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Reproductive Health Experiences and Needs of Women of Childbearing Age with Systemic Lupus Erythematosus: A Qualitative Study

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University of Central Florida
2019

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
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Abstract

Reproductive Health Experiences and Needs of Women of Childbearing Age with Systemic Lupus Erythematosus: A Qualitative Study

By Yasmine Shakur

Background: Systemic Lupus Erythematosus (SLE) is a chronic autoimmune condition that primarily affects women of childbearing age, with many patients being diagnosed during puberty. Despite existing knowledge, there remains uncertainty regarding the impact of lupus on fertility for patients with lupus.

- The purpose of this thesis was to explore the experiences and needs of minority-identified lupus patients around sexual and reproductive health.
- The secondary objectives were to identify gaps and explore where improvements can be made to inform lupus patients on how to manage their reproductive health and therefore increase patient-provider trust in their reproductive health.

Methods: Ten minority-identifying women of childbearing age with a physician-confirmed diagnosis of SLE took part in a 30-minute in-depth interview from January 2023- July 2023. Participants were members of the Georgians Organized Against Lupus cohort (GOAL), a population-based cohort derived from the Georgia lupus registry. Thematic analysis was used in MAXQDA Plus 2022 to identify themes related to reproductive health with diagnosis, pregnancy, partnerships, holistic care, career, relationships with physicians, family, and medication side effects, and improvements.

Results: 10 (n=10) Minority women of childbearing age (19- 49) with a physician-confirmed diagnosis of SLE took part in a 30-minute in-depth interview from January 2023- July 2023 online over Zoom. The participants in the study had an average age of 32.1 years and ranged in age from 26 to 44 years old. Importantly, 100% (n=10) of the participants had discussed sexual and reproductive health with a healthcare provider at some point after their lupus diagnosis. Notable themes identified were living with lupus, physician relationships to support sexual and reproductive health, and sexual and reproductive health in relation to lupus.

Conclusions: Most participants were aware of reproductive health prioritization and spoke with providers about concerns that they had about reproductive health. SLE patients expressed that their overall quality of life is affected by their lupus diagnosis. They also changed their reproductive health plans based on their diagnosis. Identified gaps include unexplored emotional and psychological impacts, cultural and social determinants that influence family planning decisions among women with SLE, and social-economic status.

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Chapter 1: Introduction

Background:

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune condition that primarily affects women of childbearing age, 15 to 44 years old, with many patients being diagnosed around puberty (Kuhn et al., 2015). Lupus presents itself in patients with a wide range of symptoms. These include mild joint and skin involvement to life-threatening renal involvement, hematologic, cardiopulmonary, or central nervous system involvement (Do et al., 2019). Treatment for SLE involves the use of the antimalarial medication hydroxychloroquine which helps to reduce disease damage, maintain symptom remission, and manage the increased cardiovascular risks stemming from the disease (Liu et al., 2020). As a chronic condition, some of these medications are even used during pregnancy, but both SLE treatments and overall symptoms impact pregnancy (Petri et al., 2020). For example, SLE patients are more susceptible to hypertension during pregnancy, leading to flares and complications (Liu et al., 2020). Further, fetal outcomes in pregnancies of people with lupus are negative compared to their non-lupus counterparts, stillbirths occur approximately 5 times more for women who are pregnant with lupus. In addition, fetal growth restrictions are more frequent than in non-lupus pregnancies (Dhar et al., 2006). Planning for healthy pregnancies is complicated by the fact that few laboratory tests can differentiate between a lupus flare and pregnancy complications, and cryopreservation of embryos or ovarian tissues, which could be an option for preserving fertility, is often inaccessible to lack of financial means (Andreoli et al., 2016).

Less research has addressed the influence of lupus on minority women's health. African American women, who have a higher prevalence of SLE and experience more organ damage and comorbidities with lupus, are particularly impacted (Chae et al., 2015). The potential risks and challenges in raising children if the mother has lupus (Cravioto et al., 2014). These risks include medication-related concerns and the increased risk of learning disabilities, non-righthandedness in males, anxiety, and depression, which are areas of concern for SLE patients that have not been thoroughly studied. The lack of knowledge in these areas affects their life planning and quality of life, and it is often not adequately discussed with patients managing the disease and its flares (Dhar et al., 2006).

In the field of lupus research, there remains a significant gap concerning the exploration of sexual and reproductive health experiences and needs specifically among minority women living with lupus (Lim et al., 2020). Despite the increasing recognition of lupus as a condition that predominantly affects minority women, studies addressing the unique challenges and concerns related to sexual and reproductive health in this population are scarce. As a result, there is limited understanding of how lupus impacts the reproductive and sexual well-being of minority women, and the specific factors that may influence their decisions and choices regarding family planning, contraception, and overall reproductive healthcare (Petri et al., 2020).

Minority women, particularly those of childbearing age, face a distinct set of social, cultural, and healthcare barriers that may intersect with their experiences of living with lupus. These barriers can potentially exacerbate the challenges they encounter in accessing appropriate and timely sexual and reproductive healthcare services (Hoge et al., 2020). Understanding the nuanced interactions between lupus, cultural norms, socioeconomic factors, and healthcare disparities is crucial for providing tailored and comprehensive care to this underserved population (Chae et al., 2015).

By delving into this unexplored area, this research aims to shed light on the intricate interplay between lupus, minority women's experiences, and their sexual and reproductive health needs. Unraveling these complexities will not only provide valuable insights into the unique challenges faced by minority women with lupus but also lay the foundation for more targeted interventions, improved healthcare practices, and enhanced support systems. Ultimately, empowering minority women with lupus to make informed decisions about their sexual and reproductive health can lead to better health outcomes, improved quality of life, and greater overall well-being for this vulnerable and often marginalized population. Through this study, we endeavor to contribute to the growing body of knowledge in lupus research, while advocating for the comprehensive and equitable healthcare that every individual, regardless of ethnicity or background, deserves.

Objectives:

- The purpose of this thesis was to explore the experiences and needs of minority-identified lupus patients around sexual and reproductive health.
- The secondary objectives were to identify gaps and explore where improvements can be made to inform lupus patients on how to manage their reproductive health and therefore increase patient-provider trust in their reproductive health.

Significance:

This qualitative study aims to investigate the perspectives of minority women with lupus on the quality of their reproductive healthcare related to lupus. Through qualitative thematic analysis, the research seeks to gain insights into the specific needs and expectations of minority women with lupus when discussing reproductive care with their healthcare providers. The decision to focus on minority women in the research question aligns to shed light on the experiences and challenges faced by this often-underrepresented group in research. By focusing on minority women, we can gain a more comprehensive understanding of how lupus uniquely impacts different racial, ethnic, and cultural groups, including their reproductive and sexual health experiences (Petri et al., 2020). The information gathered will be utilized to improve health education for both providers and patients, identify gaps in patients' reproductive healthcare knowledge, and empower patients in making informed decisions regarding their sexual and reproductive well-being. This study aims to contribute to better care for lupus patients during their childbearing years, enhancing their overall quality of life.

Definition of Terms:

1. Lupus: A chronic autoimmune condition that can damage any part of the body, commonly found among women of childbearing age (ages 15 to 49 years old) (CDC, 2022).
2. Sexual and Reproductive health: A state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled (CDC, 2018).
3. Relationships: The definition of relationships used for this study are interactions and connections between lupus patients and their healthcare providers.
4. SLE: The abbreviation for Systemic Lupus Erythematosus. A autoimmune disease in which the immune system attacks its own tissues, causing widespread inflammation and tissue damage in the affected organs. It may affect the joints, skin, brain, lungs, kidneys, and blood vessels (CDC, 2022).

5. Discoid Lupus: A form of cutaneous lupus erythematosus referring to the skin, characterized by round sores, usually on the face and scalp (Cleveland Clinic).

6. Childbearing Age: 16-49 years old, the range of ages in which a woman may become pregnant (CDC).

Chapter 2: Literature Review

Introduction

The primary purpose of the literature review was to document the existing research on lupus and sexual and reproductive health. We conducted searches on PubMed, PsychINFO, and Web of Science to identify relevant studies focusing on lupus and its impact on pregnancy, reproductive, and sexual health. The inclusion criteria for studies were that the target participants of studies were adults (18 years or older), and cis-gender women. Studies were only included if they were written in English and published within the last ten years. All study types were included due to the low overall number of studies focused on our exact participant profile. Unfortunately, due to a lack of data, only a minority of studies included racial or ethnic minority women or made conclusions for these groups.

These criteria were carefully chosen to align with the characteristics of the women who participated in our research study but also to provide the broadest possible set of information. It is crucial to highlight that we intentionally excluded studies solely involving non-minority women in this review. Out of a total of 78 articles (76 from PubMed, 1 from PsychINFO, and 1 from Web of Science); we identified and selected 11 articles that met our inclusion criteria.

Overall, this literature review serves as a critical foundation for our qualitative study, providing relevant insights from existing research while also identifying gaps in the current literature. Moreover, the review helps to establish the significance and originality of our study, which further contributes to the body of knowledge in this important area of research. By synthesizing the findings of these selected studies, we can enrich the understanding of lupus and its effects on reproductive and sexual health in minority women. The majority of studies were systematic reviews (n=8). Only one study focused on the use of contraception while ten others examined lupus management and pregnancy planning.

Use of Contraception

One study addressed contraception, specifically, the different forms of contraception SLE patients have used, and the side effects they had. Progesterone-only pills as a form of contraception have been widely accepted as the best option for women with lupus. However, Cravioto et al. (2014) conducted a randomized-control clinical trial involving 162 women with SLE that found that progesterone-only pills were the highest discontinued form of contraception for women with lupus, in comparison to intrauterine devices (IUDs) and combined estrogen-progestin contraception.

This study went on to conclude that oral contraceptives and IUD are acceptable forms of birth control methods for patients with lupus, however counseling and specialized health attention needed to be provided (Cravioto et al., 2014). It is worth noting that while progress has been made in reproductive care for women with lupus, there are still challenges and complexities to address like the challenges that many minority women face and the social determinants that impact the care they receive.

Management of Pregnancy

Ten studies examined the management of pregnancy of women with lupus focusing on pre-pregnancy counseling, medications compatible with lupus and pregnancy and breastfeeding, and antiphospholipid syndrome present in patients with lupus nephritis. Overall, the studies addressed that pre-pregnancy counseling was needed for the best pregnancy outcomes and that medications can be compatible with pregnancy and no longer cause infertility (Tavakolpour et al, 2016). Currently, the management of pregnancies in women with SLE has shown significant improvements due to advancements in medicine and better management of SLE.

However, studies addressed the risks associated with pregnancies in women with SLE, which is highlighted in a systematic review of 56 studies conducted by Do et al. (2019). Although advances in medicine have made the management of pregnancy with SLE possible there are still additional risks which include lupus flares, preeclampsia, preterm birth, fetal growth restrictions, neonatal lupus, and maternal disease flares. Preeclampsia remains the most common complication affecting 7.6-25% of all SLE pregnancies. Additionally, there is an increased risk of early spontaneous abortion and fetal death beyond 10 weeks, especially for patients with antiphospholipid antibodies or lupus nephritis (Do et al., 2014). This review concluded that when planning pregnancy disease control (symptom remission) 4-6 months ahead of conceiving is recommended and multiple medications for SLE were tolerable during pregnancy.

To improve the chances of an optimal pregnancy for SLE patients, it is crucial to have disease control before pregnancy and after. This is highlighted in the systematic review of 18 studies conducted by Tavakolpour et al, (2016), The final recommendations of this concluded that autoimmune disease managed both during and after pregnancy was necessary for a healthy pregnancy.

In a systemic review of 126 studies conducted by Nahal et al. (2018), the guidelines and recommendations for a successful pregnancy outcome with lupus were outlined. This highlights the importance of proper multidisciplinary surveillance during pregnancy, ideally starting evaluation between 4-6 weeks to closely monitor and manage potential complications associated with SLE and pregnancy (Nahal et al., 2018).

Studies examining lupus medications fell into two categories, the effects of hydroxychloroquine on preeclampsia and the use of mycophenolate mofetil. In the retrospective cohort study of 119 women diagnosed with SLE conducted by Liu et al., and colleagues (2021) it was found that hydroxychloroquine (HCQ), a medication commonly used to control disease activity in SLE patients, has been shown to decrease the risk of SLE flares, preterm birth, and neonatal lupus is considered safe for both the mother and fetus, and did not significantly reduce preeclampsia.

As we continue to advance our understanding and management of SLE in the context of reproductive health, it is essential to tailor treatment plans to individual patients and closely monitor their health throughout pregnancy. This is once again highlighted in the systematic review of 31 studies conducted by Petri et al., (2020) on pregnancy and SLE. This study concluded that SLE does not cause infertility, however, cyclophosphamide was the preferred therapy for lupus nephritis in the past which caused about one-third of the exposed women to go into premature ovarian failure. As advancements have been made in the treatment of SLE mycophenolate mofetil, is more commonly used and is the preferred medication and it does not cause infertility (Petri et al., 2020). Although mycophenolate mofetil does not cause infertility, it should not be taken during pregnancy and the preferred medication of immunotherapy for SLE patients is azathioprine, must be started at minimum 3 months before conception of a pregnancy (Petri et al., 2020).

In another area of research regarding lupus patients with varying levels of disease activity during pregnancy, different indications for birth outcomes exist. Teng et al., (2018) studied pre-

pregnancy counseling for patients with systemic lupus erythematosus in a systematic review to guide clinicians to formulate appropriate preventive strategies and patient-tailored monitoring plans during pre-pregnancy counseling of SLE patients. According to Teng's et al., (2018), high disease activity during the first trimester significantly reduces the chances of a live birth (57% vs. 84%) or full-term birth (21% vs. 50%), while significantly increasing the risk of miscarriage (29% vs. 9%). High disease activity in the second and third trimesters is associated with a significantly lower chance of full-term birth (28% vs. 63%), a higher risk of extreme preterm birth (<28 weeks) (18% vs. 5%), and higher perinatal mortality (15% vs. 4%).

A prospective study that was conducted by Ikram (2021) looked at the breastfeeding decision postpartum for women with rheumatic diseases. A total of 265 pregnancies were included in the study,88 were women diagnosed with SLE. Of those diagnosed with SLE, 39 (44%) were black, 6 (7%) were Asian and 2 (2%) were identified as other. White women accounted for 41(47%) of this study. The study concluded that the women with rheumatic diseased can breastfeed and medications were compatible with breastfeeding and included hydroxychloroquine, azathioprine, NSAIDs, prednisone, TNF inhibitors, sulfasalazine, and non-compatible medications.

Santos and colleagues (2017) conducted a systematic review and meta-analysis of 16 studies on antiphospholipid syndrome (APS) and miscarriages in women, the major antiphospholipid antibodies that are found in APS are anticardiolipin antibodies (aCLs), lupus anticoagulant (LA) and anti-β2glycoprotein I antibodies (aβ2GPI). Out of the 830 records identified in PubMed and Web of Sciences, 9 were included in the systematic review and 7 were included in the meta-analysis. The study concluded that there was a connection between APS and miscarriages.

Miscarriages were also examined by the systematic review of 77 studies conducted by Moroni et al. (2018) focused on important considerations in pregnant patients with lupus nephritis which examined pregnancy in women with chronic renal disease. It was concluded that the stabilization of disease remission is the most important factor to have a successful pregnancy, however, ethnicity was not a factor considered in this review.

These findings underscore the importance of managing lupus activity during pregnancy to achieve better birth outcomes. It also highlights the need for individualized care and close monitoring for pregnant women with lupus, particularly during periods of increased disease activity. By understanding these risks, healthcare providers can offer better support and counseling to lupus patients who are considering pregnancy or are already pregnant, ultimately improving maternal and fetal outcomes.

Gaps in Literature

The current literature on the effects of pregnancy and lupus offers valuable clinical insights and highlights the importance of counseling patients with lupus for pregnancy planning. However, there is a notable gap in capturing the perspectives of patients and the crucial questions they have about their reproductive health. Patients' voices and experiences are essential to truly understand their needs and concerns when it comes to managing lupus and their reproductive health.

In addition, the existing literature often neglects to address the significance of sexual health beyond the use of contraception. Sexual health is an integral aspect of overall well-being, and for women with lupus, it can be affected by both the disease itself and the medications they take (Watts et al., 1979). Understanding how lupus impacts sexual health and addressing related concerns should be given more attention in research and healthcare discussions.

The emphasis on pre-pregnancy in the literature can pose challenges for many women with lupus, as most pregnancies are unplanned even when contraception is used (Thaxton et al., 2017). While the protocol suggests controlling disease activity six months before conception, this may not be feasible for all patients due to the unpredictable nature of lupus flares and individual circumstances (Petri et al., 2020). This calls for more research and practical approaches to managing pregnancies in women with lupus who may not have the luxury of extensive pre-planning.

Furthermore, there is a lack of education regarding the involvement of specific doctors in multidisciplinary surveillance during pregnancy (Nahal et al., 2018). It is crucial to clearly outline which healthcare professionals should be part of the care team during pregnancy to ensure optimal outcomes for both the mother and the baby. Pre-pregnancy counseling is often highlighted, but the importance of ongoing care during pregnancy must be equally emphasized (Nahal et al., 2018).

Addressing these gaps in the literature and healthcare practice will lead to more comprehensive and patient-centered care for women with lupus. Listening to patients' concerns, providing education on sexual health, and developing flexible pregnancy management strategies can improve the overall well-being and outcomes of women with lupus who are considering or going through pregnancy.

Significance of sexual and reproductive health counseling

Overall, these studies addressed the need to have pre-pregnancy counseling with all patients who have SLE. In the 1960s, the reported loss rate of pregnancies for women with lupus was as high as 43% (Nahal et al., 2018). However, there has been a significant improvement in pregnancy outcomes for women with lupus in more recent years. Between 2000 and 2003, the pregnancy loss rate decreased to 17% (Nahal et al., 2018). This decline in pregnancy loss rate is a positive development and indicates the progress made in managing pregnancies for women with lupus.

Despite the improved outcomes, pregnancy remains a health concern for women diagnosed with lupus, and healthcare providers need to offer comprehensive contraception counseling to patients of reproductive age (Cravioto et al., 2014). Unfortunately, many women with lupus still engage in unprotected sex or rely on behavior-based contraceptive methods instead of using more reliable forms of birth control (Petri et al., 2020). This highlights the need for better education and awareness about contraception options for women with lupus.

For optimal pregnancy outcomes, it is advised that women with lupus have at least six months of controlled disease activity before conceiving (Cravioto et al., 2014). Proper disease management before conception can help reduce the risk of pregnancy loss and preterm birth. Additionally, women with antiphospholipid antibodies and active lupus at the time of conception are at an increased risk of adverse pregnancy outcomes (Do et al., 2014). Therefore, close monitoring and proper management are crucial for this group of patients.

Continued research and advances in medical knowledge will further improve the understanding of lupus and its impact on pregnancy. By providing comprehensive counseling on contraception, optimizing disease control before conception, and closely monitoring high-risk pregnancies, healthcare providers can continue to enhance pregnancy outcomes for women with lupus (Cravioto et al., 2014). It is also important to empower women with knowledge and options so that they can make informed decisions about their reproductive health and family planning.

Chapter 3: Manuscript

Abstract

SLE primarily affects minority women of childbearing age. Contraception is often recommended for women who are diagnosed with lupus in order to plan pregnancies when disease activity is low (Kuhn et al., 2015). This study seeks to explore minority-identified lupus patients' experiences and needs around sexual and reproductive health. 10 (n=10) Minority women of childbearing age (19- 49) with a physician-confirmed diagnosis of SLE took part in a 30-minute in-depth interview from January 2023- July 2023 online over Zoom. Participants were members of the Georgians Organized Against Lupus cohort (GOAL), a population-based cohort derived from the Georgia lupus registry with over 1,000 individuals. This study identifies common themes among patients when speaking of their reproductive and sexual health, living with lupus, patient-physician relationships, sexual and reproductive health in relation to lupus, and gaps in knowledge. It addresses a gap in the literature on patients' experiences with seeking reproductive healthcare and where they may need more education. It also highlights the need for more research to be done to address how different elements such as physical appearance, physical limitations, socioeconomic factors, and cultural norms. This may affect the personal lives and partnerships of SLE patients, ultimately shaping their experiences with reproductive and sexual health care and limiting the care women with SLE can receive.

Introduction

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune condition that primarily affects women of childbearing age (16-49), with many patients being diagnosed during puberty (Kuhn et al., 2015). The disease manifests with a diverse range of organ symptoms, ranging from mild joint and skin involvement to severe multiorgan involvement that may mimic other conditions (Do et al., 2019). Thus, making a diagnosis of the condition challenging and disease management complex. While not all SLE patients have exact symptomology or outcomes, the condition profoundly impacts various aspects of a patient's life, including their reproductive and sexual health (Nahal et al., 2018). SLE can impact pregnancy, fetal outcomes, and postpartum care, posing challenges in distinguishing between lupus symptoms and those related to pregnancy, which may potentially result in misdiagnosis (Dhar et al., 2006).

Treatment for SLE involves the antimalarial medication, hydroxychloroquine which helps reduce disease damage, maintain remission, and manage cardiovascular risks, even during pregnancy. Topical glucocorticoids are also used intermittently for skin lesions, while immunosuppressants like mycophenolate mofetil and low-dose intravenous cyclophosphamide are used to control lupus activity and reduce organ involvement (Kuhn et al., 2015). Contraception is recommended for women of childbearing age with lupus to prevent unplanned pregnancies, especially since certain medications used to control the disease can lead to fetal defects if taken during pregnancy (Petri et al., 2020).

Among minority populations, accessing healthcare and receiving education about reproductive and sexual health can present unique challenges and disparities, particularly in the context of managing SLE while considering family planning. A significant 1994 study called LUpus in MInorities: NAture versus Nurture (LUMINA), led by Dr. Graciela Alarcón, found that healthcare disparities disproportionately affected Hispanic and African American participants with SLE. These disparities were attributed to socioeconomic factors, ancestral genes, diminished survival in poverty, and adverse pregnancy outcomes influenced by socioeconomic factors (Lim et al., 2020).

For minority women with lupus, limited access to healthcare resources and cultural barriers can significantly impact their decision-making process and reproductive choices. To provide equitable and comprehensive care, it is crucial to address the specific needs of minority individuals and ensure they receive adequate information and support regarding family planning and reproductive health (Lim et al., 2020). By addressing these issues, healthcare providers can help improve the overall reproductive health and well-being of minority women with SLE.

Despite existing knowledge, there remains uncertainty regarding the impact of lupus on fertility. While fertility is generally believed not to be affected by lupus, concrete evidence is lacking. Women with lupus who do become pregnant should avoid specific medications, such as Mycophenolic acid, methotrexate, and leflunomide, due to potential harm to the fetus. Unfortunately, access to contraception can be limited for women with lupus in various countries, leading to serious consequences for both the patients and their children (Andreoli et al., 2016). Unplanned pregnancies in lupus patients can result in adverse fetal outcomes and an increased risk of symptom relapse, adversely affecting the patient's life (Mobini et al., 2021).

Although SLE has a significant impact on sexual and reproductive health, this area remains largely unexplored in research. SLE patients face unique challenges related to their reproductive and sexual well-being, as the disease can complicate pregnancy, increase the risk of adverse fetal outcomes, and pose difficulties in differentiating lupus symptoms from those associated with pregnancy. Consequently, there is a need for comprehensive studies to investigate the specific experiences and needs of minority women with lupus concerning sexual and reproductive health. Understanding these experiences can lead to improved education, communication, and tailored care, ultimately enhancing the quality of life for this vulnerable patient population. This study will explore those individual experiences that minority women with lupus face and fill critical gaps in the literature. This research can additionally pave the way for more effective support and counseling for lupus patients in making informed decisions about their reproductive health journey.

Methods

Study Design: This study is a cross-sectional qualitative exploratory study.

Recruitment, Sampling and Participants: This study was conducted from January to July 2023 and explored the perspectives of minority women (n=10) aged 19 to 49, who had a formal diagnosis of SLE. Participants were selected from the Georgians Organized Against Lupus (GOAL) CDC-supported database. The GOAL cohort is a population-based lupus cohort of over 1,000 individuals with lupus derived from the Georgia lupus registry (GLR). GLR is 1 of 5 US Centers of Disease Control and Prevention funded population-based lupus registries. The study cohort that includes a diverse population of clinical, biological, sociodemographic, psychosocial, and health service data along with biological material. A list of GOAL study participants was given to Yasmine Shakur (PI). This list focused on minority women diagnosed with SLE, defined in this context as non-white individuals, aged 19 to 49, with a physician confirmed SLE diagnosis *(Table 1).* This study prioritized minority women due to the higher prevalence of lupus in this population, which has been historically underrepresented in research. Participant race was gathered in the GOAL cohort, our sample included 10 minority women who were diagnosed with lupus by a physician. Although we intended to include Hispanic women in this study, all 4 who were contacted declined to participate. A total of 20 patients were contacted, and 10 agreed to take part in a 30-minute interview. This sample included 8 African-American women and 2

Asian women of childbearing age. All participants are represented by an alias, and saturation was accomplished with this sample size. Each interview took between 20-45 minutes to complete.

In-depth Interview Guide: The in-depth interview guide was designed to comprehensively explore the potential impacts of sexual and reproductive health on various aspects of the participants' lives. The guide consisted of distinct sections, starting with the participants' diagnosis stories, followed by an exploration of the medications they were taking for lupus. Specific conversations related to sexual and reproductive health, such as pregnancy planning, contraception choices, and experiences with sexual activity, were also covered during the interviews. Additionally, the guide delved into the participants' relationships with their healthcare providers and how comfortable they felt discussing these intimate topics with them. By breaking down the interview guide into these key areas, the study aimed to gain a holistic understanding of the participants' perspectives and experiences regarding sexual and reproductive health in the context of living with lupus. The interview questions aimed to gather in-depth insights into participants' experiences with lupus diagnosis, reproductive and sexual health related to lupus, and the social determinants that minority women face in accessing reproductive health care alongside managing the underlying disease of lupus.

Data Collection: A one-time 30-minute interview was conducted over Zoom with each participant. Before the interviews, participants were recruited from the GOAL cohort and invited to take part via telephone calls. Each participant was called a total of 5 times, with 2 voicemails left before being deemed unreachable. Eligibility was determined based on age, gender, and ethnicity, and participants provided oral consent before each interview. The Principal

Investigator (PI), Yasmine Shakur, handled all consent discussions and provided a clear overview of the study's purpose, interview themes, and the participants' right to decline to answer any uncomfortable questions or end the interview at any time. The PI also assured confidentiality, and participants were assigned aliases instead of using their names during the interviews to protect their identities. The demographics questions were patients' ages, year of diagnosis, ethnicity, number of children, and if they spoke about sexual and reproductive health care with their providers.

Data Analysis: After conducting all interviews, the recordings were transcribed verbatim, and a codebook was developed by two readers based on recurring themes in the transcripts. Codes that were identified for thematic analysis were isolation, living with lupus, improvements, and changes, medical side effects and impacts, relationships with family, physicians, romantic partnerships, pregnancy, career, holistic care, and diagnosis and its impacts. The transcripts were coded using MAXQDA plus 2022, and any discrepancies between coders were resolved through discussion to achieve consensus. The audio recordings were securely stored, and the transcripts were password-protected and saved in cloud storage for a recommended retention period of seven years, according to Emory University's data security protocols.

Ethical Considerations: To ensure participant confidentiality, all data were deidentified, and the use of aliases preserved anonymity. The study protocol was reviewed and approved by Emory University's Institutional Review Board (IRB) to assure the ethical conduct of this research. The approval of the IRB guaranteed that the study followed all relevant ethical norms and regulations for human subject research. Participants were informed that they were not obligated to answer any questions they felt uncomfortable with and could withdraw from the study at any time. The PI conducted CITI training and adhered to Emory University's data security policies. The study was designed with minimal risks for participants, but sensitive topics such as social support were addressed. Participants who expressed difficulty with sensitive topics were provided with the contact information for the Georgia Crisis and Access Line (GCAL) to access mental health support if needed.

Benefits and Dissemination: The study aimed to raise awareness of public health education needs for minority women with lupus regarding their reproductive and sexual health experiences. Participants benefited individually from sharing their experiences and increasing their knowledge of sexual and reproductive health education related to lupus. Compensation of a $20 Walmart was given to each participant. After the study completion, all participants received a follow-up email with the final draft of the findings. The results were also shared with the GOAL cohort, providing valuable insights to many women in the targeted population.

Demographic Characteristics: The participants in the study had an average age of 32.1 years (Mean 32.1) and ranged in age from 26 to 44 years old. Among the participants, 80% (n=8) identified as African American (AA) and 20% (n=2) as Asian. Regarding the year of diagnosis, none of the participants were diagnosed between 2000 and 2004 (0%), 5 participants were diagnosed between 2005 and 2009 (50%), 4 were diagnosed between 2010 and 2014 (40%), and 1 was diagnosed in 2015 and later (10%). On average, participants had 0.8 children, with a median of 1 child. The number of children ranged from 0 to 2 for all participants. Importantly, 100% (n=10) of the participants had discussed sexual and reproductive health with a healthcare provider at some point after their lupus diagnosis.

Table 1: Characteristics of Participants

Participant:	**Age**	**Ethnicity**	**Year of diagnosis**	**Number of Children**	**Has talked to a health care provider about sexual and reproductive health (y/n)?**
Tina	28	AA	2020	0	Y
Dani	36	AA	2005	1	Y
Connie	44	AA	2013	1	Y
Annie	30	AA	2009	2	Y
Margo	26	Asian	2013	0	Y
Corinne	37	AA	2005	1	Y
Sandy	28	AA	2016	2	Y
Eliza	32	AA	2006	1	Y
Jessica	34	AA	2010	0	Y
Jean	26	Asian	2009	0	Y

Results

Four significant themes were identified, including living with lupus, physician relationships, sexual and reproductive health in relation to lupus, and gaps in knowledge expressed by participants.

Living with lupus

Participants shared the effects of their diagnosis, and the life changes they experienced, including impacts on their reproductive and sexual health. Additionally, participants recognized the need to change how they interacted with their friends, family, and doctors over time based on the level of symptoms, which include fatigue, pain, and other physical symptoms, that they felt. For example, most of the participants discussed the importance of advocating for themselves when speaking to physicians, family, and friends. Participants also highlighted the emotional impacts of lupus on their overall life, particularly when dealing with medication side effects or the potential long-term effects on their bodies, although they were unsure about the specific questions to ask.

"The first time where I just I had to cut it (hair) off and you know everybody in my school was like "Oh, my God. Why'd you cut it off?" Because, you know, I had such long hair and stuff and I really wanted to break down and cry to them it's falling out, but I tried to, you know, keep it cool. Like I meant to do it and things like that. But yeah, that was very hard to go through to have to cut all my hair off like that, yeah."- Annie, 30 years old, diagnosed in 2009

The experience of isolation reported by many participants in this study highlights a critical aspect of living with SLE that has significant implications for their overall well-being. Feeling isolated and unsupported can have a profound impact on mental health and may exacerbate the emotional toll of managing a chronic illness like lupus. The need for a strong support system becomes evident, and this study sheds light on the importance of providing patients with opportunities to connect with others who can empathize with their experiences. One participant described why they joined a support group and the impact that it made on their overall well-being, especially during their diagnosis journey:

> *But other things that helped me was like I ended up joining a support group because I was just like, so frustrated and angry because I'm like, I feel like a Guinea pig that people keep just trying stuff on me all the time and I'm like, why can't you just figure this out already, right? – Connie, 44 years old, diagnosed in 2013*

Ultimately, patients reported that lupus diagnosis and subsequent management had a profound impact on their overall life quality, extending to sexual and reproductive health.

Patient-physician relationships to support sexual and reproductive health

Most participants expressed a wide range of relationships with their primary physicians. Most participants highlighted that they had rheumatologists and spoke to their rheumatologists only about lupus related symptoms but did not feel comfortable sharing information about their sexual and reproductive health with those providers, for example asking questions about pregnancy and what kinds of contraception would work best for SLE. A minority group explained that they had providers that they felt comfortable asking questions in regard to lupus and reproductive health and they felt that they were able to openly communicate with those providers. Many participants also explained the difficulties entailed with finding a new provider to understand their complex medical background with lupus and would ultimately stay with their provider, even if they did not have a great relationship with them, because of the difficulties they had with transferring medical documentation and updating a new physician on their SLE diagnosis. Most also highlighted that primary physicians were so focused on management of chronic lupus, that sexual and reproductive health topics came up very infrequently.

Many participants explained that the physician-patient relationship was strengthened by the patient being empowered to ask specific and direct questions during their doctors' appointments. These questions included ones around the possibility of pregnancy and fully expressing that they would like to have a child and how their medications may cause different side effects. However, this process was described as mutual, where physicians should also know what types of questions to ask, such as. One participant described this need,

"I think it's more so on the providers end that they're supposed to ask the right questions in order to provide the right treatment and not dissuade people from doing what they would like to do but helping them accomplish that. That's what I think a provider is supposed to do." – Eliza, 32 years old, diagnosed in 2006

Additionally, all participants expressed the need to have a cohesive team of doctors to get the right care needed for them during times of flare-ups and especially during the time of pregnancy. For example, doctors that are all part of the same healthcare system:

"Yeah, that's why I think really having that great, the good group of people and, and especially like in one niche is also important so that they, they know each other. So and so when they talk about me, like they know what's going on and all having, all of them at one place is also important I think. So, I really hate broken healthcare systems."- Jean, 26 years old, diagnosed in 2009

Many participants said that when a cohesive system was in place for patients, they had a better relationship with their doctors and felt more comfortable asking questions, especially ones they deemed as sensitive or private. There was a minority of patients who experienced this, however, when they did have a whole multidisciplinary team working together, they expressed more gratitude for that care and did not feel that they needed to navigate multiple health systems to get the care they needed.

"They're so supportive. Anytime I have my doctor's number, anytime I'm out of medicine, need anything, I can contact them. I think that's about it." – Sandy, 28 years old, diagnosed in 2016

Most participants expressed varying relationships with their physicians, and this extended to sexual and reproductive health. Consistently participants explained that they were given contraceptive options and told be on contraception by their physicians and wait until they were in a healthy state to conceive. Most participants who spoke about getting pregnant with their physicians often were told they should not be risking their lupus remission for a pregnancy and encountered some push back, even if it was something they were willing to pursue and felt they had stabilized their lupus.

"They were shocked as to why I wanted to get pregnant. Basically, it was just like, why? Like would you want to do that like your kidneys are functioning well, your heart's functioning well. Like, you know, like you have your flares. But like major organ systems aren't involved. Why would you want to? Have a kid like you want to come off medicines like, like they were very shocked and very like, let's not do this. And then I think it added to it the fact that it's like, since I'm not in a heterosexual relationship, I have other options. So, they, they were just kind of like, why would you not choose the other option, which is the safest?" - Eliza, 32 years old, diagnosed in 2006

Sexual and reproductive health in relation to lupus

All participants expressed that sexual and reproductive health was brought up at some point after their lupus diagnosis. However, quality, duration, and focus were not always standardized. This is in relation to the depth of knowledge that patients had when it came to the importance and impact of it on their health was not something that they fully understood, and there were many gaps in knowledge. The most common discussion participants described was the need for the use of contraception with certain lupus medications. These medications were identified as ones that impact fetal development if a person were to become pregnant. One participant described the medication they took which is typically taken to control SLE activity and can cause birth defects, however, they were unaware of the consequences and after learning of the impacts it could have on a fetus expressed the concerns that they had about taking the medication. As one participant described:

"*I was on Cellcept like constantly, I wasn't, you know skipping any days or anything of that sort. So, it was like it was brought to my attention that, that could be harmful and cost, you know, side effects if I were to get pregnant so, I mean, that was a major thing basically because I wasn't using anything to prevent a pregnancy at the time."- Jessica, 34 years old, diagnosed in 2010*

Those who did get pregnant expressed that when they did become pregnant it was often difficult to carry the pregnancy, even describing having to end all lupus management and thus having increased flares after giving birth. Most participants who had experienced pregnancy described difficulties they experienced greater flare symptoms that needed extra care after giving birth, although their physicians did not contribute these issues to pregnancy. Three participants described having suffered miscarriage or stillbirth of their pregnancies, which affected their future decision on having children, all of these participants expressed it was unclear if this was due to lupus or other contributing factors and were frustrated when they were unable to get answers. A participant described the frustrating and emotionally taxing situation trying to figure out what caused a stillbirth, attributing the outcome to the need for regular injections to manage their lupus.

"I also had a stillborn not too long ago and they want to say it was because of a clot, possibly. And I know when I ended up having my son they were giving me these injections. Well, I had to give myself these injections. I guess just the keep the blood thin or something of that nature. And I mean luckily it worked, but I wish I would have figured, figured out."- Annie, 30 years old, diagnosed in 2009

Although the topics of contraception use and management of pregnancy were more common, only a minority of participants described any kind of discussion of relationships or sexual functioning. Some described that lupus sometimes impacted the way they felt about and interacted with the interacted partners due to limitations from overall lupus or during flares. Commonly participants expressed that if they are going through a flare and need to take extra time to rest, they experience feelings of isolation. They also expressed that due to physical changes, they were making changes to their social lives to accommodate for those changes in order to not draw attention to those physical changes.

"I developed a real self-conscious being with all the surgeries or the tubes or and things like that. I was with my child's father for some time" – Corinne, 37 years old, diagnosed in 2005

Sandy a 28-year-old participant that was diagnosed in 2016 explained,

"At first, I was really like in my shell. You know, once my skin started to change, you know, it was like a new me at first."

It also has changed the way they have interacted with their partners when it comes to the emphasis on contraception their physicians have had on them. For example, a participant expressed the struggles they had with balancing relationships and their health:

"There's some restrictions and rules I need to follow, and that makes it really difficult. And like I kind of need to focus on taking care of myself I can't really be worried about somebody else right now" – Margo, 26 years old, diagnosed in 2013

Another expressed the difficulties they had with telling their partner that they had a chronic condition.

"When I first met my partner, I did not tell him I had lupus. But when we got to the point where we were going to become intimate, I felt like I needed to tell him because things that I was going to ask or do with I probably, you know, would be because of my lupus. So, I was like, OK. And I told him also, because I think he thought I was pushing him away or I wasn't attracted to him. And it wasn't that I wasn't attracted. It was like I don't know how to start this conversation [about lupus impacts]. You know." – Connie, 44 years old, diagnosed in 2013

Moreover, participants commonly expressed how their reproductive health plans evolved after being diagnosed with lupus. They were concerned about avoiding potential flares or uncertain outcomes if they were to become pregnant. There was confusion surrounding the possibility of getting pregnant with lupus and its implications on their lives after giving birth. For instance, many participants mentioned the changes they made in their reproductive health plans after their lupus diagnosis. This included speaking with their providers, both rheumatology, gynecologist, and other specialties about surrogacy and other options, speaking with family members who have lupus, and seeking out information on the internet when they were unable to get the questions answered after speaking with their physicians. One participant who already had a child abandoned plans to have another without consulting a doctor:

"I think I would have considered it, having another child. I mean it may. I definitely, would have considered it, but afterwards [after the lupus diagnosis] it was just like I don't want my body to go through what it went through before." – Connie, 44 years old, diagnosed in 2013

Finally, the two Asian participants in this study expressed that they did not engage in sex after being diagnosed with lupus.

Gaps in knowledge around sexual and reproductive health

Most participants in this study demonstrated a clear lack of knowledge regarding how to effectively manage their lupus in relation to their reproductive and sexual health. This knowledge gap was evident through the questions they raised during the interviews. Many participants expressed a strong desire to understand more about the medications they are prescribed for lupus and their potential impacts on overall health, particularly in the context of reproductive health.

It is evident that there is a significant need for comprehensive and accessible information on lupus medications, their potential side effects, and how they may influence reproductive and sexual health. Empowering patients with this knowledge is crucial to enable them to make informed decisions about their health and well-being. In this example, they express their needs: *"What does it do to your organs or what do you think it is possibly doing to anything inside, because I wasn't really worried about that at that time. So, it, you know, I was just like something new to try out, might want to try it out. But yeah, I wish I would have asked that question so they could have told me maybe a little bit more because the only thing they really told me was. You know, they didn't know."- Annie, 30 yrs old, diagnosed in 2009*

Discussion

Little research has been conducted on patients' experiences and needs around sexual and reproductive health and this study fills several crucial gaps around the needs and experiences in this area for women living with lupus. While many participants were aware of the need to monitor their reproductive health, use contraception, and plan in order to have a healthy pregnancy, they lacked knowledge about the duration of remission required and the specific steps to achieve a successful pregnancy. Even those who expressed their desire to get pregnant and had stable lupus activity were often dissuaded by their healthcare providers due to concerns about their health conditions.

This research validates the concern that patients have about the existence of potential complications during pregnancy for patients with SLE. However, it remains uncertain whether these complications directly arise from SLE or other preexisting conditions. Participants reported having unplanned pregnancies and sought information about how lupus might affect their fetuses and subsequent children, but they received minimal to no feedback on these specific questions. The confusion about whom to consult for reproductive health questions was exacerbated by the need for multiple doctors to manage their SLE, leading to conflicting information and frustrations when concerns were passed between different physicians. This finding is contradictory to the guidelines presented in Teng (2018) highlighting the need for SLE patients to be managed by a multidisciplinary team of physicians in order to have a successful pregnancy. Further, the safety issues and recommendations by Nahal also outline that providers should have holistic discussions with women about pregnancy planning and provide ideal timing for conception in order to reduce flares in women with SLE.

All participants had conversations with their providers about the importance of contraception and pregnancy prevention due to their lupus diagnosis. This is also reflected in Nahal’s 2018 safety issues and recommendations for successful pregnancy outcomes in systemic lupus erythematosus, where it is recommended that it is critical for those with SLE to have pre-pregnancy planning conversations and work with providers to have a safe and successful pregnancy. However, SLE patients expressed that their overall quality of life had been affected by their diagnosis, leading to changes in their reproductive health plans. The physical aspects of fatigue, skin rashes, and scars caused by the disease made it challenging to engage with friends, family, and partners on a daily basis. Many participants felt the need to prioritize their own well-being and were uncertain about their ability to care for another person, impacting their plans for starting a family. This is a unique finding and contribution from this study. Further research is needed to understand the impact of both lupus diagnosis and the changes in a lifetime of living with lupus on fertility.

Another unique finding is the impact of lupus on relationships and sexual functioning. Understanding why Asian participants with lupus refrained from sexual activity is crucial to provide appropriate support and care tailored to their specific needs. Cultural norms, beliefs, and perceptions related to lupus and reproductive health may play a significant role in shaping their decisions (Lim et al., 2020). Exploring these factors through more in-depth research can shed light on the complexities of managing lupus within different cultural contexts. This may be due to the stress that physicians place on pre-pregnancy counseling and the need to plan a healthy pregnancy (Do et al., 2019).

This study sheds light on the complexities and challenges faced by individuals with SLE when it comes to reproductive and sexual health decisions because of the lack of direct knowledge in this area for patient reference. The findings underscore the importance of addressing the unique needs and concerns of SLE patients regarding family planning and pregnancy but also more broad and holistic concerns around sexual and relationship satisfaction. Healthcare providers are the first point of contact to provide comprehensive and accurate information to empower patients to make informed decisions about their reproductive health (Do et al, 2014). In the context of other chronic conditions, such as cancer, there have been studies that highlight the importance of providing comprehensive and accurate information to empower patients in making decisions about their reproductive health. For example, a study published in the Journal of Clinical Oncology in 2017 examined the reproductive concerns and sexual functioning of female cancer survivors (van Dorp et al.,2018). The researchers found that cancer survivors faced similar challenges as individuals with SLE, such as the need for fertility preservation options, the impact of treatments on sexual health, and concerns about how their chronic condition may affect future pregnancies (van Dorp et al.,2018).

Similarly, in the context of diabetes, a study published by Deborah Young-Hyman and collogues (2016) explored the sexual health and satisfaction of individuals living with diabetes. The findings highlighted that diabetes could impact sexual functioning and satisfaction, and there is a need for open communication between patients and healthcare providers to address these issues. The study emphasized the importance of healthcare providers initiating discussions about sexual health during routine diabetes care visits, as well as providing resources and support to enhance patients' sexual well-being. These studies serve as examples of how healthcare providers can play a pivotal role in providing essential information and support to patients, guiding them in making informed decisions regarding their reproductive and sexual health, just as is needed for individuals with SLE. By taking a holistic approach and considering the broader impact of chronic conditions on patients' lives, healthcare providers can better meet the unique needs of their patients and promote overall well-being. This study underscores the need for healthcare providers to address the sexual and reproductive health needs of patients with chronic conditions ensuring they receive appropriate counseling and support, an area of future work.

Furthermore, the emotional and psychological impacts of living with SLE should not be underestimated. The study highlights the need for a holistic approach to care which addresses not only the physical aspects of the disease but also the emotional well-being of patients. Support services and counseling may be beneficial for individuals struggling with the impact of SLE on their quality of life and their family planning choices. Surprisingly, there was no discussion about how their medications could affect their sexual health or how the disease itself might impact it, despite participants expressing that disease activity influenced their interactions with partners over time.

Further research is warranted to delve into the factors contributing to the decision-making processes of SLE patients regarding family planning. Understanding these factors better can inform the development of tailored interventions and support systems to help patients navigate these complex and sensitive issues. Overall, this study contributes significantly to the field of SLE research and underscores the importance of considering patients' perspectives when designing healthcare interventions and policies.

Limitations and Strengths

This study should be considered in light of a few limitations. Despite making efforts to include Hispanic patients in the study, we were unable to obtain interviews from any participants within this ethnic group. Investigating the experiences and perspectives of Hispanic patients in relation to reproductive and sexual health care is essential to ensure that healthcare interventions are culturally sensitive and inclusive. By understanding the barriers and challenges faced by

Hispanic women with lupus, healthcare providers can develop targeted strategies to address their specific needs and improve the overall quality of care for this population.

Conducting research in these areas can contribute valuable insights that may not only enhance the understanding of how lupus affects reproductive and sexual health but also inform the development of more comprehensive and culturally appropriate healthcare approaches. Ultimately, bridging these knowledge gaps will lead to more equitable and effective care for all patients, irrespective of their cultural background or ethnicity. It is essential to prioritize such research endeavors to ensure that healthcare practices are inclusive, respectful, and responsive to the diverse needs of individuals living with lupus.

Strengths

This study stands as a pioneering effort, as it is the only one conducted in recent years that delves into the perspectives of lupus patients and their specific needs concerning sexual and reproductive health care. Furthermore, it represents a groundbreaking approach by addressing the effects of lupus on the intimate personal lives and relationships of the patients, shedding light on a previously unexplored area of research.

The study's uniqueness also lies in its exclusive focus on minority women, a population that has been historically underrepresented in research on lupus and reproductive health care. By centering on this specific demographic, the study not only amplifies the voices of an important group of lupus patients but also brings attention to the unique challenges and experiences they encounter when seeking reproductive health care.

Through this study, we have gained valuable insights into the dynamics between lupus patients and their physicians concerning reproductive health care. By focusing on the quality of relationships with healthcare providers, we can identify potential areas of improvement in communication, education, and support to enhance the overall reproductive health care experience for these patients.

Given the significance and novelty of this study, it underscores the importance of further research in these areas. Expanding the body of knowledge on lupus patients' needs related to sexual and reproductive health care will not only enrich our understanding of the disease's impact but also guide the development of more patient-centered and inclusive healthcare practices.

Researchers, healthcare providers, and policymakers can build upon the findings of this study to develop tailored interventions and support systems that address the unique challenges faced by lupus patients, especially minority women, when navigating reproductive health care decisions. By acknowledging and addressing these specific needs, we can work towards closing the gap in healthcare disparities and improving the overall well-being and quality of life for all lupus patients.

Chapter 4: Public Health Implications

In recent years, there has been a growing recognition of the importance of including more minority women in lupus research, considering that the majority of lupus patients are from minority communities (Lim et al., 2020). Unfortunately, the focus has historically been on white women with lupus, overlooking the fact that African American women of childbearing age are the most affected (Lim et al., 2020). It is crucial that these women receive appropriate reproductive and sexual health care to meet their unique needs (Thaxton et al., 2017). However, due to the limited research in this area, patients often struggle to find clear answers and information for their reproductive health plans. To address this issue, there is a pressing need for comprehensive communication about the medications used to manage SLE in childbearing-age patients and their potential impact on reproductive health.

Currently, patients lack adequate education about how SLE and its medications may affect their reproductive health, hindering their ability to ask the right questions and make informed decisions. This calls for an open dialogue between patients and their healthcare team, involving both rheumatologists and reproductive health physicians. Establishing a strong and trusting relationship with the healthcare team is essential for patients to feel comfortable discussing their reproductive health concerns and receiving accurate guidance (Nahal et al., 2018).

Considering that patients with lupus may continue to get pregnant, counseling should extend beyond just contraceptives. It should also provide information on the appropriate care in case of an unplanned pregnancy, ensuring that patients are well-prepared for all potential scenarios.

Additionally, more research is needed to understand the effects of SLE on patients' personal lives, particularly the issue of isolation experienced by these patients. The study's results indicate that an SLE diagnosis profoundly impacts patients' personal lives, potentially leading to increased isolation and fewer partnerships. Understanding these aspects can help healthcare providers offer better support and interventions to improve the overall quality of life for lupus patients.

Moreover, it is vital to conduct research focusing on the effects of SLE on different minority groups. Each minority group may have distinct cultural values that influence their experiences living with lupus. Tailoring healthcare approaches to account for these cultural differences can lead to more effective and patient-centered care.

Addressing the gaps in research concerning minority women with lupus is crucial to provide better reproductive and sexual health care to these individuals. Comprehensive communication, strong patient-provider relationships, and a deeper understanding of cultural influences are all necessary steps towards improving the well-being of minority women with SLE. By filling these knowledge gaps, healthcare providers can better support their patients in managing their reproductive health and overall health while living with lupus.

Conclusions

This study effectively addresses a crucial gap in knowledge concerning minority patients' experiences and needs around sexual and reproductive health. It highlights the pressing need for improved education and communication between patients and their physicians beyond contraception and pregnancy. Study participants revealed that they all sought reproductive healthcare, but their experiences varied depending on their relationships with different physicians. They encountered difficulties in accessing the reproductive health care they needed and had to advocate for themselves in these conversations. Surprisingly, there was no discussion about how their medications could affect their sexual health or how the disease itself might impact it, despite participants expressing that disease activity influenced their interactions with partners over time.

Furthermore, this study suggests potential differences among different ethnic groups based on cultural norms. However, further research is necessary to gain a more comprehensive understanding of this aspect. Although pregnancy with lupus is deemed feasible, patients face challenges in accessing the multidisciplinary care necessary during this time. It is highly recommended for patients to have a dedicated multidisciplinary team in place when they decide to conceive.

The findings of this study emphasize the critical role of effective communication between healthcare providers and patients, especially in the context of reproductive and sexual health care for individuals with SLE. It is evident that patients' experiences can vary significantly based on their relationships with their physicians, which underscores the importance of fostering trust and open communication in the doctor-patient relationship.

The lack of discussion about the potential impact of medications on sexual health is a significant oversight that needs to be addressed in medical practice. Patients with SLE should receive comprehensive information about how their treatments might affect their sexual health and overall quality of life. This can help them make informed decisions and seek appropriate support when needed.

Regarding the cultural differences observed among ethnic groups, it is essential to approach healthcare in a culturally sensitive manner. Understanding cultural norms and beliefs can lead to more personalized and effective care for patients from diverse backgrounds. It would be valuable to explore this aspect further to identify specific cultural factors that might influence reproductive health decision-making and care-seeking behaviors.

For patients with SLE who wish to become pregnant, the study's recommendation for a multidisciplinary care team is of utmost importance. The complexities of managing SLE during pregnancy require coordination among various healthcare specialists to ensure the best possible outcomes for both the mother and the baby. Implementing this approach in clinical practice can significantly improve the care and support provided to pregnant individuals with SLE.

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Appendixes

***Appendix A:** In-depth Interview Questions:*

Interview Guide

First, to start, could you tell me a little about your home life and family?

1. Relationship status/ partner/children, household makeup, daily activities. [Don't spend more than 5 minutes]

Now, I'd like to think back to your lupus diagnosis. [10 minutes]

2. Can you tell me about the process to your diagnosis?

a. How long did it take you to get your diagnosis (age/life stage, etc.)

b. Who was the provider who diagnosed you?

c. What was the impact of your symptoms [severity of disease] at the time of diagnosis?

d. Was your reproduction, reproductive health or sexual health part of the conversation when you were being diagnosed?

   i. Did you bring up any issues or concerns at your appointment?

People with lupus often take different medications to manage their condition.

3. Could you tell me about your current health management plan since being diagnosed with lupus? (medications/holistic care)

a. Do any of your medications have impacts on pregnancy or reproduction?

b. Do any of your medications have impacts on your sex life?

4. What are some of the questions you had or would have liked to get answered before starting your medications?

Thank you so much; Now, I'd like to move on to talking about your sexual and reproductive health, including your plans for pregnancy and your use of contraceptives.

5. Can you tell me about your reproductive plans?

a. Probes: Do you already have children, [if no]do you have plans for children in the future]

b. Did your diagnosis have an impact on your reproductive plans?

i.Direct Probe: Do you have any plans to delay or limit having children due to lupus?

Contraception is common and sometimes part of people's holistic care as well as a means to delay pregnancy.

6. What methods are you using to [limit] or [delay] a pregnancy [if any]?

a. Can you tell me a little about the types of contraceptives, if any, you have used since your diagnosis?

We've discussed conversation, but now I'd like to continue talking about your overall sex life since your lupus diagnosis.

7. How much do you feel that having lupus affects your sex life?

a. How does it change how you interact with your sexual partner(s)?

b. Describe how your sex life changed since your diagnosis?

c. Have your contraceptive choices affected your sex life?

Finally, we are hoping to understand how health providers have responded to or helped you navigate your sexual and reproductive health as a person living with lupus, specifically for contraceptive use and pregnancy.

8. Which providers, if any, do you discuss your reproductive health with?

9. What was the conversation [at diagnosis] with your lupus providers about contraceptives like?

a. Who brought it up (you, them, both)

b. How would you describe the decision-making process during this conversation?

i.PROBE: Shared? One-sided?

c. Did you have concerns or questions about your reproductive or sexual health that you brought to providers?

d. How did your provider react to those questions?

10. Have those contraceptive conversations changed over time?

11. Have providers discussed your contraceptive choices in relationship to your lupus diagnosis?

12. Do you feel providers have been supportive of helping you understand how lupus might affect your sexual and reproductive health?

13. Do you feel providers have been supportive in helping you navigate issues around contraception due to lupus?

14. Do you feel providers have been supportive in helping you to understand lupus' impact on pregnancy?

15. [ONLY FOR THOSE WHO HAVE BEEN PREGNANT] Do you feel providers have been supportive in helping you navigate issues around pregnancy due to lupus?

a. How confident are you that providers know the appropriate care needed for a pregnant person living with lupus?

16. What are some areas that could be improved for newly diagnosed lupus patients that are seeking reproductive healthcare?

***Appendix B**: Code Book*

Code:	Sub code:	Description:	Example:
Diagnosis		Participant describes the event of being diagnosed with lupus; this includes the symptomology or event that happened before the diagnosis or progression of the illness before diagnosis.	Jessica: “Pretty much, yeah, I lost, like I lost my appetite and then vomiting and then it was like, OK, I started feeling like I was having like, I guess, like pregnancy symptoms, so yeah, that's what made me go to the hospital first to get, you know, checked out but of course, when those results came back that I wasn't pregnant, it was like, OK, now they don't know what's wrong with me.”
	Impacts	How the diagnosis of lupus impacted their day-to-day including reproductive health and mentally.	Corinne: I got pregnant and got sick and they didn't know what was going on. So, a few blood tests led them to want to do a biopsy. But the baby was in there, so I delivered very early, 25 weeks, and they got her out. And they did the biopsy, and it was lupus nephritis, stage five

Unanswered Questions		Participants that have questions they have not been able to get an answer for regarding their medical care.	Tina: “But I'm so afraid because I keep hearing stories up. You know, if you keep pregnant on lupus, yeah it you could kill you or after you have the baby, you'll health start declining. You know, such and such died from having a baby and having lupus. You know? It's the more the stories rolled in. It was like really bad for me it put me in depression so yeah, I tried to just avoid it.”
Contraceptives/ Sex life		Participants mention what medications or methods they use for contraceptives and any changes they have seen in their sex lives.	Tina: “They always suggest that I use condoms I don't use birth control because they know I'm allergic to birth control, or use female condoms, and I don't know how to use that, so there's no question”

Other Diagnoses		Secondary diagnoses to lupus	Tina: “it gives me really bad ovarian cysts from each method that I've had.”
Living w/ Lupus		Describes the overall condition of living with lupus; includes feelings and thoughts on the condition.	Jean: “Ohh, so my lupus is actually supposed to be in remission, but things have not been going well recently, so I'm in a very different state of my health right now, but I, since my transplant, my lupus has been in remission, I'm hoping to keep it that way. I'm not sure what this little, where that, I'm having is about but. It is, it is what it is.”
Pregnancy		Participants who were pregnant, have children, or miscarried and conversations about pregnancy	Tina: “You know, if you keep pregnant on lupus, yeah it you could kill you or after you have the baby, you'll health start declining.’
Relationships		Participants describe the different relationship they have in relation to their lupus diagnosis	Tina: “I have several Uh.. friends, if you want to call them. Again, I just don't reach out.”

	Partnerships / Personal Life	Participants that have romantic partnerships or are looking for romantic connections in their lives, family and friendships.	Eliza: “Well, I'm married. I've been married, I don't do math, since 2014 to my wife, she's my high school sweetheart, and we've been together since 2006.”
	Physicians	Participants describing the negative and positives of interactions with physicians	Eliza: “Like they were supportive in my health but not necessarily supportive in like what I wanted to do.”
	Family	Those participants who had family members with lupus	Jessica: “like my great aunt had it and another family member that's not like my mom and dad side, but it was more so, like distant cousins had it.”
Holistic Care		Anything that participants do outside of what their doctors prescribe for them, dietary changes, alternatives, lifestyle changes.	Margo: “I'm on a low sodium diet right now.”

Career		Professional jobs that participants work and may be working on.	Corinne: “I have my own company I'm starting so I make like treats and stuff.”
Medication Side Effects/Impacts		Participants discuss side effects or care plan, participants speak to their physicians about how the medicines may affect them	Sandy: “whenever I get my mycophenolate refilled I always get this this big scary pamphlet about what can happen to a fetus if I do get pregnant and every time I need to get it refilled, they always ask”
Improvements/ Changes		How patients would have improved their care after diagnosis, this is usually recommendations to providers or larger lupus support community.	Tina: “whether or not lupus affects their reproductive health, and that's something that I didn't uhm, get explain to me because there were just more so focusing on we get a understanding and try to get a control of the lupus and the flares and things of that nature”

Isolation		Feelings and changes in social circles due to lupus	Corinne: “I lost a lot of my social life with just family members in general. Yeah, but also.”