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# Nursing Intervention Program for Mothers toward Care of their Children with Thalassemia

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#### Abstract

Thalassemia is an inherited blood disorder among children cause mild or severe anemia, which can damage organs and lead to death. The study aimed to evaluate the effect of nursing intervention program for mothers toward care of their children with thalassemia. Research design: A quasi experimental study was used. Setting: The study was conducted at Pediatric Specialist Clinics (hematology clinic) at Pediatric hospital affiliated to Ain Shams University hospitals in Egypt. Sample: A purposive sample was used for choosing the study subjects; composed of 75 mothers of children diagnosed with thalassemia. Tools: Three tools were used to collect data: tool 1) An interviewing questionnaire for assessing the socio-demographic characteristics of the studied sample, medical history, health needs and problems of children, and mothers' knowledge and report practices level about care of their children with thalassemia. 2) Child medical record. 3) Children physical assessment sheet. Results: indicated that, proportion of mothers had unsatisfactory knowledge about thalassemia and its treatment, and 61.3% of them, had inadequate level of total practices toward care provided for their children with thalassemia preprogram while post program, it showed highly statistically significant improvement (X2 = 91.679 &52.920 at P < 0.000). Also, there was insignificant negative correlation between complications of the studied children and the total mothers' knowledge/ practices about thalassemia pre and post program intervention. Conclusion: The study proved that there was a significant positive improvement in mothers' knowledge and practices level related to care of their children with thalassemia through implementation of the nursing intervention program for mothers which had a positive effect on the health status of their children. Recommendations: dissemination of the booklets about care of thalassemia for all mothers as a guide and standardized reference to motivate them for continuity of improving the health status of those children.

Keywords: Children with thalassemia, nursing intervention program.

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# Introduction

Thalassemia is a heterogeneous grouping of genetic disorders that result from a decreased synthesis of alpha or beta chains of hemoglobin (Hb).<sup>1</sup> Hemoglobin serves as the oxygen-carrying component of the red blood cells. It consists of two proteins, an alpha and a beta. If the body does not manufacture enough of one or the other of these two proteins, the red blood cells do not form correctly and cannot carry sufficient oxygen; this causes anemia that begins in early childhood and lasts throughout life. Thalassemia is an inherited disease; meaning that at least one of the parents must be a carrier for the disease.<sup>2</sup> It is caused by either a genetic mutation or a deletion of certain key gene fragments.<sup>3</sup>

Globally the thalassemia has a high incidence in a broad area extending from the Mediterranean basin and parts of Africa, throughout the Middle East, the Indian subcontinent, Southeast Asia, and Melanesia into the Pacific Islands. Globally, it is estimated that there are 270 million carriers with abnormal hemoglobin and thalassemia, of which 80 million are carriers of  $\beta$ -thalassemia. Recent surveys suggest that between 300,000 and 400,000 babies are born with a serious hemoglobin disorder each year (23,000 with  $\beta$ -thalassemia major) and that up to 90% of these births occur in low- or middle-income countries.<sup>4-5</sup>

Nurses play a critical role in instructing the patients and their family about the detection and reporting the serious symptoms such as fever or pain clarifying the importance of cleanliness and encouraging interaction with other health professionals especially the psychologist, family support is considered essential in managing thalassemia and this is aided through maintaining regular and prompt contact.<sup>6-7</sup>

Children with thalassemia often requires regular blood transfusions and iron chelation therapy for its management. Thus, the therapeutic regime is complex, requiring repeated hospitalizations and blood transfusions lifelong.<sup>8-9</sup> which often affects the child's physical and mental health negatively. So, mothers of those children having knowledge and health related practices about thalassemia will improve quality of health care and improve satisfaction of children with thalassemia.<sup>10</sup>

In Egypt there are 10,000 registered thal assemia cases and more than 20,000 non-registered cases. 95% are bet a thalassemia major; 5% are thalassemia intermedia or hae moglobin H disease.  $^{11}$ 

The current study was planned to assess mothers' knowledge and practices regarding care of thalassemia, to assess health status of children suffering from thalassemia, and evaluate the effect of nursing intervention programs on mothers' knowledge and practices toward care of their children with thalassemia. It was hypothesised that the nursing intervention program will improve mothers' knowledge and practices toward care of their children with thalassemia and their health status.

# Materials and Methods

A Quasi-experimental study was conducted between December 2020 and May 2021 at the Paediatric Specialist Clinics (Haematology clinic) at El-Demerdash Children's Hospital, affiliated to Ain Shams University hospitals, Cairo Governorate, Egypt after approval from the scientific research and ethical committee in faculty of nursing at Ain Shams University. The sample size was calculated using Epi-Tool, <sup>12</sup> with estimated Proportion= 0.3, desired precision of estimate =0.05, and confidence level 0.95. The sample was raised using non-probability purposive sampling technique<sup>13</sup> from the mothers attending Haematology clinic where follow-up and medical treatment are carried out in for their children with thalassemia. Those included were children diagnosed with thalassemia and aged from 6-12 years.

The tools used for assessment were an interviewing questionnaire which consisted of 5 parts, first, to assess the socio demographic data for mothers and demographic data for their children with thalassemia, second, to assess health status of children such as the complications of the disease, history of allergy, abdominal ultrasound done, enlarged liver and spleen

(Hepatosplenomegaly), allergic reaction post blood transfusion, symptoms of allergy experienced by the child, complications.

Third part, to assess the mothers' knowledge about thalassemia which consisted of 15 closed ended questions including: meaning of thalassemia, causes, symptoms and signs, methods of treatment, complications of thalassemia and its methods of prevention, also medication therapy of thalassemia, complications of frequent blood transfusion, problems of increasing iron in the blood, methods to identify high iron level, iron deficiency medication's function (Desferal or Jedneu), its side effects, and contra indication, also methods of elimination of the accumulated iron in the body. Fourth part to assess the mothers' knowledge about factors of non-adherence to thalassemia treatment. Scoring system of knowledge was calculated as follow: A correct answer was scored (1) and the incorrect answer was (zero), the total mothers' knowledge was categorised into two levels: Satisfactory knowledge  $\geq$  50%, and unsatisfactory knowledge < 50%.

The fifth part to assess the mothers' reported practices related to health care provided to their children with thalassemia which consisted of 11 open and 5 closed ended questions including: mothers' role if child has a common cold or pneumonia, follow up the doctor when the child has different symptoms, their role to protect children from infectious diseases, during fever, during difficulty in breathing, care of the children' teeth and protecting them from decay, their role when medication complications occur, role in maintaining proper nutrition for children, and role when children engages in sports activities. Scoring system of practices. The score ranged from zero to one, (inadequate = zero) and (adequate =1). The all items of total mothers' reported practices toward health care of their children with thalassemia were categorized into two levels as followings: Adequate practices  $\geq 50\%$ , and inadequate practices < 50%.

Content and face validity were performed by two professors of the Community Health Nursing department of Faculty of Nursing and one assistant professor of the Paediatric Haematology department, Faculty of Medicine, Ain Shams University, Egypt; they reviewed the tools for content accuracy. The reliability test was done by using the Cronbach alpha test which showed good internal consistency and homogeneity of items (Cronbach alpha = 0.887) through SPSS program version 21. The researchers carried out the pilot study on 10% of the study subjects (8 mothers) and made necessary modifications. Pilot sample was excluded from the study sample.

After taking informed consent from all the subjects, a template was used to systematically collect data, pre and post program intervention. The actual work of this study was carried out along 6 months from December 2020 to the May 2021. The average time consumed to fill in the tools was 45 minutes. The researchers collect data pre-program through two days/week from 8.00 a.m. to 11.00 a.m., and three days per week for implementation the program.

The participant mothers who caring for their children with thalassemia were divided into 6 groups, 2 groups /day for 3 days /week and each group consisted of 12 - 13 mothers that each group received the intervention program for 12 weeks. Where the program started from the beginning of March - May 2021, in the waiting area of haematology clinic.

The participant mothers took 8 theoretical sessions, in the form of lectures or group discussions by using videos, flipchart, posters, and power point presentation, and 4 sessions about practical care, in the form of demonstration and re-demonstration by using real objects and through role play. An illustrated booklet was developed for mothers as a reference after program implementation. The allocated time of each session ranged between 1:30 to 2:0 hour. Then the researchers evaluated the effect of implementing the nursing intervention program on the mother's knowledge and practices regarding care of children with thalassemia and their health status through post- test which was done at the last session for each group.

The collected data were analysed using appropriate statistical test as "Chi square", Wilcoxon Signed Ranks Test, and R test for number and percentage distribution, by using the SPSS program, version 21 to determine if there were statistically significant relations. P- Value = less than 0.05 was considered significant and less than 0.001 was considered as highly significant.

# **Results and Discussion**

**Table (1):** prove that there was a statistically significant relation between demographic characteristics of the studied children and their total mothers' knowledge and practices about

care of thalassemia pre-program intervention related to their gender with  $\chi 2 = 10.634$ , 5.11 and P value <0.005 but insignificant post program. Also, there was a statistically significant relation between total mothers' knowledge and practices post intervention program implementation and mothers' educational level with  $\chi 2 = 65.8 \& 50.87$  respectively and P value >0.005.

**Table (2)** presents that, there was highly statistical difference of total mothers' satisfactory knowledge/ total adequate practices about care of thalassemia between pre- and post- program with Z test = -7.526 &. -7.515 respectively and p value < 0.0001.

**Table (3)** Proves that there was insignificant statistical correlation between the complications of thalassemia among studied children and their total mothers' knowledge about thalassemia pre and post program intervention for all items except a negative correlation related to occurrence of fever as a symptom during allergy which experienced by the child with r = 0.238 and P value <0.05, and positive correlation for rapid breathing as symptom after doing any effort with r = .336 and P value <0.05, and proves that there were insignificant statistical correlation between the complications of thalassemia among studied children and their total reported mothers' practices about health care of thalassemia pre and post program intervention for all items.

Table 1: Relation between demographic characteristics of the studied mothers and their children and their total mothers' knowledge / practices of thalassemia pre and post program intervention (n=75).

	Total Mothers' knowledge				Total Mothers' practices			
	Kruskal Wallis Test		Kruskal Wallis Test		Kruskal Wallis Test		Kruskal Wallis Test	
Parameter	pre		post		pre		post	
	$\chi^2$	P value	$\chi^2$	P value	$\chi^2$	P value	$\chi^2$	P value
Child age	2.52	0.28	3.80	0.14	2.65	0.26	2.70	0.25
Gender	10.63	0.001**	0.07	0.79	5.11	0.024*	0.64	0.42
Educational level	0.43	0.80	1.40	0.49	0.73	0.69	2.02	0.36
Mother's age	0.20	0.65	0.08	0.76	0.06	0.79	0.61	0.43
Mother's educational level	14.52	0.006	65.8	0.000**	22.05	0.000**	50.87	0.000**
The Mother's job	2.93	0.08	0.89	0.34	0.01	0.94	0.01	0.91
Monthly income	3.44	0.06	3.11	0.07	0.46	0.49	0.39	0.53
Consanguinity marriage	10.80	0.001**	0.91	0.34	2.14	0.14	0.15	0.69
Place of residence	1.037	0.30	0.182	0.670	0.01	0.93	1.66	0.19

Table 2: Mean and SD of total mothers' satisfactory knowledge and adequate reported mothers' practices about care of their children with thalassemia pre and post program intervention (n=75)

(11-75).							
Devenueter	Preprogram	Post program	Wilcoxon Signed Ranks Test				
Parameter	Mean And SD	Mean And SD	Z	P value			
Total satisfactory knowledge regarding Mothers' knowledge about thalassemia	26.3467 ±8.51627	60.0933 ±11.15393	-7.526	0.000			
Total adequate reported mothers' practices toward care of their children with thalassemia	81.4933 ±15.23099	110.4400 ±11.1854	-7.515	0.000			

Table 3: Correlation between the complications of thalassemia among studied children and their total mothers' Knowledge/ reported practices about health care of their children with thalassemia post program intervention (n=75).

	Mothers	knowledge	Mothers' Practices		
Complications	post		post		
	r	P value	r	P value	
Hepatosplenomegaly	002	.985	138	.237	
Allergies after a blood transfusion	131	.263	060	.608	
Symptoms experienced by the child during allergy					
High temperature(fever)	238	.040*	110	.349	
Redness of the skin	164	.160	082	.484	
A sudden and sharp drop in blood pressure	.000	1.000	.051	.663	
Abdominal pain (nausea or vomiting)	.121	.300	.089	.446	
Shortness of breath	040	.736	004	.971	
Facial redness swelling of the face, eyes, or tongue.	162	.166	.017	.884	
Heart palpitations	.069	.556	.104	.376	
Other symptoms after doing an effort	098	.402	035	.767	
Symptoms after doing any effort					
Dizziness	041	.730	073	.531	
Vomiting	182	.119	099	.396	
Headache	200	.085	064	.585	
Rapid breathing	014	.908	051	.666	
Profuse sweating	056	.634	015	.899	
Dyspnea	168	.151	093	.426	
Rapid heartbeat	022	.851	.106	.366	

# Discussion:

The current study represents that more than half of studied children with thalassemia their age ranged between 8-12 years, the concerning child ranking were the first child in their family for the majority of them. This result in congruence with three different studies in Pakistan by **Manzoor**& **Zakar**<sup>14</sup> Iran by **Khani et al.**, <sup>15</sup> and Egypt by **Tari et al.**, <sup>16</sup> which proved that, more than half of study sample of children with thalassemia, their age ranging between 8-12 years, and the majority of them were the first child in their family.

In the present study more than half of children with thalassemia were female. Which reflect that, the female affected more than male, which agreement with **Elewa& Ahmed**<sup>17</sup> whose study title about "effect of an educational program on improving quality of nursing care of patients with thalassemia major as regards blood transfusion", and stated that, females affected more than males Also, this study result agrees with **Sorkin et al**<sup>18</sup> whose study title about "Thalassemia genetic prevalence and stated that both alpha and beta-thalassemia are usually inherited in an autosomal recessive pattern. This means that males and females are affected as it does not involve the sex chromosome and both parents must be carriers of a gene mutation.

The present study shows that more than half of their parents of the studied children suffering Thalassemia were consanguine marriage and less than half out of them were first degree of consanguinity. In relation to the history of consanguinity, it was observed that a minority of the studied thalassemia children's parents only were consanguineous. In contrast, with **Abolwafa et al**, <sup>19</sup> Whose title "Awareness among parents of children with thalassemia major" And found that consanguinity was positive in three quarter of the parents. And more than one-third of the studied B-thalassemia children showed a positive family history.

From the researcher point of view, the finding of the present study revealed that, both males and females are affected with more females' predominance than males, this may be attributed to the fact that Thalassemia are genetic blood disorders that affect both males and females more than males.

The present study revealed that, there were statistically significant differences between pre/post educational program regarding to improvement in the acquisition of knowledge for mothers, post implementation of program. Regarding to knowledge about meaning of thalassemia, methods of treatment, and its complications, less than half of mothers had correct knowledge pre-program, which improved to most of them post program implementation, while all of them had correct knowledge about causes of thalassemia post program compared to majority of mothers' pre-program. Finally, it was found that, most of mothers had satisfactory level of total knowledge about thalassemia with highly statistical significance this result agreement with **Ahmadpanah et al.**, <sup>20</sup> among studied children in Egypt whose title " In Patients with Minor Beta-Thalassemia, Cognitive Performance Is Related to Length of Education, But Not to Minor Beta-Thalassemia, acquisition of their knowledge, post implementation of program.

This study finding revealed that there was a high statistically significant correlation between total score of mother's knowledge and practices preprogram implementation. As well, the result of this study showed that there was a significant correlation between the educational level and total score of mothers' knowledge and practice. This may be due to that less than three quarter of the studied mothers, which might elaborate the current condition see that These results were supported by **Kafl & El-Shahat**, <sup>21</sup> whose that in Hong Kong, who reported that, there is a positive relation between mothers' knowledge, practice and level of education which affect quality of their children care that receive so, the standard of quality of mother care was affected by the mothers' level of education. However, the result of this study agreement with **Kafl & El-Shahat** <sup>21</sup> and with study by **Ali et al.**, <sup>22</sup> who reported that there was statistically significant relation between total mothers' knowledge about thalassemia and their total reported mothers' practices about care of thalassemia pre and post program intervention.

Regarding mothers' knowledge about thalassemia and blood transfusion, the present study showed a significant improvement in all items of knowledge and practices among the studied mothers after the educational program implementation and this led to improvement of patients' outcomes. This result comes in agreement with **Abbasi** <sup>23</sup>who conducted study children in Cairo University whose study title "Impact of education program on an adherence of Thalassemia children with iron chelation therapy in homology clinic" who stated that significant improvement in their related knowledge after implementation of the educational program.

These results may be due to the positive effect of the educational program, which improved mothers' practices. In the same line, the incompetence in mothers' level of practices pre implementation of the educational program This study findings were supported also by those of **Sarkar**, <sup>24</sup> whose title "Assessment of nurse's performance for caring of patients in mechanical ventilator", who stated that, as regards total mothers' practices near two thirds of the study mothers had inadequate practices regarding mothers' care of their children, and congruent with Khresheh and Brair<sup>25</sup> who conclude that in their study, the Jordanian mothers of thalassemic children do not have adequate knowledge on thalassemia and their practice towards their children in dealing with thalassemia was very poor.

# Conclusion

The result of study concluded that, there were highly statistically significant differences related to mothers' total satisfactory knowledge about thalassemia pre and post program with (X2 =.91.679 and p value < 0.0001). Also, there were most of mothers had adequate level of total practices post program implementation compared with one third pre-program with highly statistically significant differences (X2 = 52.920 and p value < 0.0001).

Finally, the study finding proved that the nursing intervention program for mothers having children with thalassemia improved their knowledge and practices toward care of their children which had a positive effect on their health status.

# **Recommendations:**

The study, recommended that, periodic counselling program to all mothers of children suffer from thalassemia who attended to outpatient clinics about diseases treatment, prevention, and control measure. Also, further research in other areas especially rural areas to implement counselling program about management of thalassemia and evaluation its effect. Dissemination of the

booklets about care of thalassemia for all mothers as a guide and standardized reference to motivate them for continuity of improving the health status of those children is recommended.

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