

Qualitative Patient Experiences of Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT): Diagnostic and Treatment Challenges

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Background

-  Fetal and neonatal alloimmune thrombocytopenia (FNAIT) is an alloimmune disorder of pregnancy that results when the pregnant person's immune system attacks fetal or newborn platelets, resulting in thrombocytopenia and risk of bleeding, which can be life-threatening¹
-  Currently, there are no approved targeted therapies for the prevention or treatment of FNAIT; platelet transfusions and intravenous immunoglobulin (IVIg; with or without steroids) are used to manage complications of the condition, such as low platelet counts and bleeding²
-  Few studies have examined patient perspectives on their experiences with FNAIT³

Objectives

-  The objective of this analysis was to identify patient-directed themes to better understand the experience and unmet needs with FNAIT-affected pregnancies

Methods

FNAIT Global Patient Council Advisory Boards

- Patient council members were adults (aged ≥18 years) who self-reported as having prior FNAIT experience
 - Members were recruited via a patient advocacy group
- Seven touchpoints were held from October 2021 to November 2024 using semi-structured interview guides
- There were a total of 8 group sessions and 9 1:1 interviews; each of which yielded a separate transcript
- Participant quotes were de-identified in transcripts



Transcript Analysis

- Transcripts were reviewed manually using thematic narrative analysis to identify key themes around patient experiences related to their condition, which were annotated in Microsoft Word
- Annotated transcripts, categorized by key patient themes, were uploaded into MAXQDA for detailed analysis and reference, extracting specific patient quotes around their journey



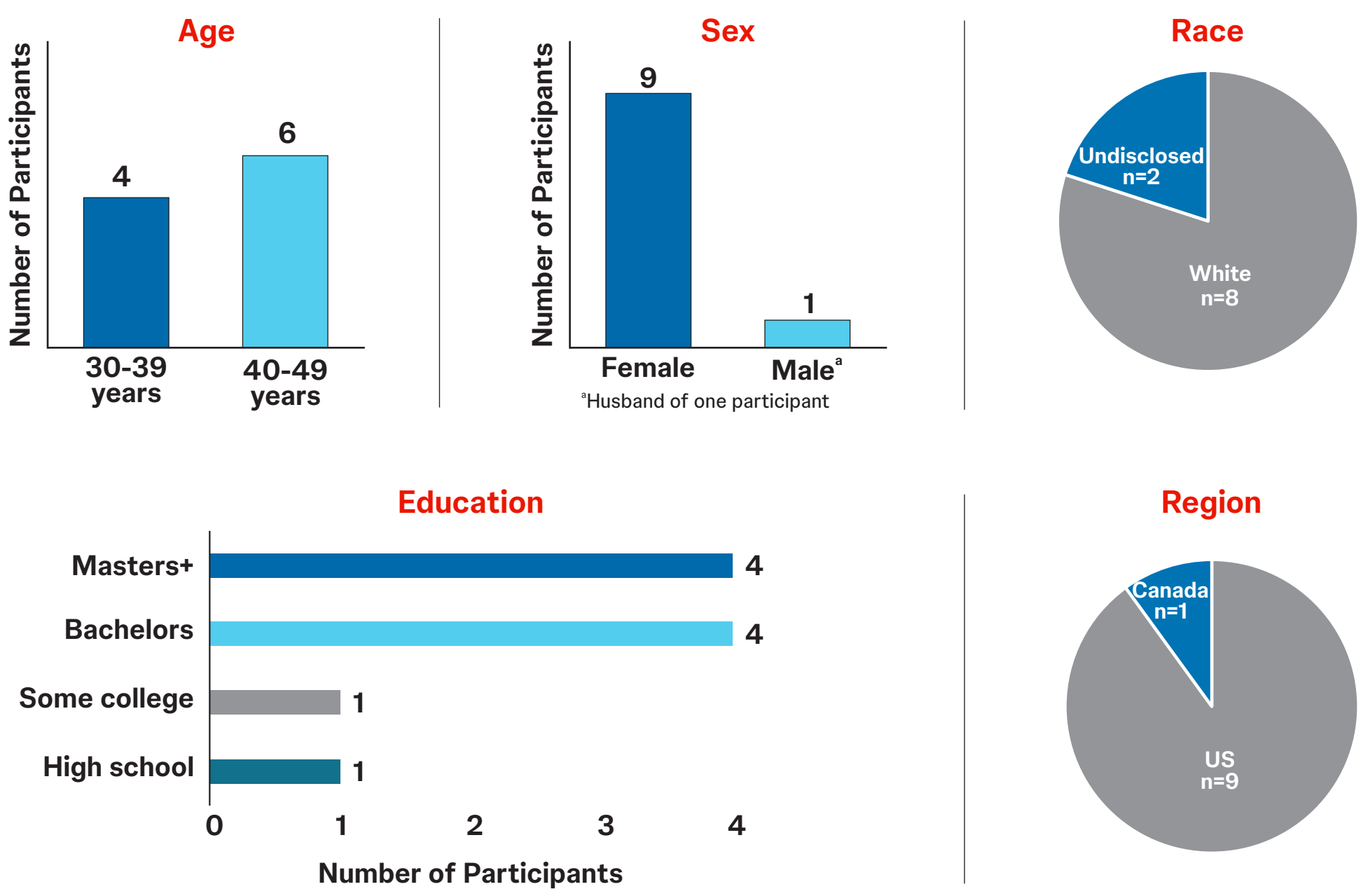
Key Takeaways

-  FNAIT diagnosis is highly inconsistent, often detected by chance; differential diagnoses are frequently suggested before a definitive determination is made
-  A burdensome treatment protocol and perceived lack of knowledge/experience in the medical community is overwhelming and contributes to significant confusion, uncertainty, and fear regarding FNAIT
-  There is a need for HCP education to reduce patients' burdensome responsibility for self-education and self-advocacy

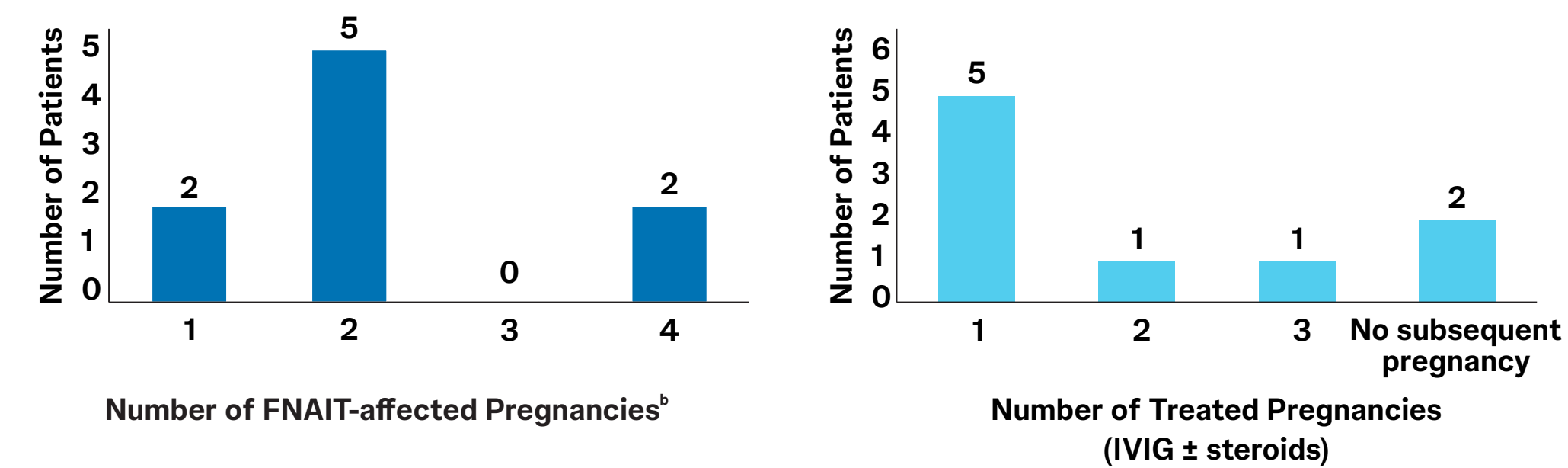
Results

Participant characteristics at time of session/interview

Demographics (N=10 participants)



Disease characteristics (n=9 female patients)



*Husband of 1 participant. ^bDuring 2009 to 2021. FNAIT, fetal and neonatal alloimmune thrombocytopenia; IVIG, intravenous immunoglobulin.

Theme 1: A challenging and inconsistent diagnostic path

Subtheme	Selected Patient Quotes
FNAIT is perceived as detected by chance due to lack of pre- or post-natal screening	"...The only reason we found out was because he had a fever. [...] they did a full blood count to see why he had a fever and that's how they found it, by just simply—almost accident" "They test for things that aren't really fatal, but it's like, why don't you start testing for things that are, like this?" "They just ended up taking mine and my partner's blood and be like, 'Yes, it's NAIT,' so obviously it's not a difficult test to do. I mean, they test for so many other things while you're pregnant so it's like why not just add it to the tests, because yes, it's pretty rare but it's pretty serious"
Differential post-natal diagnoses (eg, cancers) often occur before definitive diagnosis, leading to delay, confusion and anxiety	"Your child's life is on the line and it was almost like a guessing game. [...] We were told it was cancer, leukemia or a blood disorder. Not sure which one we really wanted it to be if we could have picked and hoped for one" "That was after they had exhausted some other — any bacterial infections, anything like — NAIT was never on the table really, or talked about, and it was all new to us, so then when they said NAIT and they wanted to do an infusion, that was really scary" "I don't think I'd ever cried that much or been so exhausted, it was just so overwhelming. But then, as soon as we got the answer that yes, it's NAIT, I was able to relax. I went up to the hotel room and I slept for hours because I was just exhausted. But up until that point I hadn't been able to sleep just because I was so anxious and worried about my son" "...So they rushed him off to a hospital about an hour away, where they have a NICU, for him to get an emergency transfusion, and we were there for two weeks. No diagnosis until about a week after we left the NICU" "That's when we found out the actual diagnosis, so it was almost two months later"
There is fear about the impact of FNAIT disease & treatment on babies	"I didn't know if this was going to be something that was going to be the rest of our life that we were always going to have him in bubble wrap because we would be scared that he might fall down, or if it was temporary, because nobody could really tell us exactly what was wrong with him" "That would require several cordocentesis though to check the baby's platelet count, which is very dangerous in itself. In the NAIT mom group you hear a lot of people going into preterm labor because of the cordocentesis so, they don't even do that early on" "And so, all these scenarios are just running through my head, and I guess probably worst-case scenarios. Picturing down the road, is he going to be mentally handicapped? Is he going to have a bleeding disorder? And so, it's very overwhelming"

FNAIT, fetal and neonatal alloimmune thrombocytopenia; NAIT, neonatal alloimmune thrombocytopenia; NICU, neonatal intensive care unit.

Theme 2: Patient responsibility for self-education and advocacy during a “brutal” treatment journey

Subtheme	Selected Patient Quotes
Patients perceive a lack of FNAIT awareness/ understanding among HCPs	"It was really terrifying thinking I'm the patient telling my doctor what's going on. It's backwards. It was so backwards. It was unreal thinking these providers have been practicing for decades and have never come across this. From a big healthcare institution, it was just mind-blowing" "We just need more doctors that know what's going on, so we don't have to fight so hard for our rights. I mean, you always have to advocate for yourself, but wouldn't it be great if we had some doctors that were able to do that for us?"
Self-education leads to strong advocacy for themselves/their babies	"There was a lack of knowledge about this condition whatsoever that made it extremely frustrating for me [...] to have to be the one to constantly give information and justify it" "There were a few times where I kind of had to put my foot down with some of these doctors and just say, 'No, I'm not going to do that' or 'No, I'd like to do this instead' [...] we weren't always on the same page" "The challenging part is that I felt like I had to be the expert because nobody else was"
Patients desire involvement in decision making & HCPs who partner & provide emotional support	"That resident hematologist is like—I actually gave him a hug because he was the first doctor who [...] made eye contact with me and said, 'We think it's NAIT'" "I think in finding the right doctor that I was able to kind of talk things through with her, and she was open to having those conversations, I think that went really well" "Yes, definitely having the doctor that I had kind of hold my hand through this and not talk down to me was very helpful, but it's also very lucky because I know a lot of people don't necessarily have that"
Treatment is perceived as effective but burdensome	"There was no question in my mind about doing the IVIG because I just wasn't going to risk my baby. There's nothing that I couldn't go through that for personal side effects that I wouldn't tolerate to make sure my baby was safe" "But it saved their [children's] lives, and that's what I kept — to get through it. Because it feels like you have a pretty severe flu that doesn't end...I would get out of the hospital on Saturday, and when I got to Wednesday, I would actually start to feel better to only turn around again and go in on Friday" "It was excruciating to go through IVIG, and it really did impact our family and our lives. But the kids are here and it's wonderful" "It was pretty brutal. I mean, it felt what I imagine chemo would feel like"

Chemo, chemotherapy; FNAIT, fetal and neonatal alloimmune thrombocytopenia; HCP, healthcare professional; IVIG, intravenous immunoglobulin; NAIT, neonatal alloimmune thrombocytopenia.