

KUALITAS HIDUP PADA ANAK DENGAN *CONGENITAL RUBELLA SYNDROME*

Erni D Kaswindiarti*, Indira L Gamayanti**, Elisabeth S Herini**

INTISARI

Latar belakang: *World health organization* (WHO) memperkirakan lebih dari 100.000 kasus baru CRS setiap tahunnya. Manifestasi *congenital rubella syndrome* (CRS) memiliki tiga karakteristik, yaitu penyakit jantung, katarak dan ketulian. Masalah *health-related quality of life* (HRQOL) menjadi populer, terutama yang berkaitan dengan kemampuan untuk bertahan hidup pada anak dengan kondisi kronis, serta kualitas hidup menjadi masalah penting dalam pelayanan kesehatan secara komprehensif. Penilaian kualitas hidup pada anak CRS sejauh ini belum dilaporkan di Indonesia.

Tujuan: Mengetahui nilai kualitas hidup anak dengan *congenital rubella syndrome*, serta faktor - faktor yang mempengaruhi.

Metode: Kami menilai kualitas hidup pada anak dengan CRS yang berobat ke RSUP. Dr. Sardjito dari bulan Januari 2010 – Desember 2015. Anak yang sakit berat, tempat tinggal diluar Daerah Istimewa Yogyakarta dan Jawa Tengah, meninggal dan tidak bisa dihubungi dieksklusi. Data didapatkan dari wawancara dengan orang tua pasien menggunakan kuesioner dan review rekam medis. Kualitas hidup dinilai dengan kuesioner modifikasi *Pediatric Quality of Life InventoryTM 4.0* (PedsQLTM) *generic* dan *Pediatric Quality of Life InventoryTM 3.0* (PedsQLTM) *cerebral palsy*.

Hasil: Sebanyak 31 subjek memenuhi kriteria inklusi dan eksklusi. Enam belas subjek (51,6 %) memiliki nilai kualitas hidup tidak normal dan 15 subjek (48,4 %) memiliki nilai kualitas hidup normal, dengan rerata skor kualitas hidup $65,76 \pm 20,66$. Nilai kualitas hidup normal dapat dipengaruhi oleh intervensi yang telah dilakukan pada subjek penelitian (operasi mata, penggunaan alat bantu dengar, operasi jantung, rehabilitasi medis). Gangguan penglihatan (OR 3,8; IK 95% 0,75-19,04; p=0,135), gangguan pendengaran (OR 2,3; IK 95% 0,18-28,47; p=0,600), penyakit jantung bawaan (OR 1,7; IK 95% 0,24-12,28; p=0,468), gangguan perkembangan (p=0,226), status gizi (OR 3,3; IK 95% 0,75-14,46; p=0,108), tingkat pendidikan ayah (OR 1,5; IK 95% 0,31-7,13; p=0,704) dan tingkat pendidikan ibu (OR 1,5; IK 95% 0,33-6,43; p=0,611) tidak mempengaruhi kualitas hidup pada anak dengan CRS.

Simpulan: Sebagian besar anak dengan CRS (51,6 %) memiliki kualitas hidup yang tidak normal. Gangguan penglihatan, gangguan pendengaran, penyakit jantung bawaan, gangguan perkembangan, status gizi, tingkat pendidikan orang tua secara statistik tidak mempengaruhi kualitas hidup pada anak dengan CRS.

Kata kunci: *congenital rubella syndrome*, kualitas hidup.

QUALITY OF LIFE OF CHILDREN WITH CONGENITAL RUBELLA SYNDROME

Erni D Kaswindiarti*, Indira L Gamayanti**, Elisabeth S Herini**

ABSTRACT

Background: *World health organization* (WHO) predicted that there will be more than 100.000 new cases of CSR each year. There are three manifestations of *congenital rubella syndrome* (CRS), which are: heart disease, cataract, and deafness. The *health-related quality of life* (HRQOL) problems have become popular, especially the one pertained with the survival ability of children suffering chronically, altogether with the quality of life that become an important matter within comprehensive health care. So far there has been no any report of the assessment of the quality life of children with CRS in Indonesia.

Objective: To understand the value of the quality of life of children with congenital rubella syndrome, as well as the particular influential factors.

Methods: We assessed the quality of life in children with CRS who went for treatment at RSUP. Dr. Sardjito from January 2010 - December 2015. Children who got severe illness, or live outside from Yogyakarta and Central Java, or died and could not be contacted are excluded. Data were obtained from interviews with patients' parents using a questionnaire and medical record review. Quality of life was assessed using modified questionnaire of the *Pediatric Quality of Life InventoryTM 4.0* (PedsQLTM) *generic* and *Pediatric Quality of Life InventoryTM 3.0* (PedsQLTM) *cerebral palsy*.

Results: A total of 31 subjects were analyzed. Sixteen subjects (51,6 %) had an abnormal quality of life and 15 subjects (48,4 %) had a normal quality of life, with a mean score of 65.76 ± 20.66 for the quality of life. A normal quality of life could be interfered by medical intervention they had such as eye surgery, hearing aid, heart surgery and medical rehabilitation. Visual impairment (OR 3,8; CI 95% 0,75-19,04; p=0,135), hearing loss (OR 2,3; CI 95% 0,18-28,47; p=0,600), congenital heart disease (OR 1,7; CI 95% 0,24-12,28; p=0,468), developmental disorder (p=0,226), nutritional status (OR 3,3; CI 95% 0,75-14,46; p=0,108), father's education level (OR 1,5; CI 95% 0,31-7,13; p=0,704) and mother's education level (OR 1,5; CI 95% 0,33-6,43; p=0,611) were not affect the quality of life in children with CRS.

Conclusions: The qualities of life of children with CRS are mostly at abnormal (51,6 %). Visual impairment, hearing loss, congenital heart disease, developmental disorder, nutritional status and parental education does not affect the quality of life in children with CRS.

Keywords: *congenital rubella syndrome*, quality of life.