

# **Quality of Nurses Care Provided for Children with Thalassemia to Meet Their Care Giver's Satisfaction**

*Thesis*

*Submitted for Partial Fulfillment of the Master Degree  
In Nursing Sciences (Community Health Nursing)*

*By*

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*✍Eman Ali Hassan Abd-elhamid*

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## **List of Abbreviations**

<b><i>Abbr.</i></b>	<b><i>Full-term</i></b>
<b>CBC</b>	: Complete blood count
<b>CVS</b>	: Chorionic villus sampling
<b>HbA2</b>	: Hemoglobin
<b>HbF</b>	: Fetal hemoglobin
<b>PGD</b>	: Pre-implantation Genetic Diagnosis
<b>SD</b>	: Standard deviation
<b>SPSS</b>	: Statistical package for social science

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## **Abstract**

### **Quality of Nurses Care Provided for Children with Thalassemia to Meet Their Care Giver's Satisfaction**

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Thalassemia is a genetic blood disorder. **Aim:** The study aim to assess quality of nurse's care provided for children with thalassemia to meet their care giver satisfaction. **Research Design:** The study was descriptive study design. **Study sample:** convenience sample for the nursing staff was 66 nurses and purposive sample for children and their care giver 222 child. **Research setting:** The study will be conducted on all nurses, children aged from 8 to 16years old accompany with care giver at thalassemia unit at Damanhur national medical institute El- Beheira governorate **Tools:** three tools were used, **Tool I:** included following parts: Assess socio-demographic characteristics related to the children with thalassemia, care givers and nurses , assess nurses' knowledge, attitude and performance and blood transfusion for children with thalassemia **Tool II:** medical record for child to assess medical history. **Tool III:** Assess care giver satisfaction regarding performance of the nurses, nurse communication skills, nurse taking care of the psychological state of caregivers of children with thalassemia. **Result:** the majority of the nurses had satisfactory knowledge, positive attitude and had high performance toward children undergoing thalassemia, less than half of care givers satisfied about delivered care nurse and more than one quadrant of them completely satisfied about delivered care nurse such as communication, physical and psychological assessment. **Conclusion:** There is statistical relationship between nurse over all knowledge and age, level of education and low and high performance of nurses and there is statistical significant relationship between overall performance of nurses and satisfaction of care giver of child with thalassemia. **Recommendation:** Developing and performing an in-service training program for nurses emphasizing the weak points to increase their knowledge and practices and continuously supervise this task.

**Keywords:** Quality of nurses' care, Children with thalassemia, Care Giver's Satisfaction

## Introduction

**T**halassemia is a genetic, autosomal recessive hemoglobinopathic disease, it is found worldwide, but most commonly in the mediterranean, it is the most common inherited disorder in the world that represents a major public concern (*He et al., 2017*).

Thalassemia is characterized by a defect in the genes responsible for production of hemoglobin, hemoglobin is a protein that consists of alpha and beta chains, if the genetic mutations prevent any formation of beta chains then beta-thalassemia occurs which involves abnormal development of red blood cells and eventually anemia (*Aljeesh et al., 2016*).

Beta-thalassemia is caused by any of more than 200 mutations that affect different levels of the beta-globin gene expression by a variety of mechanisms (*Siddiqui et al., 2014*).

Beta-thalassemia major is a chronic disorder of blood, having an extensive impact on life and presenting with hemolytic anemia, growth retardation, hepatosplenomegaly and skeletal abnormalities, it often requires regular blood transfusions, iron chelation therapy and sometimes splenectomy for its management, thus, the therapeutic regime is complex, lifelong and inconvenient, requiring repeated hospitalizations and blood transfusions,

which often affects the child's physical and mental health negatively (*Jaripour et al., 2018*).

Children born with thalassemia major are normal at birth, but develop severe anemia during the first year of life. Other symptoms can include bone deformities in the face, fatigue, growth failure, shortness of breath and yellow skin (jaundice) (*Madmoli et al., 2017*).

Blood transfusion is the mainstay of the care for individual with thalassemia major and many with intermediate, the purpose of transfusion are twofold to improve the anemia and to suppress the ineffective erythropoiesis (*Ali et al., 2015*).

Standards of safe blood transfusion must be developed and maintained to ensure a safe and rational approach to the use of blood transfusions in the management of these disorders; also careful consideration must be given to the associated dangers (*Hakeem et al., 2018*).

Quality of care is indicating that the right things are being done right, improving the outcomes for patients, their families and their communities, the criteria used to assess quality could address structure, process or outcome, it is an optimal balance between possibilities realized and a framework of norms and values (*Arian et al., 2019*).

Care giver satisfaction has been advocated as an outcome measure of quality nursing care; determinants of quality of nursing care include adequate skill, caring attitudes, effective communication, efficient organizational and management systems and effective participation (*Chaibunruang et al., 2018*).

Nurses being responsible for the final bedside check before transfusion, have the final opportunity to prevent a miss transfusion. An understanding and knowledge of the pathophysiology of transfusion reactions, symptoms and treatment is essential to safely administer and monitor transfusions (*Abdul-Zahra et al., 2016*).

The nurse should be aware of his/her responsibility for the quality of care provision to the patients, the institution, ethics, laws and professional standards, as well as performance that contributes to the evaluation of care and the patients' satisfaction, the nurse plays a critical role in any team of healthcare professionals involved in the care of patients with chronic diseases including hemoglobin (Hb) disorders such as thalassemia and sickle cell disease (*Siddiqui et al., 2014*).

## **Significant of the study**

Thalassemia represents a major public health problem in Egypt, there are 10,000 registered thalassemia cases and more than 20,000 non-registered cases, beta-thalassemia is the most common genetically inherited hemoglobin disorder in Egypt, 95% are beta thalassemia major; 5% are thalassemia intermedia or hemoglobin H disease, where 1.5 million annual live births, approximately 1000 babies are born with  $\beta$ -thalassemia (*Hakeem et al., 2018*).

## **Aim of the Study**

**This study aims to assess quality of nurse's care provided for children with thalassemia to meet their care giver satisfaction through:**

- 1- Assessing nurses' knowledge regarding thalassemia disease.
- 2- Assessing nurses' attitude regarding children with thalassemia
- 3- Assessing nurses' performance regarding nursing care and blood transfusion for children with thalassemia.
- 4- Assessing medical record of children with thalassemia.
- 5- Assessing satisfaction of care giver of children with thalassemia toward nurses and nursing care.

### **Research questions:**

- 1- Is there a relation between socio- demographics of nurses and their knowledge regarding thalassemia?
- 2- Is there a relation between nurses' knowledge about thalassemia and their performance?
- 3- Is there a relation between nurses' performance and satisfaction of care giver?