

PSYCHOSOCIAL FUNCTIONING AND HEALTH RELATED QUALITY OF LIFE OF BOYS WITH HEMOPHILIA 8-12 YEARS



emma kinderziekenhuis AMC

Hemophilia Comprehensive Care Treatment Center AMC,
Amsterdam, the Netherlands

P.F. Limperg¹, L. Haverman¹, V.T. Colland¹, C.H. van Ommen², M. Peters², M.A. Grootenhuys¹

¹ Psychosocial Department, Emma Children's Hospital, Academic Medical Center, Amsterdam, the Netherlands;

² Department of Pediatric-Hematology, Emma Children's Hospital and Hemophilia Comprehensive Care Treatment Center, Academic Medical Center, Amsterdam, the Netherlands

Background

- Children with chronic health conditions, such as hemophilia, are at risk for experiencing psychosocial problems and lower Health Related Quality of Life (HRQOL).
- In the Netherlands, boys with severe hemophilia receive adequate prophylactic treatment.
- Boys may still endure difficulties and impairments, such as frequent hospital visits, receiving injections on a regular basis and limited participation in (sport) activities.
- Up to date, research on psychosocial functioning and HRQOL of boys with hemophilia in the Netherlands is limited.

Aim

To assess:

- Psychosocial functioning
- HRQOL of boys with hemophilia

Methods

Patients

- Boys (8- 12 years) with severe and non-severe hemophilia from six Hemophilia Treatment Centers in the Netherlands.
- Inclusion criteria: participants had to be fluent in Dutch and could not have inhibitors.

Design

- Part of a larger study in boys with hemophilia and their parents.
- Paper and pencil questionnaires.

Questionnaires

- State-Trait Anxiety Inventory for Children (STAI-C, trait version; 20 items, range 20-60).
- Haemophilia Quality of Life questionnaire (Haemo-QoL, short version; 35 items, range 0-100), self-report and proxy-report by mothers.

Statistical analyses

- Descriptive statistics were used to describe the sample.
- HRQOL scores were computed.
- Two sample t-tests were performed to compare self-reported trait anxiety to the reference group and to compare scores on the Haemo-QoL between self- and proxy-report and in the severity groups.

Results

Socio-demographics

- N=31 boys (mean age 9.8 years, SD 1.7) with severe (N=17, 55%) and non-severe (N=14, 45%) hemophilia.
- N= 30 mothers (mean age 41.4 years, SD 4.4).

STAI-C

- Boys with hemophilia scored comparable (M 26.8, SD 5.5) to healthy peers from the reference data (M. 29.4, SD 6.1).

Haemo-QoL: self vs proxy-report

- Boys (M 20.1, SD 11.8) and mothers (M 19.9, SD 10.8) reported comparable total HRQOL scores.

Haemo-QoL: disease severity

- Boys with severe (M 21.5, SD 15.2) and non-severe hemophilia (M 18.4, SD 5.6) reported comparable total HRQOL scores.

Conclusions

- Boys with hemophilia report levels of anxiety comparable to healthy peers.
- Boys and their mothers report comparable HRQOL scores and HRQOL scores do not differ between the severity groups.
- The comparable HRQOL scores between the reference group and between the severity groups may be explained by the homogeneous composition of the sample and the high standard of care in the Netherlands, which integrates medical and psychosocial care.
- Although no differences were found at a group level, psychosocial functioning and/or HRQOL may be impaired at an individual level and therefore psychosocial functioning and HRQOL of boys with hemophilia should be monitored on a regular basis.

Perrine Limperg, MSc, P.F.Limperg@amc.nl, Psychosocial Department, Emma Children's Hospital, Academic Medical Center Amsterdam, tel: +31205667780

