

## INTISARI

### **ANALISIS KUALITAS HIDUP PASIEN HIRSCHSPRUNG PASCA DUHAMEL DAN SOAVE DENGAN KUESIONER *PEDIATRIC QUALITY OF LIFE INVENTORY GENERIC CORE SCALES* DI RSUP DR. SARDJITO**

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**Latar Belakang:** Penyakit Hirschsprung (HSCR) ditandai dengan ketiadaan sel ganglion *Auerbach* dan *Meissner* di kolon sehingga menyebabkan obstruksi fungsional. Operasi definitif antara lain *Duhamel* dan *Soave*. Sebagian besar penelitian jangka panjang berhubungan dengan luaran fungsional, tetapi kualitas hidup pasien kurang diteliti. Penelitian di RSUP Dr. Sardjito sebelumnya menggunakan kuesioner *HAQL* yang lebih kompleks dan fokus pada penilaian gastrointestinal. Penelitian ini menggunakan kuesioner *PedsQL Generic Core Scales* yang lebih sederhana untuk menilai kualitas hidup secara umum.

**Tujuan:** Mengetahui perbandingan kualitas hidup pasien HSCR pasca *Duhamel* dan *Soave* di RSUP Dr. Sardjito Yogyakarta. Mengetahui pengaruh usia saat operasi dan rentang waktu pasca operasi sampai pengisian kuesioner terhadap kualitas hidup pasien.

**Metode:** Campuran eksplanatori kuantitatif dan kualitatif pada pasien HSCR pasca *Duhamel* dan *Soave* di RSUP Dr. Sardjito periode Januari 2012 – Desember 2018 dengan mengakses rekam medis. Data kuantitatif diperoleh dengan instrumen *PedsQL 4.0 Generic Core Scale* dan data kualitatif diperoleh dengan wawancara ke orangtua pasien yang memiliki skor kualitas hidup tinggi dan lebih rendah.

**Hasil:** Data kuantitatif dari 9 subjek *Duhamel* dan 5 subjek *Soave* yang mengikuti penelitian ini menunjukkan tidak ada perbedaan kualitas hidup di antara kedua kelompok. Temuan kualitatif menunjukkan bahwa pasien dengan skor kualitas hidup baik dipengaruhi oleh peranan keluarga serta lingkungan sekitar (pertemanan dan sekolah), seperti pengawasan pasca operasi, pengaturan makanan, pemberian semangat, dan pelatihan kemandirian. Ukuran sampel yang terlalu kecil menyebabkan analisis usia saat operasi dan rentang waktu pasca operasi sampai pengisian kuesioner tidak dapat dilakukan.

**Kesimpulan:** Secara statistik pasien HSCR pasca *Duhamel* kualitas hidupnya tidak lebih baik dibandingkan pasca *Soave*, meskipun demikian, adanya peran dan dukungan keluarga menunjukkan kecenderungan kualitas hidup pasien *Duhamel* lebih baik.

**Kata Kunci:** Kualitas hidup, operasi *Duhamel*, operasi *Soave*, penyakit Hirschsprung

## ABSTRACT

### QUALITY OF LIFE ANALYSIS IN HIRSCHSPRUNG PATIENTS AFTER DUHAMEL DAN SOAVE PULL-THROUGH USING PEDIATRIC QUALITY OF LIFE INVENTORY GENERIC CORE SCALES AT RSUP DR. SARDJITO

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**Background:** Hirschsprung's disease (HSCR) is characterized by the absence of ganglion cells Auerbach and Meissner in colon, causing functional obstruction. Surgical procedures include Duhamel and Soave. Most long-term studies are related to functional outcomes, but the quality of life is less studied. Previous study at RSUP Dr. Sardjito used a more complex HAQL questionnaire and focused on gastrointestinal. This study uses a simpler questionnaire, *PedsQL Generic Core Scales*, to assess quality of life in general.

**Objective:** Know the comparison of quality of life in HSCR patients after Duhamel and Soave at RSUP Dr. Sardjito Yogyakarta. Know the effect of age of surgery and postoperative time span until filling out the questionnaire on the quality of life.

**Method:** Mixed-method explanatory study in HSCR patients after Duhamel dan Soave at RSUP Dr. Sardjito from Januari 2012 to Desember 2018 by accessing medical records. Quantitative data were obtained by using *PedsQL Generic Core Scales* and qualitative data were obtained by interviewing parents of patients who had high and lower quality of life scores.

**Result:** Quantitative data of 9 Duhamel subjects and 5 Soave subjects who participated in this study showed no difference in quality of life among two groups. Qualitative findings showed that patients with high quality of life scores were influenced by the role of family as well as the surrounding environment (friendship and school), such as supervision after surgery, diet management, encougarement, and independence training. Small sample size caused analysis of age of surgery and postoperative time span until filling out the questionnaire on the quality of life cannot be performed.

**Conclusion:** Statistically, the quality of life in HSCR patients after Duhamel was not better compared with Soave, however, the presence of family role and support showed the tendency of quality of life in patients after Duhamel better.

**Keywords:** Duhamel pull-through, Hirschsprung's disease, Quality of Life, Soave pull-through