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Exploring Reproductive Experiences With Women Enrolled in the International Vasculitis Pregnancy Registry

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ABSTRACT. ***Objective***. This study explored the reproductive journeys of women with vasculitis, including their conversations with healthcare providers, disease activity, medication changes, and delivery experiences.

Methods. Interviews were conducted with women registered in the Vasculitis Pregnancy Registry (VPREG), an online patient-reported registry of pregnant women with vasculitis. A team of physicians, patients, and qualitative researchers developed a qualitative interview guide. Participant responses were evaluated using thematic analysis.

Results. Eighteen patients with vasculitis who had experienced pregnancy were interviewed (10 antineutrophil cytoplasmic antibody–associated vasculitis, 4 Takayasu arteritis, 2 Behçet disease, 1 IgA vasculitis, 1 relapsing polychondritis). Thematic analysis revealed common experiences in the decision-making process during pregnancy planning, including accessing information from multiple sources, communicating with medical professionals, and changing treatment for vasculitis. Women sought information about vasculitis and pregnancy from various sources, including social media; however, opinions from their physicians and family members were most influential. Patients were more likely than providers to initiate conversations regarding family planning. Balancing differing opinions from subspecialists was challenging as many patients recalled acting as a liaison between multiple physicians during pregnancy. The need for self-advocacy was a common experience among patients. Most women had pregnancies that resulted in live births with delivery at term.

Conclusion. When making decisions about pregnancy, women of reproductive age with vasculitis used multiple resources. Patients consistently valued their medical provider's opinion over alternative sources of information. To ensure comprehensive medical care, half of women relied on self-advocacy to coordinate communication among subspecialists. Most women had pregnancies that resulted in live births with delivery at term.

Key Indexing Terms: pregnancy, qualitative research, reproductive healthcare, vasculitis, women's health

Vasculitides involve the inflammation of blood vessels leading to damage of single or multiple organ systems. Specific forms of vasculitis, classified by size and distribution of affected blood vessels and their corresponding therapies present unique reproductive challenges.[1] Patients with chronic diseases encounter difficult decisions when navigating family planning, including timing of pregnancy, medication management, and engaging with multiple specialists. To improve characterization of the patient experience throughout pregnancy and breastfeeding in women with vasculitis, this study aimed to identify common themes among individual reproductive journeys and highlight gaps in care that should be addressed. Complications of preg-

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nancy in patients with vasculitis are dependent on the type of vasculitis, vasculitis activity at conception, medication regimens, and end-organ damage from vasculitis.[2] The management of patients with vasculitis during pregnancy varies based on access to medical care and the experience of treating physicians. This study was conducted as part of the Vasculitis Pregnancy Registry (VPREG). VPREG is a research initiative of the Vasculitis Patient-Powered Research Network, an online research infrastructure that is a partnership of the Vasculitis Clinical Research Consortium and the Vasculitis Foundation (VF). This study aimed to give patients an opportunity to articulate their reproductive journey and communicate to the medical community how it can improve support for patients.

METHODS

This study population comprised patients who were registered participants in VPREG, a patient-powered registry of pregnant women with any type of vasculitis. The diagnosis of vasculitis is self-reported by patients. Between August and October 2022, 116 women who had participated in VPREG were sent recruitment email messages that described the purpose and topics of in-depth interviews. If an email address was invalid, the participant was called by a team member to solicit participation.

Of the email messages sent (N = 116), 65 women (56%) opened the link and submitted responses. Of those 65 women, 60 women (92%) responded to the request for an interview, with 48 (80%) agreeable. To recruit 12 to 20 women for interviews, with the goal of ensuring thematic saturation, a convenience sample of 20 interested VPREG participants were contacted to schedule an interview through email, telephone calls, and text messages. If no response was heard within 2 weeks, an alternative participant was contacted. Eighteen of the 20 women contacted participated in an interview. Interviews were conducted by internet-based videoconferencing. To ensure that responses reflected the pregnancy registered with VPREG, the delivery date was confirmed by the participant and only information about that pregnancy and the immediate postpartum period were recorded and analyzed. Demographic information was extracted from both the VPREG registration form and through the surveys.

Interview content. The structured, mixed methods interview guide was created with input from the VPREG primary investigators, a qualitative researcher, the VPREG research coordinator, a patient research partner, and a representative from the VF. Separate guides were created to discuss reproductive journeys with women who had live and nonlive births (Supplementary Materials S1-S2, available from the authors upon request). The questions explored pregnancy, choices regarding medications, vasculitis activity, relationships with their medical team, delivery experience, and breastfeeding. The interview guide consisted of closed-ended scale items and open-ended prompts to elicit participant experiences with pregnancy and vasculitis. All quantitative items were followed up with qualitative prompts to learn more about participants' experiences. For example, patients were asked: "During your entire pregnancy what was the worst pain you experienced because of your vasculitis? Scale (no pain) 0-10 (pain as bad as it could be)." If they reported any pain, this was followed up with a qualitative prompt asking them to describe their experience with pain. These interviews were conducted by a rheumatologist. This study was approved by the Duke Institutional Review Board (no. Pro00061688). All patients provided written and verbal consent prior to the interview.

Analysis. This study used a mixed methods approach. Quantitative questions ascertained level of vasculitis activity and pregnancy outcomes, whereas quantitative survey responses are presented as frequencies and means.

Thematic analysis was used to organize the qualitative data and identify emergent themes to the open-ended prompts.[3] The analysis was performed by a rheumatologist with expertise in reproductive health and a qualitative research specialist. All interviews were transcribed using a standard transcription protocol to ensure consistency in formatting. Coding was completed over multiple phases. First, an a priori codebook was used to categorize information in the transcripts based around topics explored in the interview (eg, advice on use of vasculitis medications during pregnancy, pregnancy planning decisions, complications experienced during pregnancy, vasculitis activity during pregnancy, delivery experience, health of the baby, breastfeeding, and experience interacting with medical staff). Analysts met repeatedly throughout the coding process to ensure intercoder reliability. Prior to these meetings, the analysts would independently apply the codes to the same transcript, then meet to discuss their individual application of the codes. Any discrepancies were discussed, and revisions were made to the codebook as needed to ensure future reliability. After completion of the initial coding, overarching topics were further explored using an inductive approach. Through comparison of participants' new responses to previously identified information, higher-level categories of information were identified. After the inductive analyses were completed, frequency tables were produced, and emerging themes were identified. Individual quotes that are representative of a specific theme and enhance the message are presented.

RESULTS

The Table displays the participants' demographics (N = 18). Each woman had 1 pregnancy registered in VPREG, with half of women interviewed within 4 years of their delivery date. The average age at enrollment into VPREG was 33 years. Several women reported prior pregnancies that resulted in a miscarriage. All women resided in North America. Antineutrophil cytoplasmic antibody–associated vasculitis was the most reported diagnosis, followed by Takayasu arteritis and Behçet disease. During pregnancy, nearly half of women were prescribed no medications to treat vasculitis. Azathioprine (AZA) and prednisone were the most reported medications taken during pregnancy. Most women experienced an induced, vaginal delivery at full term resulting in a live birth with a healthy newborn that did not require neonatal intensive care unit (NICU) hospitalization.

Theme 1: Women sought information about pregnancy from a range of sources. Almost all women (n = 16 [89%]) who participated in our study had planned pregnancies. Most women reported that they approached the topic of pregnancy planning with the physicians managing their vasculitis, as opposed to physicians first inquiring about family planning goals during clinic visits. This interaction was critical in the patient-physician relationship as women voiced the importance of their physician's opinion and support in the planning process (Figure 1). When making decisions about pregnancy and breastfeeding, women utilized multiple sources of information, including their treating physicians and online resources.

- *Physician-patient discussions*. The journey of pregnancy planning was emotional, with some women being told pregnancy was an unlikely option after their vasculitis diagnosis. One woman with Takayasu arteritis shared, "…when [the rheumatologist] gave me my diagnosis she was like, 'I don't think you're going to be able to have another baby' and I was like, 'No.'" After performing self-conducted online research, this patient requested a referral to a rheumatologist with knowledge of reproductive health and experienced a pregnancy that resulted in a live birth. For a woman with Behçet disease, these discussions highlighted a sense of isolation: "…that makes me sad that you have

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Table. Patient characteristics and birth outcomes (N = 18).

	Outcome, n
Age at enrollment, yrs, mean (range)	33 (25-43)
Country of origin	
USA	14
Canada	4
Race and ethnicity	
Asian	1
Non-Hispanic	17
White	17
Education	
Postgraduate degree	10
Postgraduate student[a]	1
Bachelor's degree	3
Some college, no bachelor's degree	3
High school graduate or GED	1
First pregnancy[b]	6
Time between date of delivery and interview, mos	
< 12	1
12-24	2
25-36	3
37-48	3
≥ 49	9
Type of vasculitis	
ANCA-associated vasculitis	10
Takayasu arteritis	4
Behçet disease	2
IgA vasculitis	1
Relapsing polychondritis	1
History of blood clots prior to pregnancy	3
History of hypertension prior to pregnancy	6
History of CYC use[c]	4
Medication(s) continued during pregnancy[d]	
None	8
AZA	4
Prednisone	4
ADA	3
RTX	2
HCQ	1
Enoxaparin	2
Aspirin	8
Birth outcome	
Live birth	17
Nonlive birth	1
Delivery method	
Vaginal	14
Induced	11
Spontaneous	3
Cesarean	4
Planned	3
Emergency	1
Gestational age at delivery, wks	
≥ 37 (full term)	13
31-36	3
26-30	1
20-25	1[e]
Required NICU hospitalization[b], days	5
1-6	3
≥ 7	2

Data are presented as n unless otherwise indicated. [a] Participated in some postgraduate studies, but did not complete a postgraduate degree. [b] n = 17. [c] n = 12. [d] Patients could be on combination therapy. [e] Nonlive birth. ADA: adalimumab; ANCA: antineutrophil cytoplasmic antibodies; AZA: azathioprine; CYC: cyclophosphamide; GED: General Education Development; HCQ: hydroxychloroquine; NICU: neonatal intensive care unit; RTX: rituximab.

groups with thousands of women having similar experiences and yet the medical community hasn't been able to make the connection yet…as a rare patient population—we are really alone in our everyday care." Despite the difficulties of these conversations, almost all women cited the approval of their physician as a determining factor in pursuing pregnancy.

- *Social media*. Women who explored resources through social media had varying experiences, with some making online connections and finding comfort in the successful pregnancies shared by others. However, a few women noted these groups were "extraordinarily depressing," as members of the online group were "severely ill," which made it difficult for the interviewed women to relate to the members of the online group (Figure 1). One woman with eosinophilic granulomatosis with polyangiitis who joined a social media page to ask about pregnancy reported feelings of guilt: "I don't really identify with very much of the discussion on there. And then I feel bad too, right?" Online resources were also used for additional topics, including prior pregnancy loss, nausea in pregnancy, and healthy lifestyle changes. All women who used online resources reported that these had no effect on their decision to become pregnant. When asked if social media influenced her decision to become pregnant, 1 woman answered, "I don't think so. I mean, I kind of knew what I wanted to do, but I think I did ask a pregnancy question at 1 point and I got a lot of great feedback."

Theme 2: Most women with vasculitis experienced pregnancies that resulted in live births with delivery at term. Most women experienced a live birth at full term without the need for cesarean delivery, although the periods prior to and during pregnancy were stressful for many women. One woman described her concerns about "my health and how it would affect me, the baby's health while I was pregnant," and another stated: "I was definitely worried that the pregnancy would put me back into flaring." There was a sense of anxiety for some women to move forward with conception, as the physician managing their vasculitis had not managed a pregnant patient before: "[My doctor] admitted to me before he doesn't have a lot of vasculitis patients and I think he had said that I've been one of the only ones that has been pregnant with the disease. So, it was unfamiliar territory for him." Although patients voiced their concerns about moving forward with pregnancy, having a planned pregnancy during periods of well-controlled vasculitis while taking pregnancy-compatible medications resulted in pregnancies that ended in live births with delivery at term for most women.

- *Conception and fertility*. Some women reported obstacles to fertility requiring assisted reproductive technology, including with both their own physiology and their partner's. A woman previously treated with cyclophosphamide (CYC) expressed her concerns about infertility, stating, "I was on a short course of [CYC] when I was very ill when I was younger. I was 19. And so I was worried that would affect my fertility." Most women previously prescribed CYC, including this participant, could not recall treatment with ovarian protective medications during the time of therapy. Most women experienced no fertility issues and conceived without the need for assisted reproductive technology.

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Figure 1. Sources of information about pregnancy and breastfeeding used by women with vasculitis. As part of the self-advocacy and decision-making process, most women synthesized information about vasculitis, pregnancy, and breastfeeding from multiple sources. Their conversations with family, friends, and medical providers were reported as the most valuable sources of information.

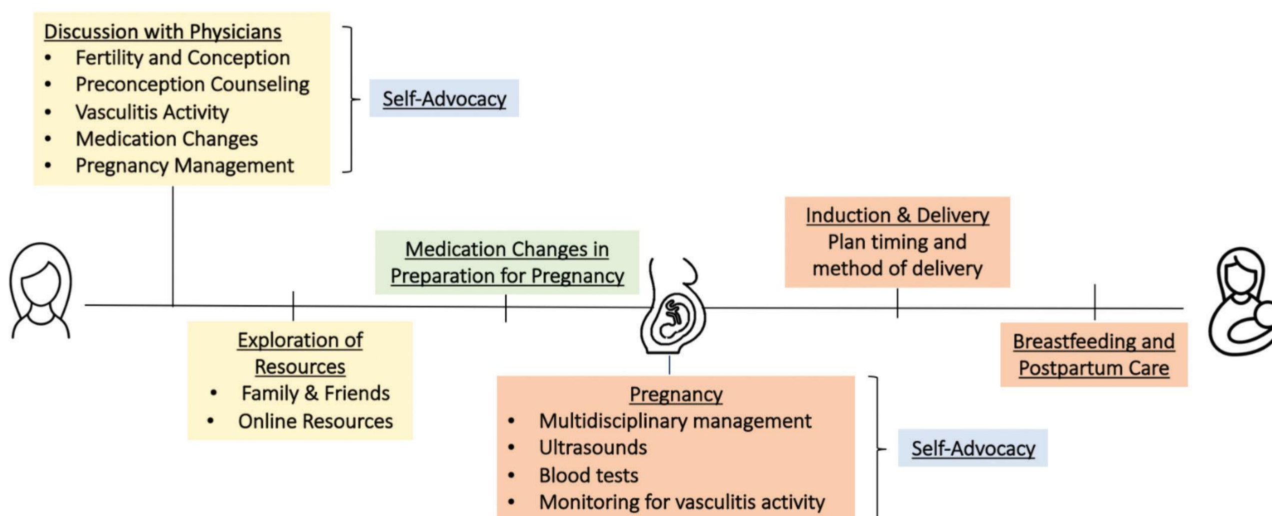

Figure 2. Common themes in the reproductive journey for women with vasculitis. Interviews revealed emergent themes demonstrating that vasculitis impacted all phases of the reproductive journey. The activity and treatment of vasculitis was an important consideration in decisions regarding reproductive health.

- *Vasculitis activity during pregnancy*. When discussing their personal health concerns, women worried about flares of vasculitis during and after pregnancy and expressed their desire to have their vasculitis well controlled prior to conception. These concerns took a toll on mental health, as described by 1 woman: "I would say it took a lot of mental strength. So, my mental wellness [was] probably a little strained, but physically I was very lucky." The majority of women had no flares of vasculitis, reported feeling "very well," and had "no pain" related to their vasculitis during pregnancy. One woman stated, "It was great. I felt fantastic during all my pregnancies." Those with decreased wellness cited flares of vasculitis, medication management, and fatigue as contributing factors. A woman with relapsing polychondritis recounted her treatment of a flare of vasculitis during pregnancy: "I had a terrible flu and it kind of triggered [the vasculitis]…I just did a short course of prednisone and I was fine."
- *Induction and delivery*. Most women experienced an induced delivery. The most commonly reported reason for induction was concern for development of hypertension and/or preeclampsia. About half of women had a good experience with induction and delivered quickly. One woman described her delivery as follows: "It was fine…[the delivery] was very quick. I was induced and then…she came very quickly after that." However, the other half cited bad experiences due to routine delivery problems. One woman recalled her induction experience, saying, "I remember it being a very stressful process that I felt like the doctors were not communicating well with each other or with the nurses and I had to be very, very on top of my care during that pregnancy to be comfortable with the decisions that were being made."

Theme 3: Women cited discussions with their family and physicians while making decisions about vasculitis treatment during pregnancy. The majority of women were taking immune-modulating therapy when pregnancy planning started. Discussions regarding medication changes centered around disease activity and personal timelines (Figure 2). This was

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often a process of ensuring well-controlled disease by using medications considered compatible with pregnancy. A woman with granulomatosis with polyangiitis described her journey by stating, "…it was a year of consulting with doctors before we tried to conceive…basically, it was waiting until [rituximab] infusion and then trying to conceive after that." Women interested in pregnancy while taking a known teratogen experienced a transition in therapy described by 1 patient as follows: "I needed to get my body off of the methotrexate. And so I slowly weaned off of the methotrexate. And then my doctor recommended being off completely…before we started trying to have a baby." Women already taking a medication considered compatible with pregnancy were typically advised to continue it throughout pregnancy, as 1 woman recalled, "…but [AZA] was definitely a discussion point…they sent me to a high-risk doctor…and he advised I should just stay on it the whole time." After discussions with their providers, women would often seek support from their partners and family. A woman with microscopic polyangiitis who struggled with providers taking ownership of her disease during the pregnancy-management process relied on her sister: "…all of the stuff, I'm always running by her."

- *Breastfeeding*. Breastfeeding was attempted after all live births. Women chose breastfeeding because they viewed it as "healthier for mother and baby" and "more affordable" than formula. Describing her decision to breastfeed, the mother of a premature infant that required care in a NICU stated, "…as a mother, whatever it is that I can do—especially after my son had such a difficult start—I just wanted to do whatever I could to make his life better." Only 2 women stopped breastfeeding to start a medication for their vasculitis; both were treated with medications the American College of Rheumatology guidelines define as compatible with breastfeeding. In 1 patient, the decision to stop breastfeeding was made after discussions with the patient's rheumatologist about her disease severity. The patient described these conversations as follows: "…[my rheumatologist is] very thorough and she makes sure I understand everything…and anything I need she's always available. She was great." Figure 1 reviews breastfeeding resources used by participants. Online resources were popular sources of information, as described: "I took a breastfeeding class while I was pregnant at the hospital and I believe the person that was running that suggested those 2 resources [KellyMom and La Leche League]."

Theme 4: Women with vasculitis develop skills of self-advocacy to optimize communication between medical providers. Women described requiring between 2 and 5 medical specialists during pregnancy, which included rheumatologists, maternal fetal medicine physicians, nephrologists, hematologists, and endocrinologists (Figure 1). The descriptions of their interactions with these medical providers often included a comment regarding the quality of communication among providers, especially if they belonged to different healthcare and/or electronic medical record systems (Figure 2).

- *Self-advocacy*. When describing situations that involved communication issues, a participant stated, "I'm a nonmedical person trying to communicate medical information and [specialists] have different focuses.…throughout my illness that is a common theme for me…having to be the go-between with a lot of different specialists." The personal onus of optimal care was explained by another woman: "I mean, you just have to advocate for yourself really. You just had to speak and try and communicate with them the best you could to get the best care." This phenomenon was described in the following quote: "…rheumatologists…were like, 'We defer to [obstetricians]'…and then [obstetricians are] like, 'well we don't know what to do…this is a rare rheumatologic disorder'…nobody want[s] to be responsible or liable." Most women were able to identify the physician responsible for managing their vasculitis in pregnancy and almost all women reported that multiple specialists gave similar, and not conflicting, medical advice.

- *Navigating discussions with providers*. In addition to self-advocacy, patients needed to navigate conversations with multiple medical specialists that left them wondering, "…are any of you monitoring [my vasculitis]?" Women described having to "remain vigilant" and "on top of my care" to ensure they received the management they needed. When faced with conflicting medical advice, 1 woman relied on "intuition" and performed her own research before deciding which provider to work with during pregnancy. Women appreciated when providers facilitated direct communication, as experienced by 1 woman: "[My obstetrician] reached out directly to my rheumatologist and they discussed everything because what I have is really rare… there was a plan of attack and everything." Another method described by a participant for optimizing communication and management was accessing multidisciplinary clinics where multiple specialists evaluated patients in 1 visit and created a single plan. This approach was described as "…a high-risk [obstetrician and gynecologist] that worked with the nephrologist…[in a] special clinic for women with kidney disease." One patient described this communication as a "…a well-oiled machine…[with] a very cohesive working relationship." Women also voiced appreciation for physicians who were personally motivated to learn more about vasculitis in pregnancy as this ensured a comprehensive approach to their care.

DISCUSSION

The women in this study used multiple resources when making decisions about their reproductive health. The most influential resources were conversations with their family and physicians, which were most often initiated by patients. Patients valued the consideration of family planning as part of the management of their vasculitis and sought the guidance of their physicians during the decision-making process. Online resources, while explored by some women, did not have a significant effect on pregnancy-related decisions. Patients' motivation to explore multiple sources of information possibly originated from their personal anxiety about pursuing pregnancy with a complex disease and the limited available information. This motivation manifested as self-advocacy throughout pregnancy, which was demonstrated by patients serving as mediators among multiple subspecialists. The emergent themes of self-advocacy, desire for treating the provider's involvement, and use of online resources are well supported by prior studies.

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Patients with rheumatic diseases have previously expressed appreciation of their rheumatologists' involvement in reproductive health conversations because they are "the doctors who know them and their medications best."[4] This is relevant since most women in this study required medication changes during the pregnancy planning process and/or throughout pregnancy. Phillips et al identified 2 emerging themes while interviewing women with rheumatic disease—of which 23 had vasculitis—about medication safety during pregnancy: desire for a "patient-centered approach" and "clear communication" from medical providers.[5] A 2022 study evaluating women with rheumatoid arthritis planning for pregnancy found that patients' views of medication safety were heavily influenced by their rheumatologists' beliefs and attitudes toward medications.[6] The use of online resources when seeking advice on the safety of medications during pregnancy and lactation has been previously described in patients with inflammatory arthritis. A 2021 study reported that 59% of participants used foundation websites, online forums, blogs, and social media.[7] In addition to exploring multiple resources, women also displayed characteristics of self-advocacy. A qualitative study regarding sexual and reproductive health in women with rheumatic conditions revealed that "women generally feel that they are intermediaries between their rheumatologists and obstetrician-gynecologists."[8] The patient-driven interventions demonstrated in the current study may have had a positive effect on the pregnancy experience.

Most women in our study experienced live births delivered vaginally at term. There are limited prospectively collected data on vasculitis and pregnancy outcomes, likely contributing to the anxiety experienced by patients during the pregnancy planning process.[2] This study provides insight into the emotional journey (concern, anxiety) and coping mechanisms (self-advocacy, patient-performed research, liaising) employed by patients. Although it is difficult to attribute these pregnancy outcomes to 1 particular element, it is notable that patient-driven advocacy played a role in the majority of pregnancies. It is hopeful that these data will inspire and empower patients to use these strategies during their own reproductive journeys.

Our patient-driven, prospective study has several strengths, including novel exploration of the decision-making process for reproductive health in women with multiple forms of vasculitis. Limitations of this study include restricting interviews to English-speaking patients located in North America, recall bias for pregnancy experiences, and selection bias for women who agreed to be interviewed. As all the participants had actively enrolled themselves in the online VPREG registry and responded positively to participate in the interviews, they may represent a group of women more inclined toward self-advocacy than other women living with vasculitis. Given that VPREG is a pregnancy registry, this study likely did not accurately capture women with vasculitis experiencing fertility issues.

Most women with vasculitis approached their treating physicians to discuss family-planning goals. Women also tended to explore online resources to supplement these conversations, but these resources did not influence their final decision about pursuing a pregnancy. Patients with vasculitis display self-advocacy before pregnancy by initiating conversations, exploring multiple resources, and liaising between multiple subspecialists during pregnancy.

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