

QUALITY OF LIFE OF PATIENTS WITH HIRSCHSPRUNG DISEASE AFTER TRANSANAL ENDORECTAL PULL-THROUGH IN DR. SARDJITO HOSPITAL USING GASTROINTESTINAL PEDS QL QUESTIONNAIRE

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ABSTRACT

Background: There were multiple studies assessing various surgical operation techniques to correct and treat Hirschsprung Disease (HSCR). Although the transanal endorectal pull-through (TEPT) is one of the most common techniques of surgical correction used, there are very limited data upon its result pertaining to the quality of life (QoL). Most of reports analyzed the functional outcomes after pull-through. Acknowledging its importance, this study was determined to assess the quality of life of HSCR patients after TEPT in RSUP Dr. Sardjito using PedsQL Gastrointestinal Scale.

Objective: To evaluate gastrointestinal aspect (GI) the quality of life of patients with Hirschsprung disease after TEPT and determining the factors affecting it in Dr. Sardjito Hospital using Gastrointestinal PedsQL questionnaire.

Method: This research was a retrospective and prospective cohort study on 25 post-TEPT patients. Data were collected from medical records, direct interviews and Indonesian adaptation of GI PedsQL questionnaire results from the parents and children. Results were compared using Mann-Whitney and Kruskal-Wallis test.

Results: 25 parents' reports and 3 childs reports were collected as quantitative data, whilst 2 subjects were interviewed in addition as qualitative data. Total GI PedsQL score and 14 dimensions score were analyzed based on factors such as sex, age of operation, post-operative duration, types of HSCR and comorbidities. No significant statistical differences in total score were found between the groups ($p>0.05$). Lower communication dimension's score were found in patients whose operated in age above 1 year old and living with comorbidities, and this was statistically significant ($p=0.015$).

Conclusion: The GI aspect of QoL in HSCR patients after TEPT operation had a relatively good result. Although factors such as sex, age of operation, post-operative duration, types of HSCR might have no statistical impact to the overall result. Qualitatively, parents-surgeons communication and anal dilatation process were an aspect found to be important in course and success of HSCR treatment.

Keywords: quality of life; Hirschsprung disease, Congenital Megacolon; transanal endorectal pull-through (TEPT); Gastrointestinal PedsQL questionnaire.

GASTROINTESTINAL PEDSQL

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INTISARI

Latar Belakang: Terdapat beberapa riset yang menilai berbagai teknik operasi untuk mengatasi penyakit Hirschsprung (HSCR). Walaupun *transanal endorectal pull-through* (TEPT) merupakan salah satu teknik operasi yang paling lazim digunakan, informasi terkait hasil operasinya dari segi kualitas hidup (QoL) masih terbatas. Banyak yang menilai hanya hasil fungsional setelah operasi. Menyadari kepentingan tersebut, riset ini berusaha untuk menilai hasil kualitas hidup pasien HSCR setelah operasi TEPT di RSUP Dr. Sardjito menggunakan Skala PedsQL Gastrointestinal (GI).

Tujuan: Mengevaluasi aspek gastrointestinal QoL pasien HSCR setelah TEPT dan melihat pengaruh faktor-faktor yang mempengaruhinya di RSUP Dr. Sardjito menggunakan kuesioner PedsQL Gastrointestinal (GI).

Metode: Riset ini merupakan sebuah cohort retrospektif dan prospektif yang melibatkan 25 pasien post-TEPT. Data diambil dari rekam medis, wawancara langsung dan hasil kuesioner GI PedsQL adaptasi Indonesia. Hasilnya dianalisis menggunakan uji Mann-Whitney and Kruskal-Wallis.

Hasil: 25 laporan orangtua dan 3 laporan anak dikumpulkan sebagai data kuantitatif, sebangkan hasil wawancara dengan 2 wali pasein digunakan sebagai data kualitatif. Nila Total GI PedsQL dan 14 dimensi dianalisis berdasarkan jenis kelamin, usia saat operasi, periode post operasi, tipe HSCR dan kelainan penyerta. Tidak ada perbedaan yang signifikan secara statistic antara nilai Total di seluruh grup ($p>0.05$). Nilai yang lebih rendah pada dimensi komunikasi ditemukan di pasien HSCR dengan usia operasi lebih dari 1 tahun dan memiliki kelainan penyerta. Hal ini bermakna signifikan secara statistik ($p=0.015$).

Kesimpulan: Aspek GI pada QoL di pasien HSCR setelah operasi TEPT memiliki hasil yang cukup baik. Walaupun faktor-faktor seperti jenis kelamin, usia saat operasi, periode post operasi, tipe HSCR mungkin tidak memiliki pengaruh yang bermakna signifikan secara statistik kepada hasil Total. Secara kualitatif, ditemukan bahwa komunikasi antara orangtua-dokter bedah dan proses businasi merupakan aspek penting dalam perjalanan dan kesuksesan penyembuhan HSCR.

Kata kunci: kualitas hidup; Penyakit Hirschsprung, Congenital Megacolon; transanal endorectal pull-through (TEPT); Kuesioner Gastrointestinal PedsQL



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