

A NEW TOOL TO ASSESS COPING AND PERCEPTION OF CHILDREN WITH HAEMOPHILIA

HCPT



emma kinderziekenhuis AMC

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Background

Children with haemophilia face lifelong control and disease management. How children cope with and perceive their disease is an important predictor of self-management and Health Related Quality of Life (HRQoL) of these children. It is important to get insight in children's coping, perception and knowledge of their disease to provide tailored health care. The Haemophilia Coping and Perception Test (HCPT) for children is a new tool to get insight in these aspects of children with haemophilia. The HCPT is based on the Asthma Coping and Perception Test, which has been tested on reliability and validity (1990). The test has been adapted for children with haemophilia.

Aim

- To investigate the feasibility of the HCPT
- To evaluate the HCPT

Methods

Patients

- Boys with mild, moderate and severe haemophilia (A+B)
- Age: 8-12 years
- Data collection started September 2011

Design

- Six Haemophilia Treatment Centres
- Patients are assessed by a paediatric psychologist, by playing the HCPT one-on-one (max. 60 minutes)

Questionnaires

- HaemoQoL (Haemophilia Quality of Life) – short version (prior to assessment, max. 10 minutes)
- Process evaluation of the HCPT (after assessment)

HCPT

- The HCPT is a questionnaire that looks like and can be used as a board game (figure 1)
- The child chooses between two versions: sports or treasure hunting
- The HCPT contains a comprehensive set of 33 questions, including:
 - coping
 - perception
 - knowledge
 - self-management
 - decision making
 - anxiety

Results

- N=25, data collection is still ongoing
- Of those, 14 have severe haemophilia, 2 have moderate haemophilia and 9 have mild haemophilia.
- So far, 63% chose the sports version



Figure 1. HCPT (board)

Expectations

- We expect the HCPT to be a feasible tool to detect and understand problems regarding coping and perception, anxiety and self-management of children with haemophilia
- We expect the HCTP to increase and facilitate communication about coping, perception and self-management of children with haemophilia

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