

# RELIABILITY, VALIDITY AND EVALUATION OF THE HEMOPHILIA COPING AND PERCEPTION TEST



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## Background

- Little is known about the perception, knowledge, competencies and coping skills children have in order to manage and cope with their disease.
- Recent advances in hemophilia treatment and the responsibility shifting towards the patient stresses the importance to get insight into these aspects.
- It is known that perception, knowledge, competencies and copings skills have a positive influence on physical outcomes as well as on psychosocial well-being.
- We developed the Hemophilia Coping and Perception Test (HCPT), a board game with 33 questions, to get insight into these aspects.

## Aim

To describe the HCPT on:

- Reliability
- Construct validity and
- Evaluation by parents and children

## HCPT

- The HCPT is a questionnaire designed as a board game.
- It contains a comprehensive set of 33 questions in two scales (coping and perception): coping, perception, knowledge, self-management, decision making and anxiety.
- The HCPT can be played one-on-one or in a group of boys with hemophilia (5 max.).

## Methods

### Patients

- Boys (8-12 years) with severe and non-severe hemophilia from six Hemophilia Treatment Centers in the Netherlands.

### Design

- Patients were assessed by a pediatric psychologist, by playing the HCPT one-on-one (max. 60 minutes) at home.

### Questionnaires for construct validity of coping

- Coping with a Disease (CODI); assesses disease related coping skills with 28 items in 6 scales.
- Questionnaire Op Koers for children (QOK-c), assesses disease related coping skills with 26 items in 6 scales.

### Questionnaire for construct validity of perception

- State-Trait Anxiety Inventory for Children (STAI-C), trait version, 20 items: assesses the tendency to respond with anxiety in a threatening situation.

### Questionnaire for evaluation

- Self-composed evaluation questionnaire (12 items for children and 8 items for parents).

### Statistical Analyses

- Internal consistencies (Cronbach's alphas) of the HCPT scales.
- Correlations (Pearson's r) between the HCPT scales and the other questionnaires.
- Evaluation questionnaire examined explorative.

## Results

### Socio-demographics

- N=32 boys (9.8 years, SD 1.6) with severe (N=18, 56%) and non-severe (N=14, 44%) hemophilia.

### Reliability

- HCPT scales showed moderate to good reliability (perception  $\alpha$  .56 and coping  $\alpha$  .80).

### Construct validity

- Correlations between the coping scales and the questionnaires (CODI and QOK-c) were not significant.
- Correlation between the perception scale and the STAI-C questionnaire was not significant.

Based on these results, content, clinical experience and expert focus groups:

- The coping scale was revised into a new scale: self-management ( $\alpha$  .77).
- The perception scale was adapted by eliminating one question, resulting in a significant correlation with the STAI-C ( $r=.39$ ,  $p<.05$ ).

### Evaluation

- Children rated the HCPT on a 10 point-scale with a median of 10.00 (range 6-10), parents with a median of 8.00 (range 7-10).

## Conclusions

- The HCPT rather assesses **self-management** and **perception**, instead of coping.
- The HCPT is a useful tool to get insight into the **self-management** and **perception** of boys ages 8-12 years with hemophilia and to provide tailored psycho-education if necessary in daily clinical practice.
- The boys and their parents are very positive about the HCPT.
- Clinical implications: the HCPT is a reliable tool to be played one-on-one with a nurse or psychologist.

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