

PATIENT REPORTED OUTCOMES IN CLINICAL HAEMOPHILIA PRACTICE



emma kinderziekenhuis AMC

Haemophilia Treatment Center AMC, Amsterdam, the Netherlands



klik

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Background

Children with haemophilia may experience Health Related Quality of Life (HRQoL) problems. Therefore, it is important to monitor their HRQoL on a regular basis. Two recent multicenter studies measuring the effect of electronic Patient Reported Outcomes (ePROs) in clinical paediatric practice pointed out that discussing HRQoL during consultation increased the psychosocial topics discussed and the identification of emotional problems^{1,2}. Children with haemophilia may also benefit from this tool. With the use of the internet, KLIK is easy to implement in clinical practice and helpful in facilitating communication about HRQoL.

Aim

To describe the implementation of ePROs in clinical pediatric haemophilia practice.

Methods

Design

- In October 2011, ePROs were introduced as part of the standard care for children at the Haemophilia Treatment Center (HTC) of the Academic Medical Center Amsterdam
- Children (8-18 years) or their parents (if the child is <7 years) completed online HRQoL questionnaires before consultation
- The answers are converted into a KLIK PROFILE (figure 1 and 2) and discussed during consultation by the paediatrician
- Answers turn red if children/parents report to encounter problems 'often' or 'almost always', orange for 'sometimes' and green for 'almost never' or 'never' problems
- Patients also completed a behavioural problems questionnaire, which is discussed by a psychologist, and a questionnaire about parental distress, discussed by a social worker

References:

¹Engelen V, et al. (2010). Development and implementation of a patient reported outcome intervention (QLIC-ON PROFILE) in clinical paediatric oncology practice. *Patient Educ Couns*;81:235-244.

²Haverman et al. (2011). Monitoring health-related quality of life in paediatric practice: development of an innovative web-based application. *BMC.Pediatrics*; 11:3-10

Interested?

- If you like to see how KLIK works, go to: www.hetklikt.nu and watch the short informative film
- You can log in as a paediatrician with 'PRO' as username and 'KLIK' as password
- The website is also available in English
- If you are interested in using KLIK, please contact: info@hetklikt.nu

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Patients

- Age: 0-18 years
- Congenital bleeding disorders

Questionnaires about the child

- TAPQoL (TNO-AZL Preschool children Quality of Life): 0-5 years
- PedsQL (Pediatric Quality of Life Inventory): 6-18 years
- SDQ (Strengths and Difficulties Questionnaire):: 4-16 years
- Evaluation KLIK: 0-18 years

Questionnaires about the parents

- Sociodemographic questionnaire
- DT-P (Distress Thermometer for Parents)

Results and conclusion

- So far, 74 children who visited the HTC since October 2011 (45% of all children under treatment) completed the online questionnaires and discussed the KLIK PROFILE during consultation
- Completing the questionnaires takes max. 10 minutes
- KLIK is a useful tool to detect and discuss HRQoL problems



Figure 1. KLIK PROFILE



Figure 2. KLIK graphs

www.hetklikt.nu