

**INSTITUT TEKNOLOGI DAN KESEHATAN MAHARDIKA
PROGRAM STUDI ILMU KEPERAWATAN**

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**Hubungan Kepatuhan Konsumsi Terapi Kelasi Besi dengan Kualitas Hidup
Anak Pada Penderita Thalasemia Mayor di RSUD Majalengka**

xiv + 85 Halaman + 8 Tabel + 2 Bagan + 18 Lampiran

ABSTRAK

Menurut World Bank menunjukkan 7% dari populasi dunia merupakan pembawa sifat thalasemia. Data penyandang thalasemia di Indonesia bulan juni tahun 2021 sebanyak 10.973 kasus. Provinsi Jawa Barat memiliki jumlah penderita thalasemia terbanyak, pada akhir 2019 jumlahnya 4.000 kasus. Ketua Perhipunan Orang Penyandang Thalasemia Indonesia (POPTI) menyampaikan terdapat 145 kasus thalasemia di Majalengka. Tahun 2023 pada bulan mei tercatat 115 penderita thalasemia yang melakukan rawat jalan di Klinik Thalasemia RSUD Majalengka. Tujuan penelitian ini adalah untuk mengetahui hubungan kepatuhan konsumsi terapi kelasi besi dengan kualitas hidup anak pada penderita thalasemia mayor di RSUD Majalengka

Jenis penelitian ini adalah kuantitatif deskriptif korelasi dengan pendekatan cross-sectional. Populasi dalam penelitian ini adalah anak penderita thalasemia mayor yang mengkonsumsi terapi kelasi besi dan berusia 6-18 tahun. Pengambilan sampel menggunakan teknik purposive sampling berjumlah 53 responden. Instrumen yang digunakan berupa kuisioner MCQ versi melayu dan PedsQL. Analisa data menggunakan uji Spearman Rank. Tempat penelitian di RSUD Majalengka pada tanggal 15 Mei 2023-10 Juni 2023.

Hasil penelitian didapatkan lebih dari sebagian anak thalasemia tidak patuh mengkonsumsi terapi kelasi besi yaitu sebanyak (64,2%) dan Fungsi Emosional mencapai nilai tertinggi dengan rerata 72,64. Fungsi sosial dengan rerata 68,49. Fungsi fisik dengan rerata 51,12. dan Fungsi Sekolah/Akademik yang paling rendah dengan rerata 46,58.. dengan nilai skor total 59,70 dalam arti kualitas hidup buruk. Hasil analisa bivariat menggunakan uji spearman rank p value $< \alpha$ dan $r < 1,00$ hubungan yang bermakna antara kepatuhan konsumsi terapi kealsi besi dengan fungsi fisik (0,00), fungsi emosional (0,00), fungsi sosial (0,00), dan fungsi sekolah/akademik (0,01). Dengan arah korelasi positif sedang hingga positif kuat yang menunjukkan bahwa semakin tinggi kepatuhan konsumsi terapi kelasi besi maka semakin baik kualitas hidup anak thalasemia. (p value = 0,00 dan 0,01, $\alpha = 0,05$, $r = 0,531$, 0,692, 0,596, dan 0,460). Bagi perawat thalasemia dengan adanya penelitian ini dapat menjadi bahan masukan untuk meningkatkan kualitas pelayanan dalam melakukan asuhan keperawatan pada anak thalasemia.

Kata Kunci : Kepatuhan, Terapi Kelasi Besi, Kualitas Hidup Anak, Thalasemia

Daftar Pustaka : 56 (2013-2023)

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***Correlation between Compliance with Consumption of Iron Chelation Therapy
and Children's Quality of Life in Patients with Thalassemia Major
at Majalengka Hospital***

xiv + 85 Pages + 8 Tables + 2 Charts + 18 Attachment

ABSTRACT

According to the World Bank, 7% of the world's population are carriers of thalassemia traits. There are 10,973 cases of people with thalassemia in Indonesia in June 2021 . West Java Province has the highest number of thalassemia sufferers, at the end of 2019 there were 4,000 cases. The Chairperson of the Association of People with Thalassemia Indonesia (POPTI) said that there were 145 cases of thalassemia in Majalengka . In 2023 in May, 115 thalassemia sufferers were recorded as outpatients at the Thalassemia Clinic at Majalengka Hospital . The purpose of this study was to determine the relationship between adherence to consumption of iron chelation therapy and quality of life of children in patients with thalassemia major at Majalengka General Hospital.

This type of research is quantitative descriptive correlation with a cross-sectional approach . The population in this study were children with thalassemia major who were taking iron chelation therapy and aged 6-18 years. Sampling using purposive sampling technique totaling 53 respondents. The instruments used were the Malay version of the MCQ questionnaire and PedsQL . Data analysis used the spearman rank test . Place of research at Majalengka Hospital on 15 May 2023 -10 June 2023.

The results showed that more than half of the thalassemia children did not adhere to taking iron chelation therapy (64.2%) and Emotional Function achieved the highest score with an average of 72.64. Social function with an average of 68.49. Physical function with an average of 51.12. and School/Academic Functions are the lowest with an average of 46.58.. with a total score of 59.70 in the sense of poor quality of life. The results of bivariate analysis using the Spearman rank test p value $< \alpha$ and $r < 1.00$ significant relationship between adherence to consumption of iron calcium therapy with physical function (0.00), emotional function (0.00), social function (0.00) , and school/academic functions (0.01). With a moderate to strong positive correlation direction which indicates that the higher the adherence to consumption of iron chelation therapy, the better the quality of life of thalassemia children. (p value = 0.00 and 0.01, α = 0.05, r = 0.531, 0.692, 0.596 and 0.460). For thalassemia nurses, this research can be used as input to improve service quality in providing nursing care to thalassemia children.

Keywords: Compliance, Iron Chelation Therapy, Children's Quality of Life, Thalassemia

References : 56 (2013-2023)