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Erasmus MC
University Medical Center Rotterdam

Partitura

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

- ✓ 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

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
- ✗ 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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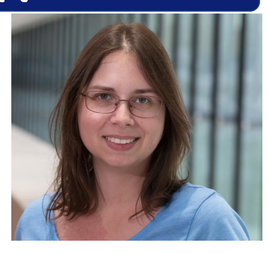
CONTACT INFORMATION

Questions or comments?
Come and find me!

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