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Influencing of Family Management in Families with Thalassemic Children on Health Related Quality of Life and Family Functioning: SEM approach

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Abstract

Purpose: To predicate the way in which families incorporate the work of managing a child with thalassemia within family life and its outcomes. **Methods:** A correlational design with a structural equation modeling (SEM) approach was used. A total of 309 parents of children with thalassemia from 4 tertiary care hospitals in Thailand completed our questionnaires. **Results:** Family life difficulties had a negative influence on the child's health-related quality of life (HRQOL) ($\beta = -2.23$, $p < 0.05$) and family functioning ($\beta = -0.27$, $p < 0.05$), whereas the child's daily life ($\beta = 5.06$, $p < 0.05$) and condition management ability ($\beta = -1.86$, $p < 0.05$) had a negative influence on the child's HRQOL. In the final model, 3 variables including the child's daily life, condition management ability, and family life difficulty could explain 33 % of variance in the child's HRQOL ($R^2 = 0.33$). This model showed that only family life difficulty could explain 2 % of variance of family functioning ($R^2 = 0.02$). **Conclusions:** The study suggests that nurses should design interventions to support families in managing their child's conditions in order to achieve a good child and family outcomes.

Keywords: Family management, family functioning, health related quality of life, children with thalassemia, parental perception

Introduction

Thalassemias are genetic disorders. There are many types of thalassemic syndrome. In each type, there is a decreased production of one or more of the globin chains that make up hemoglobin. Without sufficient amounts of alpha-and beta-globin, sufficient hemoglobin cannot be formed resulting in a decrease in the amount of oxygen in body tissues, which ultimately results in the individual experiencing poor growth, organs damage and many other health issues. Individuals with thalassemia come from all ethnic groups and almost every country in the world. The common thalassemia diseases found in Thailand are homozygous β-thalassemia disease and β-thalassemia/Hb E disease [1]. However, the incidence of thalassemia is higher in certain countries. The incidence of hemoglobin [Hb] E approaches 60 % of the population in many regions of Southeast Asia, and also has high prevalence in Thailand [2]. It has been estimated that 30 - 40 % of the population in Thailand are carriers of alpha-or beta-thalassemia [3]. According to thalassemia foundation website, in Thailand, with a population of 65 million, about 40 % have thalassemia traits or are carriers, while 1 % of the population is afflicted with this disease [1]. This disease is mostly incurable and treatment procedures incur high costs such as stem cell transplantation.