

Lived Experiences with Pregnancies Affected by Severe Hemolytic Disease of the Fetus and Newborn (HDFN): An Interview Study

Laura Bozzi¹, Divya Mohan², Adele Barlassina², Marco Boeri², Molly Sherwood³, Alexis Krumme⁴, Ellen Janssen⁴

¹Global Epidemiology Organization, Johnson & Johnson, Raritan, NJ, USA; ²OPEN Health HEOR and Market Access; ³Allo Hope Foundation, Tuscaloosa, AL, USA; ⁴Global Epidemiology Organization, Johnson & Johnson, Titusville, NJ, USA

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 anemia¹; severe HDFN is associated with substantial fetal/neonatal morbidity and mortality²



The current standard of care for HDFN in the fetus involves regular Doppler monitoring with intrauterine transfusions (IUTs) when needed.³ There remains an unmet need for treatments to improve outcomes and reduce the need for IUTs, which can have complications including increased risk of infections, emergency cesarean delivery, premature birth, or fetal loss⁴



Methodologically sound studies are needed to ensure a greater understanding of the treatment burden and experience of severe HDFN,⁵ to inform preferences mothers may have in treatment decisions

Objective



To understand the treatment experiences and preferences of participants during their pregnancy affected by severe HDFN

Methods

Patients and Interviews

- Individuals who had a pregnancy that was affected by severe HDFN in the past 5 years, who were ≥18 years of age at the time of that pregnancy, and who resided in the US or Canada were eligible
 - Severe HDFN was defined as any 1 of the following: received an IUT for treatment of HDFN, had a loss of pregnancy after 14 weeks of gestation due to HDFN, had an infant die within the first 28 days from birth due to HDFN
- Following an online survey (n=28), semi-structured 1:1 telephone interviews lasting ~60 minutes were conducted with 27 participants from 5 Aug to 11 Oct 2024; interviews were recorded and transcribed in a de-identified fashion
- The interview guide explored preferences and treatment experiences during a previous severely affected HDFN pregnancy, specifically with diagnosis, monitoring, birth, and post-partum
- Participants were recruited by the patient advocacy group Allo Hope Foundation



Transcript Analysis

- Qualitative data were analyzed using thematic analysis; de-identified transcripts were entered into Atlas.ti to facilitate coding and analysis
- Coding was based on an initial read of the first 4 transcripts
- Two study team members independently coded the first 2 transcripts, which were discussed to reach consensus; resulting changes were made to the codebook
- Data patterns and relationships between codes were identified as themes



Key Takeaways

- Seven themes were identified in patients with severe HDFN, including a need for more information about their diagnosis, the invasiveness of treatments, contributing to emotional stress, the time-consuming nature of monitoring, and the impacts on quality of life and relationships
- The findings highlighted the need for improved communication regarding HDFN and its treatment, as well as support for affected individuals
- Developing comprehensive support models and standardized guidelines for the management and treatment of HDFN, informed by patient preferences, could enhance care and support for affected families

Results

