

Original article

Desire to have children and preferences regarding to pre-pregnancy counselling in women with SLE

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Abstract

Objectives. Pre-pregnancy counselling in women with systemic lupus erythematosus (SLE) is important in order to improve knowledge on the risks of pregnancy and to optimize pregnancy outcomes. Knowledge on the preferences of women with SLE regarding pre-pregnancy counselling have not yet been studied. In a closely monitored cohort of women with SLE we enquired about the present status of their wish to have children, and wish for and experiences with pre-pregnancy counselling.

Methods. A questionnaire developed by physicians in collaboration with two women with SLE was sent to all ($n=177$) women participating in the Amsterdam SLE cohort. The questionnaire comprised 32 items, of which 15 focused on the above-mentioned three themes.

Results. A total of 124 women (70%) returned the questionnaire. The median disease duration was 13 years (interquartile range 9–19). Childlessness occurred in 51 women and 31% declared this was due to SLE [conscious decision (21%), stringent medical advice (6%), infertility due to medication (4%)]. Half of the women preferred the first pre-pregnancy counselling immediately after the SLE diagnosis (53%), together with their partner (69%). Information given by healthcare providers (81%) was preferred over information provided via brochures (35%) or the internet (26%). Pre-pregnancy face-to-face counselling from a rheumatologist and/or gynaecologist separately was preferred in 54%.

Conclusion. One-third of women attributed their childlessness to SLE-related reasons. Pre-pregnancy counselling was preferred shortly after the onset of the disease in a non-multidisciplinary setting. The results of this study underline the importance of timely pre-conceptual counselling by healthcare providers on fertility, risks and pregnancy outcomes in women with SLE.

Key words: systemic lupus erythematosus, autoimmunity, pregnancy, rheumatic disease, education, patient attitude to health, quality of healthcare

Rheumatology key messages

- Women with SLE report a great need for timely and tailored pre-pregnancy counselling.
- The desire to become pregnant is abandoned after obtaining pre-pregnancy counselling in 16% of patients.
- One in three women without children relate their childlessness to SLE.

Introduction

Systemic lupus erythematosus (SLE) often affects women of childbearing age and therefore may interfere

with family planning. The desire to have children may be influenced by the risk of SLE flares occurring during pregnancy and the risk of adverse pregnancy outcomes [1–3]. Furthermore, women with SLE are advised to

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postpone pregnancy until they have at least 6 months of low disease activity [4–6]. As a consequence, pregnancy may occur at an older age, which increases maternal and perinatal risks [7]. Although fertility is considered to be unaffected in women with SLE [3, 8], specific medication which may be used by patients with SLE, such as non-steroidal anti-inflammatory drugs (NSAIDs) and cyclophosphamide, may negatively impact fertility [9–13].

Prior research suggests women's knowledge, beliefs and attitudes about pre-conceptional health and pregnancy risks with regard to chronic conditions varies [14–17]. From a Dutch SLE cohort, we know that half of the mothers experienced an uneventful pregnancy, 20% developed an SLE flare during pregnancy and 15% had a post-partum flare [18]. Furthermore, the pregnancy complications that occur in half of the women are hypertensive disorders of pregnancy (18%), preterm birth (<37 weeks gestational age) (33%), intrauterine foetal death (4%) and intrauterine growth restriction (15%) leading to small-for-gestational-age neonates [18]. It is therefore important for women to make a conscious, autonomous decision about these kinds of life events concerning maternal and neonatal health. Consequently, timely and periodic pre-pregnancy counselling addressing (in)fertility, medication adjustments, contraceptive use and a women-tailored risk stratification on maternal and neonatal pregnancy outcomes for women with SLE has been recommended [5, 6]. This may improve knowledge on the risks of pregnancy in women with SLE and optimize pregnancy planning and outcomes. Despite the importance to connect with the perceptions of women receiving pre-pregnancy counselling, research on the preferences of women with chronic diseases regarding to pre-pregnancy counselling is limited [15, 17, 19–22] and, to the best of our knowledge, absent concerning SLE.

The objective of this study was to explore the desire to have children and preferences for and experiences with pre-pregnancy counselling of Dutch women with SLE.

Materials and methods

Study design

Data from women included in the Amsterdam SLE cohort were used for this study. The Amsterdam SLE cohort is a longitudinal cohort study from Amsterdam UMC, location VU University Medical Center (VUmc), in which adult patients with SLE according to the American College of Rheumatology (ACR) revised criteria for the classification of SLE are included and examined yearly [23, 24]. The data underlying this article will be shared upon reasonable request to the corresponding author.

The present study was approved by the Medical Ethical Review Board of Amsterdam UMC, location VUmc [protocol number 2007.125 (A2018.098)] and was

performed in accordance with the Declaration of Helsinki and Good Clinical Practice. All patients provided written informed consent prior to inclusion in the study.

Study population and data collection

A questionnaire on the desire to have children and pre-pregnancy counselling was developed by physicians from the rheumatologic and obstetric departments of Amsterdam UMC, location VUmc in collaboration with two women with SLE from the Amsterdam SLE cohort. Pre-pregnancy counselling in our hospital has been provided in separate sessions by successively a rheumatologist and gynaecologist over the last 20 years. It may be provided on the initiative of the rheumatologist or at the request of the woman herself. Before the 1980s, pre-pregnancy counselling was only given by the rheumatologist, or not given at all. The rheumatologist provides information predominantly from the rheumatologist's point of view regarding pregnancy, e.g. the importance of low disease activity around pregnancy, timing of pregnancy and organ involvement on the course and outcome of pregnancy. The gynaecologist provides information predominantly on present knowledge and the wish to evaluate the possibility of a pregnancy or confirmation to refrain from pregnancy, the risks and early signs of pregnancy complications and the effect of a pregnancy on everyday life, like the continuation of work. Both medical specialists provide information on the influence of antiphospholipid (aPL) antibodies and antibodies against Ro/SSA and/or La/SSB, the safety of present medication, medication adjustments that may be needed and the addition of low-dose aspirin in order to reduce the risk of pregnancy complications. Moreover, they advise the immediate reporting of early signs of SLE flare or pregnancy complications instead of waiting until the next check-up to enhance tailored multidisciplinary adaptation of treatment. The appointment with the gynaecologist is followed by a letter to the woman and the referring specialist summarizing the information given during the pre-pregnancy counselling visit and advising the patient to visit the website of the Dutch patient association (National Association for Lupus, APS, scleroderma and MCTD) and the Dutch obstetric guideline on SLE and setting up a second (telephone) appointment after 6 weeks in order to answer questions that emerged after the first appointment. The women receiving no pre-pregnancy counselling or receiving only pre-pregnancy counselling from the rheumatologist were considered as a historical control group. All women participating in the Amsterdam SLE cohort ($n = 177$) were invited to fill in the online questionnaire, which was developed using Castor Electronic Data Capture [25]. If e-mail addresses were not available or if women preferred to receive a hardcopy version of the questionnaire, the questionnaire was provided on paper. Data collection was conducted between March and July 2018. A reminder was provided

in case women did not return the questionnaire within 3 weeks.

The following demographic data were collected as assessed for the Amsterdam SLE cohort: age, ethnicity and highest attained educational level, stratified into low (<12 years), intermediate (12–16 years) and high (≥ 17 years) [24, 26]. Disease-related variables collected were disease duration (at the time of completing the questionnaire), Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI) and history of lupus nephritis.

Questionnaire

The questionnaire was developed by the authors of this article, including two women with SLE participating in the Amsterdam SLE cohort. They were involved in the design of this study, critically reviewed the questionnaire and provided advice to improve its clarity and completeness. The full questionnaire comprised 32 items. For the present study, 15 items were selected with a focus on three major themes: present status of a desire for children, preferences regarding pre-pregnancy counselling and rheumatologic and obstetric care experienced during pregnancy in women who received pre-pregnancy counselling. The questionnaire was written in Dutch (Supplementary Data S1, available at *Rheumatology* online) and officially translated into English (Supplementary Data S2, available at *Rheumatology* online).

Present status of desire to have children

This theme included questions on family situation (including number of children), ongoing desire for children, thoughts about fertility and, if applicable, reasons for childlessness.

Preferences regarding pre-pregnancy counselling

Questions on the timing of pre-pregnancy counselling, the preferred healthcare provider(s) for providing information on pregnancy in women with SLE, preferred other resources of information on pregnancy in women with SLE and the preferred type of visit used for pre-pregnancy counselling (presence of one clinician or a multidisciplinary visit) were included in this theme.

Experienced rheumatologic and obstetric care

Women who received pre-pregnancy counselling from successively the rheumatologist and gynaecologist in our hospital were asked to answer questions on the completeness and clarity of the pre-pregnancy information given. Furthermore, all women were asked to state recommendations for improvement in care.

Analyses

The analyses performed were primarily descriptive, providing an overview of the satisfaction and preferences of

the women with SLE. Numerical data are presented as means and standard deviations (SDs) for normally distributed data or as medians and interquartile ranges (IQRs) in case of skewed data. Differences between groups were analysed using the chi-squared test; responders and non-responders were compared, as well as women with a delivery only before the SLE diagnosis and a delivery only after the SLE diagnosis and women with and without pre-pregnancy counselling from successively the rheumatologist and gynaecologist (creating a historical control group). Moreover, an additional analysis was performed stratifying women according to the time period of delivery: before 2000, 2000–2010 and after 2010. A p -value < 0.05 was considered statistically significant. Statistical analyses were performed with SPSS Statistics version 26 (IBM, Armonk, NY, USA). All free-text data were read and categorized into different key themes and subthemes using content analysis.

Results

Population

The questionnaire was completed and returned by 124 of 177 eligible women with SLE participating in the Amsterdam SLE cohort (response rate 70%). Thirteen women declined to complete the questionnaire with the following explanations: their advanced age ($n = 5$), the sensitive topic of the questionnaire ($n = 4$) and other reasons ($n = 4$). The remaining 40 women did not respond to the questionnaire. Thirty-two patients [34% (32/93)] indicated that they received pre-pregnancy counselling from successively the rheumatologist and gynaecologist. The demographic and disease characteristics of the responders and non-responders are presented in Table 1. No statistically significant differences between pregnancy outcomes were present between responders and non-responders.

Present status of desire to have children

In total, 73 of 124 (59%) women with SLE who returned the questionnaire gave birth. Sixteen women had a (future) child wish, two women did not experience a pregnancy but chose to adopt and one woman was pregnant while when completed the questionnaire. Almost half of the women gave birth before [49% (36/73)] or after the diagnosis of SLE [47% (34/73)]. Three women (5%) gave birth both before and after the diagnosis of SLE.

Twenty percent (19/95) of women with SLE thought SLE had a negative impact on their fertility and 26% (25/95) had no idea concerning the impact of SLE on fertility. In women only delivering before the diagnosis SLE, these percentages were 7% (2/31) and 52% (16/31), respectively. Childlessness was reported by 51 women, of whom 31% declared their childlessness was due to SLE. In 21% (11/51) of the women, childlessness was a conscious personal decision, in 6% ($n = 3/51$) it was because of stringent medical advice of a healthcare

TABLE 1. Demographic and disease characteristics of responding and non-responding women with SLE

Characteristics	Responding women with SLE (n = 124)	Non-responding women with SLE (n = 53)
Age, years, mean (SD)	47 (13)	47 (13)
Caucasian ethnicity, n (%)	89 (72)	30 (57)
Education level at baseline ^a , n (%)		
Low (<12 years)	47 (40)	31 (61)
Intermediate (12–16 years)	19 (16)	9 (18)
High (≥17 years)	52 (44)	11 (22)
Disease duration, years, median (IQR)	14 (8–20)	13 (9–17)
History of lupus nephritis, n (%)	13 (11)	5 (9)
SDI score, median (IQR)	1 (0–2)	1 (0–3)
Year of birth of children, median (IQR) ^b	2002 (1989–2011)	NA

^aData from 118 responding women with SLE and 51 non-responding women with SLE. ^bData from 73 patients. Variables were assessed at the time of completing the questionnaire unless stated otherwise. IQR: interquartile range SD: standard deviation, SDI = Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; SLE: systemic lupus erythematosus.

provider and in 4% (2/51) infertility was attributed to medication use. Nine women [9/44 (20%)] stated the course of a prior pregnancy led to the decision not to pursue a subsequent pregnancy. Of these, one woman delivered a child before diagnosis, seven women delivered a child after diagnosis and one woman delivered no children. These nine women provided free-text data. For example,

I am still having doubts but I have always wanted multiple children. My pregnancy and postpartum period were very hard as a result of preeclampsia and my child having to stay in the incubator for days [...]. Permanent kidney damage and an increased risk of going through the same thing were reason for me to decide against getting pregnant again. (Patient, age 29 years, one child)

The key theme mentioned in the free-text data was concerns about pregnancy risks. Subthemes were pregnancy complications such as pre-eclampsia, prematurity, miscarriage and delivery complications experienced in a previous pregnancy, and the fear of the occurrence of pregnancy complications in a subsequent pregnancy and SLE disease activity, i.e. fear of the occurrence of a (renal) flare during or after pregnancy ([Supplementary Table S1](#), available at *Rheumatology* online).

Preferences regarding pre-pregnancy counselling

Fifty-three percent (51/97) of the women preferred to receive the first information on pregnancy immediately after SLE was diagnosed, 12% when the SLE would be under control, 11% depending upon their age, 5% as late as possible after the diagnosis and just before wishing to become pregnant. A few women did not want to receive information or were diagnosed with SLE after they got pregnant. Six women provided free-text data that showed the timing of information was important ([Supplementary Table S1](#), available at *Rheumatology* online).

The preference to receive information directly after the SLE diagnosis was not significantly different between women receiving pre-pregnancy counselling from the

rheumatologist only [45% (26/58)] compared with women receiving pre-pregnancy counselling from successively the rheumatologist and gynaecologist [66% (21/32)]. Similarly, no difference was found when stratifying between women delivering their youngest child before 2010 [56% (9/16)] and those delivering from 2010 and thereafter [60% (12/20)]. Most women [69% (64/93)] reported they preferred to be informed about pregnancy in SLE together with their partner. Only a minority of 13 patients did not discuss the desire for pregnancy with their healthcare provider, mainly because of a lack of desire for children (anymore), a communication barrier between the woman and the healthcare provider or because of insufficient knowledge of the healthcare provider about this topic. Free-text data showed some women felt they received insufficient information on the influence of a pregnancy on SLE or the desire for children was postponed. For example,

Painful subject. I would like to have children but there are too many unknown factors. (Patient, 32 years, no children)

Information on pregnancy in SLE given face-to-face by healthcare providers [81% (74/91)] was preferred over information provided via brochures [35% (32/91)] or a website [26% (24/91)]. Women delivering only after the diagnosis SLE more often preferred brochures [38% (12/32)] or websites [28% (9/32)] compared with women delivering only before the diagnosis SLE [23% (7/30) and 17% (5/30), respectively]. Women delivering their youngest child after 2010 preferred more frequently to receive information predominantly from their healthcare provider [90% (18/20)] compared with 69% (9/13) of women delivering their youngest child between 2000 and 2010. Women receiving pre-pregnancy counselling from successively the rheumatologist and gynaecologist significantly more often preferred a website as an additional source of information [43% (13/30)] compared with women not receiving pre-pregnancy counselling from both healthcare providers [19% (11/54)]. When

respondents were asked from which healthcare provider they preferred to receive the first information on pregnancy in SLE, 55% (48/88) stated the rheumatologist while 15% (13/88) preferred the gynaecologist. For women delivering only after the diagnosis SLE, 66% (21/32) preferred to receive the first information from the rheumatologist and 6% (2/32) preferred the gynaecologist.

Women were asked if they preferred to be informed about pregnancy in SLE by a rheumatologist, a gynaecologist, a rheumatologist and gynaecologist in two separate visits or a rheumatologist and gynaecologist in a multidisciplinary visit at the outpatient clinic. Twenty women reported a range of reasons for preferring to be informed by the rheumatologist (most women valued the rheumatologist's knowledge of SLE and knowledge of the woman herself). Eight women who preferred to receive information from the gynaecologist gave free-text data; the subtheme was the expertise of the gynaecologist regarding pregnancy ([Supplementary Table S1](#), available at *Rheumatology* online). A small majority of women [54% (45/83)] preferred to receive face-to-face information from a rheumatologist or gynaecologist separately and not during a multidisciplinary visit at the outpatient clinic. We stratified the 83 women who answered the question on preferred type of pre-pregnancy counselling according to age, using their mean age of 43 years as cut-off point. Women >43 years of age were more likely to wish for pre-pregnancy counselling by the rheumatologist or gynaecologist separately [60% (21/35)] compared with women ≤43 years of age. In addition, women with a low education level [69% (22/32)] and women delivering only after the diagnosis SLE [58% (18/31)] preferred separate pre-pregnancy counselling.

This way I can rest assured I have all the information I need without being overwhelmed. (Patient, age 37 years, no children)

Women delivering their youngest child after 2010 preferred a multidisciplinary visit [55% (11/20)] compared with women delivering their youngest child between 2000 and 2010 [27% (3/11)]. Free-text data show the main reasons provided for this preference were expertise of different medical specialists and received complementary information by getting the opportunity to clarify uncertainties during a second visit at the outpatient clinic ([Supplementary Table S1](#), available at *Rheumatology* online). When we corrected for women who received pre-pregnancy counselling from successively the rheumatologist and gynaecologist, 59% of women (17/29) preferred separate counselling by the rheumatologist and/or gynaecologist to a multidisciplinary visit at the outpatient clinic. The reasons provided for the preference of a multidisciplinary visit were complementary information provision and efficiency ([Supplementary Table S1](#), available at *Rheumatology* online).

Experience of rheumatologic and obstetric care

In 32 women receiving pre-pregnancy counselling successively from the rheumatologist and gynaecologist,

the experience of care was evaluated. Most respondents [88% (28/32)] stated they remembered sufficient information from the pre-pregnancy counselling consultations and 81% (26/32) stated the consultations had helped them to make a considered decision about conceiving. The desire to conceive after obtaining pre-pregnancy counselling was consciously abandoned by 16% (5/32) of women. All five women received pre-pregnancy counselling from successively the rheumatologist and gynaecologist during the last eight years, two of them received a second pre-pregnancy counselling visit four years after their first visit. One woman had a psychiatric medical history and another woman suffered from severe pulmonary hypertension and was medically advised against pregnancy. A third woman suffered from lupus nephritis in the past, as well as mitral valve insufficiency due to Libman–Sacks endocarditis; she was not medically advised against pregnancy but nevertheless abandoned her pregnancy wish after pre-pregnancy counselling. The two other women did not suffer major organ complications and were not advised against pregnancy. Of all the women who returned the questionnaire, 22 women gave recommendations for optimization of pre-pregnancy consultations. Free-text data show the key theme was information needs. The subthemes show women wished for early, tailored and repetitive medical information concerning their actual situation and the possibility and risks of a (future) pregnancy. Furthermore, women stated multidisciplinary collaboration and communication was important ([Supplementary Table S1](#), available at *Rheumatology* online). For example,

Experiences of other women on paper. Knowing you're not alone, would give us women a boost. (Patient, age 35 years, one child)

Discussion

This is the first study on the desire to have children and preferences regarding pre-pregnancy counselling in women with SLE. A minority of women (20%) thought SLE had a negative impact on fertility. Furthermore, one in three women without children related their childlessness to SLE. Women preferred to receive the first information on pregnancy in SLE personally from a healthcare provider (81%), immediately after SLE diagnosis (53%) and together with their partner (69%). These items can easily be implemented in daily practice. The desire to become pregnant was abandoned after obtaining pre-pregnancy counselling in 16%. To allow women with SLE to make a conscious and autonomous decision about conceiving, patient education with tailored, timely pre-pregnancy counselling is paramount.

To our knowledge, patients' views on fertility and SLE have not previously been studied in women with SLE. Only a Saudi Arabian study reported 15% of 400 women without SLE attending primary healthcare centres, thought fertility in men and women with SLE was affected [27]. The frequency of childlessness attributed

to SLE in our population was consistent with a recently published Korean study demonstrating 31% of women with SLE decided not to have children due to health-related reasons [2]. This case-control study, however, reports the avoidance of pregnancy (55% in women with SLE compared with 41% in controls) was higher compared with our population. This discrepancy might be explained by differences in socio-economic and healthcare systems in Korea and The Netherlands.

By providing information on pregnancy in SLE early in the disease course, women are informed not to conceive while having active disease [4]. In our population, the preferred timing of pre-pregnancy counselling was immediately after diagnosis in more than half of the women (53%). This finding is in accordance with a study in anti-Ro/SSA-positive women, reporting 54% of women would have preferred to be informed about the risk of a foetal congenital heart block before pregnancy instead of during pregnancy [21]. Regarding sources of information provision, the women in our study preferred to receive information from a healthcare provider, brochures or a website and not from magazines or discussion forums on the internet. These preferences are in line with the results of other studies on health information before, during and after pregnancy, performed in women with rheumatoid arthritis and in healthy women [17, 28–31]. Women receiving pre-pregnancy counselling from successively a rheumatologist and gynaecologist significantly more often preferred also a website as a source of information.

Despite all the recommendations given for pre-pregnancy counselling in literature, only a few studies addressed the type of information provision. Pregnant women with SLE who are treated by a multidisciplinary team around pregnancy appeared to have more frequently low disease activity and their pregnancies seemed to be less frequently associated with preterm birth [32]. In our hospital, a multidisciplinary approach to the desire to have children in women with rheumatic diseases is provided by timely, separate consultations by a rheumatologist and gynaecologist, ad hoc consultations on demand and monthly multidisciplinary conferences of the involved clinicians (rheumatologists, gynaecologists and nephrologists). The question is whether multidisciplinary consultations are desirable for both women and healthcare providers. Women with chronic diseases living in the United Kingdom stated they were satisfied with multidisciplinary consultations: only a few women considered them intimidating [20, 33]. In our study, more than half (54%) of the women with SLE preferred not to receive a multidisciplinary consultation during one session at the outpatient clinic. This was especially applicable to older women and women with a lower education level. Women delivering their youngest child after 2010 preferred more frequently a multidisciplinary visit (55%). A reason for the different thoughts about the preferred type of pre-pregnancy counselling might be that most women were satisfied with the current practice of pre-pregnancy counselling at their hospital. Women

participating in our study stated the expertise of the medical specialists and experienced complementary care were important for them. Another explanation might be the existence of a current time trend towards a preference for multidisciplinary pre-pregnancy counselling. Further research is needed to investigate the differences in attitudes regarding the preferred type of pre-pregnancy counselling consultations for women with SLE, taking the feasibility for healthcare providers into account.

Our study revealed 81% of women thought pre-pregnancy counselling helped them to make a considered decision about conceiving. This finding is in accordance with the results of studies on pre-pregnancy counselling in women with chronic kidney diseases, reporting 90% of women stated that the consultation had helped them decide about pursuing pregnancy [15, 20]. Sixteen percent of our women with SLE abandoned their desire for pregnancy after obtaining pre-pregnancy counselling. This percentage is higher than in other studies reporting that 3–6% of women with chronic diseases decided not to conceive after pre-pregnancy counselling [20, 21, 33]. The higher percentage of women with SLE abandoning their desire for pregnancy after pre-pregnancy counselling compared with women with other chronic diseases might be explained by the higher risk of developing pregnancy complications in women with SLE compared with women with other chronic diseases [15]. Our findings should be confirmed by a study in another cohort of women with SLE.

Evaluation of the free-text data provided by women who returned the questionnaire showed a preference towards early, tailored and repetitive counselling on pregnancy in SLE. In addition, women with SLE expressed a wish to receive pre-pregnancy counselling again after delivery, before a subsequent pregnancy. Collaboration between medical specialists is needed to ensure optimal and consistent information.

Our study has several strengths. First, this is the first study on the desire for children and preferences regarding pre-pregnancy counselling in women with SLE. Second, the response rate to the questionnaire was rather high (70%) and comparable to other questionnaires about perspectives on pregnancy in chronic diseases, ranging from 40 to 93% [3, 15, 19, 20, 33]. All women willing to participate were included to elucidate the wishes of women with various obstetric backgrounds and not only of successful pregnancies.

The present study is limited by possible selection bias, responder bias and recall bias. First, the study was performed in a selected patient population from a tertiary centre. Second, not all eligible women of the Amsterdam SLE cohort participated in our study. Third, pregnancies in the women participating in the study occurred over a period of 2 decades. Other limitations are the lack of a validated questionnaire on pre-pregnancy counselling, the generalizability of the results since the evaluation of care is focused on the pre-pregnancy counselling as provided in our hospital, some

returned questionnaires being incomplete and the lack of a control group. Nevertheless, we do describe a historical control group in this study that consists of patients who got pregnant without pre-pregnancy counselling from successively the rheumatologist and gynaecologist.

In conclusion, we assessed the desire for children and preferences regarding to pre-pregnancy counselling in women with SLE. They recommended timely, tailored, multimodal provision of information on pregnancy, preferably by a rheumatologist and gynaecologist separately, to make a considered, autonomous decision. Further studies are needed to confirm our findings in order to improve perceived quality of care, among others in a centre providing multidisciplinary pre-pregnancy counselling. In addition, we suggest performing a study on repeated pre-pregnancy counselling prior to a consecutive pregnancy and qualitative research on this topic in the setting of focus group discussions with women with SLE, their partners and healthcare professionals.

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Data availability statement

Data are available upon reasonable request by any qualified researchers who engage in rigorous, independent scientific research and will be provided following review and approval of a research proposal and Statistical Analysis Plan (SAP) and execution of a Data Sharing Agreement (DSA). All data relevant to the study are included in the article.

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