

**Barriers Hindering Maternal Care of
Children Suffering from Thalassemia:
An Assessment Study**

Thesis

*Submitted for Partial Fulfillment of the Requirement
for the Master Degree in Pediatric Nursing*

By

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List of CONTENTS

Title	Page No
• LIST OF TABLES	I
• LIST OF FIGURES	III
• LIST OF ABBREVIATIONS	IV
• ABSTRACT	
• INTRODUCTION & AIM OF THE STUDY	1
• REVIEW OF LITERATURE	6
✍Part 1: Overview about Thalassemia	6
✍Part 2: Barriers Hindering Maternal Care of their Children Suffering From Thalassemia	53
✍Part 3: Maternal Practices in Care of their Children Suffering From Thalassemia	67
✍Part 4: Role of Nurse in Care of Thalassemic Children	70
• SUBJECT & METHODS	82
• RESULTS	88
• DISCUSSION	127
• CONCLUSION & RECOMMENDATIONS	140
• SUMMARY	142
• REFERENCES	151
• APPENDICES	194
• ARABIC SUMMARY	

List of Tables

Table No.	Title	Page No.
(1)	Distribution of Studied Children according to their Characteristics.	89
(2)	Distribution of the Studied Mothers according to their Characteristics.	93
(3)	Distribution of the Studied Mothers according to their Family Characteristics.	96
(4)	Distribution of the Studied Mothers according to their Home Condition.	97
(5)	Distribution of the Studied Mothers according to Financial Burden of Thalassemia Management and Financial Support.	98
(6)	Distribution of Thalassemic Children according to their Time of Symptoms Appearance, Duration of Illness, Parent Consanguinity and Past Family History of Thalassemia.	99
(7)	Distribution of the Studied Children according to their Types of Iron Chelation Therapy.	100
(8)	Distribution of the Studied Mothers according to their Knowledge regarding to Knowledge Function of the Blood, RBCs and Hemoglobin.	101
(9)	Distribution of the Studied Mothers according to their Knowledge regarding to Thalassemia.	102
(10)	Distribution of the Studied Mothers according to their Knowledge regarding to the Types of Laboratory Investigations for Diagnosis of Thalassemia and before Blood Transfusion.	103
(11)	Distribution of the Studied Mothers according to Frequency and Type of Periodic Investigations of their Thalassemic Children Namely Physical Assessment, Laboratory Investigations and Cardiac Examination.	104

Table No.	Title	Page No.
(12)	Distribution of the Studied Mother's Knowledge regarding to the Types of Pre-marital Medical Examinations and Importance of Pre-marital Genetic Counseling.	105
(13)	Distribution of the Studied Mothers and their Children according to their Compliance with Iron Chelation Therapy, Causes of Not Compliance, Injection and Routes of Desferal Injection.	106
(14)	Distribution the Studied Mothers of their Children according to Types of Thalassemic Management, Compliance and Complications of Blood Transfusion.	107
(15)	Distribution of the Studied Mothers according to their Total Knowledge regarding to Thalassemic Children.	109
(16)	Physical Barriers related to Thalassemic Children.	110
(17)	Psychological Barriers related to Thalassemic Children.	111
(18)	Social Barriers related to Thalassemic Children.	112
(19)	Spiritual Barriers related to Thalassemic Children.	113
(20)	Nutritional Barriers related to Thalassemic Children	114
(21)	Educational Barriers related to Thalassemic Children.	115
(22)	Financial Barriers related to Thalassemic Children.	116
(23)	Barriers of Side Effects of Iron Chelation Therapy on their Thalassemic Children.	117
(24)	Distribution of the Studied Mothers according to their Total Barriers regarding to Thalassemic Children.	118
(25)	Relation between Socio-Demographic Characteristics of the Studied Mothers Family and their Total Knowledge regarding to Care of their Thalassemic Children.	119

(26)	Relation between Socio-Demographic Characteristics of the Studied Family and their Total Knowledge regarding to Care of their Thalassemic Children.	120
(27)	Relation between Financial Support of Thalassemic Treatment of the Studied Mothers and their Total Knowledge regarding to Care of their Thalassemic Children.	121
(28)	Relation between Socio-Demographic Characteristics of the Studied Mothers and their Barriers regarding to Thalassemia.	122
(29)	Relation between Socio-Demographic Characteristics of the Studied Family and their Barriers regarding to Care of their Thalassemic Children.	123
(30)	Relation between Financial Support of Thalassemic Treatment of the Studied Mothers and their Barriers regarding to Care of their Thalassemic Children.	124
(31)	Relation between Total Knowledge of the Studied Mothers and Total Barriers regarding to Care of their Thalassemic Children.	125
(32)	Correlation between Mother's Total Knowledge of Thalassemia and Total Knowledge of Barriers.	126

List of Figures

Figures No.	Title	Page No.
Literature Review		
(1)	Normal and Abnormal Hemoglobin	7
(2)	Hemoglobin Molecules	9
(3)	Composition of Four Globin Chains	10
(4)	Bone Deformities of Thalassemic Children	15
(5)	Lenticular Opacities and Iris Pigmentary Change	17
(6)	Facial Features of Thalassemia	18
(7)	Musculoskeletal Manifestations in Thalassemia	23
(8)	Bone Marrow Aspiration	24
(9)	Iron overload in Thalassemic Children	27
(10)	Splenomegaly	29
(11)	Complications of Thalassemia in Children	30
(12)	Craniofacial Characteristics of Thalassemia	33
Results		
(1)	Distribution of the Studied Children according to their Age in Years	90
(2)	Distribution of the Studied Children according to their Gender	91
(3)	Distribution of the Studied Children according to their Rank	92
(4)	Distribution of the Studied Mother's according to their Marital Status	94
(5)	Distribution of the Studied Mother's according to their Educational Level	95
(6)	Distribution the Studied Mothers of their Children according to Types of Thalassemic Management	108

List of Abbreviations

Abbreviations	Meaning
A	Alpha
B	Beta
γ	Gamma
Δ	Delta
BMA	Bone Marrow Aspiration
DFO	Deferoxamine
DFP	Deferiprone
DFX	Deferasirox
GH	Growth Hormone
HbA	Adult Hemoglobin
HbE	Embryonic Hemoglobin
HbF	Fetal Hemoglobin
MCV	Mean Corpuscular Volume

Barriers Hindering Maternal Care of Children Suffering from Thalassemia: An Assessment Study

ABSTRACT

Background: Thalassemia is a group of genetic disorders of blood, characterized by decreased synthesis of one or two types of polypeptide chain (α or β) that form abnormal human hemoglobin molecules. **Aim of this study:** was to assess barriers hindering maternal care of their children suffering from thalassemia. **Research design:** A descriptive design was adopted in carry out this study. **Setting:** The study was conducted at Pediatric Hematology Outpatient Clinic in both Ain Shams University and Zagazig University Hospitals. **Subject:** A Purposive sample composed of 100 mothers (50 from each study setting) provided care to their children suffering from thalassemia. **Tools of data collection:** An interviewing questionnaire sheet that was designed by the researcher to assess barriers hindering maternal care of their children suffering from thalassemia. **Results:** Barriers hindering maternal care of their thalassemic children physical (short stature), psychological (body image), social (isolation) and educational (lack of concentration). **Conclusion:** Most of the studied mothers were having physical, psychological, social, spiritual, nutritional, educational and financial barriers that hinder care of their children suffering from thalassemia. **Recommendations:** Periodic assessment of maternal practices in care of their thalassemic children and identify barriers hindering maternal care.

Keywords: Thalassemia, Barriers, Maternal Care, Pediatric, Nursing.

INTRODUCTION

Thalassemia is the most common hereditary disease in the world that is considered as one of the health problems in Egypt with high prevalence. The role of the family in children's care is very important. Due to the chronic nature of thalassemia, in spite of its physical symptoms, it gives rise to psychosocial and economic problems for the pediatric patients and their families (Vichinsky, 2016).

Thalassemia includes a number of different forms of anemia (red blood cell deficiency). The two main types are called alpha (α) and beta (β) thalassemia depending on which part of oxygen carrying protein (called hemoglobin) is lacking in red blood cells. Thalassemia can impose many adverse effects on individuals, families and society. Therefore it's necessary to identify the needs of thalassemic children's parents and determination of needs to assessment and satisfaction (Abbaspour, et al., 2014).

Thalassemia is a genetic blood disorder that requires a life-long treatment of blood transfusion and chelating therapy. It poses a range of stressors and challenges for the pediatric patients, their families and healthcare team (Mansilla-Soto, et al., 2016).

The use of frequent blood transfusion and antibodies have improving the condition for children with thalassemia. Frequent

blood transfusion makes their hemoglobin level near normal and prevent many complications of thalassemia. But repeated blood transfusion leads to iron overload, a build iron in the body can damage the heart, liver and other organs. Without treatment, the spleen, liver and heart soon become greatly enlarged. Bones become thin and brittle face bones become distorted and often look alike heart failure and infection are the leading causes of death among children with untreated thalassemia (**Shenoy, et al., 2017**).

Mothers of children with thalassemia had insufficient information regarding care of their children's health problems. Mothers have the most responsibility to care for their children, have the potential to promote positive and proactive interactions with the family members and can promote independence and the acquisition of thalassemia care skills. Therefore, families having children with thalassemia need specific interventions that promote optimal family functioning and family empowerment (**Ishfaq, et al., 2015**).

The poverty, illiteracy, endogamous marriages, lack of anti-thalassemic program and lack of awareness are the major barriers towards the better treatment and prevalence of thalassemia (**Ishfaq, et al., 2013**). Nurses play a crucial role in monitoring and managing pediatric patients with thalassemia and teaching their

mothers the proper care and follow up. Help children and parents to talk and to express feelings about the illness to accept the illness and to take care of him/her. Facilitate a normal lifestyle and encourage self-esteem as well as support the full development of an adult life. Mothers are the primary caregivers. Therefore, understanding their perception of having a child with thalassemia is very important (**Lavin, et al., 2015**).

SIGNIFICANCE OF THE STUDY

Thalassemia constitute a major health problem as a wide world hereditary disease with high incidence (7.5 million) in Egypt along with the high frequency of consanguineous marriages. This study aimed to explore barriers and challenges facing mothers in care of their thalassemic children. In children with various types of thalassemia, mortality and morbidity vary according to the severity of the disease and the quality of care provided. Severe cases of thalassemia are fatal if not treated (**Salama, et al., 2015**).

The significant impact of thalassemia on the pediatric patients and their families include physical and financial state, emotional wellbeing and social activities. The majority of the children's parents were cousins because they haven't been screened for thalassemia before marriage and they were unaware of prenatal diagnosis, therefore the level of parent's awareness with thalassemia must be elevated (**Sayani and Kwiatkowski, 2015**).

AIM OF THE STUDY

This study aimed to assess barriers hindering maternal care of their children suffering from thalassemia.

RESEARCH QUESTION

Research Question:

What are the maternal barriers hindering care for their children suffering from thalassemia?