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Exploring Family Planning, Parenting, and Sexual and Reproductive Health Care Experiences of Men With Rheumatic Diseases

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ABSTRACT. ***Objective.*** To explore family planning, parenting, and sexual and reproductive health (SRH) care needs and experiences of men with rheumatic diseases.

Methods. Men aged 18–45 years who were diagnosed with at least 1 rheumatic disease and used at least 1 antirheumatic drug were recruited from rheumatology clinics. Research coordinators engaged participants in semistructured phone interviews. A codebook was developed based on the interview transcripts and used to conduct an inductive thematic analysis.

Results. Participants ranged in age from 22 to 44 years (n = 20). Most were heterosexual and had at least 1 child. The most common disease diagnoses were spondyloarthritis, systemic lupus erythematosus, and rheumatoid arthritis. Four themes emerged from the interviews: (1) Men had family planning concerns, particularly related to the heritability of their diseases, their fertility, and potential effects of their medications on their offspring's health. (2) Men felt that fatigue, disability, and/or pain from their diseases either impaired or would impair their abilities to parent. (3) Men often did not discuss sexual dysfunction with their rheumatologists, even when they believed that it arose from their diseases or antirheumatic drugs. (4) Men rarely discussed any family planning, parenting, or SRH issues with their rheumatologists; gender discordance with rheumatologists did not affect men's comfort in discussing these issues.

Conclusion. Men expressed concerns related to family planning, parenting, and SRH, which they rarely discussed with their rheumatologists. Our study suggests that some men's SRH information needs are incompletely addressed in the rheumatology clinical setting.

Key Indexing Terms: family planning, male, parenting, physiological sexual dysfunction, qualitative research, reproductive health

While a growing body of literature describes the effect of rheumatic disease on women's sexual and reproductive health (SRH), relatively little is known about the corresponding experiences of male patients with rheumatic diseases. However, emerging studies suggest that men also experience challenges related to SRH. Low sperm counts and sperm quality have been found to cause fertility impairment among some men with systemic lupus erythematosus (SLE), rheumatoid arthritis (RA), and dermatomyositis.[1,2,3] Fertility may also be impaired by exposure to certain cytotoxic and disease-modifying antirheumatic drugs (DMARDs).[4,5,6] Men with spondyloarthritis (SpA), juvenile idiopathic arthritis, and SLE report greater rates of sexual dysfunction as compared to healthy men.[7,8,9] In addition, men with inflammatory arthritis (IA) have expressed that they experience parenting challenges related to their diseases.[10]

This qualitative study sought to explore in depth the experiences of male patients with respect to family planning, parenting, and SRH; their concerns and information needs related to their diseases and DMARDs; and preferences for family planning care and counseling in the rheumatology context.

METHODS

Study participants and recruitment. This study was approved by the University of Pittsburgh Institutional Review Board (IRB; STUDY19010092). The study team recruited participants from 2 rheumatology clinics affiliated with a large academic healthcare system in Pennsylvania.

Men aged 18–45 years were eligible to participate in the study. While many men have an even wider age range for fertility, 1 objective of the study was to elicit patients' experiences with family planning care in the clinical context. US-based public health agencies consider family planning to be an essential component of comprehensive health care for males aged 15–44 years,[11,12] so we limited our sample to a group that would be most likely to receive and describe recent experiences with family planning care.

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Additional inclusion criteria included (1) diagnosis with at least 1 autoimmune-mediated or inflammatory rheumatic disease; and (2) current use of ≥ 1 conventional or biologic DMARD, or small molecule medications.

Research coordinators approached potential patients at the time of their clinic visits, described the study, and asked if they were interested in participating in a phone-based interview. If so, patients provided informed consent and scheduled an interview time. Participants were initially compensated $30 upon completing the interview. Recruitment was suspended for 6 months because of research restrictions imposed due to the coronavirus disease 2019 (COVID-19) pandemic. After research restrictions were lifted, in-clinic appointments were still sparsely attended, and we increased compensation to $45 as a strategy to augment patient participation. The increase in compensation was approved by our IRB.

While vasectomized men were not excluded from the sample, we used a purposive sampling strategy to prioritize recruitment of men who (1) were not vasectomized, or (2) had vasectomies after their disease diagnosis, to explore if their diseases had influenced their sterilization decision making.[13]

Interviews and data collection. Our interview guide included open-ended questions on reproductive decision making, fertility, parenting, disease heritability, sexual function, and reproductive healthcare and information seeking. We chose to conduct individualized interviews as prior studies have found that focus group studies about sex and other sensitive topics elicit more socially acceptable responses than 1-on-1 interviews.[14,15,16] Interviewers used techniques such as repetition, paraphrasing, and summarization to verify patient responses during data collection.[17] Two female members of our study team (OS and NH) conducted the interviews. OS is an experienced qualitative data analyst who has conducted hundreds of semistructured interviews about SRH with male and female patients across a variety of medical illnesses. NH, a senior rheumatology fellow, was trained by OS and the female principal investigator (MBT) to give qualitative interviews on sensitive topics.

Data analysis. We used an inductive analytic framework based on grounded theory, which allowed for the consideration of new ideas and concepts as the data were being analyzed.[18] The coders (OS, NH) performed data collection and analysis simultaneously. They initially labeled interview data to identify preliminary codes, which were used to sort and synthesize the data. They met after independently coding the first 5 transcripts to compare codes and develop a preliminary codebook. MBT reviewed the codebook for comprehension and clarity as a means of investigator triangulation. The codebook was refined as additional themes were elicited from the analysis. As codes were classified into themes, we assessed if patterns of data varied by gender concordance (or discordance) of rheumatologists using the constant comparison method, an analytic approach in which codes are compared across subgroups of participants.[19] Interviewers perceived that no new themes emerged after the 12th interview.[13] Eight additional interviews were conducted to ensure that thematic saturation had been reached. The finalized codebook was reapplied to all transcripts—a process called double-coding—to ensure consistency of the analysis across all interviews.[20] The coders adjudicated all coding differences to full agreement. MBT and JR provided perspectives about coding and the thematic analysis.

RESULTS

Thirty-one men were approached for interviews; 5 men declined participation, and we did not ask them to provide a reason. Six men consented to participate in the study but did not complete an interview. The 20 men who completed the interview ranged from 22 to 44 years old, and identified as Asian (n = 2), Black (n = 2), and White (n = 16; Table 1). Sixteen men were employed and 4 were unemployed, with occupations ranging from health care and academia, to construction and food service. Most men were cisgender and married or in a heterosexual relationship; 2 men identified as bisexual, but no men were currently in a same-sex relationship. Twelve men had at least 1 child. The most common disease diagnoses were SpA (eg, ankylosing spondylitis, psoriatic arthritis), SLE, and RA. Six participants were vasectomized, 5 of whom had the procedure prior to their disease diagnosis. Eleven of the men had male rheumatologists and the remaining 9 had female rheumatologists.

Table 1. Demographic characteristics (n = 20).

	Mean (SD) or n (%)
Age, yrs, mean (SD)	36.6 (6.2) [range 22–44]
Race	
White	16 (80)
Black	2 (10)
Asian	2 (10)
Relationship status	
Married	13 (65)
In a relationship	4 (20)
Single	3 (15)
No. of children	
0	8 (40)
1	5 (25)
2	5 (25)
3	2 (10)
Disease diagnosis	
Spondyloarthritis	6 (30)
SLE	4 (20)
Rheumatoid arthritis	3 (15)
Sarcoidosis	2 (10)
Myositis	2 (10)
Inflammatory arthritis	1 (5)
Vasculitis	1 (5)
SSc and polymyositis	1 (5)
Medications[a]	
Hydroxychloroquine	6 (30)
Methotrexate	6 (30)
Azathioprine	3 (15)
Adalimumab	4 (20)
Mycophenolate mofetil	3 (15)
Prednisone	3 (15)
Etanercept	2 (10)
Infliximab	2 (10)

[a] Medications taken by only 1 participant each included apremilast, belimumab, intravenous Ig, leflunomide, rituximab, secukinumab, sulfasalazine, tacrolimus, ustekinumab. SLE: systemic lupus erythematosus; SSc: systemic sclerosis.

Men were assigned pseudonyms. The 4 major themes elicited from their interviews are described below:

Theme 1. Men had family planning concerns, particularly related to the heritability of their diseases, their fertility, and potential effects of their medications on their offspring's health.

Men were concerned about the heritability of their diseases and the potential effect on future offspring. As Robert, a 42-year-old man with an overlap of systemic sclerosis (SSc) and polymyositis, described, "There's the worry of passing on my hereditary condition. A lot of people in my family have autoimmune disorders....It's not something I'd want somebody else to have." Manuel, a 38-year-old man with SLE who had a vasectomy,

described, "I didn't want to pass anything on knowingly to my kids. I just didn't want them to get autoimmune disease."

Most men in the study were also concerned about medication safety in the context of reproduction. As Steve, a 36-year-old with RA who used adalimumab and leflunomide (LEF), stated, "Whatever the medication is doing to me would be passed on to the child. That would really be my biggest concern." Evan, a 44-year-old with SLE, described, "I would like to know the side effects of the medications I'm on. I would like data. Or maybe there would be monitoring...here's how many swimmers [sperm] he had before, here's how many swimmers he has now...birth defects, things of that nature, anything that I'm taking that could cause that. I would certainly be concerned, and if there were percentages of deformities or a nonnormal child, that would deter me from having children, for sure."

Several participants erroneously believed that their medications were unsafe to use in the context of pregnancy planning; this was particularly evident among the 3 users of azathioprine (AZA).[4] For example, Kevin, a 40-year-old with granulomatosis with polyangiitis (GPA), mentioned that medication safety was a factor in his decision to postpone parenthood: "It's been encouraged to me to not pursue having children while on [AZA]." Jorge, a 39-year-old with sarcoidosis, said, "If you're trying to get pregnant, then you shouldn't even handle [AZA]."

Theme 2. Men felt that fatigue, disability, and/or pain from their diseases impaired or could impair their abilities to parent or financially provide for their families.

Fathers expressed parenting challenges related to their rheumatic diseases. Most men in the study described their physical capabilities as a measure of their parenting capacity. Pain was often mentioned as the cause of physical limitation by the men with IA (e.g., SpA, RA). Tyrrell, a 42-year-old father with SpA, mentioned, "I have chronic joint pain...that causes me pain daily. There's [*sic*] times where my daughter and I are playing. I say, 'Daddy's got to take a break.' I can't. I can't play anymore." John, a 33-year-old with SpA, felt that pain limited his involvement with his 3 children: "Sometimes I'm in too much pain to have fun with my kids. Sometimes I can't get to their football or baseball games, like sports activities, because I'm in so much pain."

Men who were not yet parents also identified their physical impairment as a reason why they might not want to have children in the future. Robert explained, "I have a lot of muscle weakness. I'd be worried about being able to properly care for the child or lifting them properly without hurting myself or risking dropping them, or being able to even spend quality time with a child...I can't be very physically active, as I would like to be if I was going to have a child" (age 40 yrs, SSc and polymyositis overlap). Kevin was hoping to conceive a pregnancy with his wife within the next several months, but stated, "Right now, I'm not much use around the house. I help a little bit, but I would want to be physically stronger to be more helpful and be a good and useful parent" (40 yrs old, GPA).

Some men described financial insecurity related to their diseases as a reason why they had deferred parenthood. Aaron, a 22-year-old male with SLE, described, "I've had a flare-up in the past where I was in the hospital for 2 weeks....If I get sick, I won't be able to take care of the child the way I need to, and then if I'm not financially stable, then I can't afford daycare and childcare." Financial instability also was a factor in family planning for Michael: "For a long time, I didn't have health insurance, so I wasn't able to be in treatment for my chronic pain, which is [caused by the] autoimmune disease.... I also get chronic fatigue, and I used to get bad mood swings, so all of those things kept me from advancing financially. I want to make sure I'm financially stable when I start having children. I don't want to raise children in poverty" (39 yrs old, SpA).

Theme 3. Men often did not discuss sexual dysfunction with their rheumatologists, even when they believed that it arose from their diseases or DMARDs.

Eight men in the study experienced sexual dysfunction, including pain that impeded sexual activity, worsened erectile dysfunction, and/or caused low libido. Nearly all the men attributed the sexual dysfunction to their diseases or medications. For example, Manuel, a 38-year-old with SLE, described, "I have a hard time getting an erection and keeping an erection. It all started as soon as I got sick." Evan, a 44-year-old man with SLE, described, "In the beginning, the steroids made it very difficult to perform....[My rheumatologist] said it was her fault for giving me all the steroids. She apologized to my wife (laughs)."

Even though these men believed their diseases and treatments had either caused or contributed to their sexual dysfunction, only half had discussed sexual dysfunction with their rheumatologist. Aaron, a 22-year-old with SLE who had experienced erectile dysfunction for a year, said, "I actually did bring it up with [the rheumatologist] because I was really concerned, and he was trying to pass me to Urology. I didn't think it was a urology problem. I felt like it was more a rheumatologist issue since I felt it was coming either from the lupus or medication." In contrast, Robert described, "I probably had [sexual dysfunction] for a while before I felt comfortable bringing it up just because it's something that can be embarrassing to talk about. But once I was serious enough about wanting to fix it, that's when I felt comfortable to bring it up to my rheumatologist. But it wasn't their fault, it wasn't because I felt uncomfortable with them—it was because it's a weird thing to talk about" (42 yrs old, SSc and polymyositis). Robert's rheumatologist referred him to an endocrinologist, who found that he had low testosterone levels and prescribed supplementation.

Most men did not attribute gender concordance with their rheumatologists as a facilitator or barrier to discussions about sexual dysfunction. Several men did not discuss sexual dysfunction with any clinician, including John, a 33-year-old with SpA: "I just thought [sexual dysfunction] was normal. I mean, if you're in pain, you don't want to have sex." Carl, who experienced pain in his sacroiliac joints with sex but had not discussed sexual dysfunction with any provider, mentioned, "If the [rheumatologist] ever asked me, then I would be frank...but I would not expect a doctor asking me questions regarding sexual activities" (31 yrs old, SpA). Evan suggested ways in which conversations about sexual dysfunction could be initiated in the rheumatology context, "I guess it's the manner in which it is brought up. If it's, 'by the way, how's your sex life going?' Then I think that would

be a little weird. But if [the rheumatologist] brought it up in a way where, 'Hey, sometimes with the medication that I give you and the doses, these kinds of things can happen. Is this happening to you?' No, I would not be embarrassed about being asked that question in that way" (33 yrs old, SLE).

Theme 4. Men rarely discussed family planning, parenting, or SRH with their rheumatologists, who they assumed would initiate the discussion if relevant to their health.

Half of the participants had never discussed any aspect of family planning, parenting, or SRH with their rheumatologists, but most were amenable to these discussions in the rheumatology context. Men overwhelmingly preferred for rheumatologists to initiate conversations about these topics. As Steve suggested, "It's something the rheumatologist should always be bringing up, especially when prescribing medications....I think it should always be an ongoing conversation....[I]t's never been addressed to me as a patient" (36 yrs old, RA). Tyrrell, a 42-year-old with SpA described, "I think a lot of times, you're not going to be forthright with stuff because you either don't know how to bring it up because you don't know it's an issue. Or, when you start to finally realize it is an issue, maybe you're too embarrassed or don't know how to bring it up." Men used words including "uncertainty," "feeling embarrassed," or "shy" to describe how they or other men might feel about initiating conversations about SRH.

We were interested to learn if gender concordance with rheumatologists facilitated SRH conversations. Nearly equal numbers of men with either male or female rheumatologists had never previously discussed any SRH issue with their rheumatologist, regardless of gender. Gender concordance did not affect most men's comfort levels in discussing SRH, and all men preferred for the rheumatologist to initiate SRH conversations, regardless of gender.

DISCUSSION

Men in this study expressed family planning and parenting concerns that included the potential heritability of their diseases, medication safety with respect to their offspring's health and their fertility potential, and physical limitations that undermined their abilities to optimally parent. Men who experienced sexual dysfunction attributed it to their diseases and/or medications, but often did not discuss this health issue with their rheumatologists. In this sample of men, family planning, parenting, and SRH were often not addressed in the rheumatology context.

The potential heritability of rheumatic diseases was a concern for men who were fathers or considering future parenthood; however, inheritance patterns and genetic susceptibility remain poorly defined for many rheumatic diseases.[21] Several studies have reported that paternal and maternal RA and SLE similarly predict the development of rheumatic disease in the offspring[22,23]; however, the effect of parental sex on the likelihood of disease is less clear in rarer diseases including Sjögren syndrome, vasculitis, and SSc.[23]

Men in our study were also concerned that their medications might impair their fertility or harm their offspring. In general, data are reassuring about the safety of paternal medication use in the context of family planning. Seminal transfer of potentially teratogenic medications has also not been clearly linked to adverse pregnancy outcomes.[24,25] The American College of Rheumatology Reproductive Health Guideline conditionally recommends that men who are planning to father a pregnancy may continue AZA, methotrexate, LEF, and mycophenolate mofetil. While sulfasalazine (SSZ) can contribute to reversible infertility, men do not need to discontinue SSZ in the context of family planning unless unable to conceive a pregnancy.[4] Cyclophosphamide and thalidomide should be discontinued several months prior to attempted conception.[4]

Men in our study described parenting challenges that suggested they defined their parenting capacities in the context of their physical capacities. A mixed-methods study of patients with SpA found that fathers felt compelled to engage their children in physical activities even when experiencing pain and disability.[10] Our study is among the first to describe that men with vasculitis and myositis may identify physical weakness as a barrier to parenting.

Sexual dysfunction was a common experience among men in our study, which is consistent with prior questionnaires and surveys of male patients.[26,27,28,29] Men generally perceived that their diseases and medications were the cause of the sexual dysfunction and may benefit from discussions about sexual dysfunction in the rheumatology context.

While men in our study often contextualized their parenting challenges and sexual dysfunction as related to their rheumatic disease, they rarely discussed these issues with their rheumatologists. Further, they reported that rheumatologists rarely initiated these conversations. Rheumatologists may wish to take a more active role in initiating and discussing issues related to fertility, heritability, medication safety in the context of pregnancy, parenting, and sexual dysfunction. Rheumatologists should be aware that the loss of physical function affects men's abilities to parent and their satisfaction with parenthood. Rheumatologists should consider framing these conversations within the context of the patient's disease and medications, and may wish to underscore that other patients experience similar challenges.

Our results are not necessarily reflective of all men with rheumatic diseases. Qualitative analysis prioritizes in-depth exploration of a topic rather than generalizability across a population.[30,31] Thus, we believe our analysis presents the information needs and priorities of male patients who have family planning, parenting, and SRH concerns related to their rheumatic diseases and medications.

A potential strength of our study is that perspectives were elicited from men with a diverse range of rheumatic and inflammatory diseases; this enabled the collection of data from patients with rarer rheumatic diseases for which little is known about parenting, family planning, or SRH experiences. In addition, while the pathogenesis of their diseases differed, men in this study seemed to share similar experiences with regard to their family planning receipt, loss of physical functioning, and medication use. For example, we found that 3 men who used AZA, all of whom had different diseases, expressed the same misconceptions about its safety in the context of family planning. Our findings suggest that men may benefit from family planning and SRH care in the rheumatology context regardless of disease diagnosis.

This study has several limitations. It was not demographically diverse, which limited our exploration of the potential

intersections between race, culture, gender norms and expectations related to parenting, sexual orientation and gender identity, perception of illness, and pain. We believe these topics require focus in future work. By increasing patient compensation from $30 to $45 to augment recruitment during the pandemic, we may have introduced bias by increasing interest and recruitment of people of lower socioeconomic status. We also note limitations inherent to our study team. While members were diverse with respect to age and race/ethnicity, 3 of our 4 team members were female. Participants did not describe gender discordance with rheumatologists as a limitation to SRH conversations; however, it is possible that gender discordance between the male patients and female interviewers may have led some men to be less candid with their responses. During team debriefings, we discussed the potential influence of gender on our interpretation of the data to enhance the credibility and rigor of our analysis.

In summary, our qualitative study suggests that some men have specific concerns about SRH, parenting, and family planning in the context of their rheumatic diseases and medications. Future work is needed to identify resources by which patients might better conceptualize the heritability of their diseases and medication safety related to family planning. In addition, rheumatologists should be aware that men may experience sexual dysfunction related to their diseases and medications. In general, our study suggests that men with rheumatic diseases may benefit from more frequent discussions initiated by rheumatologists about family planning, parenting, and SRH.

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