

# **Assessment of Nurse's Role Regarding Care of Children with β-Thalassemia**

*Thesis*

**Proposal Submitted in Partial Fulfillment for  
the Master Degree**

*By*

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## Introduction

Thalassemias are heterogenous group of genetic disorders of hemoglobin synthesis. All of which result from reduced rate of production of one more of globin chains of hemoglobin. They are divided into  $\alpha$ - $\beta$  thalassemia according to defect in globin chain synthesis (*Aessopos et al., 2001*). Thalassemia comes from the Greek word "thalassa" that mean sea, the name refers to descendants of living near Mediterranean Sea who have the highest incidence of the disease and spread all over the world (*Weatherall, 2001*).

In Egypt, screening program, in high school student were developed at early 1999 under supervision of ministry of health for detecting the definite carrier rate, reported a carrier rate of 9-10 % (*El-Beshlawy et al., 1999*). However high rates of thalassemia are known to occur in Egypt, over 1000 children affected with  $\beta$  thalassemia are expected to be born out of the 1.5 million live births in Egypt per year (*El-Beshlowy, 2003*).

Older children with  $\beta$ -thalassemia presented with similar physical changes include prominent forehead and cheeks, eyes slanted slightly downward and an enlarged maxilla with poorly aligned misshapen teeth. Growth retardation usually occurs as a consequence of severe anemia. Other features include gallstones, pericarditis and leg ulcers (*Stead and Vaughn, 2001*).  $\beta$ -thalassemia major should be suspected when a 12 month old child has anemia with splenomegaly. Therapeutic management of  $\beta$ -thalassemia major remain complex, difficult, painful and time consuming and very

expensive. It includes packed blood cells transfusion, splenectomy chelating therapy and bone marrow transplantation (***Stead and Vaughn, 2001***).

Nurses play an important role in nursing care of children with  $\beta$ -thalassemia major. The pediatric nurse should advise or supervise as well as to give expert nursing care. She should be able to give the most care for children during the period of hospitalization and act as mother substituted for children in the hospital (***Stelle, 2001***). Meanwhile nursing process is a dynamic continuous process that require mutual participation in decision making. Helping nurses to solve many problems of  $\beta$ -thalassemia children to relieve their suffering and to help them to cope with environment effectively (***Ellis and Hartley , 2000***).