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Exploring the Preferences of Women Regarding Sexual and Reproductive Health Care in the Rheumatology Context: A Qualitative Study

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Abstract

Objective: To explore the sexual and reproductive health (SRH) care and counseling needs of young women with rheumatic diseases in the context of their rheumatology care.

Methods: Semi-structured qualitative telephone interviews were conducted with female patients with rheumatic diseases aged 18–45 years (N=30). Women were recruited from outpatient rheumatology clinics in western Pennsylvania. Interviews were audio-recorded and transcribed verbatim. A codebook was inductively developed based on the interview transcripts, and the finalized coding was used to conduct a thematic analysis.

Results: Four themes emerged from interviews: 1) Women want rheumatologists to initiate conversations about SRH and revisit the conversation over time; 2) Women desire clear and complete information regarding fetal, pregnancy, and infertility risks associated with their diseases and DMARDs; 3) Women want to be treated holistically, with SRH addressed in the context of their life circumstances and personal values in addition to their rheumatic diseases; 4) Women generally feel that they are intermediaries between their rheumatologists and obstetrician-gynecologists (OB/GYNs), but preferred providers to communicate about their SRH.

Conclusion: Patients strongly desired rheumatologists to play an active role in their SRH, by initiating family planning conversations, providing SRH education in the context of their diseases

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and DMARDs, and directly coordinating SRH care with OB/GYNs. To meet patients' SRH needs, further work is needed to clarify the specific role of rheumatologists in providing SRH care and to identify ways to better facilitate communication between rheumatologists and reproductive health care providers.

Introduction

Women with rheumatic diseases are at greater risk of adverse pregnancy and perinatal outcomes as compared to healthy women (e.g., preeclampsia, preterm birth, intrauterine growth restriction, and fetal loss across a broad spectrum of rheumatic diseases) (1–7). Therefore, sexual and reproductive health (SRH) care and counseling are essential components of the comprehensive health care of these women. By providing SRH care and counseling, the rheumatologist may be activated to provide preventive reproductive health care that could potentially enhance patients' SRH outcomes (8).

However, patients in several studies report that their rheumatologists rarely address pregnancy planning or prevention, and that their various health care providers give inconsistent SRH advice and counseling (9–12). Fewer studies have evaluated what SRH-related information patients feel that they need in order to make informed SRH decisions, and the extent to which these needs are met in the rheumatology context. This qualitative study explored the attitudes and preferences of reproductive-age women with a broad range of rheumatic diseases regarding their SRH needs concerning their diseases, DMARDs, and health care interactions.

Patients and Methods

This study was approved by the University of Pittsburgh Institutional Review Board.

Study Participants

Patients were recruited from two outpatient rheumatology clinics affiliated with a large academic medical institution in western Pennsylvania. Inclusion criteria included female gender, ages 18 to 45 years, prior establishment of care in one of the two rheumatology clinics, and at least one of the following rheumatic disease diagnoses: systemic lupus erythematosus (SLE); rheumatoid arthritis (RA); spondyloarthritis (e.g., psoriatic arthritis); undifferentiated connective tissue disease (UCTD); Sjögren's syndrome; systemic sclerosis; inflammatory myopathies (e.g., dermatomyositis); vasculitis (e.g., Takayasu arteritis, Bechet's disease).

Research coordinators reviewed clinic schedules to identify potentially eligible patients, who were subsequently approached for recruitment during their clinic visits. Interested patients provided informed consent and scheduled an interview time with the research coordinator. Interviews were conducted via phone between January and April 2019. Participants were assured of anonymity and received a \$45 honorarium.

Interviews

Semi-structured qualitative interviews were conducted via telephone by individuals trained in qualitative interviewing (O.S., A.C.). The interviews broadly explored participants' reproductive histories, experiences with contraception and abortion, their perceptions of pregnancy and childbearing in the context of their rheumatic disease, and their expectations of their rheumatologists and other providers with respect to SRH. This manuscript focuses on patients' information needs and reproductive health care experiences in the rheumatology context.

Data Collection and Analysis

Interviews were audio-recorded and transcribed verbatim. Interviews were conducted until the point at which no new themes were elicited— i.e., thematic saturation (13). The interviewers perceived that thematic saturation occurred after the 26th interview; four additional interviews were conducted to verify that thematic saturation had been reached. This yielded a final sample size of 30 women.

The analytic framework for this study was based in grounded theory, an inductive methodology that seeks to uncover theory directly from the data (i.e., patient interviews) and therefore allows for the discovery of novel ideas and concepts (14). Our analysis utilized the 'editing' method described by Crabtree and Miller (15). In this approach, the coder engages the data without a predefined codebook, and relies on the interaction with the data and with the other coder(s) to generate codes. To help to reduce potential bias in codebook development and analysis, we involved an independent qualitative analyst (T.W.) in the analytic process.

The analyst and a member of the research team (O.S.) used the transcript content to make a preliminary codebook. This codebook was reviewed by the principal investigator (M.B.T.) for comprehension and clarity, and to facilitate investigator triangulation. The codebook was further modified as new themes emerged during the coding process. The coders applied the final codebook to all transcripts (i.e., "double-coding") (16). To assess interrater reliability, a Cohen's kappa score was calculated based on 91 individual codes generated by the two coders. Each code was used an average of 15 times across the 30 interviews, and the rate of agreement and disagreement between the coders was calculated for each code. Cohen's kappa was calculated to 0.69, indicating substantial agreement between coders (17). However, the coders subsequently adjudicated all coding differences to full agreement. Themes identified by the coders were discussed with the principal investigator as a means of investigator triangulation. Quotations from the interviews were selected to illustrate major themes and are presented in the text by women's ages and disease diagnoses; women who shared these basic demographic characteristics are distinguished numerically (e.g., #1, #2).

Results

Thirty-three women were invited to participate, and a total of thirty women completed interviews. Demographic characteristics are presented in Table 1. The average age of participants was 35.1 years (range: 21–44 years); 13% were non-Hispanic black, 74% were

non-Hispanic white, 10% were Asian, and 3% were multiracial. RA, SLE, Sjögren's syndrome, and UCTD were the most prevalent diseases. Forty-seven percent of women did not have children, and two women were pregnant. Nineteen women were employed, seven were unemployed, one woman was an undergraduate student, and three women did not share current or past employment information. Four distinct themes emerged from the interviews, which are summarized below.

Theme 1: Women want rheumatologists to initiate conversations about SRH and revisit the topic over time.

Women in the study expressed a strong preference for rheumatologists to initiate discussions about SRH, particularly at their first clinic visit, as described by one patient:

I think an initial conversation and opening the door to conversations about sexual and reproductive health on the initial visit is really helpful in building that relationship and that line of communication with the rheumatologist. [34 years old, spondyloarthritis]

While some women felt confident initiating SRH conversations with their rheumatologists, nearly half of participants did not feel comfortable introducing these topics, as described by one patient:

I would just say [the rheumatologist] should bring it up. I know with my [rheumatologist], they didn't bring it up, I brought it up. It made it even more uncomfortable when I brought it up because of my age. I was still kind of shy, I guess, and it was hard for me to bring it up. I think if they would bring it up once in a while it would make it more open, you know? [29 years old, SLE, #1]

Participants also expressed that as their pregnancy plans and desires were likely to change over time, they preferred for SRH counseling to be addressed longitudinally by their rheumatologists. One patient, who described that her family planning goals had changed since establishing care with her rheumatologist, mentioned a misconception about the safety of azathioprine in the context of pregnancy:

[My rheumatologist] was relieved that I told her that I wasn't planning on getting pregnant. But the fact that I've been married for five years now and my husband wants his own kids... I'd like the option [for pregnancy] in the future. My friend told me that it takes eight months to get off the [azathioprine] to get pregnant, but my rheumatologist and I haven't talked in detail or anything. I see [my rheumatologist] every four months. I'm not satisfied with the response that I get from her because [my reproductive goals] have changed... and I'd like to know if I could actually conceive someday... But I don't bring it up [with my rheumatologist]. I haven't for a year. [35 years old, SLE, #1]

Women generally preferred for SRH conversations to occur at least several times a year, with around half of patients expressing that they preferred for SRH to be discussed at every rheumatology visit:

I would just say always keep that conversation on the table. Like, I think it is good to at least check in on the subject every visit with rheumatologists. I really think

that, as a female at my age, I would expect that my PCP, my gynecologist, and my rheumatologist are all going to check in on that subject because, you know, that's pertinent to my real life right now and my real health situation, and it's, like, a big deal, it's a really big deal. [29 years old, SLE, #2]

While many women used websites, blogs, or chat groups to learn information about SRH, they preferred for SRH information to be delivered by rheumatologists and other health care providers:

"I googled and it was saying how a baby can develop lupus in utero and you hear about lupus and all these bad things about it, so it kind of freaked my boyfriend out about that, but you still have to sit down and talk to your doctor and see what they say." [31 years old, Sjogren's syndrome]

Theme 2: Women desire clear and complete information from rheumatologists regarding fetal risks, pregnancy risks, medication risks, and risk of infertility associated with their diseases.

Along with a regular assessment of pregnancy goals and plans, women wanted rheumatologists to provide individualized and accurate information regarding risks of pregnancy in the context of their rheumatic diseases and overall health. Women preferred for rheumatologists to be "black and white" about the possible risks related to pregnancy and to "not sugarcoat" the possible complications of pregnancy [31 years old, UCTD]. Rather than being protected from information "because they don't want me to worry about something" [25 years old, Sjögren's syndrome], patients desired transparency about potential outcomes prior to making the decision to conceive. As described by one woman,

Really, I just expect honest answers, like I really appreciate how knowledgeable he [my rheumatologist] is on it and how honest he is with me about—with the reality of it. You know, lupus is not a good disease; it's a really brutal, ugly disease that manifests in a lot of ways, this being one of them, and I want to be prepared for the future. So I appreciate that he is able to tell me what this is really going to look like, and what's going to help me have the smoothest pregnancy. [29 years old, SLE #1]

Other women also expressed that they wanted their rheumatologists to address if they had an increased risk for infertility related to their rheumatic diseases and DMARDs, and that they would be interested in learning about assisted reproductive technologies.

I mean, I would hope they wouldn't be afraid to have that discussion [about fertility] early because I do know women who've been able to have children. I know that's difficult for some, but if you had that discussion early before you start taking all those harsh medications, I think your doctors could take that into consideration that that's something you really want in your life and can adjust their plan to fit what it is that you want. I just think they need to be vocal about it right away. [35 years old, SLE, #1]

All women expressed concerns about the safety of their DMARDs during pregnancy, primarily citing concerns about the potential effects on the health and development of their children. As one woman explained, "I wouldn't want to do anything to jeopardize the

pregnancy, I wouldn't want to do anything to jeopardize the health of the child" [43 years old, UCTD]. Most women were generally aware which of their DMARDs were potentially teratogenic, either due to physician counseling or their own research. Some women expressed that they would be "terrified to take [my] medications" [39 years old, Takayasu arteritis] in the event of pregnancy. Women felt that rheumatologists should educate patients about DMARD safety in the context of SRH care and counseling.

I think that's a big thing is just being aware of medications that you're going to go on or if you want to plan on having a child, what you need to do in order to do that because you want to obviously not have any of those things in your system for so long if you're going to try to have one because then that could be bad too. [38 years old, RA]

Several women also indicated that while they were reluctant to use DMARDs during pregnancy, they would generally follow their physician's recommendations regarding medication use during pregnancy. This response emerged primarily from patients who had reported that their rheumatologist regularly provided education on medication safety in the context of SRH care.

[My rheumatologist] is always asking if I'm using some sort of birth control and reminding me about the complications that the medication and things that could happen if I were to get pregnant. He always iterates that I need to be using some type of birth control. [43 years old, spondyloarthritis]

Other women received less support from their rheumatologists in terms of DMARD management regarding pregnancy or fertility. As one woman described, "When he [my rheumatologist] prescribed medication [methotrexate] for me, I don't think he asked me if I would want kids" [35 years old, Sjögren's syndrome]. Another woman, who was pregnant at the time of interview, was unsure of the effects of her medications when she initially learned she was pregnant but decided to manage her own regimen: "I kind of self-discontinued my medication and I didn't know if that was ok to do or if I'd be hurting myself or my baby" [34 years old, spondyloarthritis].

Theme 3: Women want to be treated holistically, with SRH addressed in the context of their life circumstances and personal values as well as their rheumatic disease.

Though women acknowledged that their rheumatic diseases were important to consider with respect to pregnancy, they also underscored the importance of stable partnerships, financial stability, completion of education, reaching an appropriate age, and/or feeling it would be "the right time for our family" [31 years old, UCTD]. Women wanted their rheumatologists to acknowledge that factors beyond their rheumatic disease were integral in pregnancy planning.

I think people when they get so focused on their specialty, sometimes they're not thinking about how that can affect other aspects of someone's life... Thinking holistically about their approach to an individual's care, they need to consider other parts of their life, mental, physical, and what your plans are, what your life is about. [34 years old, RA]

Another woman described how her disease management did not reflect recent changes in her reproductive goals and plans:

Rheumatologists don't really make [SRH] a priority. They care more about how you're feeling day-to-day... When I first started to see my rheumatologist, I was in law school... I would have liked to have foreseen that maybe five years from then I would have been engaged and getting married... I would have liked her [rheumatologist] to talk with me about this before ever starting the chemo drugs. I would have liked her to say, ok, before we start, do you want to freeze any eggs?... I would have liked to have known that 10 years ago. I would have frozen my eggs. [35 years old, SLE, #2]

Theme 4: Women generally feel that they are intermediaries between their rheumatologists and obstetrician-gynecologists (OB/GYNs).

Most women expressed frustration that they were required to relay information between their rheumatologists and OB/GYNs and felt that communication between specialties is the responsibility of health care providers. These patients expressed that they would prefer rheumatologists to consult with their OB/GYNs in advance of and during pregnancy.

I think providers in a sense should be able to collaborate amongst themselves. So if I'm needing my gynecologist to communicate with my rheumatologist, I shouldn't be a middle person for that, so they should be able to connect and discuss my plan of care. But right now, how it's set up, I am the mediator for that plan of care. [34 years old, RA]

The preference for care coordination was underscored by the experiences of several women, who believed their obstetrician-gynecologists were not sufficiently knowledgeable about the rheumatic diseases, or whose advice conflicted with their rheumatologists':

Before we were thinking about trying [to conceive], we were referred to maternal fetal medicine because I'm high-risk pregnancy ... my rheumatologist seemed really supportive of me wanting to get pregnant... my [maternal fetal medicine physician] said, 'Are you sure you want to do this? You know, a million horrible things could happen.' Like, I know, that's why I'm coming to you, so they don't." [29 years old, SLE, #2]

Some women were not sure which of their providers was responsible for managing their SRH. As expressed by one patient:

I'd probably [talk to] my OB [obstetrician] because I don't know how much my rheumatoid arthritis doctor knows. You know what I mean? Because she's female, I'd probably go to my OB, I wouldn't know who else to go to. [39 years old, RA]

Besides updating other providers on changes in patient management, most women expected their rheumatologists to guide their OB/GYNs on disease-specific issues that may arise during pregnancy or pregnancy planning:

I expect [my rheumatologist] to advise my OB/GYN when it comes time. To tell them what I have and what to watch out for. For instance, to watch out for lupus in

the infant or in the womb.... Not all OB/GYNs I've seen know about that. [35 years old, SLE #2]

Discussion

A patient-centered approach to sexual and reproductive (SRH) care in the rheumatology context is required in order to better meet the information needs and priorities of patients with rheumatic diseases. However, few studies to date have explored what patients need from their rheumatologists regarding their SRH care. Our qualitative study indicates that women strongly desire for rheumatologists to assume a prominent and sustained role in SRH care and counseling.

Patients wanted rheumatologists to provide SRH care and conversations beginning at their first clinic visit, and to continue to address SRH at subsequent visits. Many patients felt uncomfortable initiating SRH conversations with rheumatologists. However, our prior qualitative study involving a national sample of rheumatologists found that rheumatologists prefer for patients to initiate conversations regarding SRH (12). This preference discrepancy may explain why various studies report that SRH conversations rarely occur between rheumatologists and female patients of reproductive age. For example, one patient survey reported that 59% of women with SLE who were at risk of unintended pregnancy did not receive any contraceptive counseling within the prior year (9). A separate patient survey found that only 32% of young women with autoimmune diseases including SLE and RA had received family planning care from rheumatologists or other health care providers (10). An important message to rheumatologists is that even if reproductive-age, female patients do not initiate questions about their SRH, it should not be assumed that they do not have SRH-related questions or concerns that are within the purview of the rheumatologist. Future quality initiatives are needed to explore how SRH can be better operationalized in the rheumatology clinical context. For example, prompts could be built into the routine office workflow via either the electronic medical record or intake forms to remind rheumatologists to address relevant SRH care with patients (18, 19).

Patients also had strong preferences regarding the information they wished to be conveyed in SRH conversations with rheumatologists. Patients overwhelmingly desired clarity about their specific pregnancy-associated risk factors, effects of their diseases and DMARDs on their fertility, and safety and compatibility of their DMARDs in the context of pregnancy planning. These findings suggest that patients need their rheumatologists to address medication safety and side effects specifically in the context of SRH. As participants were hesitant to use DMARDs during pregnancy, rheumatologists may need to underscore that many DMARDs are pregnancy-compatible. Patients may also need to learn that discontinuation of treatment may lead to undertreated, uncontrolled disease that will increase a patient's risk of maternal and fetal morbidity and mortality (20–22). This is particularly important as previous studies have found that 31% to 67% of women with rheumatic diseases self-discontinue even safe DMARDs during pregnancy (23–25). Resources about DMARD safety in pregnancy include the American College of Rheumatology Reproductive Guideline (26), European League Against Rheumatism consensus guidelines (27, 28), the patient-oriented MotherToBaby website by the Office of

Teratology Information Specialists (29), and the provider-oriented Healthy Outcomes in Pregnancy with SLE through Education of Providers website (HOP-STEP, www.lupuspregnancy.org).

Another key finding of our study was that patients desired greater collaboration between their rheumatologists and OB/GYNs regarding their SRH care, without relying on the patients to serve as intermediaries for communication. Studies suggest that multidisciplinary collaboration may help women to gain better access to reproductive health care; for example, women who received care from both a rheumatologist and gynecologist in several studies have been more likely to receive contraception and highly effective contraception methods than women who received care from a rheumatologist alone (9, 30). Referral to an OB/GYN may be a good first step for rheumatologists to facilitate SRH care for patients. A future challenge is to find ways to better coordinate care between rheumatologists and OB/GYNs or other reproductive health providers, particularly among providers practicing in different medical systems. Furthermore, rheumatologists must also not assume that patients have an OB/GYN who will provide SRH care; our prior work indicated that only one third of young women with rheumatic diseases had visited an OB/GYN over a multi-year period, even though they saw rheumatologists more regularly (30).

This study has several limitations. Although we achieved thematic saturation, and patients saw different rheumatologists across the health care system, we did recruit from a single health care system. Thus, sampling bias could affect the generalizability of our findings. However, our questions were designed to elicit patients' general preferences for SRH care in the rheumatology context. Outcomes of our study may have further been affected by selection bias, as patients who entered the study may have had greater interest in reproductive planning than those who chose not to participate. However, 91% of women who were approached for the study ultimately chose to participate, which may suggest that SRH is a major concern for many female patients. We chose to prioritize women's privacy and confidentiality by limiting the number of demographic characteristics that we collected, but in retrospect, assessing women's educational attainment could have helped us to better contextualize their information needs as described in Theme 2. Finally, our findings may be affected by social acceptability bias, in that participants might have answered questions based on social acceptability rather than expressing their real perspectives or experiences. We tried to mitigate this bias by ensuring that the interviewers were not rheumatologists or involved in the health care of the participants.

To summarize, this study found that patients are deeply invested in their reproductive health, and that they desire for their rheumatologists to provide continual SRH care and counseling and address specific SRH concerns related to their diseases and DMARDs. Future work is needed to clarify the specific role of rheumatologists with respect to meeting these specific SRH needs, streamlining communication between rheumatologists and other reproductive health providers, and better coordinating the SRH needs of reproductive-age women with rheumatic diseases.

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Significance and Innovations

- This is the first qualitative study to explore specific preferences of women with a diverse range of rheumatic diseases regarding their sexual and reproductive health (SRH) care
- Some patients are uncomfortable initiating sexual and reproductive health-related conversations with their rheumatologists, and prefer for their rheumatologists to initiate and continue these conversations over time
- Patients desire clear and complete information from rheumatologists regarding pregnancy or infertility risks related to their diseases or disease-modifying anti-rheumatic drugs
- Patients want their rheumatologists and obstetrician-gynecologists to collaborate about their SRH care, and do not wish to be intermediaries between these health care providers

Table 1.

Demographic Characteristics (n=30)

	Frequency	Percent (%)
Age (Mean, S.D.)	35.1 (5.84)	
Race		
Black	4	13
White	22	74
Asian	3	10
Multiracial	1	3
Relationship Status		
Single	11	41
Married	14	52
Divorced	2	7
Children		
None	14	47
One	7	23
Two	5	17
Three or More	4	13
Pregnant at Interview	2	7
Diagnosis[†]		
RA	7	23
SLE	7	23
Sjögren's	5	17
UCTD	3	10
Spondyloarthritis	2	7
DMARD Usage	28	93

[†]The following diseases were each reported by 1 patient (3%): Dermatomyositis, Behçet's Disease, Granulomatosis with Polyangiitis, Takayasu Arteritis, Psoriasis, Mixed Connective Tissue Disease, Psoriatic Arthritis, Autoimmune Hepatitis.