

## **PREDIKTOR KUALITAS HIDUP ANAK LUPUS ERITEMATOSUS SISTEMIK (LES)**

### **INTISARI**

**Latar belakang:** Anak dengan penyakit kronis dan episodik seperti LES, hampir selalu membutuhkan pengobatan dan monitoring jangka panjang, dengan risiko kematian yang cukup tinggi. Dalam penanganannya, aspek psikososial seringkali terabaikan. Salah satu pendekatan pengukuran kualitas hidup anak LES melalui PedsQL.

**Tujuan:** Untuk menilai serta mengetahui prediktor yang memengaruhi kualitas hidup anak LES.

**Metode:** Studi kohort retrospektif dilakukan dengan data sekunder dari rekam medis dan pengambilan data primer pasien instalasi anak RSUP Dr.Sardjito Yogyakarta, Indonesia. Pasien anak yang didiagnosis lupus eritematosus sistemik antara 1 April 2017 – 31 Maret 2018 dimasukkan dalam studi. Usia onset, usia pasien, keparahan LES, aktivitas penyakit, kadar vitamin D, kepatuhan terapi, status pendidikan keluarga, status sosio-ekonomi keluarga dan dukungan sosial dianalisis sebagai faktor yang berhubungan dengan kualitas hidup serta dipresentasikan sebagai rasio relative (RR) dan *confidence interval* 95% (CI 95%).

**Hasil:** Sebesar 95,3% subyek adalah perempuan dengan 90,6% berusia 12-18 tahun. Terdapat 84,4% subyek yang terdiagnosis lupus berat dan 89,1% subyek dengan defisiensi vitamin D. Sebanyak 17,1% subyek tidak melanjutkan pendidikan. Hasil penilaian kualitas hidup didapatkan 70,3% memiliki fungsi fisik rendah, 43,8% fungsi emosi rendah serta 60,9% fungsi akademis rendah. Fungsi sosial terbilang sangat baik dengan 85,9% subyek memiliki fungsi sosial baik. Keparahan penyakit (RR 7,2; 95% CI: (1,4-36,0); p=0,01) dan status pendidikan keluarga (RR 5,4; 95% CI: (1,3-22,3); p=0,01) berhubungan secara signifikan terhadap fungsi fisik pasien. Fungsi emosi dipengaruhi oleh usia saat terdiagnosis (RR 0.1; 95% CI: (0,0-0,6); p=0,02), fungsi sosial dipengaruhi oleh dukungan sosial (RR 17.3; 95% CI: (2,4-123); p=0,02) dan fungsi akademis dipengaruhi oleh aktivitas (RR 1.7; 95% CI: (1,4-985,3; p=0,02).

**Simpulan:** Kualitas hidup pasien lupus masih rendah terutama dari fungsi fisik, psikis dan akademis. Keparahan lupus, aktivitas penyakit, usia onset, status pendidikan keluarga dan dukungan sosial merupakan prediktor terhadap kualitas hidup anak dengan LES.

**Kata kunci:** kualitas hidup, faktor risiko, lupus eritematosus sistemik, anak

## PREDICTORS OF QUALITY OF LIFE AMONG PEDIATRIC SYSTEMIC LUPUS ERYTHEMATOSUS

### ABSTRACT

**Background:** Systemic lupus erythematosus (SLE) is a chronic, autoimmune disease, associated with multiple organ damage. Approximately 20% of lupus patients are diagnosed in childhood, predominantly females during their reproductive age. Childhood SLE presents to be more severe than among adult patients. Patients tend to have more frequent disease activity and need long term treatment. During treatment, patients could experience low health-related quality of life (HRQoL). Pediatric quality of life (PedsQL) is instrument to measure HRQoL consists 4 domains: (1) physical functioning, (2) emotional functioning, (3) social functioning, and (4) school functioning.

**Objective:** To identify the predictors of quality of life among pediatric systemic lupus erythematosus.

**Methods:** A retrospective cohort study was conducted using secondary data from medical records of pediatric department of Dr. Sardjito Hospital Yogyakarta. The inclusion criteria were children with SLE, according to ARC and SLICC, in Sardjito hospital Yogyakarta from April 2017 to March 2018. Subject with incomplete required medical record data were excluded from this study. Age of onset, chronological age, lupus severity, disease activity, vitamin D level, therapy adherence, family education, socioeconomic status and social support were analyzed as predictors on quality of life in lupus children and presented as relative risk (RR) and confidence interval 95% (CI 95%).

**Results:** Sixty four patients were included in this study with female predominance. Around 70,3% patient had low physical functioning and multivariate analysis showed lupus severity (RR 7,2; 95% CI: (1,4-36,0); p=0,01) and family education status (RR 5,4; 95% CI: (1,3-22,3); p=0,01) were statistically significant as predictors of physical functioning. Out of 43,8% subjects had low emotional functioning and age of onset was statistically significant as a predictor of emotional functioning (RR 0.1; 95% CI: (0,0-0,6); p=0,02). A total of 60,9% subject had low school functioning and multivariate analysis showed disease severity (RR 1.7; 95% CI: (1,4-985,3); p=0,02) was statistically significant as a predictor. Around 85,9% subject had good social functioning and social support was statistically significant toward this function (RR 17.3; 95% CI: (2,4-123); p=0,02).

**Conclusion:** Quality of life among lupus children are stil poor especially on physical, emotional and school functioning. The predictors of QoL among children with SLE are lupus severity, disease activity, age of onset, family eductaion and social support.

**Keywords:** quality of life, systemic lupus erythematosus, children