

Exploring the experiences of young children with severe hemophilia and their caregivers

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Exploring the experiences of young children with severe hemophilia and their caregivers.

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BACKGROUND AND OBJECTIVE

- To delivery the best possible healthcare experience for patients, it is essential to gain insight into the patient experience with the care provided and their disease in general.
- How do young children with severe hemophilia and their caregivers experience their health journey?

CONCLUSION

- Parents and patient are primarily positive about their regular consults at the HTC.
- The negative experiences were primarily related to the diagnosis process, emergency room visits and daily life.
- The negative experiences and subsequent identified areas of improvement can be used to improve patient experiences and hemophilia care in general.

METHODS



Semi-structured interviews with young hemophilia patients treated prophylactically and their caregivers.



Patients and caregivers were asked to fill in a sensitizing



Hemophilia treatment centers (HTCs) Erasmus MC – Sophia Children's Hospital & Amsterdam UMC – Emma Children's Hospital.



Patients and caregivers were asked about their experiences with

- 1) The process leading up to diagnosis
- Care provided at the hemophilia treatment center
- Treatment process
- 4) Dealing with hemophilia in their daily lives
- Experiences were analyzed and visualized in a patient journey (will be).

(PRELIMINARY) RESULTS



Seven families of young hemophilia patients aged between 1,5 and 11 years old were interviewed.



3 Hemophilia A 4 Hemophilia B



7 Mothers 4 Patients 3 Fathers 2 Siblings

Diagnosis

- Parents appreciate the approach of the pediatric team of the HTC
- Little is known about hemophilia by healthcare professionals/medical authorities
- Sear for suspicion of child abuse led to delayed diagnosis
- Information provision is general and not adapted to personal needs

Treatment

- Starting prophylactic treatment and the ability to administer treatment themselves provides freedom and peace of mind
- Children should be involved in decision making and during the treatment administration process
- Wrong administration of treatment can lead to fear of needles

Emergency room

- The behavior and attitude of the parent is crucial in the child's experience with a bleeding episode
- Children know what they need to do and what needs to happen during a bleeding episode
- Operation Doctors at the emergency department are not familiar with hemophilia
- Parents need to build confidence and become assertive to get the best care for their child

Regular consults

- Children see visiting the hospital as a nice outing
- Children are able to separate a visit to the HTC from a emergency visit or visit to a different specialism
- Knowing what is going to happen during the visits is important for a child
- Parents appreciate the relationship and commitment of the medical team
- Parents do not always agree with the medical team but feel obligated to follow their advice

Daily life

- The parents behavior and attitude influences the child's behavior and attitude towards hemophilia
- Involving brothers and sisters in the disease/ treatment process is important
- Children know they are different then others
- **©** Children are sometimes
- more cautious for fear of missing fun events such as a school trips
- Parents need to learn to let
- their child go and experience

Areas of improvement



Lack of knowledge by healthcare professionals not working at a HTC



Information provision by the hemophilia treatment center



Inclusion of patient's opinion during shared decision making



Perceived lack of control and fear for bleeding episode

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