UNIVERSITI TEKNOLOGI MARA

DEPRESSION AMONG CAREGIVERS OF THALASSEMIA CHILDREN IN TWO GOVERNMENT HOSPITALS IN KLANG VALLEY

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ABSTRACT

Background: Caregiving for patients with chronic diseases causes distress that predispose the caregivers to depression. Thalassemia is a chronic debilitating illness that is common in this country. It has been proposed that caregiving for children with thalassemia increases risk of developing depression.

Objective: This study aims to determine the prevalence of Major Depressive Disorder among caregivers of children with thalassemia in Hospital Selayang and Hospital Sungai Buloh. It also aims to determine the associated factors of depression among the caregivers.

Methodology: This is a cross-sectional study involving 64 caregivers of children with thalassemia under follow up at Hospital Selayang and Hospital Sungai Buloh. Those who fulfilled the inclusion criteria and gave informed consent were recruited. Caregivers' sociodemographic, clinical and children's clinical data were obtained from an interview with the caregivers and from the medical records. The diagnosis of Major Depressive Disorder was confirmed by Mini International Neuropsychiatric Interview (M.I.N.I.) for Major Depressive Episode. The level of caregiver strain was assessed using the Caregiver Strain Index (CSI) tool. Data was analysed using the Statistical Package for Social Sciences (SPSS) version 26.

Results: The prevalence of depression among the caregivers is 17%. From bivariate analysis, factors found to be associated with depression were caregivers' age (p= 0.155), marital status (p=0.177), education level (p=0.100), household income (p=0.176), financial support (p=0.006), history of death in the family (p=0.201), personal history of mental illness (p=0.172), duration of illness (p= 0.093), comorbidities (p=0.201) and high caregiver strain (0.001). From multivariate analysis the factor found to be significantly associated with depression is high caregiver strain (OR: 10.04,

CI: 1.41-71.58, p= 0.021).

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CHAPTER 1

Introduction

1.1 Overview of Thalassemia disease

Thalassemia is disease resultant from defective formation of haemoglobin in the red blood cells. It is a heterogenous blood disorder and the commonest genetic disorder in this country (Ainoon & Cheong, 1994). This study further expounds on the types of thalassemia commonly seen in Malaysia, which include α-thalassemia, β-thalassemia, Haemoglobin E, Haemoglobin Constant Spring and δβ-thalassemia.

Clinically, thalassemia is divided into thalassemia minor, intermedia and major. Carriers or those with heterozygous genes for thalassemia are considered to have thalassemia minor and remain free of symptoms other than some, who are afflicted with mild pallor (Ministry of Health Malaysia, 2009). They are commonly mistaken to have iron deficiency and erroneously treated with iron replacement therapy.

Thalassemia intermedia and major on the other hand can lead to considerable morbidity and mortality. Perinatal death can result from a homozygous defect in the α-globin chain production leading to Bart's hydrops fetalis. Those with thalassemia major suffer from severe anaemia and its consequences of lethargy, growth retardation, developmental delay, as well as skeletal abnormality from the extra-medullary blood production. Children manifest symptoms of severe anaemia after the first year of life. In the absence of blood transfusion, most children will succumb to an early death (Ministry of Health Malaysia, 2009).

The intermediate manifestation of this disease includes anaemia when there is a concurrent infection but an otherwise mild to moderate anaemia, jaundice and enlarged liver and spleen. They are typically symptomless, have normal physical development and have no thalassemic facial deformities. An accurate diagnosis at early age is important to avoid unnecessary blood transfusions and labelling them as transfusion dependents.