

Penilaian Hemophilia Joint Health Score (HJHS), Pediatric Haemophilia Activities List (PedHAL) short dan Haemophilia-Quality of Life (Haemo-QoL) sebagai Parameter Evaluasi Klinis Sendi, Aktivitas Fungsional dan Kualitas Hidup Anak Hemofilia = Assessment of the Hemophilia Joint Health Score (HJHS), the Pediatric Haemophilia List (PedHAL), and the Haemophilia Quality of Life (Haemo-QoL) as Parameters for Clinical Evaluation of Joints, Functional Activities, and Quality of Life in Children with H

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Abstrak

Latar belakang: Perdarahan sendi berulang merupakan morbiditas utama pada pasien hemofilia karena dapat menimbulkan artropati hemofilik yang menyebabkan keterbatasan gerak dan disabilitas sehingga menurunkan kualitas hidup. Penelitian bertujuan mengetahui korelasi pemeriksaan klinis sendi, penilaian aktivitas fungsional dan kualitas hidup pada anak hemofilia.

Metode: Penelitian dengan desain potong lintang di RSCM pada Agustus-November 2022 pada anak 416 tahun, hemofilia A atau B derajat sedang atau berat yang mengalami perdarahan sendi berulang. Penelitian dilakukan dengan menilai HJHS, PedHALshort serta Haemo-QoL dan mencari korelasi skor HJHS dengan skor PedHALshort dan Haemo-QoL.

Hasil: Sebanyak 95 subyek hemofilia, dengan hemofilia A (77,3%) dan 70,1% hemofilia berat. Skor HJHS median 4 (19), skor PedHALshort median 74,5 (62,73-89,09), skor Haemo-QoL mean (SD) 74,51 (15,58). Skor HJHS berkorelasi negatif sedang dengan PedHALshort ($r = -0,462$, $p < 0,0001$), skor HJHS berkorelasi sedang dengan Haemo-QoL ($r = 0,469$, $p < 0,001$).

Simpulan: Semakin tinggi skor HJHS menunjukkan adanya kerusakan pada sendi maka semakin rendah skor PedHALshort dan semakin tinggi skor Haemo-QoL yang menunjukkan semakin terganggu aktivitas fungsional serta kualitas hidupnya.

.....Background: Recurrent joint bleeding is the major morbidity in patient with hemophilia that can cause hemophilic arthropathy causes limitation of daily activities, disability, and reducing quality of life. Research objective are to determine the relationship between the clinical evaluation of joints, the assessment of functional activity determined and assessment of the quality of life with HJHS, so we can diagnose arthropathy, prevent disability and better management.

Methods: Study with cross-sectional design at RSCM on August-November 2022, children aged 4-16, with moderate or severe hemophilia A and B with recurrent joint bleeding. The study was conducted by assessing HJHS, PedHALshort and Haemo-QoL, determine the relationship between HJHS with PedHALshort and Haemo-QoL score.

Result: A total of 95 hemophilia subjects, with hemophilia A (77.3%) and 70.1% severe hemophilia. HJHS median score 4 (1-9), PedHALshort median score 74.5 (62.73-89.09), Haemo-QoL mean (SD) 74.51 (15.58). The HJHS score had a moderate negative correlation with PedHALshort ($r = -0.462$, $p < 0.0001$), the HJHS score had a moderate correlation with Haemo-QoL ($r = 0.469$, $p < 0.001$).

Conclusion: The higher of HJHS score indicates a joint disorder, the lower of PedHALshort and the higher

of Haemo-QoL indicates the more impaired functional activity and poorer quality of life.