The Open Rheumatology Journal
ISSN: 1874-3129
DOI: 10.2174/0118743129469927260621172030, 2026, 20, e18743129469927

RESEARCH ARTICLE **OPEN ACCESS**

Exploring Needs and Barriers to Pregnancy Counselling in Women with Systemic Lupus Erythematosus: Insights for Developing Interventional Strategies

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Abstract:

Introduction: Many women with systemic lupus erythematosus (SLE) still face unmet needs in pregnancy counselling, which can influence their relationships, reproductive choices, and overall mental health. We aimed to assess pregnancy counselling needs in women with SLE, identify clinical and psychosocial barriers and facilitators, and explore strategies to inform the development of targeted interventions to improve counselling and support.

Methods: We conducted a focus group study that included women of reproductive age with SLE and healthcare professionals. Participants were recruited through purposive sampling from a single healthcare network. We analyzed the data thematically using grounded theory.

Results: Twenty-four women with SLE and 14 healthcare professionals participated in 11 unique focus groups that lasted 1 hour each. We identified three overarching themes among women with SLE regarding pregnancy planning: anxiety, confusion, and frustration. Similarly, three themes emerged among healthcare providers: timing, communication, and resources. Participants suggested potential strategies to address these barriers, which included facilitating access to psychosocial support during pregnancy, developing educational tools tailored to women with SLE, providing a checklist of questions for medical encounters, and implementing a multi-disciplinary approach, such as reproductive rheumatology clinics, when caring for women with SLE.

Discussion: Consistent with prior studies, women with SLE reported anxiety, unclear information, and inconsistent counselling, while our findings add the integrated perspectives of SLE patients at different reproductive stages and clinicians. This revealed important communication gaps and the need for clearer, earlier, and more patient-centered reproductive guidance. Limitations include recruitment from one province and a predominantly well-educated sample. Future research should evaluate multidisciplinary, educational, and psychosocial interventions to improve counselling and support.

Conclusion: This study highlights persistent challenges in pregnancy counselling for women with SLE and identifies shared gaps across patients and clinicians. Our findings underscore the need for more coordinated, multidisciplinary reproductive care and provide practical strategies to guide future improvements in SLE pregnancy outcomes.

Keywords: Systemic lupus erythematosus, Pregnancy, Qualitative research, Focus groups, Quality of life, Health care professionals.

Received: December 15, 2025
Revised: March 03, 2026
Accepted: April 02, 2026
Published: July 01, 2026

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Cite as: Farhat R, Neville A, Dayan N, Da Costa D, Bernatsky S, Vinet E. Exploring Needs and Barriers to Pregnancy Counselling in Women with Systemic Lupus Erythematosus: Insights for Developing Interventional Strategies. Open Rheumatol J, 2026; 20: e18743129469927. http://dx.doi.org/10.2174/0118743129469927260621172030

1. INTRODUCTION

Pregnancy presents unique challenges for individuals with systemic lupus erythematosus (SLE), which is a chronic autoimmune disease characterized by multi-systemic inflammation and immune dysregulation [1]. SLE predominantly affects women of reproductive age, with Canadian data estimating a prevalence of approximately 1 in 2000 individuals, of whom 90% are females [2, 3]. Although advances in disease management have expanded reproductive options, pregnancy in individuals with SLE remains high risk, requiring careful planning and multidisciplinary care to optimize disease control while on pregnancy-compatible immunosuppressives [3, 4]. Despite disease quiescence, approximately 20% of SLE pregnancies experience placenta-mediated adverse outcomes, such as preeclampsia/eclampsia, preterm birth due to placental insufficiency, fetal growth restriction, and fetal death [4, 5]. The risk is substantially higher in those with positive antiphospholipid antibodies [6]. Women with positive anti-Ro antibodies face the added concern of neonatal lupus, in particular, complete atrioventricular (AV) block, requiring additional fetal monitoring [7] Furthermore, there is an elevated risk of disease flare during both pregnancy and the postpartum period, in which SLE flares can impair the maternal ability to care for a newborn [8, 9].

Given that reproductive health considerations in SLE women differ from those in the healthy population, evidence-based recommendations and guidelines have been established to address these concerns and to optimize pregnancy outcomes in women with rheumatic diseases [10-12]. Despite advances in treatment and family planning, significant gaps still exist, particularly regarding medication safety, personalized risk stratification, and integration of pregnancy counselling into routine rheumatology care, which contribute to uncertainty in reproductive decision-making [9]. As a result, many women with SLE experience unmet needs in pregnancy counselling, which can influence their relationships, reproductive choices, and overall mental health [9, 13]. Notably, a survey of 124 women with SLE found that 21% of SLE women deliberately chose not to have children due to concerns about the impact of pregnancy on both maternal disease and fetal health [14].

While prior research has explored pregnancy-related concerns in SLE, existing studies have typically focused on either patient or healthcare provider perspectives, neglecting a holistic, bidirectional understanding of the patient-provider dynamic [15-17]. Moreover, most studies have not adequately addressed the distinct needs of women with prior pregnancies compared to those contemplating pregnancy. To our knowledge, this is the first study to comprehensively explore pregnancy counselling in SLE by integrating the perspectives of women at different reproductive stages and healthcare professionals within a universal healthcare system, using focus group methodology to identify strategies to address existing gaps in care. By identifying key barriers and facilitators to pregnancy counselling in women with SLE, our findings aim to inform targeted interventions, advocate for specialized reproductive rheumatology services, and ultimately improve reproductive health for women with SLE.

2. MATERIALS AND METHODS

2.1. Participant Selection and Recruitment

Participants were recruited through purposive sampling from community-based practices, as well as from peripheral and tertiary care centers from McGill University’s health network, which covers 63% of the Quebec landmass, encompassing communities including diverse ethnicities, including Indigenous (Inuit and Cree), Black, Asian, Hispanic, as well as Caucasian (both Francophone and Anglophone). Purposive sampling was conducted to capture a range of perspectives, with criteria including pregnancy status (contemplating *vs.* pregnant/recently pregnant), age (within reproductive range), ethnicity, community of residence (urban *vs.* rural), and disease duration. The main goal of purposive sampling is to focus on the characteristics of a population that are of interest and will best enable answering the research question.

SLE women of reproductive age (*i.e.*, 18-45 years) who met ≥4 American College of Rheumatology (ACR) classification criteria were approached by the research team [18]. Similarly, healthcare professionals within the McGill healthcare network who were in close clinical contact with SLE patients and had at least 2 years of relevant clinical experience in rheumatology, obstetrics/gynecology, or nursing were identified and invited to participate in the study. Patients with SLE who were not able to provide informed consent and who did not speak English or French were excluded. To facilitate attendance, we provided childcare assistance, a 50 Canadian dollar gift card for participation, and reimbursement for travel and parking expenses to all participants. While incentives were intended to reduce participation barriers and encourage participation, they were unlikely to have influenced the content of the focus group discussions or their interpretation. All invited participants who agreed to attend completed the study; no dropouts or refusals were recorded. We therefore did not encounter non-participation during data collection.

2.2. Data Collection

Participants were divided into 3 groups: 1) women with SLE who were contemplating their first pregnancy or trying to conceive for the first time; 2) women with SLE who were pregnant or had recently been pregnant (≤2 years to balance recall accuracy with capturing recent experiences); and 3) healthcare professionals (*i.e.*, nurses, rheumatologists, obstetricians-gynecologists, including maternal-fetal medicine specialists). Non-mixed focus groups of 2 to 6 participants, with sessions comprised of only one type of participant, were carried out, lasting approximately 1 hour each. The discussions during the focus groups were held in either English or French, based on participants' language of preference. Focus groups were moderated by AN, a research coordinator experienced in qualitative research methods, who was not involved in the direct clinical care of participants. No prior relationship was established with participants before the study, although all were informed that the moderator was a researcher interested in pregnancy counselling in SLE. AN moderated each focus group following a semi-structured format, where the discussions were guided by, but not limited to, predetermined questions. The guide for the focus group questions was developed based on a review of the literature and our research objectives [19, 20]. The full focus group guide is available in Supplementary Material. During the sessions, the moderator created a non-threatening and supportive climate that encouraged all group members to share their views, presenting questions in an unbiased way, remaining nonjudgmental (verbally and nonverbally) to participants' responses, and encouraging involvement and interaction among all members. All focus group sessions were audio-recorded and transcribed verbatim, with name substitution to mask participant identity.

2.3. Data Analysis

Three investigators (RF, AN, EV) independently read all transcripts to familiarize themselves with the data. The analytic team had expertise in rheumatology and reproductive care (EV, RF) and qualitative research (AN). Reflexivity, defined as awareness of how the research team's backgrounds and assumptions may influence the discussions and interpretation, was actively maintained through structured team debriefings after each focus group session to discuss initial impressions and emerging ideas, as well as through independent coding and regular team discussions during analysis to compare interpretations, refine codes, and settle potential biases. Discrepancies were resolved by consensus and revisiting participants' original transcripts. Focus group transcripts were reviewed using the constant comparative method and analyzed thematically using analytic techniques informed by constructivist grounded theory to develop an in-depth conceptual understanding of participants' experiences to identify emergent themes rather than to generate theory. Analysis occurred concurrently with data collection to allow emerging insights to guide ongoing data interpretation. Transcripts were then divided into segments of varying sizes based on the required segment length to understand the context of the pertinent ideas and concepts. The investigators derived initial codes independently through open coding, then the research team met regularly to compare interpretations and refine codes. Related codes were subsequently grouped into broader categories through axial coding, with discussions focused on identifying relationships and patterns across themes. Data coding and thematic analysis were performed manually without the use of qualitative software. After the first 2 sessions were completed and following each subsequent session, transcripts and moderator notes were reviewed and analyzed for newly emergent themes. We stopped scheduling group sessions and data collection when thematic saturation was achieved, indicating that no new themes emerged from focus groups. Quantitative participant characteristics were analyzed using descriptive statistics to contextualize the qualitative findings. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (available in Supplementary Material) [21].

Ethics approval was obtained from the McGill University Health Centre (MUHC) research ethics board, project number 2017-2653. All subjects gave written informed consent before participation. This study was supported through funding from a Canadian Rheumatology Association - Canadian Initiative for Outcomes in Rheumatology Care (CIORA) grant.

3. RESULTS

Eleven non-mixed focus groups were held between August 2017 and November 2018, each with 2 to 6 participants, lasting approximately one hour. In total, 24 SLE women and 14 healthcare professionals participated in the focus groups.

Among women with SLE, 10 were contemplating their first pregnancy, whereas 14 were already pregnant or had been recently pregnant at the time of the study. Of these 14, two were experiencing their first pregnancy. The characteristics of these women are presented in Table **1**.

Among SLE women who experienced at least one pregnancy, only 59% of pregnancies resulted in a live birth, while 22% ended by a miscarriage, 8% by an induced abortion, and 3% as a stillbirth (Table **2**). Moreover, 57% (8/14) of pregnant SLE women never had pregnancy counselling before conception, whether from a rheumatologist, obstetrician/gynecologist, or any other clinician.

Table 1. Characteristics of SLE women's groups.

	Pregnant SLE Women (n=14)	**SLE Women Contemplating Pregnancy (n=10)**
Mean age, years (SD)	33.4 (4.9)	33.3 (5.8)
Mean disease duration, years (SD)	12.4 (6.4)	11.3 (6.5)
Marital status, n (%)		
Married/partnered	11 (79)	5 (50)
Single	3 (21)	5 (50)
Ethnicity, n (%)		
Caucasian	6 (43)	4 (40)
Hispanic/Latina	2 (14)	2 (20)
Black	3 (22)	0 (0)
Asian	1 (7)	2 (20)
Other	2 (14)	2 (20)
Education, n (%)		
High school	3 (21)	0 (0)
College/Undergraduate	9 (64)	7 (70)
Master/Doctorate	2 (14)	3 (30)
Employment, n (%)		
Working	7 (50)	7 (70)
Homemaker	3 (21)	0 (0)
Student	2 (14)	1 (10)
Sick leave Other	1 (7) 1 (7)	2 (20) 0 (0)
Comorbidities, n (%)		
Hypertension	4 (27)	2 (20)
Kidney disease	3 (21)	2 (20)
Diabetes	0 (0)	0 (0)
Dyslipidemia	1 (7)	2 (20)
Blood clotting disorders	2 (14)	2 (20)
Joint deformities	1 (7)	0 (0)
Mental Illness	1 (7)	1 (10)
Medication exposure in the past 2 years, n (%)		
Pregnancy compatible		
Prednisone	7 (50)	5 (50)
Antimalarials	11 (79)	10 (100)
Azathioprine	3 (21)	3 (30)
Anticoagulants	4 (29)	1 (10)
Pregnancy incompatible		
Methotrexate	1 (7)	1 (10)
Mycophenolate mofetil	3 (21)	6 (60)
Cyclophosphamide	0 (0)	0 (0)
Belimumab or rituximab	0 (0)	1 (10)

Table 2. Obstetrical history of SLE women groups.

	Pregnant SLE Women (n=14)
Mean number of pregnancies (SD)	2.6 (1.2)
Pregnancy outcomes (Total pregnancies n=37)	
Live births, n (%)	22 (59)
Miscarriage, n (%)	8 (22)
Stillbirth, n (%)	1 (3)
Therapeutic abortion, n (%)	3 (8)
Not specified	3 (8)
Consulted doctor before conception, n (%)	
Yes	6 (43)
No	8 (57)

Among the healthcare professionals in the focus groups, more than half (8/14) were rheumatologists, while others were obstetrician-gynecologists (4/14, including 3 maternal-fetal medicine specialists), and nurses (2/14). The characteristics of healthcare professionals are shown in Table **3**.

The focus group discussions covered a range of topics related to reproductive health and pregnancy counselling for individuals with SLE. Some of the domains covered were related to barriers and facilitators in accessing counselling, primary resources for pregnancy and postpartum information, personal concerns about pregnancy, the postpartum period, breastfeeding, experiences with reproductive counselling, support systems before, during, and after pregnancy, and potential strategies to overcome counselling barriers.

3.1. Women with SLE

From the discussions, we identified three overarching themes in the SLE groups relating to their disease and pregnancy/postpartum: anxiety, confusion, and frustration. Themes and subthemes with supporting illustrative quotations are presented in Table **4**.

3.1.1. Anxiety

Participants feared their disease would affect the health of their offspring and prevent them from breastfeeding and/or caring for a newborn. They discussed concerns over passing lupus along to their children. They also worried over the anticipated extra stress and fatigue associated with pregnancy and expressed concerns that the stress could cause a lupus flare. They expressed concerns about the possibility of flare-ups when tapering or modifying medications before conception and/or during pregnancy, but trusted their physicians' ability to manage disease activity. The systematic categorization of their pregnancy as "high risk" was verbalized as a source of anxiety. Moreover, many women sought information on the internet, which was perceived by many as "extremely scary."

"[…] everybody's done some form of research, and it's just knowing the risks, that what could the baby have, we can probably give lupus to the child too. That's something that stays in your mind." (SLE patient contemplating pregnancy)

3.1.2. Confusion

The consensus was that available information on pregnancy and SLE was limited and often unclear. This was particularly evident on the forums found on the internet, which were viewed as unreliable and misleading. While participants considered their rheumatologists to be the primary providers of information, they perceived that the counselling and information provided about pregnancy were vague until they voiced their intention to conceive.

Table 3. Characteristics of healthcare professional group.

	Healthcare Professional Group (n=14)
Specialty, n (%)	
Rheumatologist	8 (57)
Maternal-Fetal Medicine Specialist	3 (21)
Obstetrician-Gynecologist	1 (7)
Nurse	2 (14)
Mean years practising (SD)	13.9 (11.6)
Academic Position, n (%)	
Assistant Professor	5 (36)
Associate Professor	5 (36)
Professor	2 (14)
Nurse	2 (14)
Mean years in position (SD)	9.9 (9.3)
Sex, n (%)	
Male	7 (50)
Female	7 (50)
Mean age, years (SD)	46.4 (10.2)
Marital Status, n (%)	
Married/Common Law	10 (71)
Single	4 (29)
Children, n (%)	
Yes	8 (57)
No	6 (43)
Ethnicity, n (%)	
Caucasian	9 (64)
Hispanic/Latino/Latina	0 (0)
Black	0 (0)
Asian	2 (14)
Other	3 (21)

Table 4. Themes and subthemes of women with SLE with supporting illustrative quotations.

Theme	Subtheme / Assertion	Speaker Identifiers	Illustrative Quotations
Anxiety	Fear of the disease effect on newborn care	SLE participant contemplating pregnancy #8	“So I also think, when I have a child, if I have pain and all that, how will I hold them in my arms and take care of them? It’s something that worries me.”*
	Fear of transmitting lupus to the child	SLE participant contemplating pregnancy #10	“I also read that you can pass it on to the child, but there isn’t much information about it. It’s just a possibility, but I haven’t found any other information.”*
	Concerns over stress or medication modifications causing flares during pregnancy	SLE participant contemplating pregnancy #1	“I think that’s one of my major concerns, is stopping medication and being able to be off medication and try and get pregnant? Cause, like what if you can’t stop the medication? What if you stop it and it’s like ‘no you’re not healthy enough, you need to go back on’ and then it’s like another year of waiting”
	Disease is systematically categorized as “high risk”	SLE participant contemplating pregnancy #7	“It is painted as being tough for us. You know you talk to the doctor, and they say you know you're going to be high risk! Like nothing's even started yet, and they're like you're going to be high risk!”
	The Internet portrays as pregnancy in SLE “extremely scary”	SLE participant contemplating pregnancy #2 Pregnant/recently pregnant SLE participant #6	“The doctors for me are the main source; every time I read the internet, it’s a bit scary or overwhelming” “If you Google lupus and pregnancy, it’s like I’m going to die, the baby is going to die, everything is going to be dramatic.”*
Confusion	Limited and unclear information about SLE and pregnancy	SLE participant contemplating pregnancy #4	“I feel like the information out there is not super clear, like there is RA, lupus, mixed connective tissue disease, and I don’t know if there’s any difference with those three pregnancy-wise.”
	Forums viewed as unreliable and misleading	SLE participant contemplating pregnancy #10	“I have already been [on a forum] but I always wonder if the information is true or not because it has never been verified, so you can rely on it [...].”
Frustration	Family pressure is not taken seriously by the support system	SLE participant contemplating pregnancy #4	“I don’t even tell my family I have lupus because they don’t know what it is, to them, it’s something, this unknown condition, they don’t know what would be the outcome in fact.”
	Being advised to plan pregnancy at quiescence	SLE participant contemplating pregnancy #9	“A year and a half of preparation, meaning we had waited for my lupus to be 100% in remission. We switched medications. I had been on one I couldn’t take while pregnant, so we made the change, and despite all that, there was still a flare-up.”*
	Falls outside cultural/personal value system	SLE participant contemplating pregnancy #7	“That was something else I was going to bring up, and it was kind of, I just felt like it was, I understand it's pushed on you if you say, they ask, ‘are you sexually active? Yes? Well, you better be on contraceptives.’ It was kind of umm, I don't feel like that's the only option to tell me you know. Umm, so I didn't like that, I mean, personally, this is my viewpoint. Like I'm a practicing Catholic, and so for me and for what I believe in, I'd much rather not be on it.”
	Forgetting questions / not having enough time during appointments	SLE participant contemplating pregnancy #2	“Sometimes I leave, and I’m like, oh shoot, I should have asked her that question, and next time I come in, I forget about it.”
	Acting as intermediaries between multiple specialists	Pregnant/recently pregnant SLE participant #12	“So I feel like they both, [my high-risk obstetrician] and [my rheumatologist], had been here forever so they both trusted each other so [my rheumatologist] would ask me what does [your high-risk obstetrician] say and I'd say [my high-risk obstetrician] said this and [my high-risk obstetrician] would ask me what does [your rheumatologist] think, well [my rheumatologist] thinks this and then they would just both go that way.”

Note: * Illustrative quotations from SLE participants were translated from French to English where applicable.

“I’ve already gone [online], but I always wonder if the information is true or not because it’s never been verified. So, you can’t rely on it [...]” (SLE participant contemplating pregnancy)

3.1.3. Frustration

Participants were frustrated that their concerns and anxiety were not taken seriously by members of their support system, as few of them understood what SLE was and how it impacted pregnancy. Being advised to plan a pregnancy at a time of disease quiescence, which was not always feasible, was also frustrating. This can fall outside their personal narrative or cultural value system. Pregnancy planning was a substantial stressor, not always appreciated by loved ones or doctors who seemed to remain focused on stabilizing the disease as per the patients. Furthermore, not remembering some of the questions or not having time to ask them all during medical encounters was a common source of frustration among participants. Many women with SLE also found it frustrating to act as intermediaries between their healthcare providers to coordinate and manage communication across multiple sub-specialists.

“I have a great relationship with my family, but I don't think they fully understand everything I'm going through right now.” (Translated from French - SLE patient contemplating pregnancy)

3.2. Healthcare Professionals

Likewise, three themes among healthcare professionals emerged: timing, communication, and resources. All emergent themes and subthemes with illustrative quotations are shown in Table **5**.

Table 5. Themes and subthemes from healthcare professionals with supporting illustrative quotations.

Theme	Subtheme / Assertion	Speaker Identifiers	Illustrative Quotations
Timing	Importance of pregnancy counselling	Rheumatologist #7 Rheumatologist #1	“Like many physicians, the last thing we want to get is the phone call, usually on a Friday afternoon, that the patient is already pregnant, so pre-pregnancy counselling I think, is the most important issue.” “[...] it’s all about planning and time. Making them understand that if their disease is quiescent, then their pregnancy outcomes are favorable.”
	Early discussions help set expectations	Rheumatologist #3	“The adequate planning ahead of time, I think that’s very important issue they need to know that there is planning that needs to occur before they get pregnant, related to how to manage their medications ahead of time, what’s going to happen to their condition, what are the risks associated with pregnancy, associated with their medical condition and medication, risk to the foetus and baby.”
Communication	Need for ongoing discussions about pregnancy	Rheumatologist #6 Rheumatologist #5	“[...] but if they still haven’t or still planning a pregnancy in the future, then you open up the discussion. I open it up from the time of diagnosis, and then you probably have to reintroduce different concepts, like follow-up visits.” “I think that very often even if the first time they say ‘no, I’m not planning a pregnancy,’ it’s a discussion that you have to bring up again.”
	Conflicting advice from different healthcare providers	Nurse #1	“[Patients] get different things told to them [...] [physicians] don’t always see eye to eye.”
	Obstetricians unacquainted with rheumatologists affecting co-management	Maternal-fetal medicine specialist #4 Maternal-fetal medicine specialist #1	“I don't know about you, but I don’t even really know face-to-face the rheumatologists … it makes discussions easier.” “We don’t see [the rheumatologists] [...] it makes discussions easier [in reference to seeing the rheumatologists].”
Resources	Limited time during appointments	Rheumatologist #8	“Time is a barrier… you’re telling them about their medications, their disease, trying to reassure them about side effects, and then having to bring up this whole pregnancy thing, it can be a half-hour talk in itself.”
	Lack of up-to-date educational material and reliable resources	Rheumatologist #5 Rheumatologist #7	“[...] until a year ago, there was no pamphlet from the Arthritis Society on pregnancy… what they had was old and out of date.” “It doesn’t really have anything on pregnancy” (when asked about RheumInfo)
	Shortage of healthcare providers constrains care	Maternal-fetal medicine specialist #2 Rheumatologist #7	“I guess one of the problems here is a lot of patients don’t have a family physician or don’t have anyone following them regularly” “A lot of our patients don’t have family doctors, so that is a real starting point, and family doctors are knowledgeable about a lot of these issues.”

All healthcare professionals who participated in the focus groups spoke English; therefore, the illustrative quotations did not require translation.

3.2.1. Timing

Healthcare professionals concurred with the importance of pregnancy counselling to determine disease activity, assess the safety of pregnancy, and manage patient anxiety. Moreover, there was a unanimous agreement that conversations about conceiving are mostly efficient when they happen as early as possible to ensure patients have well-informed pregnancy and postpartum expectations with SLE.

“Making sure that the patients understand the expectations of the disease effects on the pregnancy, the medications that they are on, whether they are safe, and what’s going to happen in the postpartum period so that they have a clear understanding of whether right now it’s a safe time to get pregnant […]” (Rheumatologist)

3.2.2. Communication

The importance of ongoing discussions about pregnancy planning at regular intervals was very evident among the healthcare participants. In addition to that, they stated that patients often receive conflicting information regarding pregnancy and their disease from different healthcare providers. Obstetricians noted that they are unacquainted with most rheumatologists, and specifically knowing the treating rheumatologist makes co-management of SLE pregnancies easier by facilitating communication.

“They get conflicting information from other doctors, so it’s a person of authority and a person of authority and a person of authority all giving different information, so it’s hard, who do you want to trust.” (Rheumatologist)

3.2.3. Resources

Participating healthcare professionals recognized that access to information resources for SLE patients was not always available or reliable. For instance, access to care in Canada could be challenging for some patients due to the restricted availability of appointments. Participants attributed this to the shortage of healthcare providers, namely family doctors and specialists. Furthermore, appointments with patients have a limited duration; hence, addressing all questions or concerns is unattainable in one appointment, and scheduling future appointments could take months. Lastly, they acknowledged the scarcity of educational materials that are tailor-made to address the unique needs and concerns associated with pregnancy in individuals with SLE.

“I feel like in our clinic we don’t have any pamphlets really, […].” (Rheumatologist)

3.3. Strategies to Address the Barriers and Needs of Pregnancy Counselling in Women with SLE

Based on these discussions, we also identified potential strategies to address the needs and barriers in pregnancy counselling of women with SLE. Details on these themes and strategies are provided in Table **6** along with participant illustrative quotations.

3.3.1. Psychosocial Support

SLE participants noted that access to psychosocial support before, during, and after pregnancy would be beneficial to address their mental health, along with their physical health. They mentioned the importance of learning techniques to deal with stress and anxiety associated with pregnancy.

“A social worker or a psychologist who can accompany us in it because we have decisions to make, and the family is biased in their perception of the whole situation and can be frustrated about it.” (Translated from French - SLE patient contemplating pregnancy)

Table 6. Strategies to address barriers and needs of pregnancy counselling in women with SLE with supporting illustrative quotations.

Theme	Subtheme / Assertion	Speaker Identifiers	Illustrative Quotations
Psychosocial support	Importance of physical and mental health support	Rheumatologist #1	“I also think one of the barriers I think part of this team discussion is psychological resources for patients. […] So yes, I can give her a lot of information, but there are no resources. I tried to call - psych resources with knowledge of her condition would be helpful, but there’s none.”
	Importance of learning techniques to deal with stress and anxiety associated with pregnancy	Pregnant/recently pregnant SLE participant #7	“It feels like when you’re pregnant you have so many appointments... you’re stressed, but at the same time you’re trying to manage all the emotions and all the fear you have.”*
Educational tools	Booklets and pamphlets as a reference before, during, and after appointments	Maternal-fetal medicine specialist #2 Rheumatologist #2	“Specifically for SLE, we don’t have any printed information that we give them; we discuss it with them.” “Literature, written things, pamphlets, books you can refer them to.”
	Dedicated programs for sharing personal experiences	SLE participant contemplating pregnancy #8	“Honestly, I was thrilled when the project was proposed to me, because it would be great if something like this could exist as a program, for example, where interested people could sign up... something organized by the hospital so that we can be sure and feel confident.”
	Reliable websites with answers to common questions	Rheumatologist #2 Pregnant/recently pregnant SLE participant #11	“We should use more online stuff. […] I’m sure as soon as a patient is told you have arthritis or SLE, they go online, if they are thinking about getting pregnant, they’ll search lupus and pregnancy, drugs [...] need an online website” “The frequently asked questions could be nice like maybe there's a site for high-risk Lupus patients that instead of me Googling, I could just go find it on that site if it's not there.”
	Knowledge translation and exchange activities involving healthcare providers	SLE participant contemplating pregnancy #7 SLE participant contemplating pregnancy #6	“Even if it wasn't that we were asking the doctors to gain this knowledge, it would be about having that role being taken on by somebody, if it's not the doctor, it's a nurse or a clinical specialist of another sort that can gather that kind of information and give a little bit more structure [...]” “[...] there are lupus support groups or lupus information guides and all this, but they are not necessarily run by people that can provide the right scientific information. They mean well but we still need to be careful with what kind of information you’re getting from them.
	Dedicated forums to facilitate communication among women with SLE	SLE participant contemplating pregnancy #8 Rheumatologist #4	“I’ve already read forums, but I haven’t come across comments from people who have actually experienced a pregnancy... it’s hard to find...”* “Forums can be good, it’s just that there is no moderating.”
Checklists / structured guidance	Creating checklists or “cheat sheets” of questions for medical consultations	Pregnant/recently pregnant SLE participant #11	“Well maybe they can provide us with already common questions so that we don’t ask them again [...]”
Multidisciplinary care	Importance of team-based care	Pregnant/recently pregnant SLE participant #12 Maternal-fetal medicine specialist #4	“so I feel like they both, [my high-risk obstetrician] and [my rheumatologist], had been here forever, so they both trusted each other [...] they would just both go that way.” “Like if they have, for example, a dedicated rheumatologist for pregnancy, one or two, like the other subspecialties do, I think it will really help. They can come and do a clinic here like the others.”

Note: *Illustrative quotations from SLE participants were translated from French to English where applicable. All healthcare professionals who participated in the focus groups spoke English; therefore, the illustrative quotations did not require translation.

3.3.2. Educational Tools Tailored to Women with SLE

SLE and healthcare participants expressed the need for booklets and pamphlets that they could refer to before, during, and after medical appointments. Moreover, other suggestions included the creation of dedicated programs for sharing personal experiences, reliable websites with answers to common questions, knowledge translation and exchange activities involving other healthcare professionals in detailed discussions on pregnancy planning, and dedicated forums to facilitate communication among women with SLE.

"Pamphlets, or planners for obstetrics, when you are planning, when you are ready, what medications you can take, what medications you can't take, and if you are on this or that, refer to your doctor first because those are teratogenic or just of risk" (Maternal-fetal medicine specialist)

3.3.3. Checklists/Structured Guidance

Creating a 'cheat sheet' for patients to refer to during appointments (*e.g.*, frequently asked questions, planners, *etc.*) was among the suggestions, noting that this might help patients address their questions effectively during their appointments.

"I guess having some information we could give them would be good. People tend to get inundated with information sometimes, and they don't take everything in, so maybe having some sort of summary or resume or cheat sheet." (Maternal-fetal medicine specialist)

3.3.4. Multi-disciplinary Care Teams

A multi-disciplinary team approach to patient care, involving rheumatologists, obstetricians-gynecologists (including maternal-fetal specialists), family doctors, psychologists, nurses, and others, ideally at the same time and location, was encouraged by both SLE patients and healthcare professionals. The aim was to optimize communication between healthcare providers and to provide consistent information and care to SLE patients while avoiding the need for patients to act as intermediaries between different specialists.

"That's why having a team approach might be beneficial - the high-risk internists could manage diabetes, hypertension, things like that, and we manage the autoimmune disease and medication aspect, and the gynecologist addresses the aspects related directly to the pregnancy." (Rheumatologist)

4. DISCUSSION

Our study is the first to qualitatively examine pregnancy counselling in SLE by integrating the perspectives of both women with SLE (at different reproductive stages) and healthcare professionals within a universal healthcare system. We identified three overarching themes among women with SLE (*i.e.*, anxiety, confusion, and frustration) and three themes among healthcare professionals (*i.e.*, timing, communication, and resources) in reference to pregnancy counselling. Anxiety has been frequently reported in the broader non-pregnant SLE population, with quantitative studies suggesting that approximately a quarter to a third of individuals with SLE experience clinically significant anxiety; however, pregnancy-specific prevalence estimates remain limited. In contrast, feelings of confusion and frustration related to pregnancy counselling are more commonly described as qualitative themes in studies of women with SLE, particularly in the context of high-risk pregnancies and complications [17, 22-24]. By examining these perspectives side by side, we were able to highlight not only converging concerns such as patient anxiety about adverse outcomes but also gaps in mutual understanding, such as patients perceiving vague or delayed counselling, while clinicians emphasized timing and disease quiescence. Importantly, our focus groups moved beyond describing barriers to generate patient and provider-driven strategies, including access to psychosocial support, tailored educational tools, checklists for consultations, and multidisciplinary models of care. By documenting solutions that emerged directly from patient and provider discussions, our study extends prior research that has primarily identified concerns, thereby offering concrete and feasible directions for future interventional studies.

The majority of women with SLE participating in our study expressed fear over the impact their disease might have on the health of their offspring, anticipating challenges during pregnancy and the postpartum period. Those fears were often not appreciated by their support system and vaguely addressed by professionals until patients explicitly voiced their concerns and/or were actively planning a pregnancy. Other studies exploring the perspective of women with SLE on pregnancy also reported that patients expressed similar concerns, some even making autonomous decisions not to get pregnant due to the fear of gestational and neonatal complications associated with lupus [14, 25]. In a qualitative study including 26 SLE women, it was found that those who previously experienced gestational or neonatal losses were more prone to get anxious about the health of their offspring, suggesting that these women may benefit from adequate psychological support to help patients cope with losses and overcome their fear in future pregnancies [17, 26, 27]. Notably, nearly half of the SLE pregnancies in our study resulted in fetal loss, which may have contributed to participants' apprehension regarding pregnancy and may have influenced the emotional tone of the discussions, with increased expressions of anxiety and fear related to pregnancy planning. SLE participants in our study also mentioned the potential advantages that psychosocial support may have on their mental health; however, they noted that access to psychologists or social workers is very limited.

Interestingly, more than a third of SLE women who participated in our study and were pregnant never engaged in pregnancy-related discussions before conceiving. Our data were collected between 2017 and 2018, coinciding with the publication of the 2017 European Alliance of Associations for Rheumatology

(EULAR) recommendations for women's health in patients with SLE and antiphospholipid syndrome and preceding the 2020 ACR guidelines for the management of reproductive health in rheumatic diseases [11, 12]. The 2017 EULAR recommendations emphasize the importance of family planning as early as possible after diagnosis, while taking into consideration the risk stratification for adverse pregnancy outcomes [11]. Among the many recommendations, the development of individualized monitoring plans and preventive measures before and after pregnancy appears to be a crucial step to optimize pregnancy outcomes. Similarly, the 2020 ACR guidelines for the management of reproductive health in rheumatic diseases highlight the significant role of healthcare providers in addressing reproductive health concerns in patients with rheumatic diseases to enhance mutual decision-making [12]. Despite the availability of the EULAR recommendations, healthcare providers in our focus groups acknowledged the importance of pregnancy counselling, which may not be consistently implemented for all women with SLE. Although planning pregnancy according to disease quiescence and safe treatment profile was widely recognized among all healthcare professionals as essential to optimize pregnancy outcomes, our findings highlight the persistent gaps between guideline recommendations and clinical practice. Thus, the experiences in our study reflect challenges in the implementation of guideline-based care rather than a lack of guidance, supporting the continued relevance of our findings despite evolving recommendations.

Our findings reveal a critical gap in pregnancy-related discussions between SLE women and their healthcare providers, with many patients initiating these conversations themselves. SLE women in our study noted that their primary physicians often did not adequately address reproductive health concerns unless explicitly raised by the patients. Similarly, a study exploring a multifaceted educational program on provider skills for lupus pregnancy planning and management found that nearly half of rheumatologists reported that conversations about pregnancy were initiated by the patients first [28, 29]. However, even when pregnancy was discussed, both groups in our study mentioned that conflicting information from different healthcare providers was not uncommon, leading to confusion and frustration among patients. Many women with SLE reported having to navigate multiple healthcare providers to ensure comprehensive pregnancy care, but poor communication between providers often forced them to act as mediators between specialists, leading to fragmented and inconsistent management. This highlights a broader care gap, as not all SLE women possess the medical literacy, educational background, or emotional and physical capacity to coordinate communication between specialists. Importantly, our findings should not be interpreted solely as a reflection of individual healthcare providers' awareness or knowledge. Healthcare professionals in our study highlighted structural barriers such as limited consultation times, high patient volumes, and the scarcity of institutional resources tailored to reproductive counselling in SLE. These constraints are further compounded by systemic factors, including the lack of reimbursement structures for extended pregnancy counselling and inadequate institutional support for multidisciplinary clinics [30]. Addressing these system-level barriers is essential to enable providers to deliver patient-centered and psychosocially responsive care. Both patients and healthcare providers in our study emphasized the importance of multidisciplinary collaboration and improved communication to deliver consistent and accurate information, which is consistent with findings from prior studies [13, 14, 17, 31]. A key consideration emerging from our findings is the need for enhanced reproductive rheumatology care. Integrating reproductive health discussions into routine rheumatology visits and strengthening collaboration among rheumatologists, obstetricians, and maternal-fetal medicine specialists could significantly improve the pregnancy experiences of people with SLE. Establishing specialized reproductive rheumatology services that offer comprehensive, multidisciplinary care may help address gaps in pregnancy counselling and provide better support for SLE women. Additionally, while patients identified rheumatologists as their primary source of information, they also emphasized the need for educational tools tailored to women with SLE, such as pregnancy planning websites and platforms managed by professionals to address major concerns.

We acknowledge several potential limitations of this study. First, participants were recruited from community-based practices, as well as from peripheral and tertiary care centers within McGill University's health network, all located within the province of Quebec. Since the management, organization, and delivery of healthcare services for residents in Canada fall under the jurisdiction of provincial and territorial governments, the experience and perspectives of patients and healthcare professionals may differ in other provinces across Canada or in countries without publicly funded universal healthcare access. Our findings may therefore be less transferable to lower resource settings or healthcare systems without universal coverage, where access to specialist care and reproductive counselling services may be more limited. Second, although we purposively sampled and did include SLE women from varied racial and ethnic backgrounds, most SLE participants were Caucasian and well-educated. As a result, the identified counselling needs, communication challenges, and proposed strategies may not fully reflect the experiences of individuals with lower health literacy who may face additional barriers to understanding pregnancy-related risks and navigating complex healthcare systems. Third, the majority of SLE women in this study had had their disease for several years; thus, our findings may not reflect the experience of SLE women with early disease. We also did not collect validated measures of disease activity or organ damage, which could have provided further clinical context. Additionally, although participants highlighted the need for multidisciplinary or reproductive rheumatology care, the applicability of these findings to settings without such services may be limited, and the challenges we identified may be amplified in such contexts. Lastly, we acknowledge that modest compensation and logistical support provided to facilitate participation may have influenced willingness to participate; however, they were unlikely to have influenced the content of discussions or their interpretation.

CONCLUSION

This qualitative study highlights key barriers to effective pregnancy counselling in SLE from both patient and healthcare professional perspectives and identifies actionable strategies to improve care. Among these strategies, enhancing multidisciplinary collaboration and establishing specialized reproductive rheumatology services may help bridge existing gaps and improve reproductive health outcomes for women with SLE. Our findings provide a foundation for future interventional studies, which are needed to further evaluate their effectiveness and optimize pregnancy care in SLE.

AUTHORS’ CONTRIBUTIONS

The authors confirm contribution to the paper as follows: N.D., D. D-C., S.B., and E.V.: Designed the study; A.N. and E.V.: Recruited participants; A.N.: Conducted focus group interviews; R.F., A.N., and E.V.: Analyzed and interpreted the data; R.F. and E.V.: Drafted the manuscript. All authors reviewed the results and approved the final version of the manuscript.

LIST OF ABBREVIATIONS

ACR = American College of Rheumatology
COREQ = Consolidated Criteria for Reporting Qualitative Research
EULAR = European Alliance of Associations for Rheumatology
MUHC = McGill University Health Centre
SD = Standard Deviation
SLE = Systemic Lupus Erythematosus

ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

Ethics approval was obtained from the McGill University Health Centre (MUHC) research ethics board, project number 2017-2653.

HUMAN AND ANIMAL RIGHTS

All human research procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

All subjects gave written informed consent before participation.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The data and supportive information are available within the article.

FUNDING

This work was supported through funding from a Canadian Rheumatology Association (CRA) - Canadian Initiative for Outcomes in Rheumatology Care (CIORA) funding award #2022-001, by which the investigators conducted the research independently.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

Declared none.

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