

# Kualitas hidup anak sindrom nefrotik menggunakan penilaian Pediatric Quality Of Life Inventorytm (PedsQLTM) = Quality of life in children with nephrotic syndrome using Pediatric Quality of Life InventoryTM (PedsQLTM)

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## Abstrak

Latar belakang. Sindrom nefrotik (SN) merupakan penyakit ginjal yang sering ditemukan pada anak. Komplikasi SN terkait perjalanan penyakit, terapi, fisik dan psikososial yang memengaruhi kualitas hidup. Tujuan. Mendapatkan gambaran tentang kualitas hidup anak SN yang berobat di Departemen Ilmu Kesehatan Anak (IKA) Rumah Sakit Dr. Cipto Mangunkusumo (RSCM) dan faktor yang berhubungan. Metode. Studi deskriptif analitik dengan desain potong lintang di poliklinik nefrologi dan rawat inap Departemen IKA RSCM periode April 2012 - Desember 2013. Subjek berusia 2-18 tahun. Penilaian kualitas hidup menggunakan PedsQLTM 4.0 modul generik dan pola asuh menggunakan Kuesioner Pola Asuh Anak (KPAAn).

Hasil. Seratus pasien SN mengikuti penelitian dan didapatkan gangguan kualitas hidup berdasarkan laporan orangtua dan laporan anak 19%. Usia 5-7 tahun, usia 13-18 tahun, status sosioekonomi rendah, dan kondisi relaps jarang pada SN sensitif steroid (SNSS) merupakan faktor risiko gangguan kualitas hidup pada laporan orangtua ( $p<0,05$ ) dengan rasio prevalens secara berurutan 5,22, 7,5, 3,48, 10,33. Penggunaan steroid saat penelitian memiliki hubungan dengan kualitas hidup berdasarkan laporan orangtua ( $p<0,05$ ). Tingkat pendidikan ayah yang semakin rendah merupakan faktor risiko gangguan kualitas hidup pada laporan anak ( $p<0,05$ ) dengan rasio prevalens 5,22. Lama diagnosis memiliki hubungan dengan kualitas hidup pada laporan orangtua dan anak ( $p<0,05$ ). Status sosioekonomi dan pola asuh merupakan faktor risiko gangguan kualitas hidup.

Simpulan. Usia prasekolah, remaja, kondisi relaps jarang, penggunaan steroid, lama diagnosis, tingkat pendidikan ayah semakin rendah, status sosioekonomi dan pola asuh akan memengaruhi kualitas hidup anak SN. Gangguan kualitas hidup pada pasien SN merupakan masalah yang perlu diperhatikan dalam tata laksana.

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Background. Nephrotic syndrome (NS) is the most common kidney disease in children. Complication of NS is associated with course of disease, therapy, and psychosocial condition affecting the quality of life (QoL).

Aim. Describing the QoL in children with NS and its associated factors in pediatric outpatient clinic and ward in Dr. Cipto Mangunkusumo Hospital.

Method. Cross sectional study was performed in pediatric nephrology clinic and ward in Dr. Cipto Mangunkusumo Hospital, from April 2012 to December 2013. Subjects were 2 to 18 years old. Quality of life was assessed using PedsQLTM 4.0 generic module and parenting style was assessed with Kuesioner Pola Asuh Anak.

Results. One hundred subjects participated in this study and QoL impairment was reported in 19% subjects based on report from parents and children. Factors associated with impairment QoL from parent's report were age group 5 - 7 years old, age group 13 - 18 years old, low socioeconomic status, and infrequent

relapse condition in steroid sensitive NS ( $P<0.05$ ), with prevalence ratio 5.22, 7.5, 3.48, 10.33, respectively. Steroid use was also associated with QoL according to parent's report ( $P<0.05$ ). Lower father's education was risk factor for QoL impairment according to patient's report ( $P<0.05$ ) with prevalence ratio 5.22. Duration of diagnosis was associated with QoL according to parent's and patient's report ( $P<0.05$ ). Socioeconomic status and parenting style were risk factors of QoL impairment in children with NS. Conclusion. Preschool age, teen age, infrequent relapse, steroid use, duration of diagnosis, low father's education, socioeconomic status, and parenting style are associated with QoL in children with NS. Quality of life impairment is important in management of children with NS.