

ABSTRACT

Background : *Thalassemia is a chronic disease that causes high mortality rates in children. This serious condition can affect the quality of life of children suffering from thalassemia major, which is generally indicated by low physical, emotional, social and academic function.*

Method : *A cross-sectional design was conducted in this study. Samples were all children with β -thalassemia major who receiving treatment at hospital in Jambi City and their parents. Socio-demographic and clinical data were collected during interview and health related quality of life was measured using PedsQL 4.0. Parents proxy reports and child self-reports were analyzed by Mann-Whitney U test and Kruskal Wallis test.*

Results : *We had 41 children and 34 parents completed the PedsQL as appropriate. The school functioning dimension showed the lowest score (parent proxy report: 56.35; child self-report: 54.72). The emotional functioning dimension showed the highest score (parent proxy report: 73.41; child self-report: 75.27). No significant differences between the child and parental proxy report ($p>0,05$). According to parent's report, the school functioning dimension decreases as children get older. According to a child's report, the physical, emotional, social, and school functioning dimensions decrease as children get older.*

Conclusion : *As children get older, their quality of life decrease.*

Keywords : *Thalassemia, Quality of Life, PedsQL*

ABSTRAK

Latar Belakang : Thalassemia merupakan salah satu penyakit kronis yang menyebabkan angka kematian yang tinggi pada anak. Kondisi berat yang dialami dapat mempengaruhi kualitas hidup anak penderita thalassemia mayor yang umumnya ditunjukkan dengan rendahnya fungsi fisik, emosi, sosial, dan akademik.

Metode : Penelitian ini menggunakan desain penelitian *cross-sectional*. Sampel penelitian yaitu anak penderita thalassemia beta mayor yang melakukan pengobatan di rumah sakit di Kota Jambi beserta orang tua. Data sosiodemografi dan klinis anak diperoleh melalui wawancara dan kualitas hidup anak diukur menggunakan PedsQL 4.0. Hasil pengisian PedsQL anak dan orang tua dianalisis menggunakan uji Mann-Whitney U dan uji Kruskal Wallis.

Hasil : Hasil pengisian kuesioner PedsQL oleh 41 anak dan 34 orang tua memperoleh domain fungsi sekolah mendapat skor terendah (laporan orang tua: 56.35; laporan anak: 54.72). Domain fungsi emosi menempati skor tertinggi (laporan orang tua: 73.41; laporan anak: 75.27). Tidak terdapat perbedaan yang bermakna antara laporan anak dan laporan orang tua ($p > 0,05$). Menurut laporan orang tua, semakin bertambah usia anak, domain fungsi sekolah semakin menurun. Menurut laporan anak, semakin bertambah usia anak, domain fungsi fisik, emosi, sosial, dan sekolah semakin menurun.

Kesimpulan : Kualitas hidup anak semakin menurun seiring bertambahnya usia anak.

Kata Kunci : Thalassemia, Kualitas Hidup, PedsQL