

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

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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 utilized in carry out this study. **Setting:** The study was conducted in Pediatric Hematology Outpatient Clinic at 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:** Most of the studied mothers were having physical, psychological, nutritional, educational barriers and sleep disorders that hinder care of their children suffering from thalassemia. **Conclusion:** There are barriers that prevent the mothers from provide care of children with thalassemia and considers physical barriers as the main barriers are meeting the mothers when care her child with thalassemia. **Recommendations:** Periodic assessment of maternal practices in care of their thalassemic children and Identify barriers hindering maternal care.

Key words: Thalassemia, Barriers, Maternal Care, Pediatric, Nursing.

Introduction

Thalassemia is a group of autosomal recessive genetic disorders characterized by abnormalities in synthesis of the globin of Hb. Disorders of the alpha and beta globin polypeptides, which cause imbalance in the production of the globin and lead to an overall deficiency of pediatric Hb (John, 2012). The term thalassemia which is derived from the Greek word (thalass meaning sea and emia meaning blood). In addition to, thalassemia can cause many adverse effects on individuals, families and society (Rani, et al., 2013).

The poverty, illiteracy, endogamous marriages, lack of anti-thalassemic program and lack of awareness to disease are among the major barriers towards the better treatment of the thalassemic children and prevalence of the disease.

Mothers of children with thalassemia, had insufficient information on how to solve children health problems, provide the best child-care and child-rearing practices. Mothers have the most responsibility to care for their children, have the potential to promote positive and proactive interactions with families 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 (Wacharasin, et al., 2015).

Mothers play the key role in provision of care to their children. This may cause burden and most mothers need support. Mothers need to assess barriers and burden when care of their children with thalassemia (Mashayekhi, et al., 2014).

Nurses play a crucial role in overcome and managing barriers of pediatric patients which develop transfusion-related iron overload from receiving red blood cell transfusions for chronic anemia. Understanding iron overload is critical to prevent life-threatening consequences, including end-organ damage (Oncology Nurse Advisor, 2016).

Significance of the study

Thalassemia is a hereditary disease with high incidence in Egypt along with the high frequency of consanguineous marriages. The burden of this disorder in many regions is a magnitude that it represents a major public health concern, β -thalassemia in Egypt (9 %) and carrier rate of 9-10.2%. 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 fetal if not treated (Salama, et al., 2015).

Aim of the study

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

Research Questions:

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

Subject and Methods

The subject and methods of the current study are discussed under the following four designs:

- I. Research Design
- II. Operational Design
- III. Administrative Design
- IV. Statistical Design

Research design:

A descriptive design was utilized to achieve the aim of this study.

Study setting:

The study was conducted at Hematology Pediatric Outpatient Clinics affiliated to both Ain Shams University and Zagazig University Hospitals.

Subjects:

A purposive sample of 100 mothers (50 from each study setting) having children suffering from thalassemia and attending the previously mentioned study setting. Data was collected over period of 6 months. Inclusion criteria: all children suffering from thalassemia and their accompanying mothers regardless their characteristics (age, educational level, residence and socioeconomic standards). Exclusion criteria: children suffering from any acute and/ or chronic illness.

Technical design

Tool of data collection:

Interview questionnaire sheet:

The questionnaire was designed by the researcher after reviewing the related literature and was written in simple Arabic language to suit studied sample level of understanding as the following parts:

Part (1): It included characteristics of the studied children and their mothers (as age, level of education), family (as family type, residence, the number of children in the family, consanguinity) and home

environment (as type of home, number of rooms).

Part (2): Questions to assess the mother's knowledge about thalassemia disease (definition, causes, manifestations, complications and treatment).

Questions were in the form of open, close-ended and multiple choices. The time consumed to fill out the questionnaire by the researcher for each mother was 15-20 minutes.

❖ **Scoring system**

Two scores for good knowledge, one for average knowledge and zero for poor knowledge. The total score level for the mother's knowledge was 80 scores.

The maternal knowledge was checked with a model key answer and accordingly their knowledge were categorized into either score < 60% for unsatisfactory knowledge and score from $60 \leq 100$ for satisfactory knowledge.

Part (3): Barriers hindering maternal care of their children suffering from thalassemia (physical, psychological and nutritional barriers).

❖ **Scoring system**

One score for children without barriers and zero score for children with barriers. The scores of items were categorized into both present barriers in the children score < 60% and not present barriers score from $60 \leq 100$.

Operational design

The operational design for the study entails three main phases:

Preparatory Phase:

A review of the past and current local and international related literature using

books, journals, scientific periodicals, magazines and online was done to develop the study tool and to get acquainted with the various aspects of the research problem.

Tool validity was evaluated by a jury of experts in the field of the study to assure its content validity.

Exploratory phase:

A Pilot study was conducted including 10% of the sample size to evaluate efficiency and validity of the study tool. Results of the pilot study were helped in a necessary modification of the used tool. The partionals in the pilot were excluded later for the study.

Field work:

The actual field work was carried out over 6 months period from the first week of March, 2017 to the end of August, 2017. The researcher was available in the above-mentioned setting 2days/week (Saturday and Sunday) from 9 am to 2 pm.

Each mother was interviewed individually to gather the necessary data of the study. The researcher started by introducing herself to the mother gave them a brief idea about the study and its expected outcomes.

Administrative design:

An official permission was obtained from the director of each study setting through a formal letter that was issued by the Dean of the Faculty of Nursing, Ain Shams University to the administrator of the study setting. The aim of the study and it's expected outcomes were explained.

Ethical consideration:

Each study will be informed that the collected data will be used for the research purpose only, the study is harmless and confidentiality will be secured.

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Statistical analysis:

The data collected were revised, coded, tabulated and statistically analyzed by using

a number and percentage distribution, means, standard deviation and chi-square test were used to estimate the statistically significant difference between variables of the study.

Result

Table (1): Distribution of the Studied Children according to their Characteristics (n=100).

Children's Data	No	%
Age in years:		
1: < 3	7	7
3 : < 6	25	25
6 : < 12	31	31
12 ≤ 18	37	37
$\bar{X} \pm SD$	10.41 ± 6.77	
Gender :		
Male	48	48
Female	52	52
Rank :		
1 st	39	39
2 nd	19	19
3 rd	3	3
The last	26	26
The only	13	13
Educational level:		
Beyond	38	38
Primary	26	26
Middle school	5	5
Secondary	31	31
Compliance in school attendance:		
Yes	21	21
No	79	79

Table (1): This table shows that, the mean age of children was 10.41 ± 6.77 years. As regards children's gender, it was found that (52%) were females and the rest of them (48%) were males. 39% were ranked as the first child and (38%) of them were beyond the age of education. Also, (79%) of them were not complying in their school attendance.

Table (2): Distribution of the Studied Mothers according to their Characteristics(n=100).

Mother's Data	No	%
Age in years:		
< 20	2	2
20:< 30	25	25
30:< 40	54	54
≥ 40	19	19
$\bar{X} \pm SD$	34.59±11.41	
Educationallevel:		
Illiterate	20	20
Read and write	14	14
Technical diploma	55	55
University	11	11
Marital status of the mothers:		
Married	89	89
Widowed	10	10
Divorced	1	1
Job of the mothers:		
Employed	73	73
Housewife	27	27

Table (2): This table shows that, the mean age of the studied mothers was 34.59±11.41years and it was found that (55%) of the mothers were qualified with a technical diploma. As regards marital status of mothers, it was found that (89%) of them were married. Also, (73%) of them were housewives.

Table (3): Distribution of the Studied Mothers according to their Financial Burden of Thalassemia Management and Financial Support(n=100).

Mother's Data	No	%
Cost of thalassemia burden on family:		
Yes	98	98
No	2	2
Financial support for treatment of thalassemia		
Health insurance hospitals	85	85
On country's cost	13	13
Special	2	2

Table (3): This table shows that, the majority (98%) of the studied mothers reported that thalassemia management imposes financial burden on family and (85%) of them mentioned that they receive financial support from health insurance hospitals.

Table (4): Distribution of Thalassemic Children according to their Past Medical Historyand Consanguinity between Parents of the Children(n=100).

Children's Data	No	%
Consanguinity between parents of the child:		
Yes	60	60
No	40	40
Past family history of thalassemia:		
Yes	62	62
No	38	38

Table (4): This table shows that, (60%) of the studied children have consanguinity between parents of the child and (62%) of them have past family history.

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Table (5): Distribution of the Studied Mothers according to their Knowledge regarding to Thalassemia (n =100).

Items	Complete Correct Knowledge		Incomplete Correct Knowledge		Incorrect Knowledge	
	No	%	No	%	No	%
Concept of thalassemia	50	50	26	26	24	24
Causes of thalassemia	73	73	25	25	2	2
Signs and symptoms of thalassemia	65	65	30	30	5	5
Complications of thalassemia	73	73	21	21	6	6
Prevention of complications related to thalassemia	82	82	15	15	3	3

Table (5): This table reveals that, (50%), (73%), (65%) and (82%) of the studied mothers had complete correct knowledge about the concept of thalassemia, causes, signs and symptoms, complications of thalassemia and prevention of complications related to thalassemia respectively.

Table (6): Physical Barriers Related to Thalassemic Children (n=100).

Items	Yes		No	
	No	%	No	%
Physical Barriers				
Facial changes	78	78	22	22
Short stature	80	80	20	20
Retardation of growth	31	31	69	69
Blood transfusion reactions	47	47	53	53

Table (6): This table clarifies that, as regard physical barriers 78%, 80%, 31% and 47% of the studied children have facial changes, short stature, retardation of growth and some reactions related to blood transfusion respectively.

Table (7): Psychological Barriers Related to Thalassemic Children (n =100).

Items	Yes		No	
	No	%	No	%
Psychological Barriers				
Change in body image	27	27	73	73
Change in life style	53	53	47	47
Poor relationship with others	77	77	23	23
Feel different from others children	91	91	8	8

Table (7): This table clarifies that, as regard psychological barriers 27%, 53%, 77% and 91% of the studied children have change in body, change in life style, poor relationship and feel different from others children respectively.

Table (8): Social Barriers Related to Thalassemic Children (n =100).

Items	Yes		No	
	No	%	No	%
Social Barriers				
Social isolated and withdrawal	86	86	32	32
Hospitalization of thalassemic children	57	57	43	43
Social stigma and identity	11	11	89	89
			8	8

Table (8): This table clarifies that, as regard social barriers 86%, 57% and 11% of the studied children facing social isolated and withdrawal, hospitalization of thalassemic children and social stigma and identity respectively.

Table (9): Nutritional Barriers related to Thalassemic Children (n=100).

Items	Yes		No	
	No	%	No	%
Nutritional Barriers				
Avoid food contain iron	27	27	73	73
Take food decrease absorption of iron	40	40	60	60
Take calcium and vitamin D regularly	20	20	80	80

Table (9): This table clarifies that, as regard nutritional barriers 73%, 60% and 80% of the studied children don't avoid food contain iron, don't take food that decrease absorption of iron and don't take calcium and vitamin D regularly respectively.

Table (10): Educational Barriers of their children (n=100).

Items	Yes		No	
	No	%	No	%
Educational Barriers				
Poor school performance	72	72	28	28
Compliance in school attendance	40	40	60	60
Lack of concentration	56	56	44	44

Table (10): This table clarifies that, as regard educational barriers 72%, 60% and 56% of the studied children occur poor school performance, not compliance in school attendance and lack of concentration respectively.

Table (11): Relation between Total Knowledge of the Studied Mothers and Total Barriers regarding to Thalassaemia (n=100).

Mother's Total Knowledge Regarding to All Barriers	Children total knowledge regarding thalassaemia				Chi-square test	
	Satisfactory (n=70)		Unsatisfactory (n=30)			
	No	%	No	%	x ²	p-value
Satisfactory (n=44)	39	55.7%	5	16.7%	11.458	0.007*
Unsatisfactory (n=56)	31	44.3%	25	83.3%		

Table (11): This table shows that, there are statistically insignificant differences between knowledge of the studied mothers and their barriers regarding to thalassaemia p-value (>0.05).

Table (12): Correlation between Mother's Total Knowledge of Thalassemia and Total Knowledge of Barriers (n=100).

Items	Children total knowledge regarding thalassemia	
	r	p-value
Mothers total knowledge regarding to all barriers	0.521	0.012*

Table (12): This table clarifies that, positive correlation and significant between mothers total knowledge of thalassemia and total knowledge of barriers, which increase knowledge lead to increase ability to overcome the barriers.

Discussion

Thalassemia is a genetic blood disorder that considered as a major public health problem. It is a challenge for the pediatric patients, their families and health care system since it requires a life-long treatment of blood transfusion and chelating drugs. Maternal education is an essential component in providing care of their thalassemic children.

Regarding to children characteristics, the results of the present study revealed that, more than one-third of the studied children were at the age group from 12 to 18 with $\bar{x}SD10.41 \pm 6.77$ and more than half of them are female. Also, more than one third of them are ranked as the first child . This result is consistent with (Tantiworawit et al., 2016) study which entitled "The Prevalence and Risk Factors for Cardiac Iron Overload and Cardiovascular Complications among Patients with Thalassemia in Northern Thailand" they reported that, less than two thirds of the studied children are females and more than half was the first born child in the family.

Concerning to educational level of the studied children results of the current study revealed that, more than one-third of studied children under beyond level of education and more than three-quarters not complying education according to their ages and the rest of them not complying education because of difficult regular in education. The young ages and the educational level could help to increase disease and how to avoid it. This result is agreement with (Yahia et al., 2013) study "The Predictors of Anxiety and

depression in Egyptian Thalassemic Patients" they stated that, parents considered thalassemia as a factor that makes their children slow learners and low level of education and the studied children not complying their education they reported that, occur increase absence level from school because learning difficulties to understanding the information and low level of concentration related to thalassemic complications.

According to mothers characteristics, the results of the current study concluded that, more than half of them between age 30 to 40 years and with $\bar{x}SD 34.59 \pm 11.4$, more than half of them had technical diploma and more than four-fifths of them are married. Also, about three-quarters of them were housewives and more than half of them from the rural areas. As regard their family income about three-quarters of them reported 500: <1000 pounds, monthly. This result is agreement with (Mostafa and AbdElaziz, 2014) study "Factors Affecting Compliance Plan of Thalassemic Children and Their Mothers in the Outpatient Clinic at Zagazig University Hospitals" they reported that, more than half of mothers were from rural area and more than one-third of them were qualified diploma education. Majority of mothers were housewives and more than one-third of them had insufficiently monthly income but disagreement with fifty mothers were aged from 20 to 30 years.

Regarding to marital status of the mothers, the result of the current study

concluded that, more than four-fifths of them are married. In the same line with **(Mirbehbahani, et al., 2014)** study which entitled "Prevalence and Intensity of Depression in Mothers of Children with β -Thalassemia Major in Talghani Hospital of Gorgan, Iran" they found that, more than three-quarters of them are married.

Concerning to residential areas of the studied children the result of the present study mentioned that, more than half of the studied children have past family history of thalassemia while about two-third have consanguinity between parents of the child. Also, a majority of financial support of treatments through health insurance. This result is agreement with **(Goyal, et al., 2015)** study "Awareness among Parents of Children with Thalassemia Major from Western India" show that, more than half of them have past family history of thalassemia and less than one third have consanguinity in the family from brothers. The frequency of consanguineous marriages this may be due to lack of proper knowledge about premarital counseling and not opting for genetic testing during pregnancy

This result in disagreement with **Mostafa and Abdelaziz (2014)** show, half of them have good knowledge of the concept of thalassemia and two-thirds of them have good knowledge of causes, sign and symptoms and complications of thalassemia. Also, about four-fifths of them have good knowledge of prevention complications related to thalassemia.

Regarding to physical barriers the present study show that, more than half of the studied children don't participate in any type of activities and nearly half of them don't participate because the fear of feeling tired and symptoms occur when doing an effort. More than two-thirds occur differently because of the change in physical appearance, physical capacity. This result in accordance with **(Saha, at al., 2016)** study "School Functioning Activity of Bengali Thalassemic Children Attending A Tertiary Care Hospital of Eastern India" show that, half of the thalassemic children had fair to cooperate in activities because symptoms.

In the current study reported that, less half of them occur shortness in the height because of the accumulation of iron in the body and glands and reduce secretion of growth hormone. This result in agreement with **(Baker, et al., 2013)** study "Growth Pattern And Sexual Maturation Rate in β -Thalassemia Major Patients from Thalassemia Center Erbil" show that, more than half of thalassemic children were underweight and more than three-quarters was short stature. Also, about the total number of thalassemic children occur delayed in sexual maturation and have risk factors for growth failure as result from direct relation to iron toxicity especially endocrine glands to decrease growth hormone.

In the current study show that, more than half thalassemic children feel unsatisfaction and more than four-fifths of them feel different from other children. This result highly supported with **(Baiee, et al., 2014)** study "Depression among Children of Children with Thalassemia in Babylon Province Iraq" mentioned that, more than three-quarters feel unsatisfaction because impact on social life negative self-concept from others lead to lack of trust, loss of self-esteem, increased dependence and fear of being ridiculed causes of different. Also, more than three quarters didn't discuss their illness with friends.

The result are in accordance with **(AbdElmoneim, at al., 2015)** study "The Impact of Diet Modification on Serum Ferritin Level in Thalassemia Children in Almadinah Almounourah, KSA" reported that, less than three-quarters of children take food that reduce iron absorption and avoid food that increases iron absorption. Also, more than four-fifths of them follow thalassemic nutritional guidelines and important of food regulation. Control of diet through the limitation of foods that contain higher levels is a way to minimize iron intake in thalassemic patients. Recently, certain foods and beverages are found to help iron body excretion and minimize iron absorption.

The results are in agreement with **(Saha, at al., 2016)** show that, more than half of children thalassemia affect on concentration and more than one-third of children were

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absenteeism from school or not compliance at work because about half of them have difficult in concentration and understanding their lessons and slightly one-quarter of the children were presently not going to school.

The result is agreement with **(Rogers and Lance 2017)** study "Sleep, Fatigue and Neurodevelopmental Outcomes in Pediatric Sickle Cell Disease in the USA" show that, more than half of thalassemic children occur sleep disorders such as short duration and poor quality sleep due to pain walking early or poor sleep hygiene or both. Sleep problems have been associated with lower academic achievement, cognition and behavioral performance in thalassemic children about healthy children memory.

Regarding to side effects of desferal the present study show that, most of the studied children were occurred topical effects in injection site and less than half of them occurred nausea, vomiting and abdominal pain due to desferal. This result is accordance with **(Fathi, et al., 2017)** study "Evaluation of Desferal Efficacy in Reducing Ferritin Levels in Patients with Thalassemia Major in Iran" reported that, nausea and vomiting are the most prevalent side-effect and topical effects in the site of injection in patients after receiving desferal.

Regarding to side effects of exjad the present study shows that, more than half of the studied children were occurred vision, hearing loss and night blindness and five-sixths of them occur change liver and kidney enzymes. This result in accordance with **(Ashayeri, et al., 2016)** study "Efficacy of Deferasirox (Exjade) Versus Desferal in the Treatment of Iron Overload in Patients with β -Thalassemia Major in Iran", reported that, skin rash was seen in more than one-quarter of patients and increasing liver transaminase levels. The rising of serum creatinine and kidney failure was significantly higher in more than half and vision and hearing loss in exjade group. This result may be due to side effects of exjade.

The result are is accordance with **(Belen, et al., 2016)** study "Frequency of Neutropenia among Turkish and Syrian Pediatric Thalassemia Patients under Deferiprone Monotherapy" reported that, less than two-thirds of the studied children was occurred leucopenia and thrombocytopenia due to side effects of kelfar. Also, more than one-third of them was occurring a change in appetite, urine and half of them occur arthritis and zinc deficiency due to side effects of ferriprox.

Regarding to relation between total knowledge of thalassemia of the studied mothers and their total knowledge of barriers of thalassemia reported that, there are statistically significant differences between knowledge of the studied mothers and their barriers regarding thalassemia. This result in disagreement with **(Karimzaei, et al., 2015)** study "Knowledge, Attitude and Practice of Carrier Thalassemia Marriage Volunteer in the Prevention of Major Thalassemi" a show that, positive correlation with knowledge, behavior, perceived barriers of the children. This result may be due to when increase level of knowledge of mothers lead to decrease barriers.

Conclusion

The current study concluded that barriers hindering maternal care of their thalassemic children were having physical, psychological, social, spiritual, nutritional, educational and financial barriers in addition to side effect of iron chelation therapy in care of their children suffering from thalassemia.

Recommendations

Periodic assessments of maternal practices in care of their thalassemic children and identify barriers hindering maternal care and educates them to overcome of these barriers.

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