

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 booklet.
- 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
 - 2) Care provided at the hemophilia treatment center
 - 3) 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
 3 Fathers
 4 Patients
 2 Siblings

Diagnosis

Treatment

Emergency room

Regular consults

Daily life

- | | | | | |
|--|--|---|--|--|
| <ul style="list-style-type: none"> ✓ Parents appreciate the approach of the pediatric team of the HTC ✗ Little is known about hemophilia by healthcare professionals/medical authorities ✗ Fear for suspicion of child abuse led to delayed diagnosis ✗ Information provision is general and not adapted to personal needs | <ul style="list-style-type: none"> ✓ 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 | <ul style="list-style-type: none"> ✓ 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 ✗ 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 | <ul style="list-style-type: none"> ✓ 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 | <ul style="list-style-type: none"> ✓ 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 |
|--|--|---|--|--|

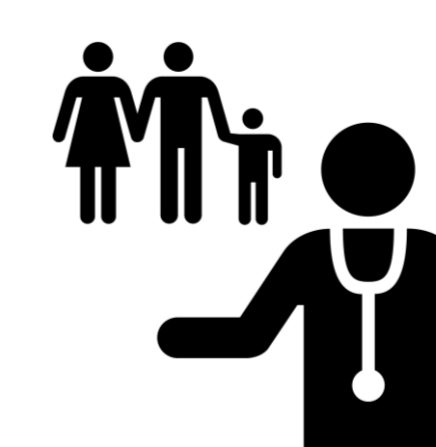
Areas of improvement



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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