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# Sexual and reproductive health from the perspective of patients with autoimmune rheumatic diseases in Mexico: a qualitative study

Cassandra Michelle Skinner-Taylor,[1] Lorena Perez-Barbosa,[1]
Abraham Yair Lujano-Negrete,[2] Fanny Arévalo-Nieto,[2]
Maria Eugenia Corral-Trujillo,[2] Andrea Aguilar-Leal,[2]
Génesis Guadalupe Sandoval-Torres ,[2] Cecilia Rodríguez-Ruiz,[2]
Melanie Gabriela Rios-Medina,[2] Amaranta Manrique de Lara,[3]
Dionicio Angel Galarza-Delgado ,[1] Ingris Pelaez-Ballestas [3]

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CMS-T and LP-B are joint first authors.

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For numbered affiliations see end of article.

**Correspondence to**
Dr Ingris Pelaez-Ballestas;
pelaezin@gmail.com

## ABSTRACT

**Objectives** To explore the experiences and perspectives of female patients with autoimmune rheumatic diseases (ARDs) regarding sexual and reproductive health, including contraception, family planning, and pregnancy.

**Design** Qualitative descriptive study using semi-structured interviews.

**Setting** Specialised rheumatology clinic in a tertiary hospital in Monterrey, Mexico.

**Participants** 21 female patients aged 18–49 with a confirmed ARD diagnosis who were receiving care at the clinic. Participants were selected using convenience sampling, ensuring diversity in age, disease type and stage, socio-economic and cultural background, sexuality and disability status. All participants completed the study.

**Results** Four main themes emerged from the analysis. First, participants expressed confusion and concern about the safety and effectiveness of contraceptive methods in the context of their disease and treatment. Second, many participants shared anxiety about infertility, heredity and the risks of pregnancy associated with their ARDs, leading to uncertainty in pregnancy planning. Third, there was concern about the safety of medications during pregnancy and breastfeeding, indicating a lack of guidance and information from healthcare providers. Lastly, patients often deferred decision-making about contraception and medication to their rheumatologists but recognised the importance of a multidisciplinary care approach for comprehensive sexual and reproductive health management.

**Conclusions** The study revealed that women with ARDs experience significant challenges and unmet needs related to sexual and reproductive health, particularly in understanding safe contraception, pregnancy planning and medication use during pregnancy and lactation. These findings emphasise the need for rheumatologists to provide clearer guidance on these issues and collaborate closely with gynaecologists and other specialists to ensure comprehensive, patient-centred care. Enhancing communication and education strategies in rheumatology consultations could address these gaps and improve the sexual and reproductive health outcomes and decision-making processes of women with ARDs.

### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study used a qualitative approach, allowing for a detailed exploration of the perspectives and experiences of women with autoimmune rheumatic diseases (ARDs) regarding sexual and reproductive health.
- ⇒ This study highlights the concerns about heredity as a relevant aspect impacting the well-being of patients with ARDs who want to plan a pregnancy.
- ⇒ The inclusion of a diverse group of participants across various dimensions enhanced the richness of the data and made the findings applicable to a broader range of patients with ARDs.
- ⇒ The study was conducted in a specialised rheumatology clinic, which might limit the generalisability of the findings to patients in different healthcare settings; however, it provides valuable insights into patients receiving specialised care.
- ⇒ The analysis was performed using rigorous thematic analysis techniques, ensuring that the results were systematically interpreted and validated by multiple researchers.

## INTRODUCTION

Autoimmune rheumatic diseases (ARDs) mainly affect female patients of reproductive age. Importantly, ARDs can increase the risk of complications during pregnancy or even cause a reduction in fertility during periods of disease activity.[1] As such, topics related to sexual and reproductive health, family planning and high-risk pregnancy management should be prioritised during the rheumatology consultation to encourage shared decision-making.[2 3]

In recent years, the rheumatology consultation has begun incorporating sexual and reproductive health counselling. In Mexico, a recent study[4] found that 28.9% of patients with ARDs did not use any contraceptive method, despite 71% being sexually active. Finally, patients conveyed little to no counselling about contraception from their managing rheumatologist.[4]

Wolgemuth *et al* conducted a qualitative study with women with ARDs in the USA, who reported wishing that rheumatologists initiated conversations about sexual and reproductive health and that they provided information about any risks to the fetus related to the disease or medication.[5] This study highlights the importance of communication and follow-up of sexual and reproductive health during the rheumatology consultation. Similarly, a qualitative study done in Brazil highlights the lack of use or improper use of contraceptive methods among women with systemic lupus erythematosus (SLE), which reflects an important limitation in the care of this group of patients.[6]

Overall, people with ARDs have unmet information and support needs regarding sexual and reproductive health, including the lack of a multidisciplinary approach to care.[7]

Considering the above, this study aims to describe and analyse the experiences surrounding, and information about, the sexual and reproductive health of patients with ARDs in Mexico, using a qualitative approach. This study was conducted in a specialised rheumatology clinic in a tertiary hospital, which offers a unique opportunity to explore the experiences and perspectives of women with ARDs regarding sexual and reproductive health, as they receive care in a multidisciplinary environment.[8]

## METHODS

### Study design

This was a qualitative descriptive study using semistructured interviews,[9 10] in order to gain an in-depth understanding of the experiences, perspectives, knowledge, attitudes and concerns of patients with ARDs in relation to their sexual and reproductive health.

### Study setting

The study was conducted at a specialised rheumatology clinic in a tertiary hospital in Monterrey, Mexico. This clinic provides comprehensive care for patients with ARDs, including sexual and reproductive health counselling, and serves a diverse patient population with varying socio-economic backgrounds.

### Sample and study population

We recruited 21 female patients aged 18–49 with a confirmed diagnosis of an ARD, including RA, SLE and spondyloarthritis.

Participants were recruited from a specialised reproductive health and pregnancy clinic that focuses on the unique needs of patients with ARDs. This clinic employs a multidisciplinary-care model[11] incorporating rheumatologists, obstetricians, psychologists, genetic counsellors, a paediatrician and social workers. The clinic is structured into three stages: preconception, prenatal and postnatal care. Access to the clinic is facilitated through referrals from the Rheumatology, and Obstetrics and Gynecology Departments. Notably, the services provided at this clinic are offered free of charge, alleviating financial burdens and enhancing access to essential care.

Convenience sampling was used to ensure a diverse representation in age, disease type and stage, socioeconomic and cultural background, sexuality and disability status. Inclusion criteria included being of reproductive age, having an ARD diagnosis for at least 6 months and being willing to participate in an in-depth interview. Patients with cognitive impairments or severe psychiatric conditions that could affect their ability to participate were excluded.

### Data collection

Semistructured interviews were conducted from June 2022 to December 2022, each lasting from 45 to 60 min interviews.[9 10] Depending on the participant's preference, interviews took place either in a private setting within the clinic or virtually via a secure video conferencing platform. The interviews were conducted by a clinical psychologist and a social worker, both experienced in qualitative research. As part of the healthcare team at the clinic, the interviewers were previously known to the participants. However, interviewers reiterated their position, background, and previous research experience before each interview.

An interview guide (online supplemental file 1) was carefully developed in consultation with researchers and patient experts (two rheumatologists, two patients with ARDs, a psychologist, a medical anthropologist and a social worker), based on their experience in reproductive healthcare and non-systematic reviews of the literature. The guide was subsequently validated through a pilot test with a subset of the participants. It encompassed key topics such as contraceptive methods, pregnancy planning, medication use during pregnancy and lactation, and decision-making related to sexual and reproductive health. All interviews were audio-recorded and transcribed verbatim for thorough analysis. Interviews were conducted in Spanish.

### Data analysis

Thematic analysis of the interviews was performed, following Braun and Clarke's framework: familiarisation with the data, generation of initial codes, search for themes, review of themes, definition and naming of themes and writing of results.[12] Transcripts were independently coded by four researchers (CMS-T, LP-B, AYL-N, IP-B), three of whom were women (rheumatologists and a medical anthropologist) and one man (internal medicine resident). Each researcher summarised their coding in a table with representative quotes for each theme.

**Table 1** Participant characteristics

| n=21 | |
|---|---|
| Mean age (range) | 28 years (20–36) |
| Schooling | |
| Primary | 1 (4.8%) |
| Secondary | 7 (33.3%) |
| High school or vocational school | 4 (19.0%) |
| Undergraduate | 9 (42.9%) |
| Marital status | |
| Married | 8 (38.1%) |
| Domestic partnership | 7 (33.3%) |
| Single | 6 (28.6%) |
| Family planning | |
| Desire to bear children | 8 (38.0%) |
| Pregnant | 7 (33.3%) |
| Post-partum | 3 (14.3%) |
| Autoimmune rheumatic diagnosis | |
| Rheumatoid arthritis | 10 (47.6%) |
| Systemic lupus erythematosus | 10 (47.6%) |
| Mixed connective tissue disease | 1 (4.8%) |

Group meetings were held to discuss discrepancies, reach a consensus on interpretations and finalise the themes. The ATLAS.ti software was used to assist with data organisation and coding. Data saturation was reached when no new themes or information emerged from the interviews,[13]; this occurred after 18 interviews and any additional interviews were unlikely to provide further insights.

### Patient and public involvement

Patients were actively involved in the development and validation of the interview guide. A group of five patients provided feedback on the clarity, relevance and comprehensiveness of the questions. Additionally, a subgroup of participants reviewed the preliminary findings to confirm that the themes accurately reflected their experiences, perspectives and concerns. This feedback was incorporated into the final analysis, ensuring that the study results were patient-centred and grounded in the real-world experiences of women with ARDs.

## RESULTS

We interviewed 21 female patients of reproductive age diagnosed with ARDs (table 1). We identified four main themes, each with various subthemes, as follows.

### Theme 1: contraceptive methods

Participants knew several contraceptive methods but reported doubts about their suitability, effectiveness and safety in the context of ARDs. Many participants relied on non-medical sources for information, such as family members, friends, online forums, social media and other patients with similar conditions, rather than seeking guidance from their healthcare providers. The most common concern was the potential interaction between ARD medications and different contraceptive methods, as well as concerns about the possible impact on fertility (table 2).

### Theme 2: considerations for reproductive health and pregnancy planning

Participants expressed uncertainty regarding reproductive health, often feeling that they lacked the necessary information to make informed decisions. The impact of ARDs on pregnancy, concerns about heredity and fears of infertility were recurring issues. Many participants voiced concerns about the impact of their condition on their ability to conceive and carry a pregnancy to term. Additionally, they expressed anxiety about passing on their condition to their children, although they often felt ill-informed about the actual risks involved (table 3).

### Theme 3: care and medications during pregnancy and lactation

Participants discussed the need for specialised care during pregnancy and lactation, noting that the presence of ARDs made this period particularly challenging. They reported feeling anxious about medication safety and potential side effects during pregnancy and breastfeeding, expressing that the information provided by healthcare professionals was often inadequate or inconsistent. Many participants expressed a desire for clearer guidelines and more comprehensive counselling from providers (table 4).

### Theme 4: reproductive healthcare and decision-making

Most participants shared that discussion of sexual and reproductive health topics only occurred in the rheumatology consultation when they explicitly asked. Additionally, some reported feeling berated when asking questions, discouraging further patient-initiated conversations. Even so, participants frequently described delegating decisions about their reproductive health to their rheumatologists, indicating that patients trust the specialists' guidance. This included decisions such as choice of contraceptive method, medication safety, pregnancy management and difficult choices. Contrastingly, patients tended to determine for themselves when to get pregnant, regardless of provider insights into the optimal timing for conception. Participants expressed a desire for a more collaborative, multidisciplinary approach to their care. Though participants had access to a multidisciplinary care team in the specialised clinic, some reported that this care was not consistently available due to a lack of communication between providers. They highlighted the importance of care teams including specialists from different disciplines to address the complexities of ARDs and family planning (table 5).

Overall, these findings indicate that patients with ARDs face significant challenges in accessing clear, consistent information about sexual and reproductive health, and

**Table 2** Theme 1: contraceptive methods

| | |
|---|---|
| Knowledge of contraceptive methods | "Contraceptive methods mostly work to, well the condom works to avoid a sexually transmitted disease but talking about the pill, the implant, the IUD [intrauterine device], um yeah many methods like that work to prevent a pregnancy." (*20–25*)<br>"I never asked because I, well I wasn't planning on using hormonal contraceptives anymore, the last one I used was hormonal and I didn't like it … we ended up preferring a vasectomy." (*30–35*) |
| Perceived importance of contraception | "Well, yes, because if I ended up pregnant it's my understanding that the medication I'm taking could hurt the baby and myself, so yeah, that's why I have to use some method of contraception." (*20–25*) |
| Safety of contraceptive methods | "I've heard that the IUD is one … Um, when I went to the health center they give some talks and they say it's one of the safest ones, um, in my case I disagree because I had it and ended up pregnant … Well, they've told me no method es 100% safe." (*25–30*)<br>"It depends on whether you visit your rheumatologists and it depends on your disease … Obviously a barrier method is always recommended because of sexually transmitted diseases … It depends on tastes and preferences." (*20–25*)<br>"I'm not sure, I really don't know which [methods] could interfere. I've never wondered if my arthritis could interfere with some method." (*20–25*)<br>"Side effects related to my disease is something I don't know anything about and I would like to know, but I mean I also know that there are side effects for any person taking contraceptives." (*30–35*) |
| Factors influencing the choice of method | "My mom helped me decide. She gave me advice. I've always said 'I have lupus.' When I was in the hospital they told me at that moment, when they about to take me to the operating room they said 'which device do you want?' and I asked 'I have lupus, is there a problem with which one I choose or any recommendation?' They're not that flexible here, they don't give good explanations, they just told me 'whichever one you want is fine or if you want to choose injections or pills, it's your choice' and I wasn't that interested in the injections because of my disease, what if they triggered something, and I chose the IUD." (*20–25*) |
| Accessibility | "I mean it can be in any health center or if you have some type of insurance then wherever they tell you or even if you have IMSS [Mexican Institute of Social Security] you can go to a, um, to a preventive medicine unit … When they gave me mine they did give me a prescription … I went to ask for it at the pharmacy, then I went up for my consultation and that's where they applied it." (*20–25*) |

many rely on their rheumatologists for guidance. Participants emphasised the importance of multidisciplinary care and expressed a desire for more comprehensive support in making informed decisions about their sexual and reproductive health.

## DISCUSSION

The present study highlights significant gaps in knowledge about sexual and reproductive health among patients with ARDs, as well as deficient communication about these topics. We identified four main aspects of sexual and reproductive health from the patients' perspectives and based on their experiences, which should be taken into consideration for any interventions and incorporated into clinical care guidelines.

Our results show that, though the importance of contraception is clear to many patients, steps are still needed to facilitate its implementation. Most of the participants lack sufficient understanding to discern between available methods or use them inconsistently, like what has been previously reported about patients with ARDs and other chronic conditions.[6 14 15] This knowledge gap often leads to increased risks.[6 14–16] Tools such as ReproKnow could be beneficial in assessing knowledge gaps in this area.[17–19] Guidance on the safest and most effective options should consider the characteristics of each particular patient, including sociocultural and financial characteristics, their ARD diagnosis and potential interactions with medications or active disease.[5 20] Particularly concerning is that patients using teratogenic medication or those with active disease are not necessarily more likely to receive contraceptive counselling or to use contraception, leading to further risks in case of an unplanned pregnancy.[21]

Another relevant issue is disparities in access to care. Our participants mention barriers to access contraception based on a person's social security or health insurance status; this gap in access to low- or no-cost contraception for patients with rheumatic diseases has been previously documented.[21] In addition to socio-economic background, patient characteristics such as age and race/ethnicity are relevant to the use of contraception, potentially causing further disparities.[22]

Notable aspects of reproductive health identified in this study are heredity and its implications for family planning. The genetic basis of ARDs is complex, and while familial aggregation has been documented,[23–25] environmental factors also play a significant role in disease development. Many patients with ARDs are aware of the genetic basis of their conditions or they may have noticed a tendency in their own family histories, potentially leading them to believe in genetic predispositions for ARDs. Therefore, many patients are uncertain whether their offspring are at significant risk of developing the same condition, as has been reported in lupus and other ARDs.[26] This

**Table 3** Theme 2: considerations for reproductive health and pregnancy planning

| | |
|---|---|
| Fertility with an autoimmune rheumatic disease | "I honestly don't know, but I think that because of the medications that you take, then you could have some trouble [conceiving]." (*20–25*)<br>"I would say no, I mean I'm not sure, but according to what I asked my rheumatologist, considering the um taking the necessary precautions it [fertility] shouldn't decrease, I mean I can have a normal life." (*30–35*)<br>"That it was harder for me to get pregnant … because of the medication." (*20–25, pregnant*) |
| Heredity of the autoimmune rheumatic disease | "I spoke to my doctor, she said that there were three factors that um influence, um the genetic, the environmental and the unrecognized factor, and um, each one has a small percentage of truth, and that um the probability was high." (*30–35*)<br>"Well, there is a certain percentage according to what the geneticist told me when I went to see her. Um, I did know something about it because my mom has rheumatoid arthritis and so do I, so I do know that there is a certain percentage of probability or a higher probability, but not that it's a fact that my baby will have it." (*30–35*)<br>"I did read about that when I was pregnant, um, what I remember is that it was more likely that I would pass it on to a girl than to a boy, but I don't know if it's because of the chromosomes or what the reason is, but it's more likely that a girl inherits a disease like lupus than a boy." (*20–25*) |
| Risk perception | "Um, they could have health complications, or, I mean, the baby could be affected as well. There are many things that could happen when a disease is active and there's a pregnancy … I would have to take more care of myself and well I would have to be under control if I want my baby to be born healthy and if I want to be there for them as well." (*35–40*)<br>"Hmm, negative consequences well it could cause a stronger flare-up … If that had happened to me um well I don't know if the medication that I need to get better could influence the pregnancy or cause a spontaneous miscarriage." (*20–25*)<br>"Well when your disease is active, I don't know, that their kidneys are not working correctly or um that … for example, when I had my son, I had preeclampsia but I wasn't feeling badly and the doctor told me 'if you get pregnant again and you have preeclampsia again' something like that could happen." (*30–25*)<br>"Yeah, I mean, the disease could progress more, it could be stronger right? It could be that the baby can't be born for the same reason, or that they're born with something um or, I mean, they told me that the baby could also inherit my disease. I, um, I think those are the risks of not planning them well, as they should be." (*25–30*)<br>"The disease can be altered or the baby can be hurt. They run the risk of dying." (*20–25*) |
| Special preconception care measures | "Vitamins, so that my body is ready, because before that I think my arthritis would have been very altered and an unplanned pregnancy would have been very different. Now that it has been asleep well that was an advantage, I really think that if it had been active it would have been very different." (*20–25*) |
| Perceived importance of family planning | "I feel like I'm preparing for the changes that my body could have, the reactions, and also the reactions that I may have post-partum, how my disease will flare up again … And that um that I'm feeling well and healthy, because I did notice a big change from when I started having arthritis. I mean it wasn't like I was planning to get pregnant from the start because I knew I wouldn't have been able to handle it." (*20–25*)<br>"Because first you have to make sure that everything is good with your health, for example people with autoimmune diseases have to see that their disease is asleep, that nothing is altered, that everything is under control, that you have time so that you can, um, let's say to handle it if they take you off medication. I mean, that your disease has to be fully asleep for you to carry on with your pregnancy without any complications." (*20–25*) |

concern was consistently expressed by participants in the present study, even though most of them had high levels of schooling and some had even received some previous genetic counselling. Since uncertainty about the heredity of ARDs often influences family planning,[7 27] and since patients may over- or underestimate genetic risks, we highlight the need for rheumatologists to provide guidance on this topic. This should include information about both genetic and non-genetic risk factors, enabling patients to make informed decisions about family planning without undue fear or misconceptions.[7]

Disease activity and medication use also emerged as key considerations for family planning. Many participants viewed disease management as a priority when planning for pregnancy, expressing concerns about the impact of ARDs on preconception health and pregnancy outcomes. This aligns with previous studies conducted in Brazil and Iran, where women with lupus reported varying levels of concern about disease activity and pregnancy risks.[6 15 17] Similarly, many women with ARDs were uncertain about which treatments were compatible with pregnancy, reflecting a significant unmet need for clear and consistent information from healthcare providers.[19 28] These findings highlight the necessity of addressing disease management and medication safety in reproductive health education for women with ARDs as pregnancy counselling plays a critical role in this process.[5 27 29]

The rheumatologist–patient relationship plays a crucial role in reproductive healthcare and decision-making. There is often a disconnect between the need for guidance and the willingness of rheumatologists to engage in these discussions, with specialists frequently expressing discomfort or uncertainty about addressing sexual and reproductive health.[5 30]

However, patients overwhelmingly prefer that their rheumatologists initiate these conversations.[5] This discrepancy may be due to concerns about managing high-risk pregnancies, ethical considerations or a lack of confidence in discussing topics such as contraception, pregnancy or genetic risks.[30]

**Table 4** Theme 3: care and medications during pregnancy and lactation

| | |
|---|---|
| Care in pregnancy | “Um, they did some bloodwork to see about the arthritis and sexually transmitted diseases, and to see how I was doing in general. They also did the genetic ultrasound and, that’s generally it, and well my consultations, that I go get a checkup each month.” (*20–25*)<br>“I saw my rheumatologist, um, the psychologist, the nutritionist, um I forgot the name, yeah the gynecologist and I also went to the endocrinologist because the pregnancy altered my thyroid, it was out of control … I don’t remember the names of the studies they did, but there were a lot of studies to see that my disease and everything was ok. They did some ultrasounds um well to see that the baby didn’t have any malformations and to hear that everything was ok. They did studies just to see how I was controlled so that it wouldn’t affect the baby.” (*20–25*)<br>“I imagine that the follow-up [during pregnancy] is monthly. And the frequency, well um in my case I image that it might be a little more frequently than monthly because of the lupus.” (*30–35*)<br>“No, we haven’t talked about frequency. I would think that every two months, I don’t know, because I imagine it’s like a normal appointment for example for the lupus I go every 3 to 4 months, but it wouldn’t be like a monthly appointment like with a gynecologist.” (*30–35*) |
| Counselling on medication use | “Hmm no, I haven’t asked. It’s just that, I mean, when she [the rheumatologist] told me ‘you know, if you get pregnant then I have to take you off so many medications and it’s a whole process’ so then I was like um no then and I never asked any questions.” (*20–25*)<br>“Well, first I would look for my doctor’s counseling and I would ask if it affects the baby, I mean if it’s harmful or not.” (*35–40*)<br>“Hmm no, but I won’t be able to breastfeed because well they can’t take me off hydroxychloroquine … Look, since I already have a little boy, when I had him, at the full health coverage center they did tell me that I should breastfeed but nothing was coming out and it hurt a lot and, I mean, nothing else. I left and around two days after I think I came back and they told me to stop because I was taking hydroxychloroquine and I don’t know what …” (*30–35*) |
| Knowledge of medication use during pregnancy and post partum | “Before, well I, still, I mean, they told me that I’d have to be off methotrexate 3 or 4 months before to detoxify the body to conceive, but I didn’t realize I was pregnant [*laugh*] … Yeah, I stopped the medication when I knew I was pregnant and, um, afterwards I had an appointment with the rheumatologists and they, um, changed them.” (*25–30*)<br>“Well, the ones I was taking they told me that they were very strong and actually high-risk if I got pregnant, um, the baby wouldn’t be born or would be born with malformations, so yeah, it’s a little bit worrying to take the medication and not be cautious because well you’re worried that it’ll happen, you know. I don’t really know which ones they are now that I’m, that they prescribed new ones that I’m taking right now, ones that I can take during pregnancy. But really, I don’t know in detail which medications to take, no … I can’t remember, to be honest.” (*25–30*)<br>“The biggest greatest fear is always the malformations that babies can have, or that if when you’re breastfeeding you’re taking a medication you can pass it on through um through breastfeeding. So um I think that the biggest fear would be that for example the patients that are taking methotrexate that their babies would later have problems in their development, in their [*laughs*] organogenesis … very embryology but … yeah, that would be the biggest issue, that they had developmental problems.” (*20–25*)<br>“I know that there are a lot of myths that you can’t take medication or even eat certain foods when you’re lactating, I mean, I feel like there’s a lot of disinformation about this and that really it’s a very limited number of medications that interfere with breastfeeding.” (*30–35*) |

According to our participants, reproductive health decision-making is almost always delegated to the rheumatologist, following a traditional model of care where the physician’s role is to provide information vertically and unilaterally, instead of facilitating a dialogue with patients, encouraging equal contribution and participating in horizontal exchanges for the co-construction of care.[31] Alternative models of participatory healthcare are necessary for patients to fully exercise their agency and autonomy in the context of their ARD, especially regarding sexual and reproductive health where consideration for their life circumstances, and personal and cultural values is central.[5 32 33] Understanding autonomy from a relational perspective, rheumatologists, along

**Table 5** Theme 4: reproductive healthcare and decision-making

| | |
|---|---|
| Reproductive health decision-making | “Um, I don’t really know…I trust in what most doctors tell me … I trust their knowledge.” (*20–25*)<br>“Well, my rheumatologist should be in charge of that…um, my disease, if I’m in remission or not, etc.” (*25–30*)<br>“The rheumatologist only told me that when I wanted to, when I started planning, that I should tell her, for her to start thinking about what changes to make, but that we would do it together. I mean, that I had to tell her when I started looking and she would guide me.” (*30–35*) |
| Mutidisciplinary care | “I think that’s very important, because both the gynecologist and the rheumatologist work hand in hand and explain things and tell you ‘you know what, you’re doing great,’ ‘you know what, this is wrong,’ I think it’s a very positive way to do things for you as a patient…the way they’re caring for me and that makes me feel safe … I feel comfortable this way, the rheumatologist and the gynecologist, I’m also seeing a nutritionists and things like that, but yeah, the psychologist is also very good.” (*R30–35*)<br>“Hundred percent a gynecologist, right? Working hand in hand with the rheumatologist.” (*30–35*) |

with family and community, can help shape patients' self-determination and are central to their capacity to make informed decisions.[34]

Improving communication and shared decision-making are necessary to enhance outcomes and adequately face the ethically complex situations and dilemmas that arise in the context of sexual and reproductive health, development and the beginning of life. Rheumatologists might be currently ill-equipped to ethically, sensitively and adequately navigate these complexities[35] when they are required to act as facilitators and not assume a role of moral authority over decision-making which imposes their own values.[22]

The importance of a multidisciplinary approach was also evident in our study as participants emphasised the need for coordinated care involving rheumatologists, gynaecologists and other specialists. This finding aligns with existing guidelines from organisations such as the American College of Rheumatology, the European Alliance of Associations for Rheumatology and others, which recommend collaboration among healthcare providers to ensure comprehensive care for women with ARDs.[5 36 37]

An overarching theme that should be considered in sexual and reproductive healthcare is gender, considering that ARDs mainly affect the female population. The intersection between gender identity, sexual orientation, sociocultural expectations and chronic illness creates unique challenges for women and people able to conceive with ARDs, affecting their ability to navigate reproductive health decisions effectively.[17 38 39]. Recognising these gendered experiences is crucial for providing empathetic, patient-centred care that respects autonomy and reproductive rights.[39] Importantly, though most patients identify as cis women, including all of this study's participants, the gendered experiences of trans men, and non-binary and gender nonconforming patients able to conceive must be central to comprehensive sexual and reproductive healthcare.

Some of the study limitations are related to the participant population. Our participants generally had more schooling than the average in Mexico. We only included women from a single healthcare centre in the country, which provides specialised sexual and reproductive healthcare for patients with ARDs. These characteristics explain the relatively higher knowledge of sexual and reproductive health topics among our study population compared with previous studies. However, information and communication with rheumatologists remains limited even considering these factors. An additional limitation is the missing perspective from rheumatologists which could help contrast experiences and provide a more complete understanding. Finally, social and cultural aspects of pregnancy were not explored in depth.

In conclusion, the experiences of patients with ARDs regarding sexual and reproductive health were varied, reflecting a general scarcity of knowledge about sexual and reproductive health, including family planning and prenatal/postnatal care. Participants recognised the crucial importance of a multidisciplinary team, led by their rheumatologist, to ensure consistency in the information provided. Such an approach helps generate trust in the quality of the information provided and facilitates better decision-making based on patients' beliefs, preferences and reproductive rights. Overall, it is important to develop educational strategies that consider the best available scientific evidence alongside the lived experiences and perspectives of patients and, when appropriate, their partners. Finally, incorporating a gender perspective at the centre of these strategies is vital to address the unique challenges faced by women and people able to conceive with ARDs when navigating their sexual and reproductive health.

**Author affiliations**
[1]Rheumatology, Hospital Universitario. Dr. José Eleuterio González, Monterrey, Mexico
[2]Hospital Universitario. Dr. José Eleuterio González, Monterrey, Mexico
[3]Rheumatology, Hospital General de México "Dr. Eduardo Liceaga", Mexico City, Mexico

**X** Lorena Perez-Barbosa @lorenapbmd

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## ORCID iDs

Génesis Guadalupe Sandoval-Torres http://orcid.org/0009-0007-3600-9313
Dionicio Angel Galarza-Delgado http://orcid.org/0000-0001-9714-2109
Ingris Pelaez-Ballestas http://orcid.org/0000-0001-5188-7375

## REFERENCES

1. Perez-Barbosa L, Skinner-Taylor CM, Lujano-Negrete AY, *et al*. Construction and validation of a reproductive behavior questionnaire for female patients with rheumatic diseases. *Clin Rheumatol* 2023;42:2453–60.
2. World Health Organization. Contraception. Available: https://www.who.int/health-topics/contraception#tab=tab_1 [Accessed 01 Oct 2024].
3. Ramsey-Goldman R. Reproductive Health in the Post Roe v. Wade Era. *J Clin Rheumatol* 2024;30:S1.
4. Skinner-Taylor CM, Perez-Barbosa L, Barriga-Maldonado ES, *et al*. Reproductive health counseling and contraceptive use in Mexican women with rheumatic diseases: a cross-sectional study. *Rheumatol Int* 2021;41:409–14.
5. Wolgemuth T, Stransky OM, Chodoff A, *et al*. Exploring the Preferences of Women Regarding Sexual and Reproductive Health Care in the Context of Rheumatology: A Qualitative Study. *Arthritis Care Res (Hoboken)* 2021;73:1194–200.
6. Rodrigues L, Alves VLP, Sim-Simc MMF, *et al*. Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: A qualitative study. *Midwifery* 2020;87.
7. Colmenares-Roa T, Gastelum-Strozzi A, Crosley E, *et al*. Digital Narratives of Living With Lupus: Lived Experiences and Meanings for Latin American and Latino Patients and Their Families. *Arthritis Care Res (Hoboken)* 2023;75:540–9.
8. United Nations Department of Public Information. Platform for Action and Beijing Declaration. Fourth World Conference on Women, Beijing, China. New York, NY, United Nations, 1995.
9. Gillham B. The Research Interview. Continuum Ed. London, 2000.
10. Trundle C, Gardner J, Phillips T. The Ethnographic Interview: An Interdisciplinary Guide for Developing an Ethnographic Disposition in Health Research. *Qual Health Res* 2024;0:1–15.
11. Perez-Barbosa L, Carrazco-Chapa A, Cardenas-de la Garza JA, *et al*. Reproductive health and pregnancy clinic for patients with rheumatic diseases: A multidisciplinary-care model description. *Int J Rheum Dis* 2024;27:39039913.
12. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
13. Catherine P, May N. Qualitative Research in Health Care. BMJ Ed. London, 2016.
14. DeNoble AE, Hall KS, Xu X, *et al*. Receipt of prescription contraception by commercially insured women with chronic medical conditions. *Obstet Gynecol* 2014;123:1213–20.
15. Moghadam ZB, Faezi ST, Zareian A, *et al*. Experiences of Iranian female patients with systemic lupus erythematosus: A qualitative study. *Arch Rheumatol* 2021;36:120–8.
16. Yazdany J, Trupin L, Kaiser R, *et al*. Contraceptive counseling and use among women with systemic lupus erythematosus: a gap in health care quality? *Arthritis Care Res (Hoboken)* 2011;63:358–65.
17. Petrocchi V, Visintini E, De Marchi G, *et al*. Patient Experiences of Systemic Lupus Erythematosus: Findings From a Systematic Review, Meta-Summary, and Meta-Synthesis. *Arthritis Care Res (Hoboken)* 2022;74:1813–21.
18. Ackerman IN, Jordan JE, Van Doornum S, *et al*. Understanding the information needs of women with rheumatoid arthritis concerning pregnancy, post-natal care and early parenting: A mixed-methods study. *BMC Musculoskelet Disord* 2015;16:194.
19. Sammaritano LR. Therapy Insight: guidelines for selection of contraception in women with rheumatic diseases. *Nat Rev Rheumatol* 2007;3:273–81.
20. Birru Talabi M, Clowse MEB, Blalock SJ, *et al*. Contraception Use Among Reproductive-Age Women With Rheumatic Diseases. *Arthritis Care Res (Hoboken)* 2019;71:1132–40.
21. Clowse MEB, Li J, Talabi MB, *et al*. Frequency of Contraception Documentation in Women With Systemic Lupus Erythematosus and Rheumatoid Arthritis Within the Rheumatology Informatics System for Effectiveness Registry. *Arthritis Care Res (Hoboken)* 2023;75:590–6.
22. Frisell T, Holmqvist M, Källberg H, *et al*. Familial risks and heritability of rheumatoid arthritis: role of rheumatoid factor/anti-citrullinated protein antibody status, number and type of affected relatives, sex, and age. *Arthritis Rheum* 2013;65:2773–82.
23. Balakrishnan A, Mehta P, Gupta L. Pregnancy counseling in rheumatic diseases: Where science meets the steps. *Indian J Rheumatol* 2021;16:322.
24. Brophy S, Hickey S, Menon A, *et al*. Concordance of disease severity among family members with ankylosing spondylitis? *J Rheumatol* 2004;31:1775–8.
25. Andreoli L, Lazzaroni MG, Carini C, *et al*. "Disease knowledge index" and perspectives on reproductive issues: A nationwide study on 398 women with autoimmune rheumatic diseases. *Joint Bone Spine* 2019;86:475–81.
26. Stransky O, Hunt N, Richards JS, *et al*. Exploring Family Planning, Parenting, and Sexual and Reproductive Health Care Experiences of Men With Rheumatic Diseases. *J Rheumatol* 2022;49:251–5.
27. Rebić N, Munro S, Garg R, *et al*. "The medications are the decision-makers…" Making reproductive and medication use decisions among female patients with rheumatoid arthritis: a constructivist grounded theory. *Arthritis Res Ther* 2022;24:31.
28. Chakravarty E, Clowse MEB, Pushparajah DS, *et al*. Family planning and pregnancy issues for women with systemic inflammatory diseases: patient and physician perspectives. *BMJ Open* 2014;4:e004081.
29. Birru Talabi M, Clowse MEB, Blalock SJ, *et al*. Perspectives of Adult Rheumatologists Regarding Family Planning Counseling and Care: A Qualitative Study. *Arthritis Care Res (Hoboken)* 2020;72:452–8.
30. Manrique de Lara A, Peláez-Ballestas I. Beyond Empowerment in Rheumatology Care. *J Rheumatol* 2022;49:864–6.
31. Hall J, Chawla M, Watson D, *et al*. Addressing reproductive health needs across the life course: an integrated, community-based model combining contraception and preconception care. *Lancet Public Health* 2023;8:e76–84.
32. Hammarberg K, Stocker R, Romero L, *et al*. Pregnancy planning health information and service needs of women with chronic non-communicable conditions: a systematic review and narrative synthesis. *BMC Pregnancy Childbirth* 2022;22:236.
33. Manrique de Lara A, Colmenares-Roa T, Pascual-Ramos V, *et al*. Sociocultural and moral narratives influencing the decision to vaccinate among rheumatic disease patients: a qualitative study. *Clin Rheumatol* 2023;42:2199–207.
34. Cano-Gámez T, Lobato-Belmonte AC, Peláez-Ballestas I, *et al*. Termination of pregnancy in lupus nephritis: A bioethical analysis with the integrative method. *Reumatol Clin (Engl Ed)* 2024;20:20–3.
35. Saavedra Salinas MÁ, Barrera Cruz A, Cabral Castañeda AR, *et al*. Clinical practice guidelines for the management of pregnancy in women with autoimmune rheumatic diseases of the Mexican College of Rheumatology. Part I. *Reumatol Clin* 2015;11:295–304.
36. Sammaritano LR, Bermas BL, Chakravarty EE, *et al*. 2020 American College of Rheumatology Guideline for the Management of Reproductive Health in Rheumatic and Musculoskeletal Diseases. *Arthritis Rheumatol* 2020;72:529–56.
37. Andreoli L, Bertsias GK, Agmon-Levin N, *et al*. EULAR recommendations for women's health and the management of family planning, assisted reproduction, pregnancy and menopause in patients with systemic lupus erythematosus and/or antiphospholipid syndrome. *Ann Rheum Dis* 2017;76:476–85.
38. Williams D, Pell B, Grant A, *et al*. Identities of women who have an autoimmune rheumatic disease [ARD] during pregnancy planning, pregnancy and early parenting: A qualitative study. *PLoS ONE* 2022;17:e0263910.
39. Sánchez Bringas Á. Nuevas maternidades o la deconstrucción de la maternidad en México. *Debate Fem* 2004;30:55–86.