



# NEEDS AND BARRIERS TO PREGNANCY COUNSELLING IN WOMEN WITH SLE



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## OBJECTIVES

Published data suggest barriers to pregnancy counselling exist among women with SLE; however the specific needs of this population are not well known. Using focus groups, we assessed the needs for pregnancy counselling in SLE women and identified potential clinical and psychosocial barriers and facilitators to enhance peripartum care.

## METHODS

Our focus group study included: 1) SLE women contemplating pregnancy or trying to conceive, 2) SLE women who were pregnant or had recently been pregnant ( $\leq 2$  years), and 3) healthcare professionals such as rheumatologists, obstetrician-gynecologists, and nurses. Participants were recruited through purposive sampling from a single tertiary healthcare centre. We analyzed the data thematically using grounded theory.

Twenty-four SLE women and 14 healthcare professionals participated in 11 unique focus groups that lasted 60 minutes each. The following themes emerged:

### SLE WOMEN GROUPS

**Anxiety:** Participants feared their disease would affect the health of offspring, prevent breastfeeding and/or impair their ability to care for a newborn. They also anticipated extra stress and fatigue associated with pregnancy. The knowledge that their pregnancy was considered “high risk” also generated anxiety.

**Confusion:** Information on SLE pregnancy was limited and vague, and rarely volunteered by the physician without a woman explicitly voicing her desire to conceive.

**Frustration:** Participants felt their concerns were not taken seriously by family/friends/other members of their support system since few understand SLE and lupus-related pregnancy concerns. Planning a pregnancy at a time of disease quiescence was also frustrating. Not remembering some of their questions or time limitations during medical encounters was a common source of frustration.

### HEALTHCARE PROFESSIONAL GROUPS

**Timing:** All healthcare professionals agreed that pre-conception counselling is critical to determine disease activity, assess the safety of pregnancy, and manage patient anxieties.

**Communication:** Ongoing discussions about pregnancy planning at regular intervals can help with the management of medications, including contraceptives. Patients often receive conflicting information from different specialists, as well as pharmacists.

**Resources:** Limited access to care (appointment availability, time with patient, family doctor shortage) and limited educational materials specifically for SLE pregnancies.

Potential strategies to address these barriers might include facilitating access to psychosocial support during pregnancy, developing educational tools, providing a checklist of questions for medical encounters, and designing prenatal classes dedicated to SLE women and their partners.

## RESULTS

**Table 1. Characteristics of SLE women groups**

	Pregnant SLE women (n=14)	SLE women contemplating pregnancy (n=10)
Mean age, years (sd)	34.8 (4.6)	33.3 (5.8)
Mean disease duration, years (sd)	12.4 (6.4)	11.3 (6.5)
Marital status, n (%)		
Married/Common	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 (%)		
Secondary School	3 (22)	0 (0)
College/University	9 (64)	7 (70)
Master/Doctorate	2 (14)	3 (30)
Employment, n (%)		
Working	8 (58)	7 (70)
Homemaker	2 (14)	0 (0)
Student	2 (14)	1 (10)
Sick Leave	1 (7)	2 (20)
Other	1 (7)	0 (0)

**Table 2. Obstetrical history of SLE women groups**

	Pregnant SLE women (n=14)
Mean number of pregnancies (sd)	2.6 (1.2)
Live births, n (%)	22 (59)
Miscarriage, n (%)	8 (22)
Stillbirth, n (%)	1 (3)
Therapeutic abortion, n (%)	3 (8)
Currently pregnant, n (%)	3 (8)
Consulted doctor before conception, n (%)	
Yes	8 (62)
No	5 (38)

**Table 3. Characteristics of healthcare professional groups**

	Healthcare professional group (n=14)
Specialty, n (%)	
Rheumatologist	8 (57)
Maternal-Fetal Medicine Specialist	4 (29)
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 (22)

## CONCLUSION

Our qualitative study provides important insights into the needs and barriers to effective pregnancy counselling in SLE women, and suggests strategies that could be tested in future studies.