

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

Van Hoorn, E.S.; Kerimoglu, E.; Melles, M.; Gielen, M.A.; Reitsma, S.H.; Cnossen, M.H.; Lingsma, H.F.

Publication date

2023

Document Version

Final published version

Citation (APA)

Van Hoorn, E. S., Kerimoglu, E., Melles, M., Gielen, M. A., Reitsma, S. H., Cnossen, M. H., & Lingsma, H. F. (2023). *Exploring the experiences of young children with severe hemophilia and their caregivers*. Poster session presented at ISQua's 39th International Conference 2023, Seoul, Korea, Republic of.

Important note

To cite this publication, please use the final published version (if applicable).
Please check the document version above.

Copyright

Other than for strictly personal use, it is not permitted to download, forward or distribute the text or part of it, without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license such as Creative Commons.

Takedown policy

Please contact us and provide details if you believe this document breaches copyrights.
We will remove access to the work immediately and investigate your claim.



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

E.S van Hoorn¹, E. Kerimoğlu², M. Melles², M.A. Gielen², S.H. Reitsma³, M.H. Cnossen³, and H.F. Lingsma¹, for the PARTITURA consortium

¹ Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, the Netherlands

² Department of Human-Centered Design, Faculty of Industrial Design Engineering, Delft University of Technology, Delft, the Netherlands

³ Department of Pediatric Hematology and Oncology, Erasmus MC Sophia Children's Hospital, University Medical Center Rotterdam, Rotterdam, the Netherlands

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

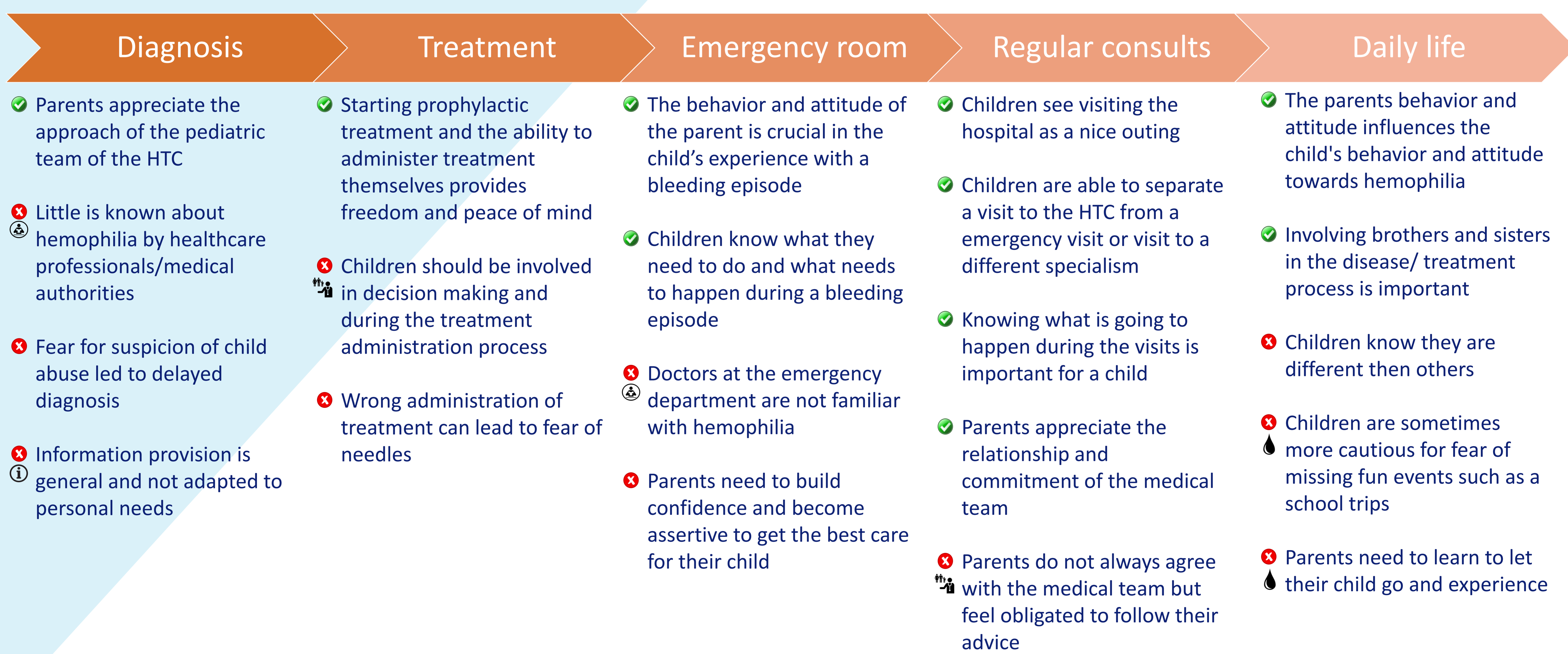
(PRELIMINARY) RESULTS

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



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

ACKNOWLEDGEMENT

Partitura is a multicenter side project of the SYMPHONY consortium which aims to orchestrate personalized treatment in patients with an inherited bleeding disorder. This research was funded by Roche and the SYMPHONY NWO-NWA consortium (NWA.1160.18.038; Principal investigator: Dr. M.H. Cnossen; project manager: Dr. S.H. Reitsma). More information: www.symphonyc consortium.nl.



CONTACT INFORMATION

Questions or comments?
Come and find me!

Or send an e-mail to
e.vanhoorn@erasmusmc.nl

