

Subjective Physical Functioning and Health-Related Quality of Life in Children with Severe Haemophilia in the UK – Results of the SO-FIT Study

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Introduction

- Boys born with severe haemophilia in the UK are nowadays routinely treated with prophylaxis [1] and are increasingly growing up to be active members of society with near-normal lifestyles and lifespans.
- Contemporary haemophilia health care demands collection of Patient-Reported Outcomes (PROs) evaluating patient's views of care and health [2]. PROs have only recently been incorporated into routine clinical care; previously they were used only in clinical trials and observational research studies.
- The **Study Of physical Functioning In adolescents with haemophilia (SO-FIT)** is a UK multi-centre, cross-sectional study, assessing self-reported function and health-related quality of life (HRQoL) of children and teenagers with severe haemophilia compared with objective assessment of joint function [3].
- The study was sponsored by Pfizer/Aspire Award.

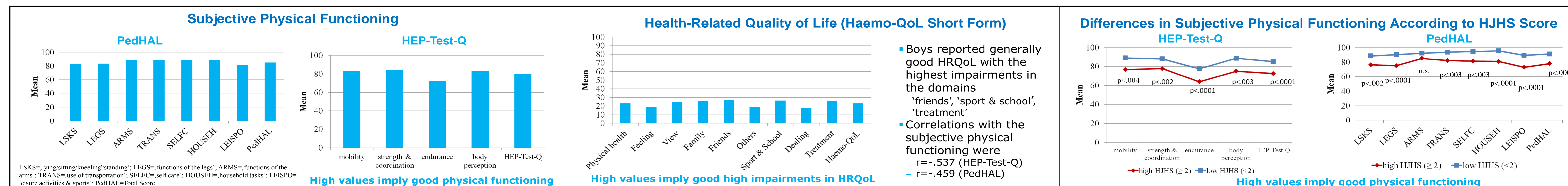
Methods

- Children aged 8-16 years with severe haemophilia A or B (with or without inhibitors) from 16 Haemophilia Treatment Centres (HTC) in the UK were included in the study.
- Clinical Data (such as bleeding history, treatment regimen, history/presence of inhibitors, etc.) were collected by nurses from patient files. Physiotherapists evaluated the orthopaedic status via the Hemophilia Health Joint Score (HJHS v2.1 [4]).
- Subjective physical functioning was assessed via self-reported questionnaires by haemophilia boys (PedHAL [5], HEP-Test-Q [6]). Boys rated as well their Health-Related Quality of Life (HRQoL) via the haemophilia-specific Haemo-QoL Short Form [7].

Results

- In the study 161 boys aged 8-16 years with severe haemophilia A or B from 16 UK haemophilia centres were approached:
 - 34 declined
 - 127 boys were recruited
 - 4 had missing data and therefore were excluded from data analysis

- 89.4% had haemophilia A (n=110)
- 97.5% received prophylactic treatment (n=120); 44.7% primary (n=55), 52.8% secondary (n=65)
- 20.3% had an inhibitor; past inhibitor (n=16), current (n=9); failed ITI (n=8), still ITI on-going (n=1)
- Boys had a median of 1 bleed (range 0-24) in the previous 6 months
- Boys had a median of 0 target joints (range 0-5)



Conclusion

The SO-FIT Study has demonstrated that children with severe haemophilia in the UK generally report good HRQoL and good subjective physical functioning which is also reflected in objective assessment of their joint health. There was a significant difference in the subjective physical performance between boys with a high HJHS (≥ 2) and those with a low HJHS (<2). Similar results were found as well for HRQoL, but were not that dominant as for the subjective physical performance.

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