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## **A Cross Sectional Assessment of Health-related Quality of Life among Patients with Thalassaemia in Malaysia**

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HRQOL is referring to patients' perceptions that is related to physical and mental of thalassaemia patients. HRQOL measurement is crucial in assessing the extent of impact that this chronic disease has affected the thalassaemia patients' lives. HRQOL measurement also includes identifying the effects of the treatment and disease towards wellbeing of the patients. Quality of Life (QOL) of individuals with thalassaemia major are affected by many influence factors such as the effect of diagnosis and treatment, chronic conditions state, appearances, treatment's components such as frequent hospital visits for the transfusion, nightly mixture of subcutaneous, late arrival or absence, sexual development and complications from the disease[1-2].

The study aims to assess the Health Related Quality of Life (HRQoL) among thalassaemia patients and identify the significant factors that contribute to HRQoL in thalassaemia patients in Malaysia. A cross sectional based study was conducted at Kedah Thalassaemia Society Club in Kedah, Malaysia. The HRQoL was measured using a Short form survey version 2 (SF-36). Descriptive study was used to describe the demographic and disease related to the thalassaemia patients. The HRQoL was compared using the Mann-Whitney and Kruskal-Wallis test. The analyses were performed using the Quality Metric Health Outcomes Scoring software for SF-36 and SPSS v 22. Three hundred and ninety thalassaemia patients were enrolled in the study. The majority of the participants (n = 221, 58.5%) were categorized in the age group of 18-27 years (25.40 ± 10.2). The HRQoL measure of less than 50 for the physical component summary (PCS) and mental component summary (MCS) among thalassaemia patients were rated as poor. Patients with higher education levels were significantly associated with PCS (p=0.002) and showed higher mean scores for PCS (52.0) compared to the others. Age, marital status, employment status, monthly income, health check-ups before screening of thalassaemia

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and medical insurance was associated with PCS levels compare to the others. The type of thalassaemia, the medical treatment received and the side effects of the conventional treatment were significantly associated with p-values of less than 0.001 and PCS and MCS scores of below 50.

The present study identified many demographic and disease related factors which may contribute to the HRQoL of thalassaemia patients. Results showed that patients with thalassaemia will affect their quality of life because PCS and MCS scores indicated lower readings than other individuals. Other studies showed that the thalassaemia patients have lower HRQoL proceedings when they faced the complications and effects of medications due to their illness. It also refers to the side effects of chelation therapy[3]. It showed that the life quality assessment is necessary to improve understanding of the impact on patients of thalassaemia and allow patients to get the support they need.

**Keywords:** Health Related Quality of Life; thalassaemia; SF-36; Malaysia

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