

HEALTH RELATED QUALITY OF LIFE OF BOYS WITH HAEMOPHILIA AND PARENT'S ILLNESS PERCEPTIONS



emma kinderziekenhuis AMC

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Background

Children with haemophilia may experience Health Related Quality of Life (HRQoL) problems. Parents' attitudes are thought to influence treatment adherence and consequently their child's HRQoL. To date, no studies have focused on parent's illness perceptions. Moreover, the relation between parent's perceptions and the illness severity of their son with haemophilia has never been studied. Parents of children with haemophilia often experience illness burden and psychosocial strains which can have adverse effects on their social and family life.

Aim

The aim of the present study was to examine:

- 1) The HRQoL of boys with haemophilia
- 2) Illness perception of parents
- 3) The association between illness severity and illness perception

Methods

Patients

- The cohort (2007) includes 128 boys (8-18 years; mean age 12.82 ± 2.84) with haemophilia A (88%) or B
- Treated at 5 Haemophilia Treatment Centers in the Netherlands (Amsterdam, Utrecht, Rotterdam, Groningen and Nijmegen)
- All boys with severe haemophilia (N=51) received prophylaxis at home

Outcome measurements

- Revised Illness Perception Questionnaire (IPQ-R) for parents
- Haemophilia Quality of Life (Haemo-QoL) Index version for children
- Information regarding the diagnosis (severity and type of haemophilia) was retrieved from the medical records

Results

1) HRQoL of children with haemophilia

	Mild			Moderate			Severe		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Sumscore HaemoQoL	57	9.67	2.80	20	10.65	3.17	51	11.55***	4.31

1. *** $p < .001$ versus mild haemophilia

2. p values at two sample t-test

2) Illness perception and illness severity

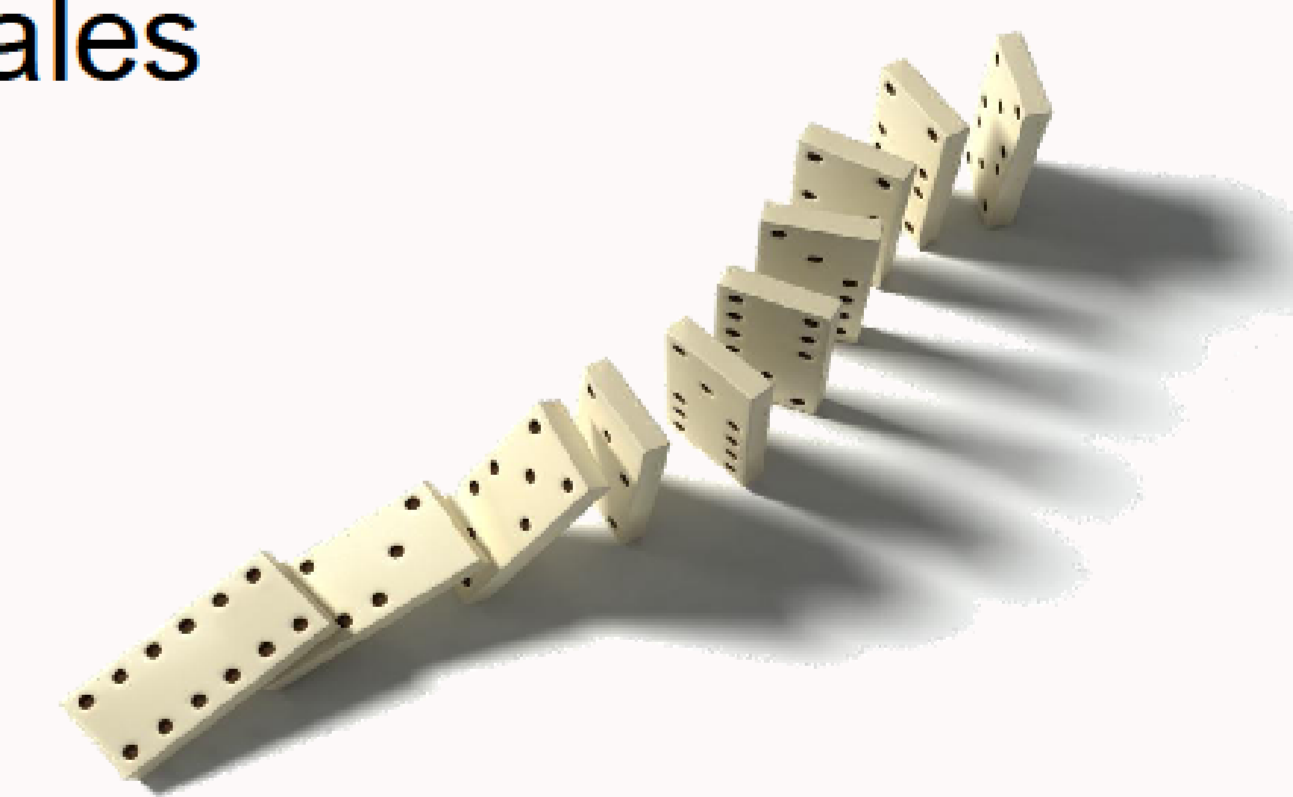
	Severity		
	Mild	Moderate	Severe
	Median (Range)	Median (Range)	Median (Range)
<i>Negative directed subscales</i>			
Consequences	12.0 (6-22)	14.0 (7-23) ¹	17.0 (7-27) ³
Timeline cyclical	8.0 (4-18) ⁵	12.0 (4-20) ³	9.5 (4-16) ⁴
Emotional Representations	10.0 (6-25)	10.5 (6-19)	13.5 (7-24) ²
<i>Positive directed subscales</i>			
Personal Control	20.0 (11-26)	20.5 (8-30)	20.5 (11-27)
Treatment Control	17.0 (10-24)	18.0 (6-25)	18.0 (8-25)
Illness Coherence	19.0 (14-22)	19.0 (15-21)	19.0 (13-21)

1. ¹ $p < .05$, ² $p < .01$, ³ $p < .001$ versus mild haemophilia

2. ⁴ $p < .01$ versus moderate haemophilia

3. ⁵ $p < .05$ versus severe haemophilia

- Children with severe haemophilia scored significantly higher on the Haemo-QoL than children with mild haemophilia, indicating a lower HRQoL
- Parents of children with moderate haemophilia reported significantly more negative beliefs on the subscales cyclical nature and consequences of the illness on the IPQ-R than parents of children with mild and severe haemophilia
- Parents of children with severe haemophilia reported significantly more negative emotional representations than parents of children with mild haemophilia
- There were no differences found in the positive directed subscales



Conclusions

- Children with severe haemophilia have a lower HRQoL than children with mild haemophilia
- Parents of children with moderate haemophilia believe the illness to be more chronic and their perceptions have a more negative impact on the physical, social and psychological functioning of their child compared to parents of mild and severe haemophilia
- The HRQoL of a child with haemophilia is associated with his parent's illness perceptions, especially negative perceptions

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