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Experiencing pregnancy in the context of lupus and antiphospholipid syndrome: a grounded theory

Vivenciando a gestação no contexto do lúpus e da síndrome antifosfolípide: uma teoria fundamentada

Experimentando el embarazo en el contexto del lupus y del síndrome antifosfolípido: una teoría fundamentada

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ABSTRACT

Objective: To understand the meanings attributed to pregnancy in the context of Lupus and antiphospholipid syndrome by women and healthcare professionals.

Method: Qualitative research, using Symbolic Interactionism as a theoretical framework and Grounded Theory, a constructivist perspective. Data were collected between January and August 2022, through online interviews with 27 women with Lupus located on the social network Facebook and in-person or remote interviews with 12 healthcare professionals.

Results: The theoretical model constructed has two categories: "Equal conditions, distinct experiences: experiencing the gestational process" shows that obstetric complications and lack of connection with healthcare professionals trigger negative meanings to the experience; and "Therapeutic management interfering in the attribution of meanings to the experience", demonstrates that the way women interact with healthcare professionals and how they manage treatment favors a positive reframing.

Final considerations: The meanings attributed to pregnancy are elaborated and modified according to the interpretation of previous and current experiences, healthcare trajectory and interactions with healthcare professionals. Previous guidance, planning, bonding and trust in healthcare professionals enable positive meanings, while obstetric complications, unqualified assistance and lack of bonding with professionals provide negative meanings.

Descriptors: Lupus erythematosus, systemic. Antiphospholipid syndrome. Pregnancy, high-risk. Thrombophilia. Grounded theory. Nursing.

RESUMO

Objetivo: Compreender os significados atribuídos à gravidez, no contexto do Lúpus e da Síndrome Antifosfolípide, por mulheres e profissionais de saúde.

Método: Pesquisa qualitativa, que utilizou como referencial teórico o Interacionismo simbólico e metodológico, a Teoria Fundamentada nos Dados, vertente construtivista. Os dados foram coletados entre janeiro e agosto de 2022, mediante entrevistas *on-line* com 27 mulheres com Lúpus, localizadas na rede social *Facebook* e em entrevistas presenciais ou remotas com 12 profissionais de saúde.

Resultados: O modelo teórico construído possui duas categorias: *"Condições iguais, experiências distintas: vivenciando o processo gestacional"* mostra que complicações obstétricas e ausência de vínculo com os profissionais de saúde desencadeiam significados negativos à experiência; e *"O manejo terapêutico interferindo na atribuição dos significados à experiência"* demonstra que a forma com que a mulher interage com os profissionais de saúde e conduz o tratamento favorece a ressignificação positiva.

Considerações finais: Os significados atribuídos à gestação são elaborados e modificados conforme a interpretação de experiências anteriores e atuais, trajetória assistencial e interações com os profissionais de saúde. A orientação prévia, o planejamento, o vínculo e a confiança nos profissionais de saúde possibilitam significados positivos. Já, as complicações obstétricas, a assistência não qualificada e ausência de vínculo com os profissionais produzem significados negativos.

Descritores: Lúpus eritematoso sistêmico. Síndrome antifosfolipídica. Gravidez de alto risco. Trombofilia. Teoria fundamentada. Enfermagem.

RESUMEN

Objetivo: Comprender los significados atribuidos al embarazo en el contexto del Lupus y del síndrome antifosfolípido por mujeres y profesionales de la salud.

Método: Investigación cualitativa, que utilizó como marco teórico el Interaccionismo simbólico y metodológico, la Teoría Fundamentada, una vertiente constructivista. Los datos fueron recolectados entre enero y agosto de 2022, a través de entrevistas online a 27 mujeres con Lupus ubicadas en la red social Facebook y entrevistas presenciales o remotas a 12 profesionales de la salud.

Resultados: El modelo teórico construido tiene dos categorías: "Condiciones iguales, experiencias diferentes: vivir el proceso gestacional" muestra que las complicaciones obstétricas y la falta de conexión con los profesionales de la salud desencadenan significados negativos a la experiencia; y Gestión terapéutica interfiriendo en la atribución de significados", demuestra que la forma en que las mujeres interactúan con los profesionales de la salud y cómo conducen el tratamiento favorece la resignificación positiva..

Consideraciones finales: Los significados atribuidos al embarazo son elaborados y modificados según la interpretación de experiencias pasadas y actuales, trayectoria de atención e interacciones con profesionales de la salud. La orientación previa, la planificación, la vinculación y la confianza en los profesionales de la salud posibilitan significados positivos, mientras que las complicaciones obstétricas, la asistencia no calificada y la falta de vínculo con los profesionales proporcionan significados negativos.

Descriptores: Lupus eritematoso sistémico. Síndrome Antifosfolípido. Embarazo de alto riesgo. Trombofilia. Teoría fundamentada. Enfermería.

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INTRODUCTION

Characterized as a rheumatic, autoimmune disease challenging to diagnose, Systemic Lupus Erythematosus (SLE) predominantly affects women of reproductive age (15 to 45 years old)(1), constituting an significant gestational risk factor(2). Nevertheless, pregnancy can exacerbate disease manifestations(3,4), as some medications used to control it are contraindicated during this period, significantly increasing the risk of gestational complications(5,6). Therefore, it is recommended that pregnancy be planned and occur during the period of disease remission, which favors the therapeutic management of both conditions(7,8) and contributes to better maternal and neonatal outcomes.

For women with SLE, preconception monitoring for those who intend to become pregnant, reproductive planning and prenatal care in a specialized high-risk medical outpatient clinic are essential for better pregnancy outcomes(2,8).

Antiphospholipid Syndrome (APS) during pregnancy is one of the main underlying conditions of SLE, with an incidence of approximately 40%. It is a clinical, autoimmune and systemic condition, characterized as a thromboembolic condition that is manifested by the intensified clot formation, which increases the risk of venous or arterial thrombosis(6). Placental thromboembolism represents one of the main causes of obstetric complications in women with SLE(7).

Without adequate treatment for APS, about half of cases progress to gestational loss(7). Além Besides fetal death, there are other important complications of APS: repeated miscarriages, premature birth, pre-eclampsia, eclampsia, HELLP Syndrome, Deep Vein Thrombosis (DVT), Stroke and Pulmonary Embolism(8–10).

A multidisciplinary approach throughout the gestational period, with regular monitoring of the pregnancy and SLE, is essential for the early diagnosis of possible complications and their appropriate treatment. This requires the work of professionals from different specialties: rheumatology, dermatology, hematology, nephrology and gynecology and obstetrics. Cases of APS involve, for example, preventive anticoagulation, such as the use of Acetylsalicylic Acid (ASA) (low doses) and/or Low Molecular Weight Heparin (LMWH) in prophylactic or therapeutic doses according to the woman's clinical conditions(6,10,11).

Some studies address the gestational process in women with SLE from the perspective of those who have experienced it(12–14), or from a clinical perspective(6,9,11). Others focus on the clinical and therapeutic management of APS(6,11). However, there is a gap when considering the combination of these two conditions in pregnancy.

Thus, when considering the severity of the association of SLE and APS in women of childbearing age, due to the gestational complications it may cause and, based on the clinical and psychological aspects of the possibility of pregnancy not progressing in women who wish to experience motherhood, this study aims to contribute to science and to women who experience such clinical conditions. This is particularly important when considering that, within the scope of the Unified Health System (*Sistema* Único *de Saúde*), the therapeutic management of people with rare diseases poses an important challenge, especially regarding comprehensive care and, in the case of women with SLE, the right related to reproductive planning. Therefore, the results of the study may contribute to sensitizing healthcare professionals, providing support for planning care strategies that enable these women to access qualified and comprehensive care, with timely diagnosis and the early implementation of appropriate therapies, aiming to minimize gestational complications and allow the pregnancy to progress to its fullest and with good outcomes.

Given this context, the objective of this study is to understand the meanings attributed to pregnancy, in the context of Lupus and Antiphospholipid Syndrome, by women and healthcare professionals.

METHOD

This is an explanatory qualitative research, which is part of a larger study entitled "Meanings attributed to high-risk pregnancy in women living with Systemic Lupus Erythematosus". The presentation of the report follows the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

As a theoretical framework, the precepts of Symbolic Interactionism (SI) are used, which presupposes that the value of a particular experience and the action triggered in relation to it arises from the meaning that the individual attributes to it, based on the lived experience, and is defined as starting from interaction with the object, with the social environment and with the individual themselves(15). SI studies individual behavior, allows us to interpret how people define events, attitudes, actions and behaviors in the face of facts and how they relate to the phenomenon experienced(15).

Pregnancy itself already has impact on the life of the woman and those she lives with, and brings with it diverse feelings and sensations. When pregnancy is accompanied by relatively rare conditions with significant impacts on the gestational process, new feelings, perceptions and meanings can be attributed to it, transcending the concepts of a normal pregnancy. Therefore, the SI was chosen as a theoretical reference because it approaches the object of study by allowing to understand and explain the phenomenon of pregnancy from the perspective of healthcare professionals and, above all, women with SLE, highlighting, in a subjective way, the way in which that they experience the process, signify the phenomenon and deal with its peculiarities.

As methodological reference, the Grounded Theory (GT) was used, a constructivist perspective that aims to observe the way in which individuals perceive their life circumstances, based on the idea that the researcher carries out in the interpretative and constructive work with the participants, with ability to portray the reality studied and bring scientific evidence that can modify and improve the scenario under investigation(16).

Data were collected from January to August 2022, through open interviews, conducted remotely or in-person. Considering the assumptions of GT, data collection occurred concomitantly with the transcription and analysis of interviews with 33 participants, 27 women with SLE and 12 healthcare professionals, who made up five sample groups, constituted according to the principles of theoretical sampling and the theoretical saturation recommended by GT(16).

The 27 participating women were recruited on the social network Facebook®, specifically in the private group "*Lúpus Brasil – o desabafo*", which has more than 30 thousand members (people with SLE – majority female, and family members – spouses, parents, children) and around 300 posts per month. The invitation to participate in the study was made through a public post by the first author, who has been a member of the group since 2018, when carrying out research aimed at understanding the perception of people with SLE about living with the disease(12). In this invitation, the researcher informed that she was developing a doctoral study in nursing and that she would like to hear them regarding their experience of pregnancy with SLE and that the results of the research could contribute to the health care offered before, during and after pregnancy with SLE.

The theoretical sampling of this study consisted of 39 participants, approached once, distributed into five sample groups, arranged as shown in Chart 1:

The first sample group was intentionally constituted by 14 women who experienced a high-risk pregnancy, who, in response to the public post or via direct, expressed interest in participating in the research and met the following inclusion criteria: being 18 years old or over, diagnosis of SLE and access to the internet network with technological devices that allowed video calls (mobile internet networks with low speed could compromise the interview).

Only one possible participant was not included because she was deaf, which would have made it difficult to conduct and record the interview, as no sign interpreters were expected to participate and data collection in written form was not planned.

Data analysis from this sample group showed that 10 of the 14 participants had developed APS and seemed to have a different gestational experience. Therefore, the following hypothesis emerged: having APS secondary to SLE seems to make the gestational process more complex, changing the way in which women perceive, behave, and signify pregnancy. To confirm or not this hypothesis, it was defined that the second group should be made up of women who, in addition to the previous criteria, had reported having developed APS during pregnancy. Therefore, another six women who met

Chart 1 – Composition of sample groups. Maringá, Paraná, Brazil, 2023

Sample Group	Composition
1st Sample group	Fourteen women with SLE who had experienced a pregnancy
2nd Sample group	Six women with SLE who had APS during pregnancy
3rd Sample group	Four Women who experienced pregnancy loss
4th Sample group	Three women with SLE who experienced pregnancy outside Brazil
5th Sample group	Twelve healthcare professionals who cared for women with SLE during pregnancy

Source: The authors, 2023.

this criterion and who had expressed interest in participating were contacted and included in the study.

The data analysis from this group raised the following question: is the perception of the pregnancy experience and the meaning attributed to it modified when pregnancy loss occurs? To answer this question, we sought to constitute the third sample group only with women who accepted the invitation in which the condition of having suffered a pregnancy loss was specified. The third sample group, therefore, consisted of four women and all of them also reported APS, reaffirming how much this condition constitutes a risk for the gestational period. A difference that emerged in the data analysis from this group was the participation of a Brazilian woman who was an immigrant in Italy and who had a different perception of the pregnancy experience in Brazil, provided, above all, by the lack of family support and the quality of healthcare received.

Therefore, when constituting the fourth sample group, the search was for women willing to share the experience of pregnancy with SLE outside Brazil. Four women got contacted to schedule the interview, but it could only be conducted with three of them (Japan, Sweden and Germany). The woman with experience in France could not participate due to personal issues.

The data analysis from these four sample groups showed that, far beyond a personal perception of the experience, in the context of relationships with healthcare professionals, marked by their governance over the pregnancy of a woman with SLE, the neglect, negativity and pessimism. The lack of bonding and trust between women and healthcare professionals, the lack of early guidance, the lack of multiprofessional and longitudinal follow-up, and also the lack of humanization and empathy in care showed direct and negative impacts on the way women meant pregnancy. On the other hand, reports about a positive social interaction, characterized by the presence of bond, trust and comprehensive, humanized, and longitudinal follow-up, resulted in positive perceptions, which allowed us to infer that the way in which healthcare professionals act, behave and perceive pregnancy in women with SLE directs, creates and recreates the way in which they signify the experience.

Thus, the fifth sample group consisted of 12 healthcare professionals who met the following inclusion criteria: being a rheumatologist or gynecologist/obstetrician or nurse and having experience in caring for women with SLE during pregnancy. They were recruited using the snowball technique, with the first participant being intentionally invited by email. This is a doctor responsible for the discipline and the outpatient clinic specializing in rheumatology at a university hospital in the Northwest of Paraná.

All interviews were previously scheduled for the day and time chosen by the participants. Those carried out with women were via video call, on the WhatsApp® or Messenger applications. The interviews with the five healthcare professionals indicated and who lived in the municipality of the study were in person, and with the seven who lived in other regions of the country they were remote. All interviews took place on a day and time defined by the participants; the in-person sessions took place in a reserved room at the institution – University Hospital.

Interviews with women with SLE lasted an average of 75 minutes; and those carried out with professionals, an average of 25 minutes. The remote interviews were, after authorization, recorded in audio and video, and the in-person interviews, only audio recorded. All were conducted by the first author (nurse, PhD student in Nursing with previous experience in qualitative data collection and analysis) who had no personal relationship with the participants, although member of the group "*Lúpus Brasil – o desabafo*", where she occasionally participates, but not as a healthcare professional.

During the interviews, a semi-structured questionnaire was used, consisting of two parts: the first, with questions regarding sociodemographic characterization and clinical and obstetric/professional history; the second part consisted of the following guiding question: Tell me about your pregnancy with SLE (GROUP 1), Tell me about your pregnancy with SLE and APS (GROUP 2), and As a healthcare professional, what is your perception about pregnancy and assistance during this period for women with SLE and APS? (GROUP 3).

All interviews were transcribed in full, preferably on the same day they were conducted. In the initial data analysis, the MAXQDA plus software, 2020, was used, following the coding steps proposed by the constructivist aspect of GT: initial and focused coding. In the initial coding, the data was fragmented and analyzed with the objective of conceptualizing ideas and/or meanings expressed by the participants, transforming them into codes. For this, coding was done word by word, line by line and incident by incident, with identification and use of codes in vivo, resulting in 4,441 initial codes. The first author was responsible for the initial coding, but two other researchers with considerable experience in qualitative data analysis met periodically to monitor the analytical process and seek consensus.

In focused coding, the most frequent, significant codes that enabled better analytical understanding of the data gave rise to subcategories and categories, which were subsequently interconnected in an explanatory manner, allowing the identification of the central phenomenon of the research.

It is noteworthy that memos and diagrams were used throughout the entire investigation process, as indicated for studies with GT(16), and that the data were interpreted in the light of Symbolic Interactionism. The interviews were not returned to the participants for confirmation and/or approval. However, the substantive theory originating from the study, with its processes and sub-processes, underwent validation, with the participation of six women with SLE, belonging to the four sample groups of the overall study, and six physicians (four rheumatologists and two gynecologists). Invitations to participate in the validation process was sent via WhatsApp to all members of the sample groups and those who responded affirmatively were included within a week. The evaluators received, via Google forms, instructions on how they should proceed (highlighting the most discrepant and/or similar aspects of their experiences), along with the substantive theory diagram, with explanations about the relationship between the categories and subcategories.

The study was developed in compliance with the guidelines set out in Resolution 466/12 of the National Health Council/MH, and in compliance with the guidelines for research procedures in a virtual environment from the National Research Ethics Commission (*Comissão Nacional de Ética em Pesquisa* – CONEP). The project was assessed and approved by the Permanent Ethics Committee on Research with Human Beings (*Comitê Permanente de Ética em Pesquisa com Seres Humanos* – COPEP) of the signatory institution (CAAE: 53038321,8.0000,0104; Opinion no. 5.132.482/2021).

All participants signed the Informed Consent Form (ICF). Participants in remote interviews received the ICF via messaging application and returned it through the same method. Additionally, before the start of the interview, verbal confirmation of consent to participate in the study was requested. In in-person interviews, the ICF was signed in two copies of equal content, one of which was kept by the researcher and the other by the interviewee.

To ensure the anonymity of participants, excerpts from their statements were coded with the letter P, followed by an Arabic number corresponding to the order of the interviews; the letters W to indicate a woman with SLE; R to identify rheumatologist; GO to indicate gynecologists/obstetricians; and N for nurse.

RESULTS

From the 39 study participants, 27 were women with SLE and 12 were healthcare professionals. The women lived in the following states: Paraná, Rio Grande do Sul, São Paulo, Rio de Janeiro, Pernambuco, Mato Grosso do Sul, Santa Catarina, Minas Gerais, Goiás, Paraíba, Espírito Santo and Distrito Federal. Furthermore, three lived in other countries: Germany, Japan, and Sweden.

The 14 members of the first sample group were aged between 24 and 38 years old, SLE diagnosis time between two and twenty years and ten of them had APS. The number of gestations in this group ranged from one to six, ten had already had miscarriages, the number of which ranged from one to four. The main complications experienced were miscarriages, premature birth, pre-eclampsia and stroke. The six women in the second sample group were between 24 and 33 years old. The time since diagnosis of SLE ranged from four to 12 years, and experience of three to four pregnancies. All reported repeat miscarriages (two to three) and premature births. The four participants in the third group were between 26 and 46 years old, had been diagnosed with SLE for between five and 16 years, with a history of four to six pregnancies and three to five miscarriages. All reported the development of APS during their pregnancies. The three women in the fourth sample group were 32, 34 and 36 years old, with SLE diagnosed between seven and 28 years ago, with a history of one to two pregnancies, and although only one reported a miscarriage, they all developed APS during gestation.

Finally, the fifth sample group consisted of 12 healthcare professionals, seven rheumatologists (four female), four gynecologists and obstetricians (three male) and one nurse. The age of healthcare professionals ranged from 30 to 69 years old for men and from 29 to 70 for women. The experience in caring for women with SLE ranged from two to 43 years. Five professionals were interviewed in person and were residents of the city where the research was conducted. Seven participated in the remotely and lived in the states of Paraná, Rio de Janeiro, and Pernambuco.

Data analysis allowed the construction of a theoretical model, whose central phenomenon was entitled: "**Experiencing gestation with Lupus and Antiphospholipid Syndrome: experiences and meanings**", which revealed that experiencing APS during a pregnancy with SLE is signified as a complex and dynamic process that changes as pregnancy progresses and is influenced by the way in which both conditions behave over time. This phenomenon is made up of two interconnected categories: *Category 1* – "**Equal conditions, distinct experiences: experiencing the gestational process**", showing that, even with the same clinical conditions, women can follow different paths within the scope of motherhood. Thus, the presence of obstetric complications and the lack of bonding with healthcare professionals are predictors of unfavorable gestational outcomes and the attribution of negative meanings to the experience of pregnancy. However, social support and the experience of an uncomplicated pregnancy favor the construction or reframing of the experience. *Category 2* – **"Therapeutic**

management interfering in the attribution of meanings to the experience". The theoretical illustration of this category demonstrates that the experience of therapeutic management influences the meanings attributed to pregnancy with SLE, and the way in which women interact with their social environment and conduct treatment are mediating factors for the results obtained. Getting pregnant with an active disease, without understanding the chronic condition and how it will progress during gestation, makes the process more complex, as, in addition to the underlying disease, women experience difficult and painful treatment, which does not always avoid suffering and gestational complications. Thus, there is also a redefinition of the meanings attributed to the gestational experience. Figure 1 presents the explanatory diagram of the central phenomenon, the linked categories, and subcategories.

Equal conditions, distinct experiences: experiencing the gestational process

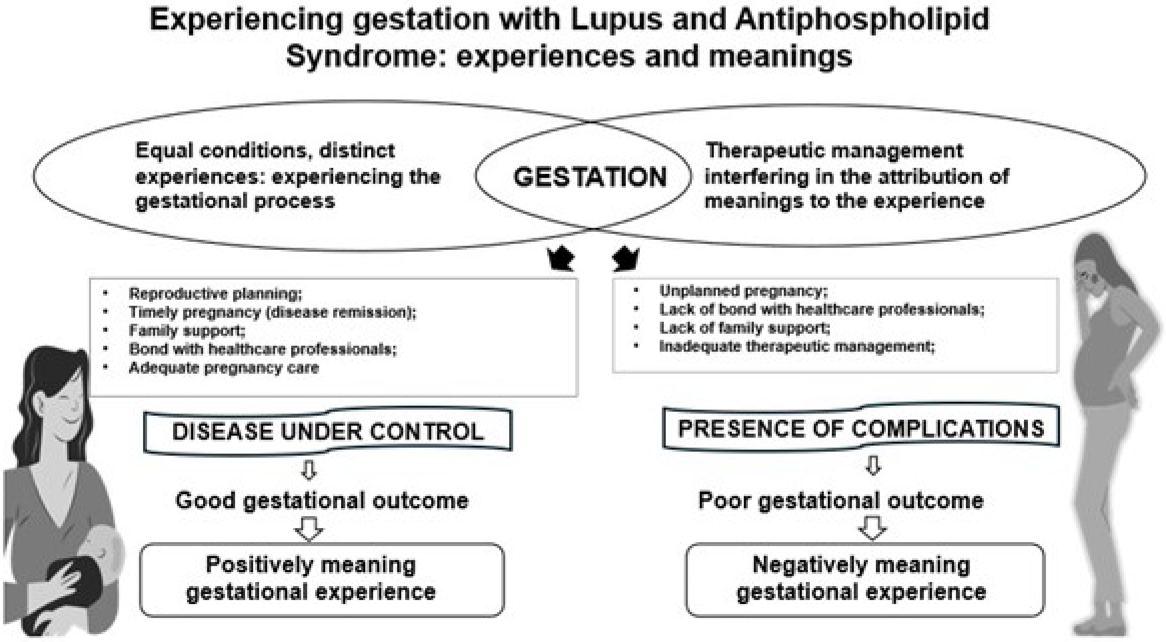
Experiencing a pregnancy with a diagnosis of SLE and APS is perceived by women as a difficult and complex process, because the path ahead is not always known, making complications and unfavorable gestational outcomes possible.

> *It's not easy to be a pregnant woman with two serious diseases, we don't know what could happen along the way, we don't know if we'll make it to the end of the pregnancy. It's very difficult, complex. There are many complications. I'm afraid of a new gestation.* (P15, W)

Faced with experiencing gestational complications, women experience days of struggle and suffering, understanding that pregnancy with SLE and APS is not normal, being considered an experience marked by suffering, especially when, among the complications, the woman experiences gestational loss, a complex, traumatic condition that leads to feelings of incapacity and frustration.

> *It's very hard to talk about this, you know? Because it causes a lot of suffering. I went through hell because of this APS and SLE. So, I suffered a miscarriage, had pre-eclampsia, eclampsia and even a stroke because of it. So for me, getting pregnant with these two diseases is something horrible, it's not normal, I don't have a good memory of this experience.* (P8, W)
>
> *Losing a child, whether through miscarriage or any other way, is a pain that only those who lose can understand. It's a feeling of inability, of frustration, we keep thinking*

Figure 1 – Representative diagram of the central phenomenon: "Experiencing gestation with Lupus and Antiphospholipid Syndrome: experiences and meanings". Maringá, Paraná, Brazil, 2023



Source: The authors, 2023.

> *that we weren't born for this, that we'll never be able to be a mother. We feel like the worst of women, it's sad and complicated.* (P11, W)

Not receiving early guidance from healthcare professionals about the particularities of a pregnancy with SLE and APS and the importance of carrying out reproductive planning prior to gestation is perceived as a complicating factor for unfavorable pregnancy outcomes. However, the lack of bonding and trust between women and healthcare professionals favors complex experiences, leading women to postpone their desire for motherhood.

> *In my first pregnancy, I was not followed by a healthcare team as I should have been, I did not receive any guidance about pregnancy or planning and I did not have any type of professional support. I didn't go through an investigation before getting pregnant, I only found out about APS after the miscarriage, no one had ever told me about it, there was a lack of care. So, for me, it was a traumatic experience, it took me a long time to get pregnant again.* (P1, W)

On the other hand, when there is good social interaction between women and healthcare professionals, pregnancy tends to occur in a more peaceful and healthy way, because there is a bond and trust between the parties, which favors an easier and safer journey, as well as achieving more favorable gestational outcomes.

> *During my second gestation, I went to the capital and paid for a team to accompany me, a rheumatologist, and a gynecologist, and it was totally different. We did all the tests before pregnancy, I was monitored throughout the pregnancy, and this was essential. I felt safer, more confident with less fear and things went well, my son was born perfectly. So, I believe it is very important to be well monitored and have a medical team you can trust.* (P1, W)

Building bonds, trust and empathy between professionals and patients is considered essential for the successful management of pregnancy, both from the perspective of the woman experiencing the phenomenon and the healthcare professional who accompanies and acts directly during the gestational process.

> *You need to have empathy, put yourself in the patient's place. I believe that having Lupus is very difficult, so you need to put yourself in someone else's place, do your best to help this woman overcome the obstacles she will face. It is necessary to create a bond, trust, affection, all of this will be positive in the outcome of the pregnancy both for the patient and for us professionals who are very involved in this.* (27, R)
>
> *I had great support during the pregnancy, both from my rheumatologist and the obstetrician and that was great, it helped me to trust more that it would work out and it did, right?* (P12, W)

It is important to emphasize that the presence of two relatively rare and complex conditions increases the risk of obstetric and neonatal complications, although they do not constitute contraindications. They are conditions subject to investigation and early interventions, which can favor the experience of pregnancy in a positive way.

> *Having APS secondary to SLE ends up worsening the gestational condition because the chances of complications, such as pre-eclampsia and intrauterine growth restriction, increase. So, if the patient has both conditions, her risk is increased. However, everything is statistics! There are risks, but it doesn't mean that the pregnancy will go wrong, it's all a matter of planning, support and teamwork.* (P32, GO)

It is possible to experience a new planned gestational process, after previous complications and unfavorable outcomes, which provides a more favorable experience and, consequently, the attribution of positive meanings.

> *I fought for my dream, I did everything to achieve it. Since I was a little girl, I heard that women with SLE couldn't get pregnant, but it was my biggest dream. I planned the pregnancy with my rheumatologist, I took all the tests he requested beforehand, I planned psychologically to take the injections and I did everything with the certainty that it would work out. So, for me it was a dream come true, I feel victorious.* (P14, W)

Considering this, healthcare professionals emphasize the importance of previous reproductive planning, differentiated care and early investigation of APS in women with SLE. They emphasize that, in the presence of these conditions, additional care needs to be implemented, to provide a gestational process with lower risks of complications and more favorable gestational outcomes.

> *A patient who has SLE and APS requires more care, more attention, needs to be monitored even closely, this patient needs to carry out prior planning for this pregnancy, an early investigation of APS before becoming pregnant. This care is fundamental for managing the pregnancy, with reduced risks of complications and the opportunity to achieve more positive gestational outcomes.* (P24, R)

Therapeutic management interfering in the attribution of meanings to the experience

The treatment imposed by SLE and APS is signified as a complex moment experienced with difficulties at the beginning of the gestational process, in which the woman does not have the physical and psychological preparation to deal with the complexity of the treatment.

> *The treatment for SLE is already complicated because you live on medication your whole life, then having to take injections because of APS is even more complex, it hurts. It's not nice, it bleeds, bruises, it's difficult. It's even more difficult at first, until you get used to the shots it's complicated.* (P7, W)
>
> *The treatment for APS was one of the worst things I had to go through in my life. I don't even like to remember it, it makes me sick just thinking about it, it's very difficult, I often thought about giving up, I just didn't do it because it was my only hope. Treating SLE was easier than APS, but it's a lot. A lot all at once.* (P19, W)

In addition to the need for daily injections and their consequences, women also refer to the high costs and difficulties in acquiring the medication, as the bidding process and release of high-cost medication takes time, and the and not always do women have the financial means to cover the costs.

> *Nobody likes injections, especially every day. It bleeds, it hurts. It's too difficult, not to mention the difficulty of getting it through the SUS. When the medication comes out you are already three, four months pregnant and need to buy it and it is quite expensive, we don't always have money to buy it and then we need help from other people to continue with the treatment.* (P6, W)
>
> *One of the biggest difficulties is having to buy the medications, they are very expensive. In SUS the process takes a long time, so we have to buy, I spent more than 1,500.00 per month.* (P9, W)

Moreover, as it is an injectable medication, some women need the help of others for daily administration, and the participation of the spouse, family and healthcare professionals is considered essential in this process.

> *My luck was my husband, my eldest daughter, they applied it to me, and I never had the courage to do it alone. It was amazing support, I don't know if I would have managed it without them.* (P2, W)
>
> *At first, I went to take it at the health center, the nurse and technicians administered it to me every day and taught me how to do it, until I had the courage to do it by myself. But their support was essential.* (P5, W)
>
> *Another important point during the treatment of this woman is the support network, both from the family and the medical team. If this woman has support during care, during injectable medication, if she has support from her gynecologist, from her team, the process will certainly become easier and less painful.* (P29, GO)

Appropriate therapeutic management is considered by healthcare professionals to be the key to achieving more favorable gestational outcomes, requiring women to take responsibility for self-care and understand the importance of treatment during the gestational process.

> *The diagnosis of APS and SLE requires attention. This woman must be monitored more closely and undergo appropriate therapy, using anticoagulants and medications that are not teratogenic for the fetus.* (P22, R)
>
> *It is essential that women who have both SLE and APS correctly follows the treatment prescribed by the doctor. She needs anticoagulation and it is important that she is well-informed about this, that she learns how to administer the anticoagulant and that she understands its importance in managing the pregnancy. This will determine gestational outcomes.* (P28, R)
>
> *Pregnant woman needs to understand that without proper treatment, the risk of complications is higher. It is important that she takes all necessary precautions, uses medications, injections and attends prenatal appointments.* (P30, GO)

Overall, after experiencing the complexity of unplanned pregnancy and the need for injectable treatment, some women are able to recognize the importance of correct treatment and prior reproductive planning to pregnancy and emphasize that even though it is a difficult and complex process, which requires strength, it can be faced.

> *It is necessary to treat it, take the medication, enoxaparin, do everything correctly, as the doctors advise, and it is also necessary to plan the pregnancy to avoid problems. But there's no point in saying that it's easy, that it's cool, because it's not. It's very painful, we were scared throughout the pregnancy, anguished, not knowing what tomorrow will bring. So, you need to plan, take care, treat, but it's not a nice experience.* (P17, W)
>
> *Only those who go through this treatment can understand that it is not easy, we try hard, we overcome ourselves. It's like facing a challenge every day in pursuit of the dream of having a child.* (P11, W)

Professionals also consider that both conditions are complex, but it is possible to overcome them with appropriate therapy, support and shared decision-making between women and professionals, and prior reproductive planning.

> *It's a completely feasible pregnancy. The important thing is for the woman to plan this pregnancy together with her medical team, and together choose the best time for gestation. Once this is done and taking all the necessary precautions, the pregnancy goes very well, without any major complications.* (P25, R)
>
> *Gestation in Lupus requires planning, especially if this patient has associated APS. With prior planning, rigorous care during pregnancy and good patient adherence to therapy, outcomes are better.* (P30, GO)
>
> *Taking care of this woman, monitoring the treatment, encouraging her to take care of herself before, during and after gestation is the most important thing. Once this is done, the pregnancy goes well, perfectly, without any major complications.* (P33, N)

DISCUSSION

The results show that gestation in the context of SLE and APS is perceived by women and healthcare professionals as something difficult and complex, especially when it occurs without reproductive planning and without the support and effective interaction with a multiprofessional health team. In this context, both women with SLE and healthcare professionals perceive and give meaning to pregnancy based on the way this phenomenon is experienced and how they participate in it, mediated by the interactions that occur during this process. Such perspectives are in line with the premises of the theoretical framework adopted, which assumes that the meanings attributed to a given experience are mediated by the way in which the process is experienced in personal interaction, and by the way in which others act, behave and perceive the process experienced through social interaction(15).

Thus, it is evident that when experiencing a complex gestational process, permeated by possible complications – miscarriages, premature births, pre-eclampsia, and stroke -, ends to result in negative meanings attributed to the experience. It is worth noting that, although these are the most frequent complications in cases of pregnancies with SLE and APS, other complications such as cardiac, hematological, pulmonary, intrauterine growth restriction, and placental insufficiency may also occur(2–7).

Among all possible complications, gestational losses stand out as one of the most significant. Research that investigates the perception of women who experience abortion identifies reports permeated by negative feelings: fear, anguish, loneliness, guilt, depression and anger(17,18). The presence of these feelings can trigger psychological illness, as, most of the time, women experience the grief of pregnancy loss alone, without support from family and friends(17,18).

The reports also highlight a lack of professional support, a lack of bonding and trust between women and healthcare professionals, which impacts the management and handling of pregnancy and coping with gestational loss. It is noteworthy that the aspects of dehumanization in care, lack of multiprofessional health support and obstetric violence are highlighted by Brazilian women participating in a study on living with SLE who have gone through one or more miscarriage experiences(12). Participants in a study in Kenya report cases of abuse (verbal and sexual), lack of privacy during care, stigma, and inappropriate involvement in decisions about the nature and type of care they receive. The reports also allow the identification of differentiated treatment offerings based on some attributes: spontaneous versus induced abortion, single versus married, young versus older(19).

Findings of this nature constitute justification for conducting research that evaluates the quality of abortion care from the perspective of users. In this sense, the instrument entitled QualiAborto-Pt is in the process of being refined in Brazil, which emphasizes and evaluates five dimensions of care: reception, guidance, inputs/physical environment, technical quality and continuity of care(20).

The absence or deficiency of guidance on reproductive planning in autoimmune diseases has already been identified as a complicating factor in the gestational process in different contexts, including Colombia(21) and South Africa(22), which occurs because the focus of assistance is on disease management. In this sense, a qualitative study developed with Iranian women(1), and also in a literature review, indicate that multiprofessional pessimism about the combination of SLE and gestation contributes to the occurrence of unplanned pregnancies permeated by complications(5).

Therefore, for a long time, healthcare professionals from different countries have advocated the incompatibility of the combination of gestation and SLE, and that these women should not get pregnant(21,22). However, with the advancement of science, it is possible to consider the pregnancy in this population, although it is high-risk and requires specialized, continuous monitoring in a high-risk outpatient setting(2,23).

Previous reproductive planning, along with adequate social interaction, creation of bonds and trust between women and healthcare professionals constitutes an elementary condition for better coping with gestational risks, enabling the achievement of more favorable obstetric results and, therefore, a positive meaning of the gestational experience.

It is important to highlight that, in addition to reducing gestational risks and the occurrence of unplanned pregnancies, reproductive planning provides female empowerment, as it allows women to be protagonists of their obstetric history(24) and make informed choices. Furthermore, it favors comprehensive and longitudinal care with multiprofessional health monitoring. It is noteworthy that care in high-risk pregnancies involves practices that transcend procedures, requiring respect for singularities, attention, care and trust, so that woman feels confident in professional work(25).

In therapeutic terms, SLE requires the control and remission of signs and symptoms before conception, because some medications used in its treatment are contraindicated during pregnancy(2). In this regard, a study conducted in South Africa, with 25 women with SLE, reports that the combination of patient-centered care, focusing on effective contraception and medication aimed at disease remission, along with constant counseling, consistent information and a controlled pregnancy jointly by an obstetrics and rheumatology team favors the achievement of excellent obstetric outcomes(23).

The treatment of APS, the main condition associated with SLE during gestation, as reported by the women in the present study, is very complex, especially due to the need for daily administration of low molecular weight heparin (LMWH) (26), which is essential to achieve good gestational outcomes, as it prevents thrombotic events(27). It is worth highlighting that preventive prophylaxis and an adequate approach to this condition during pregnancy and postpartum are fundamental for women's health during the gestational and postpartum period and even in the future. Maternal hypercoagulability can persist up to 12 weeks after delivery, with a high risk of complications resulting from APS during this period(26,27), and it is recommended to maintain preventive prophylaxis with LMWH for up to six weeks postpartum to reduce the risk of maternal thrombosis(27). Furthermore, there is also a long-term risk of thrombosis in patients with obstetric APS. In this sense, a cohort conducted in Beijing, between June 2008 and August 2022, reveals the development of venous and arterial thrombosis in 5.9% of the 186 women with APS participating in the study, with approximately four year interval between the first delivery and the first thrombosis(27).

However, despite this evidence, it is important to highlight that the women participating in the present study mention some inconveniences of this treatment: pain, high cost and difficulty in obtaining free treatment, especially in a timely manner. This corroborates the results of a study involving 17 women with SLE, in Iran, which shows that they experience needs that are often forgotten, including financial support from family members and the government for better coping with the disease(28).

In addition to adequate treatment, women with SLE, especially those of childbearing age, need to receive early guidance on family planning, implications of a pregnancy associated with SLE and treatment possibilities. This is important even for those who, theoretically, do not want to get pregnant, as they may have health behavior that is not effective in preventing pregnancy(8). Proper and timely guidance allows these women to make informed decisions and commit to therapeutic adherence, thereby reducing the risk of maternal-fetal morbidity and mortality, characterizing a positive pregnancy experience.

Therefore, treating these two conditions (SLE and APS) concomitantly impacts the way women perceive, behave and attribute meaning to pregnancy. However, despite reports of pain, fear and insecurity, the participants in this study, who managed to become mothers, report feelings of overcoming and accomplishment.

Another relevant factor for a positive experience of this condition is family, marital and professional support, which is perceived as a source of strength in managing the pregnancy and in building a positive "social self". A study conducted in the Southern Brazil, aimed to understand the perception of pregnant women and their families about the vulnerable condition of a high-risk pregnancy, shows that meeting their needs and family support are essential, especially in the implementation of care in everyday situations, and allows pregnant women to feel supported and safer(29).

The importance of family, marital and professional support for good control of the disease appears in studies conducted with people with SLE in Brazil(12), Turkey(14) and Iran(28). This importance is also evident in a meta-synthesis, identified in half of the 26 studies included and which address the experience of 565 adult patients (95% women). Regarding this finding, it is worth noting that patients need unconditional and "always present" family support to deal with everyday life, and to feel safe in the context of an unpredictable disease(30). On the other hand, the lack of family support, associated with the unpredictable course of the disease, contributed to the emergence of different feelings: fear, frustration, social exclusion and incapacity(1,24,30), especially when experiencing a pregnancy associated with SLE(1,23).

Possible limitations of the study refer to the online recruitment of women with SLE, limiting the theoretical sample to participants who have access to this private group. The fact that participants are identified based on a response to a post may also constitute a bias, as it corresponds to those willing to share their stories, possibly because they are already dealing better with the experience, while those who were not ready to talk about it, possibly still experience pain and suffering in a very latent way, which would certainly influence the meanings attributed. Furthermore, the non-inclusion of the deaf woman with SLE, due to the researcher's communication inability, and due to methodological options for data collection, also constitutes a limitation, as her experience would certainly enrich the findings.

Furthermore, the fact that the fifth sample group consisted mostly of rheumatologists and only one nurse, may be considered an additional limitation, as their answers may have been influenced by the experiences of the professional category and limit the depth of the findings regarding other members of the healthcare team.

FINAL CONSIDERATIONS

The gestational process of women with SLE and APS is perceived as complex and dynamic by women experiencing this condition and by professionals who assist them during the gestational period. The meanings attributed to pregnancy are elaborated and modified according to the interpretation of previous and current experiences, the care trajectory, and interactions with healthcare professionals. There is a clear relationship between the meanings attributed to pregnancy and periods of remission or exacerbation of the disease because they influence the gestational period and obstetric outcomes. Previous guidance, adequate reproductive planning, establishing a bond with healthcare professionals and adequate therapeutic management favor the construction of positive meanings, marked by the condition of becoming (once again) a mother. However, the absence of these elements, associated with unqualified care, can trigger obstetric complications and, consequently, the attribution of negative meanings to the experience.

It is believed that the results of this study can contribute to the advancement of knowledge about how women and healthcare professionals understand pregnancy in the context of SLE and APS, highlighting the need for comprehensive care for this population, focusing on reproductive planning and management of chronic conditions. Furthermore, the results are powerful in qualifying obstetric care for women with high-risk pregnancies, resulting from SLE/APS associated with pregnancy, and raising reflections regarding the care process for women in different contexts of chronicity and high-risk pregnancy, contributing to reducing rates of maternal and fetal complications and favoring positive gestational outcomes.

In the field of nursing, understanding this phenomenon can enhance the development of care plans that meet the real health needs of this population, and contribute to early diagnoses and the implementation of appropriate therapies, reducing the rates of complications and unfavorable gestational outcomes. Moreover, such knowledge can foster the scientific advancement of nursing in the context of autoimmune conditions that may occur during the gestational process and, additionally, raise interest in conducting new studies that investigate, for example, the role of support family members in the reproductive planning of women with SLE, or how families support women during the experience of miscarriage.

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