Exploring Reproductive Experiences with Women Enrolled in the International Vasculitis Pregnancy Registry (VPREG)

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Introduction

There are limited data on the reproductive experiences of patients with vasculitis. Patients with chronic disease face difficult decisions during family planning. Pregnancies in patients with vasculitis are at higher risk for complications and poor pregnancy outcomes. Exploration of these experiences can identify ways the medical community can offer support.

Methods

18 Individual, semi-structured, qualitative interviews with patients registered in the Vasculitis Pregnancy Registry (VPREG).

Results

**Theme 1: Women Sought Information for Pregnancy and Breastfeeding from a Range of Sources**

Most patients brought up the subject of pregnancy and viewed their providers as supportive of their decisions. While online resources were frequently used, all patients denied it influenced their decision to become pregnant or breastfeed.

“I don’t really identify with very much of the discussion on [social media]. And then I feel bad too, right?”

“…I did ask a pregnancy question at one point and I got a lot of great feedback”

**Theme 2: Most Patients had Successful Pregnancy Outcomes**

“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”

“It was fine…[the delivery] was very quick. I was induced and then…she came very quickly after that”

**Theme 3: Women Cited Discussions with their Family and Physicians while Making Decisions about Vasculitis Treatment during Pregnancy**

“…it was a year of consulting with doctors before we tried to conceive…basically it was waiting until that infusion [rituximab] and then trying to conceive after that.”

**Theme 4: People with Vasculitis Display Skills of Self-Advocacy to Optimize Communication between Medical Providers**

“…rheumatologists…were like, “We defer to OB”…and then OB’s like “well we don’t know what to do…this is a rare rheumatologic disorder”…at that point everybody’s like nobody want to be responsible or liable.”

All images from The Noun Project

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Study Objective

*Explore the reproductive journeys of patients with vasculitis*, including their conversations with healthcare providers, disease activity, medication changes, and delivery experiences.