

Kualitas hidup anak dengan hemofilia di rumah sakit dr. Cipto Mangunkusumo = Quality of life children with hemophilia in dr. Cipto Mangunkusumo hospital

Febrini Agasani, author

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Abstrak

Latar belakang: Hemofilia merupakan salah satu penyakit kronik yang dapat memengaruhi kualitas hidup. Penilaian kualitas hidup merupakan indikator keberhasilan terapi, dasar pengembangan strategi pengobatan dan penilaian pelayanan kesehatan. Belum ada data mengenai kualitas hidup anak dengan hemofilia di Rumah Sakit Dr. Cipto Mangunkusumo RSCM.

Tujuan: Mengetahui prevalens, gangguan kualitas hidup, kesesuaian kualitas hidup berdasarkan laporan anak dan laporan orangtua serta pengaruh faktor sosiodemografis dan faktor medis terhadap kualitas hidup anak hemofilia di RSCM.

Metode: Penelitian potong lintang dilakukan pada pasien hemofilia usia 5-18 tahun di Poliklinik Hematologi Departemen Ilmu Kesehatan Anak RSCM selama bulan September-Desember 2016. Pengisian kuesioner PedsQLTM 4.0 modul generik dilakukan dengan metode wawancara. Faktor-faktor risiko yang dianggap berpengaruh dianalisis secara multivariat.

Hasil: Gangguan kualitas hidup 52,9 rerata 64,37 11,75 menurut laporan anak dan 60,8 rerata 64,37 13,87 menurut laporan orangtua dari total 102 anak hemofilia. Dimensi yang paling terganggu adalah dimensi fisik menurut kelompok 5-7 tahun, sedangkan menurut kelompok 8-18 tahun adalah dimensi fisik dan sekolah. Terdapat ketidaksesuaian antara laporan kualitas hidup anak dan orangtua pada kelompok usia 5-7 tahun. Kekakuan sendi merupakan faktor risiko terjadinya gangguan kualitas hidup menurut laporan anak $p=0,005$, RP 4,335, IK 95 1,550-12,126 dan orangtua $p=0,04$, RP 2,902, IK 95 1,052-8,007.

Simpulan: Terdapat 52,9 laporan anak dan 60,8 laporan orangtua anak hemofilia yang kualitas hidupnya terganggu. Kekakuan sendi merupakan faktor yang paling memengaruhi kualitas hidup anak dengan hemofilia. Untuk menilai kualitas hidup anak usia 5-7 tahun diperlukan laporan anak dan orangtuanya, sedangkan untuk anak usia 8-18 tahun cukup laporan anak atau orangtua saja.

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Background Hemophilia is a chronic disease that can affect quality of life QoL . Assessment of QoL is an indicator of therapeutic success, base for development of the treatment strategy, and assessment of health services. There are no data for QoL of children with hemophilia in Dr. Cipto Mangunkusumo Hospital CMH.

Aim To evaluate the prevalence, QoL, congruence of QoL based on self report and parents proxy report as well as the influence of sociodemographic and medical factors on the QoL of children with hemophilia in CMH. Method A cross sectional study was conducted in patients with hemophilia aged 5 18 years old who visited the outpatient clinic of Pediatric Hematology Division of CMH from September to December 2016. Data questionnaire PedsQLTM 4.0 generic scale were collected by interviewing children and their parents. Risk factors were analyzed with multivariate analysis.

Result From a total of 102 children with hemophilia, there were 52.9 self report and 60.8 parent proxy report of children with impairment of QoL with mean score 64.37 11.75 and 64.37 13.87, respectively. The most

impaired dimension were the physical dimension for age group 5-7 years whereas for age group 8-18 years, there was impairment on the physical and school dimensions. There is a discrepancy report the QoL of children and parents in the age group 5-7 years. Joint stiffness is a risk factor for impaired QoL according to the self report $p = 0.005$, PR 4.335, 95 CI 1.550 to 12.126 and parent proxy report $p = 0.04$, PR 2.902, 95 CI 1.052 to 8.007.

Conclusion There were 52.9 self report and 60.8 parent proxy report of children with hemophilia who had impaired QoL. Joint stiffness is a factor that mostly affect the QoL of children with hemophilia. Assessment of QoL for children aged 5-7 years required reports from both children and parents, while for aged 8-18 years required either child report or the parents report alone.