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Qualitative Patient Experiences of Hemolytic Disease of the Fetus and Newborn (HDFN): Psychosocial Impacts Reported During an Ongoing Patient Council

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Background

Hemolytic disease of the fetus and newborn (HDFN) is a rare disease where maternal antibodies, or alloantibodies, produced in a pregnant person's immune system cross the placenta and attack fetal red blood cells, causing fetal hemolysis leading to anemia[1]

There is no approved treatment for HDFN; although intrauterine transfusions (IUTs) can improve fetal survival, they are invasive and carry a 5%–10% overall perinatal mortality as well as risks such as bradycardia, bleeding, and fetal loss[2]; intravenous immunoglobulin (IVIG) treatment may delay timing of the first IUT[3]

A 2025 systematic review of the literature concluded that there is a need for further representative observational studies to aid a greater understanding of the burden and experience of HDFN[4]

Objectives

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

Methods

HDFN Global Patient Council Advisory Boards

- Patient council members were adults (aged ≥18 years) who self-reported as having prior HDFN experience
  - Members were recruited via patient advocacy groups and through healthcare provider referrals
- Seven touchpoints (TPs) were held from September 2021 to January 2024 using semi-structured interview guides
- There were a total of 14 sessions (meetings/interviews) across each TP (TP1, n=6; TP2 and TP4, n=2 each; all others, n=1 each); each session yielded a separate transcript
- Patient quotes were de-identified in transcripts

Transcript Analysis

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

Key Takeaways

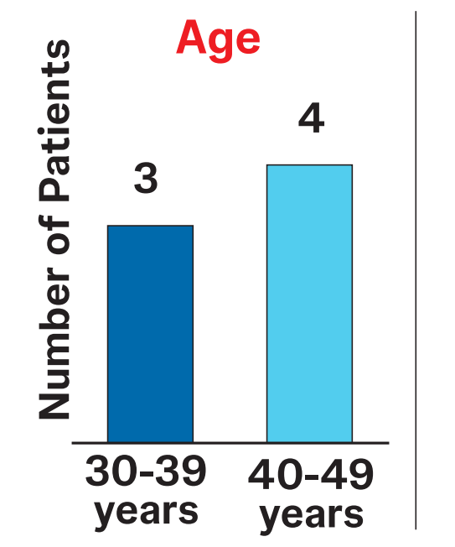
- ✓ **Patients feel the need to self-advocate, which contributes to the stress, anxiety, and trauma impacting quality of life. Social support and personalized, responsive medical care is highly valued**
- ✓ **Practical considerations of HDFN care place a substantial burden on patients' lives and put pressure on family and personal relationships**
- ✓ **The short- and long-term implications of alloimmunization/HDFN are unclear, and patients experience a lack of comprehensive, and coordinated care. Additional education on HDFN recognition and management is needed for HCPs beyond the maternal-fetal medicine specialist**

Results

Patients: Baseline characteristics

Demographics

TOTAL 7 female patients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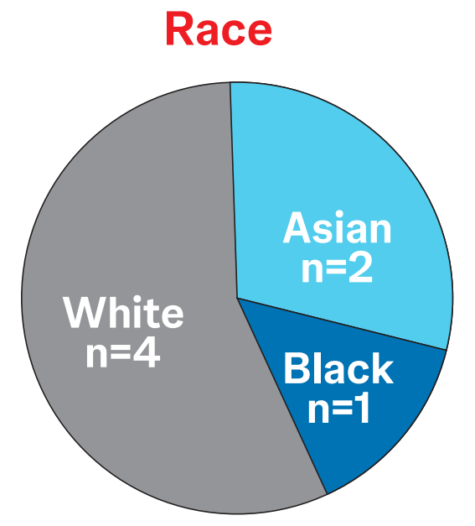
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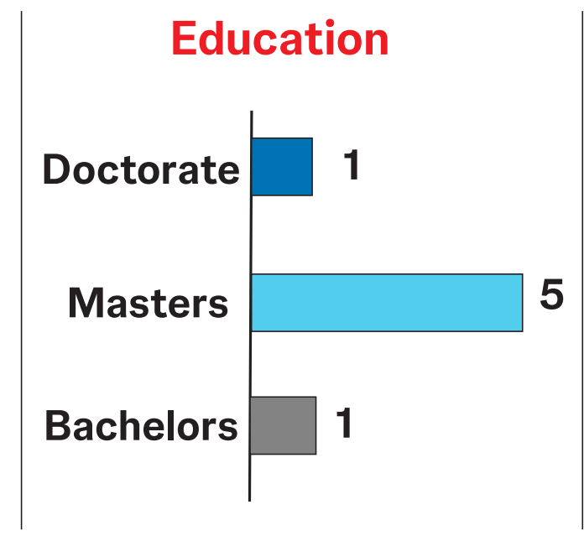
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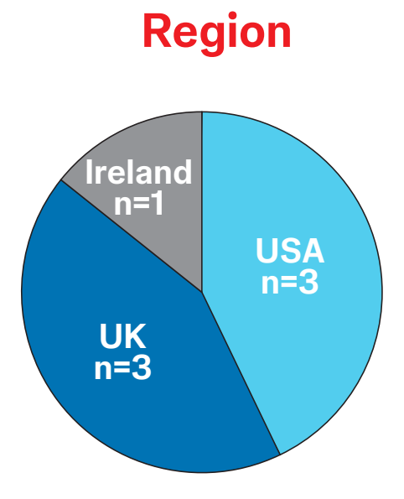
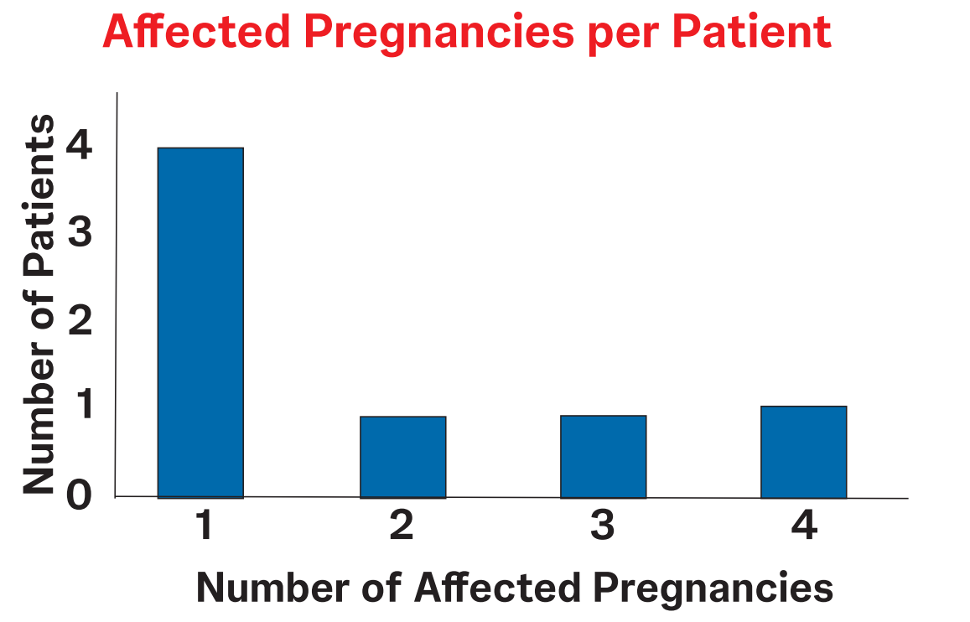
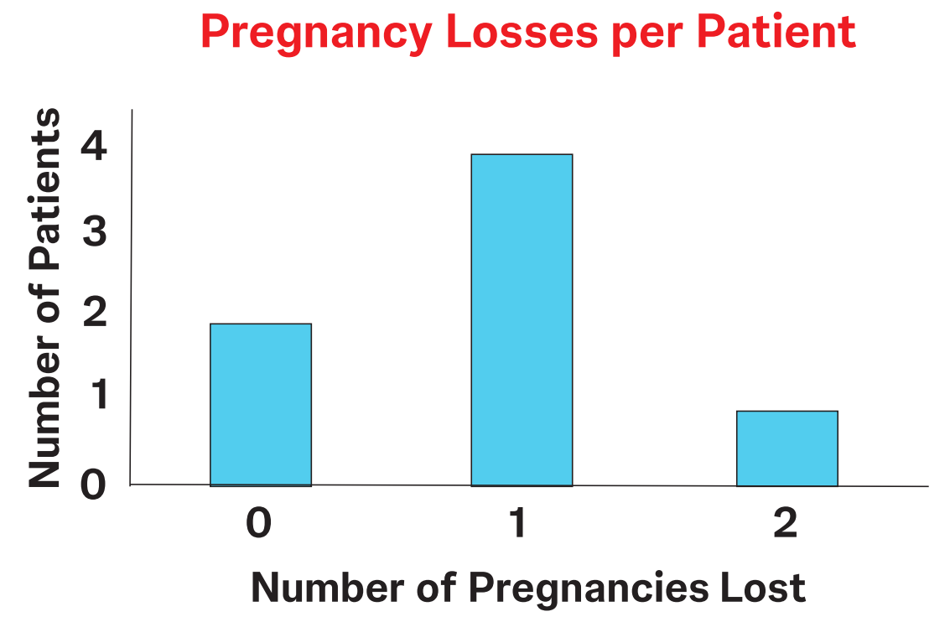
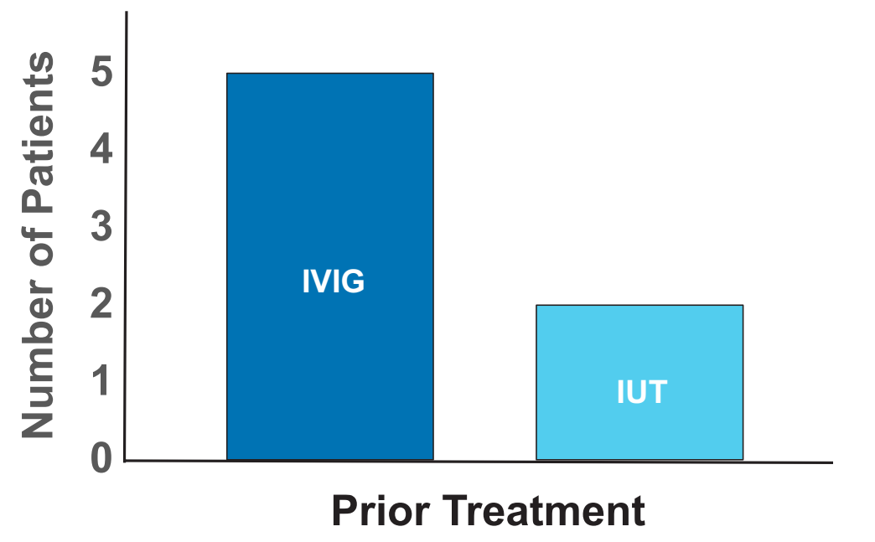

Region

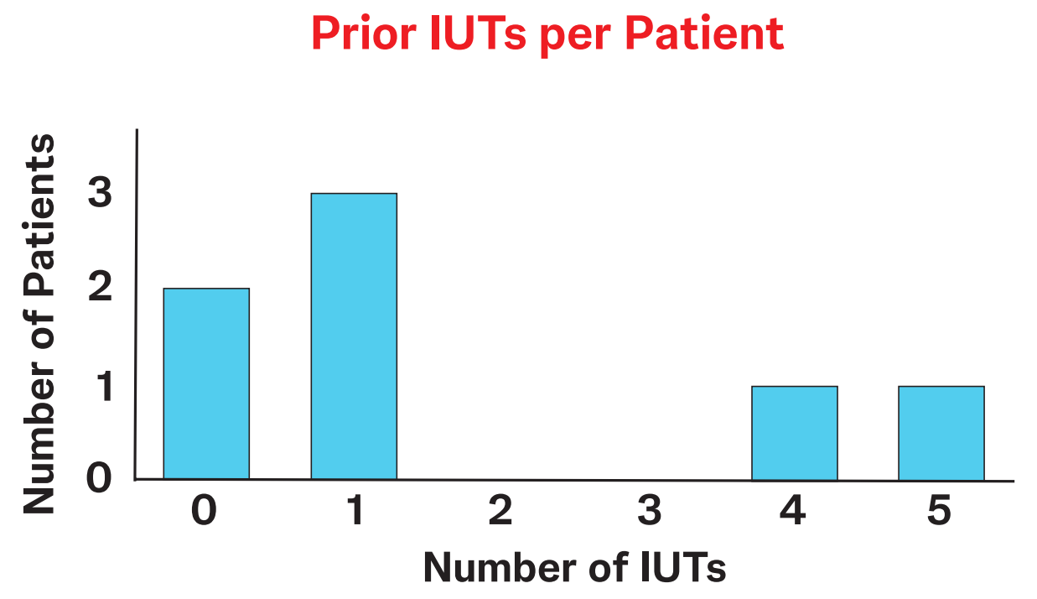
Disease Characteristics


Affected Pregnancies per Patient


Pregnancy Losses per Patient

Prior Treatment for HDFN




Prior IUTs per Patient

IUT, intrauterine transfusion; IVIG, intravenous immunoglobulin.

Pillar 1: Need for self-advocacy to ensure appropriate care

Theme	Sub-theme	Selected Patient Quotes
Responsibility to self-advocate due to lack of clarity	Lack of clarity about why HDFN develops & its short- and long-term implications at diagnosis	*"I had no idea of the severity, or what this meant, or anything like that"* *"The doctor didn't really know a lot about [HDFN]"* *"...The lack of knowledge that is generally out there, even amongst health professionals. Unless you're able to get to a fetal specialist, which is not that easy to do in this country"*
	Need to advocate for themselves & their babies, often relying heavily on online communities	*"It's a time in your life where you don't want to have to feel like you're having to take control and tell people what to do"* *"And within the group, moms supporting each other, to advocate for their babies and say...'It's OK to speak up and say, 'I'm not comfortable with this,' or ....'You know best for your baby and your body' ...the group really gave you confidence to be able to do that"* *"[Regarding inconsistent healthcare providers]: ...I feel like there were things missed that way as well"*
Desire for improved coordination & communication, as well as involvement in care	Improved care coordination & communication across providers	*"I asked [the nurse] 'What does that mean?' And she said, 'you need to look it up yourself [alloimmunization]"* *"I hardly ever saw the same person doing my scans. That was really a weird feeling"* *"Being able to connect with their whole team [...] because doctors aren't known for their bedside manner, but the others around them often are"*
	Involvement in treatment, ability to question HCP expertise	*"Because when I was telling my doctor, 'You need to monitor my kid,' when I was pushing for extra monitoring, he said, 'No, we are following the protocol.' And I didn't have enough data to fight or argue for my child"* *"I guess one of the biggest things was making us feel like a partnership, if that's the right word, in the whole process, rather than the patient"*
Need for a clear treatment plan with personalized, responsive care	No clear treatment plan during pregnancy nor information about possible therapy (eg IVIG)	*"Having a clear plan for treatment I think is very, very important"* *"I think knowing what the treatment options were. I had absolutely no idea about IVIG during my first pregnancy, let alone my second pregnancy. And it was only because I found out about it myself"*
	Personalized, responsive care	*"[H]aving a consistent person – even if it's a point person – that you know that you can connect with"* *"[T]here were too many people in the whole mix. And I much rather would have had one consistent team, one consistent doctor that I could develop a trusting relationship with throughout"*

HCP, healthcare professional; HDFN, hemolytic disease of the fetus and newborn; IUT, intrauterine transfusion; IVIG, intravenous immunoglobulin.

Pillar 2: Lifestyle and emotional impacts; trauma and guilt with childbearing

Theme	Sub-theme	Selected Patient Quotes
Difficulty managing practical aspects of care, logistical burden, & psychosocial impacts	Additional HDFN impacts include reduced work productivity & the burden of testing, treatment & transportation for care	*"...Trying to chase up my blood results from this hospital and talk to the midwife about that schedule and then scan, appointments. It's so much, besides you have a life and a job, or other things maybe are also going on. It's a monumental amount of stuff to process"* *"And I sat there waiting for hours sometimes, and so what I thought was going to be a quick scan – maybe an hour total there – I was there for five hours one day, for example, just waiting. And then that's not even including the transport back and forth"*
	Relationship strain	*"But we have been in therapy and it has kind of wrecked on our marriage and everything. We are still working on that"* *"[A]t the time I had a four-year-old son who, he didn't understand what had happened to his brother. And he didn't understand why his mom was so upset. He didn't understand why his dad was so upset"* *"His parents would have to babysit, and they'd have overnights and they were under extra pressure and stress, so it kind of had a knock-on effect for everybody. Everybody was probably in a way affected by it because of extra pressure put on us"*
Feelings of guilt & not doing enough, as well as stress & anxiety related to treatment burden	Guilt about their bodies "fighting" their babies	*"[W]hat's happening is it's your body that's attacking this baby, essentially. It's very difficult to take away those emotional feelings that you've done this to your child"*
	"Not doing enough" to prevent complications & feel helpless	*"...I think the most overwhelming feeling was guilt, to be honest. Guilt and helplessness. And it was guilt that I didn't know enough to be able to advocate for my baby, at that point"* *"I think when you're in it, you have a lot of feeling of things like guilt, and that you didn't know enough, or that you were too naïve, or that you trusted in the healthcare team, or that you should have done more, or I should learnt more [...} I had that for such a long, long time after we lost [baby], which was really unresolved grief"*
	Doubt the effectiveness of current treaatments (IVIG/IUT) & undergo painful, invasive procedures	*"...they're not the most pleasant of procedures to go through, and they are very anxiety provoking, and make you feel very unwell, and obviously have many potential side effects, or complications that can happen from that"* *"But the actual reality of that procedure is extremely distressing. It's very traumatic. And it's not – it's traumatic beforehand; it's traumatic afterward. And if you have that experience of them failing, it's obviously heartbreaking and it sticks with you. I still have the scars of my IUTs and they're a constant reminder even now, six years later, that I had to have that experience"*
Sentiments around trauma & implications for future pregnancies	Stress and anxiety throughout pregnancy & fear of losing their babies	*"You have lots of mixed feelings throughout the whole pregnancy of – although you should feel really happy that you're pregnant again, and that you've maybe got a baby, it's always tinged with all these difficult feelings and emotions of what could happen, or what might happen, or constant how many movements? Is everything fine?"*
	Future decisions to conceive are difficult; emotional trauma occurs with subsequent pregnancies	*"I think trying to go back into that situation and putting yourself back into that situation as a mother, knowing what has previously happened, and having those experiences, is very, very difficult. And very traumatic actually. I hadn't anticipated maybe how traumatic"*

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REFERENCES: 1. Hemolytic disease of the newborn. Medline Plus. Accessed: July 6, 2025. https://medlineplus.gov/ency/article/001298.htm; 2. Zwiers C, et al. *Expert Rev Hematol* 2017;10(4): 337-344; 3. Maisonneuve E, et al. *J Gynecol Obstet Hum Reprod* 2021;50(7):102119; 4. Maurice P, et al. *BMC Pregnancy Childbirth* 2025;25:114.

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