

Employment and quality of life among transfusion dependent thalassaemia adults

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Abstract

Improvement in medical management has enabled transfusion dependent thalassaemia (TDT) patients to survive beyond childhood, building families, and contributing to the labour force and society. Knowledge about their adult life would provide guidance on how to support their needs. This study aims to explore the quality of life (QOL) on TDT adults, their employment status and challenges. We contacted all regional Thalassaemia societies in Malaysia to invite TDT members aged 18 years or over to participate. Participants were also recruited from the two participating hospitals. A self-administered questionnaire including 'Healthy-days', WHOQOL-BREF and employment measurements were used. We received 206 completed questionnaires meeting our inclusion criteria. Being in good health was perceived by 75% of participants, 53% were satisfied with life and 63% rated their life quality as good. They scored above average (mean[SD]) for each QOL domain: physical health 56(15), psychological health 65(15), social relationship 64(17), environmental health 59(21). Multiple linear regression showed that unwillingness to disclose thalassaemia status, presence of comorbidities and discrimination experiences were associated with lower QOL scores. Although 77% were employed, 81% received a salary below RM2000 and 59% felt discrimination at work. Eighty one percent felt thalassaemia as a burden. Within a month, there was a mean of 7.9 (11.5) unhealthy and 2.7 (4.9) activity limitation days. TDT adults appeared to be fairly positive about their life in spite of high unhealthy and activity limitation days. Efforts to reduce these days and improve employer and public awareness are needed.

Keywords: thalassaemia, quality of life

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