most patients who did not receive counseling had not proactively requested it from their physicians. This finding underscores the need for the healthcare team to systematically inform and counsel all women with SLE of childbearing age[9]. In our study, 16% of patients reported that they had postponed their desire to have children after pre-conception counseling because of the risks. Although our study found that 66% of SLE patients received information about pregnancy and its risks, it is an important finding that the patients who received information were also the ones who requested it. Even if the patient does not request information, healthcare professionals should be aware of the pregnancy and address the idea of pregnancy in order to make plans to prevent negative pregnancy outcomes.

Adverse maternal/fetal outcomes during pregnancy may lead to negative feelings in SLE patients[15,24]. Therefore, SLE patients' concerns about pregnancy go beyond the ability to become pregnant and include questions about the heritability of the disease, the ability to maintain a successful pregnancy, the effects on the fetus, the outcome of the pregnancy, and the risks of the medications to the child[3,25]. In addition to feelings of guilt, stigma and loneliness, in which psychological factors may play a key role, SLE patients need special support because they are concerned about their physical and functional abilities as mothers and their ability to care for themselves and their children and family[25]. There are few studies examining SLE patients' views on pregnancy. Blomjous et al. (2021) reported in a study of 95 SLE patients that 20% of women with SLE thought that SLE had a negative impact on their fertility, while 26% had no idea about the impact of SLE on fertility[16]. In our study, agreement rates to the statements "Pregnancy has a negative effect on my disease," "My disease has a negative effect on the baby's health" and "My disease is an obstacle to pregnancy" were significantly higher among SLE

patients ($p<0.05$). However, agreement with the statement "I want a baby more than anything else" was higher among SLE patients ($p=0.024$). Based on this result, it appears that patients desire to have a baby despite knowing the negative maternal and fetal outcomes of pregnancy.

For patients with SLE who are considering starting a family, the rheumatologist/nurse is the best source of information and support. Patients should be in remission before considering pregnancy. However, they should have an individualized treatment plan that maximizes the chances of a healthy pregnancy and baby and includes appropriate counseling about the risks and benefits of the disease and medications. In our study, SLE patients were found to have more miscarriages and stillbirths than RA and HC patients. Although most SLE patients were informed about pregnancy and its risks, the desire to have a new baby was higher in SLE patients than in other groups. The fact that the majority of patients who reported using contraception were using an unreliable method shows the need for education. Determining whether SLE patients are considering pregnancy is very important in guiding treatment and disease progression, and patient education in this regard is crucial.

Limitations

Our study contributes to the limited literature on SLE patients' thoughts about pregnancy, but also has several limitations. The study included a relatively limited number of patients, which limits the generalizability of the results. Further studies with larger sample groups could improve the accuracy of the results. However, the inclusion of retrospective data (e.g., information on pregnancy) and some patient-reported data (e.g., disease activity, contraceptive use) makes it difficult to fully establish causal relationships. The socio-cultural characteristics of the patients, their psychosocial status and their level of education in relation to pregnancy planning were not investigated in detail. The impact of these factors on disease management and pregnancy thoughts needs to be investigated more comprehensively.

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