Assessment of Mothers' Care for their Children with Thalassemia

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Abstract

Background: Thalassemia is an inherited blood disorder among children cause mild or severe anemia, which could damage organs and lead to death. The study aimed to assess mothers' care of their children with thalassemia. ***Research design:*** Descriptive analytical design. ***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 the study subjects; composed of 75 mothers of children with thalassemia disease. ***Tools:*** Three tools were used to conduct this study. *First tool* was an interviewing questionnaire for assessing the socio-demographic characteristics, of the studied children and their mothers, past and current medical history, current health needs and problems. Also mother's knowledge and practices level about the care of their children with thalassemia. *Second tool:* Child's medical record, and *Third tool:* Child's physical assessment to assess physical health status of the children. ***Results:*** Study finding indicated that, 55% from the studied children with thalassemia were female, 23% of them had many complications from the medications used. 81.3% of mothers had unsatisfactory knowledge about thalassemia and its care, and 61.3% of them, their total practices about the care provided for their children with thalassemia were inadequate. Also, there were 94.7% of studied children always adhere to the treatment plan and 98.7% of them always conduct follow up regularly to the especial clinic. ***Conclusion:*** The result of study concluded that, there was insignificant negative correlation between the complications of thalassemia among studied children and their total mothers' knowledge about thalassemia management and their total reported mothers' practices about health care of thalassemia for all items. ***Recommendations:*** Periodic counseling program to all mothers had children suffer from thalassemia who attended to outpatient clinics about diseases treatment, prevention and control measures.

Keywords: Children with thalassemia, mothers' care

Introduction

Thalassemia is a heterogeneous grouping of genetic disorders that result from a decreased synthesis of alpha or beta chains of hemoglobin (Hb). 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. It is caused by either a genetic mutation or a deletion of certain key gene fragments **(Angastiniotis, 2019).**

When there isn't enough hemoglobin, the body's red blood cells don't function properly and they last shorter periods of time, so there are fewer healthy red blood cells traveling in the bloodstream. Red blood cells carry oxygen to all the cells of the body. Oxygen is a sort of food that cells use to function. When there are not enough healthy red blood cells, there is also not enough oxygen delivered to all the other cells of the body, which may cause a person to feel tired, weak or short of breath. This is a condition called anemia. Children with thalassemia may have mild or severe anemia. Severe anemia can damage organs and lead to death **(Christian et al, 2018).**

Globally the thalassemia have 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 in to 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 β-thalassemia. Recent surveys suggest that between 300,000 and 400,000 babies are born with a serious hemoglobin disorder each year (23,000 with β-thalassemia major) and that up to 90% of these births occur in low- or middle-income countries **(Kountouris et al, 2018).**

Alpha thalassemia is caused by reduced or absent synthesis of alpha globin chains, and beta thalassemia is caused by reduced or absent synthesis of beta globin chains. Imbalances of globin chains cause hemolysis and impair erythropoiesis. Silent carriers of alpha thalassemia and persons with alpha or beta thalassemia trait are asymptomatic and require no treatment. Alpha thalassemia intermedia, or hemoglobin H disease, cause hemolytic anemia. Alpha thalassemia major with hemoglobin Bart's usually results in fatal hydrops fetalis. Beta Thalassemia major causes hemolytic anemia, poor growth, and skeletal abnormalities during infancy. Affected children will require regular lifelong blood transfusions. Beta thalassemia intermedia are less severe than beta thalassemia major and may require episodic blood transfusions. Transfusion-dependent children with thalassemia will develop iron overload and require chelation therapy to remove the excess iron. Bone marrow transplants can be curative for some children with beta thalassemia major. Children with the thalassemia trait have a normal life expectancy. Persons with beta thalassemia major often die from cardiac complications of iron overload by 30 years of age **(Angastiniotis, 2019).**

The necessity for lifelong treatment, the prevention of serious complications through regular monitoring, and premature deaths in many patients make these disorders a significant health burden requiring public health planning and policy making. This is a process which countries with few resources are often unable to follow. Even in the well-resourced countries of the West, the rarity of the condition does not always allow for expertise to develop **(Hockham et al, 2019).**

Blood transfusion is the mainstay of the care for individual with thalassemia major and many with intermediate. The purpose of transfusion is twofold: to improve the anemia and to suppress the ineffective erythropoiesis. Chronic transfusions prevent most of the serious growth, skeletal and neurological complications of thalassemia major. In spite of its vital role in saving lives and enhancing patients' lives, blood transfusion is associated with risks. Making mistakes in blood transfusion and insufficient control of patients who receive blood during the transfusion can lead to death for such patients. So, 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. Nurses being responsible for the final bedside check before transfusion, have the final opportunity to prevent a mistransfusion. **(Taylor et al, 2019).**

Nurses play a critical role in instructing the patient 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. School children with thalassemia often requires regular blood transfusions and iron chelation therapy for its management. Thus, the therapeutic regime is complex, lifelong requiring repeated hospitalizations and blood transfusions, which often affects the child's physical and mental health negatively. So, nurses having knowledge and health related practices about thalassemia will improve quality of nursing care and improve patient satisfaction among school age children **(Singha et al, 2019).**

Significance of the study

Despite the fact that thalassemia is a major health problem in the world that challenges children, parents and health care

system. It requires extensive attention and management. Thalassemia is a major public health problem which could cause a psychosocial burden on the patient and family. This is as a consequence of hospital visits for supportive lifelong treatment and the special care needed to have a good quality of life. Thalassemia is the most common monogenic hematologic disease that affects millions in the world and kills thousands of patients every year. Without transfusion or transplantation, patients with thalassemia major are expected to die within months of diagnosis. However, long-term transfusion and chelation therapy is highly challenging for many developing countries where the disease is prevalent, representing a major and unsustainable health burden. In Egypt there are 10,000 registered thalassemia cases and more than 20,000 non-registered cases. 95% are beta thalassemia major; 5% are thalassemia intermedia or hemoglobin H disease.

Aim of the study

The aim of this study is to assess the mothers' care of their children with Thalassemia through: -

1- Assessing health needs and health problems of children suffering from Thalassemia.

2- Assessing mothers' knowledge regarding Thalassemia.

3- Assessing mothers' reported practices regarding their children with Thalassemia

Research questions

1.What are the health needs and problems of children suffering from Thalassemia?

2.Is there relation between mothers' knowledge and their reported practices regarding care of their children with Thalassemia?

3.Are there relations between mothers' knowledge and their reported practices regarding their children with Thalassemia and health problems of children?

Subjects and Methods

Research design: -

Descriptive analytical research design was utilized to fulfill the aim of this study.

1-Technical Design:

A-Research Setting:

The study was conducted in Pediatric Specialist Clinics (Hematology clinic) at El-Demerdash Children's Hospital, affiliated to Ain Shams University hospitals Cairo Governorate, Egypt.

Sampling:

Sample size: -

A purposive sample was used for choosing the study subjects. The sample size was 75 mothers of children diagnosed with thalassemia, which represents 25% out of the total annual average of children attending the hematology clinic, (300) children diagnosed with thalassemia where follow-up and medical treatment are carried out in the previously mentioned setting. The study sample was chosen according to the following criteria: including children diagnosed with thalassemia from aged 6 to 12 years old.

Technique: -

It is a non-probability sample that is selected based on criteria and agreement to participate in the study. Where cases are selected until the specified number of the sample is completed.

B- Data collection tools:

Three tools were used for data collection to conduct this study after reading the related literature and taking expert's opinion, it was written in Arabic language.

First tool: An interviewing questionnaire it includes five parts as follow**.**

Part I (a): The demographic data of the studied children: as age, gender, school level, and child's ranking among his/her siblings.

Part I (b): The socio-demographic data of the studied children' mothers: as age, social status, Consanguinity, consanguinity degree, living place, education level, type of work, monthly income, and home crowding index.

Part II: This part consisted of 25 closed ended questions to assess the past and present medical history of the children and family history including: the onset of disease, how was the disease discovered, family history of thalassemia, symptoms at beginning of the disease, past history of allergy, another diseases, abdominal ultrasound done, enlarged liver and spleen (Hepatosplenomegaly), allergic reaction post blood transfusion, symptoms of allergy experienced by the child, type of medications, and its complications.

Part III: **Assessment of current health needs and problems** which consisted of 10 close ended questions including: nutrition; number of meals per /day, the content of meals, sleeping hours/day, sports, and leisure, practicing physical activities, and its types, also if child feel any symptoms after doing an effort, favorite hobbies, and compliance is medications plan.

Part IV a: This part developed to assessed the **mother'sknowledge about thalassemia** which consisted of 16 closed ended questions including: meaning of thalassemia, causes, symptoms and signs, methods of treatment, complications of thalassemia and its methods of prevention, also mothers' knowledge about medication therapy of thalassemia such as: medications delayed symptoms, 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), side effects of iron deficiency medications, and its contra indication, also methods of elimination of the accumulated iron in the body and the mothers' sources of information.

Part IV b: This part developed to assess the mothers' knowledge about factors of non-adherence to thalassemia treatment, four questions included in this part: the consequence of failure to adhere to treatment, family-specific factors that affect the treatment of the child, factors specific to treatment, and factors specific to the place where health care is provided to the child**.**

Scoring system of knowledge:

A correct answer was scored (1) and the incorrect answer was (zero). The items of the questionnaire were checked against a model key answer. According to mothers' answers, the total mothers' knowledge was evaluated and scored according to two levels:

• Satisfactory knowledge ≥ 50%.

• Unsatisfactory knowledge < 50%.

Part V: This part developed to assess the mother's reported practices related to health care provided to their children with thalassemia which consisted of 15 open and 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 or 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 ≥ 50%.

-Inadequate practices < 50%.

Second tool: Child's medical record (hematology follow up card) to collect data about lab investigations and treatment. Adhering to the treatment plan, follow up regularly to the hematology clinic, sleep pattern.

Third tool: child's physical Assessment to assess physical health status of the children including: height, weight, BMI, head circumference, hair density texture, flashing, face, mouth, teeth, lymph nodes, skin, temperature, respiratory system, the digestive system, musculoskeletal system, nervous system, and the cardiac system.

The equation to calculate BMI:

BMI = Weight (kg)/height^2 (m2).

According to the recommendations of Centers for Disease Control and Prevention **(CDC) (2020)**, BMI categorization for children and teens between age 2 and 20 is as follows:

- Underweight <5%.
- Normal weight 5% - 85%.
- Overweight 85- 95%.
- Obese > 95%.

Tools validity:

Content and face validity were performed by two professors of the

Community Health Nursing Department of Faculty of Nursing and one assist professor of the Hematology Department from Pediatric Department, Faculty of Medicine. Ain Shams University, Egypt; they reviewed the tools for content accuracy.

Tools reliability:

The reliability test was done by using the Cronbach alpha test which showed internal consistency and homogeneity of items (Cronbach alpha = 0.887).

2-Administration Design:

Permission for conduction of the study was obtained by submission of an official letter issued from the Faculty of Nursing, Ain Shams University to the director of El-Demerdash Children Hospital.

Ethical Consideration:

Ethical approval was obtained from scientific research and ethical committee in faculty of nursing at Ain Shams University. A written consent was obtained from participants. Confidentiality of data was given by assurance that; no individual would be identifiable in any publication of the data. Individual anonymity was achieved by coding participant's information. Participant mothers were also informed verbally about their right to withdraw from the study at any time.

Pilot Study:

The pilot study was carried out on 10% of the study subjects (8 mothers) to test applicability of the tools and determine time needed to collect data then the necessary modifications were done according to the result of pilot study. Pilot sample was excluded from the study sample.

3-Field Work:

An official letter was submitted to the director of pediatric hospital at Ain Shams University, the actual field work started data collection from the beginning of December 2019 to the end of February 2020. The average time consumed to fill in the tools was 45 minutes. The previously mentioned setting was visited by the investigator two days/week (Mondays & Wednesdays) from 8.00 a.m. to 11.00 a.m. Subject who met the inclusion criteria were identified through reading medical record of the children and asking mothers accompanying with the children. Each mother was individually in the Hematology clinics. The investigator started by introduce herself to the mothers of children with thalassemia in the previously mentioned setting and explain the aim of the study, assured that data collected will be confidential and would be only used to achieve the purpose of the study. The investigator faced some troubles because the questionnaire was too long and it took a lot of time from the mother's to finished it, so every case took a lot of time to finished it and some time the case not complete the questionnaire. Major of cases wanted to explain every item to respond it and it took a lot of time for every case to end questionnaire, so

investigator took three months to complete all number of cases which equal 75.

Statistical design:

The collated data were tabulated and analyzed using appropriate statistical test as Wilcoxon Signed Ranks Test, and R test for number and percentage distribution, by using the Statistical Package for Social Science (SPSS), version 20 to determine if there were statistically significant relations. Chi-square (X^2) and P- value = less than 0.05 was considered significant and less than 0.001 was considered as highly significant.

Results

Table (1): - This table shows that 34.7% of the children, their age was ranged from 8 < 10 year for just like the other group from 10: 12 years, 45.3% of the studied children were male while 54.7% of them were female, as well as all studied children 100% went to school and 57.3% were graded from 1st to 3rd class. Concerning child ranking 34.7% of the studied children were the first child in their own family.

Figure (1): This figure illustrates that 79% from the studied children were diagnosed with β-Thalassemia major (Cooley's anemia) and 21% of them were thalassemia intermedia.

Table (2): This table clarifies that, 77.3 % of the studied children had three meals a day and 89.3 % of them their diet contains low iron and 96.0 % of children had an adequate fluids per day. Also, the table demonstrates that, 69.3 % of the studied children slept less than 12 hours/day. 78.7 % of the studied children were practicing physical activities. Finally this table reflects that, 78.7 % of the studied children were practicing physical activities and 55.9 % of them practicing walking activity, as well as, 92.0% of them were taking medications regularly.

Figure (2): Reveals that there were 81.3% of study sample of mothers had unsatisfactory total knowledge about thalassemia.

Figure (3): Illustrates that there were 61% of study Sample of mothers had inadequate total reported practices about thalassemia.

Table (3): Presents that, there were 94.7% of studied children always adhere to the treatment plan and 98.7% of them always conduct follow up regularly to the especial clinic.

Table (4): Proves that there were insignificant statistical correlation between the complications of thalassemia among studied children and their total mothers' knowledge about thalassemia for all items except a negative correlation related to occurrence of fever as a symptom during allergy which experienced by the child with r = -.238 and P value <0.05.Also there were positive correlation for rapid breathing as symptom after doing any effort with r = .336 and P value <0.05.

Table (5): Proves that there were negative insignificant statistical correlation between the complications of thalassemia among studied children and their total reported mothers' practices about health care provided to them in all items.

Table (1):- Distribution of the studied children suffering from Thalassemia according to their demographic data. (n=75)

Items	N=75	100%
Age		
From 6 < 8 years	23	30.6
From 8 < 10 years	26	34.7
From 10 : 12 years	26	34.7
Gender		
Male	34	45.3
female	41	54.7
Go To school	75	100
Educational level as primary class		
1st- 3rd class	43	57.3
4 th-6th class	22	29.4
7th or more	10	13.3
Child ranking		
First	26	34.7
Second	23	30.6
Third	17	22.7
Fourth and more	9	12

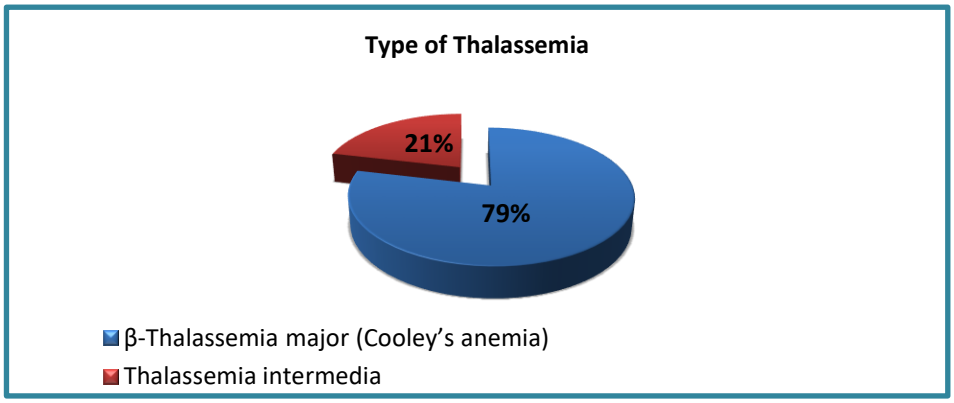

Figure (1): Number and Percentage Distribution of Children regarding the types of thalassemia (N=75).

Table (2): Number and percentage distribution of children according to their health needs as their mothers reported (N=75).

Items	N=57	100 %
Nutrition		
Number of meals per /day		
Three meals a day	58	77.3
More than three meals a day	7	9.3
Less than three meals a day	10	13.4
the content of meal*		
Low iron diet	67	89.3
Contains an appropriate rate of carbohydrates, starches and fats	27	36.0
High in proteins, such as meat and chicken	53	70.7
Dairy products	41	54.7
Vegetables and fruits	55	73.3
enough fluids (8 cups) during the day	72	96.0
Sleeping habits		
Sleeping hours a child need/day		
12 hours/day	11	14.7
More than 12 hours / day	12	16.0
Less than 12 hours/day	52	69.3
Sports and leisure		
Practicing physical activities	59	78.7
The type of physical activity* (N=59)		
Running	32	54.2
Swimming	4	6.8
Walking	33	55.9
Playing ball	30	50.8
Bicycle riding	10	16.9
Taking medication regularly	69	92.0

N.B. * items not mutually exclusive

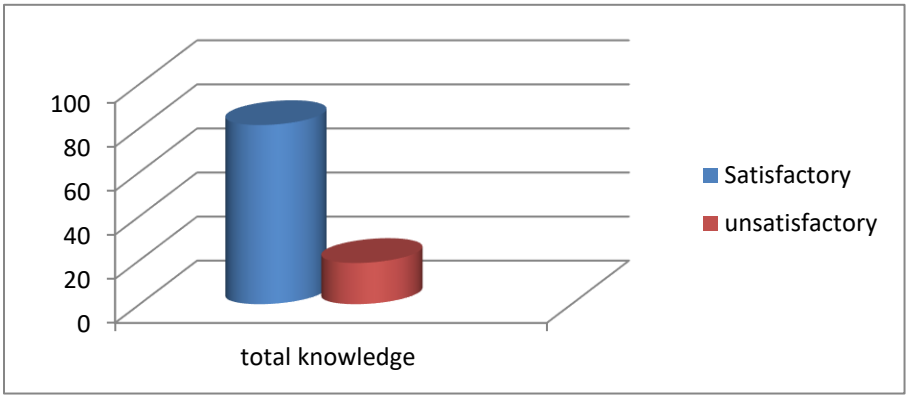

Figure (2): The distribution of mothers' total knowledge about thalassemia (n=75).

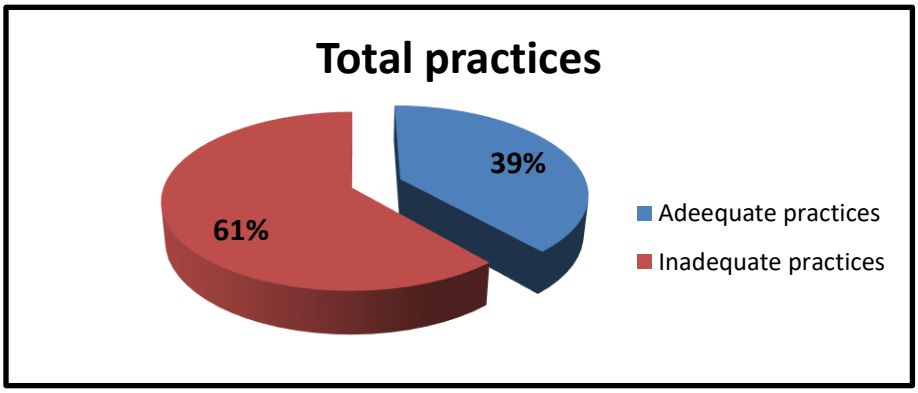

Figure (3): The distribution of mothers' total reported practices about thalassemia (n=75).

Table (3): Number and Percent Distribution of Children According to their reported needs (n=75)

Parameter	N	%
Adhering to the treatment plan		
Sometimes	4	5.3
Always	71	94.7
Follow up regularly to the clinic		
Sometimes	1	1.3
Always	74	98.7

Table (4): Correlation between the complications of thalassemia among studied children and their total mothers' knowledge about thalassemia (n=75).

Complications	Total Knowledge	
	r	P value
Child suffer from hepatosplenomegaly	-.022	.853
Child exposed to allergies after a blood transfusion	-.104	.372
High temperature(fever)	-.077	.513
Redness of the skin	-.024	.839
A sudden and sharp drop in blood pressure	.063	.594
Abdominal pain (nausea or vomiting)	.115	.326
Shortness of breath	-.087	.458
Facial redness swelling of the face, eyes, or tongue.	.005	.966
Heart palpitations	-.024	.837
Child feel any symptoms after doing an effort	.126	.280
Symptoms after doing any effort		
Dizziness	.106	.367
Vomiting	-.274	.017*
Headache	-.176	.131
Rapid breathing	.336	.003*
Profuse sweating	.013.	.911
Two approaches	.033	.777
Rapid heartbeat	-.261*	.024

Table (5): Correlation between the complications of thalassemia among studied children and their total reported mothers' practices about health care of thalassemia (n=75).

Complications	Practices	
	r	P value
Child suffer from hepatosplenomegaly	-.141	229
Child exposed to allergies after a blood transfusion	-.008	.948
Symptoms experienced by the child during allergy		
High temperature(fever)	.023	.842
Redness of the skin	.023	.842
A sudden and sharp drop in blood pressure	-.053	.652
Abdominal pain (nausea or vomiting)	.007	.956
Shortness of breath	-.055	.638
Facial redness swelling of the face, eyes, or tongue.	-.035	.763
Heart palpitations	-.076	.520
Child feel any symptoms after doing an effort	-.076	.519
Symptoms after doing any effort		
Dizziness	.176	.132
Vomiting	-.023	.845
Headache	-.042	.718
Rapid breathing	.063	.593
Profuse sweating	-.045	.699
Two approaches	-.125	.285
Rapid heartbeat	-.198	.089

Discussion

Thalassemia is a complex group of diseases common in Mediterranean regions and Southeast Asia. Worldwide, there are 350,000 births per year with serious hemoglobinopathies. Blood transfusion is the mainstay of care for individuals with thalassemia major characterized by defective hemoglobin synthesis. Symptoms and signs result from anemia, hemolysis, splenomegaly, bone marrow hyperplasia, and, if there have been multiple transfusions, iron overload. Diagnosis is based on genetic tests and quantitative hemoglobin analysis. Treatment for severe forms may include transfusion, splenectomy, chelation, and stem cell transplantation. In Egypt there are 10,000 registered thalassemia cases and more than 20,000 non-registered cases. 95% are beta thalassemia major; 5% are thalassemia intermedia or hemoglobin H disease (**Laghmich et al, 2019)**.

The nurse plays a vital role in the care of patients with thalassemia so it is importance to have a suitable nursing services integrated for patients in both the acute and community setting. Nurses are also essential in helping patients with thalassemia to become aware in their own condition, teaching them the effective techniques for self-management, prevention measure of complications during the transition period for pediatric patients as well as genetic counseling **(Cappellini, 2020).**

The current study represent that more than half of studied children with thalassemia their age ranged between 8-12 years old, as well 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 **(Ammad et al., 2016),** Iran **(Khani et al., 2017)** and Egypt **(Tari et al., 2018)** which proved that, more than half of study sample of children with thalassemia, their age ranging between 8-12 years old, and the majority of them were the first child in their family.

The present study the sample included three quarters of the studied children were diagnosed with β-Thalassemia major (Cooley's anemia). This result in congruence with study done by **(Singha et al, 2019)** in a study title about" Erythrocyte indices in a large cohort of β-thalassemia carrier: Implication for population screening in an area with high prevalence and heterogeneity of thalassemia" It revealed that the majority of the children were diagnosed as β-thalassemia major by the first year of life.

In the present study, many subjects with thalassemia reported taking additional dietary supplements. The current study findings revealed to that more than three quarter of the studied children with Thalassemia received three meals, their diet contains low iron and taking adequate fluids per day these results are congruent with (**Aslani et al, 2019)** in their study title about **"**Nurses' knowledge of blood transfusion in medical training centers of Shahrekord University of Medical Science **"** in which they found that regular sleep pattern was among 61% and taking adequate fluids per day, all children their diet contains low iron this is important in protecting these children from the risk of accumulation of iron in their bodies.

Regarding the physical activities, the findings of the present study reflects that, more than three quarter of the studied children were practicing physical activities and more than half of them practicing walking activity but more than three quarter of them feel some symptoms after doing any effort such as heavy sweat for of those children. These findings agree with the results of the study done by **Caocci (2018)** under the title (health related quality of life in Middle Eastern children with beta thalassemia) in which they found that the majority of the children with thalassemia had many problems related to all the items of physical activities domain such as walking, running which revealed that two thirds of the children were unable to play in outdoor with children in same level, majority of them complained from fatigue and bodily weakness due to their health conditions and remain dependent on their parents or siblings with few peers from the same age group.

The current study findings revealed poor levels of knowledge about thalassemia among mothers regarding causes, signs and symptoms, complications, methods of treatment and Methods of prevention of complications for Thalassemia. The average total scores for knowledge among participants were 30.7%.

This poor knowledge could be explained due to the lack of health education programs for mothers carry children with thalassemia. These results are congruent with the findings of a previous study in India by **(Saxena et al, 2017)** whose study title about "Knowledge, practice and experiences of parents with a thalassemic child". They found that the knowledge and awareness about thalassemia was inadequate among most participants in their study. They found that only 47.5% of parents were aware about thalassemia as a genetic disorder, but many parents (55%) did not know any permanent cure for it.

Results of the present study found that less than half of the mothers had inadequate knowledge and care of practice for their children with thalassemia**.** These findings are consistent with the findings of other studies from developing countries that reported inadequate knowledge of the mothers regarding beta thalassemia and its management in general public which could negatively affect the health and safety of children with thalassemia **(Saxena et al, 2017; Basu, 2019).** This could be the absence of structured educational programs for patients with thalassemia and their guardians in Jordan. **Basu in 2019** found only 14.02% had satisfactory level of practice towards thalassemia among participants as a result of recommended awareness programs implementation about management of thalassemia to be offered for general public**.** Mother's knowledge related to thalassemia prevention is very important to the know mothers the strategies for prevention of thalassemia which will decrease the number of thalassemia among the population so it is important to conducted health educational program in the governmental hospital for the mother to improve their knowledge and care practices for children with thalassemia in Jordan.

Presents finding revealed that, there was more than three quarters of studied children always adhere to the treatment plan and of them always conduct the follow up regularly to the especial clinic. Compliance of children with thalassemia to their medication is very important as it helps them adapt with their disease. In turn this will prevent development of further complications. The current study findings showed that the majority of studied children were always in compliance with medication. As well also reduce the difference between them and their peers**.** So, no discrepancy will be experienced. Findings of **(Mettananda, 2018)** in his study were not in the same line with the findings of the current study where they reported that near than half of children were never compliance with medication and about half of them were sometimes compliance and only small percent of them were always compliance with their medication and follow up regularly to the especial clinic .

The present study showed that there were insignificant statistical correlation between the complications of thalassemia among studied children and their total mothers' knowledge about management of thalassemia for all items except a negative correlation related to occurrence of fever as a symptom during allergy which experienced by the child with r = -.238 and P value <0.05.Also there were positive correlation for rapid breathing as symptom after doing any effort with r = .336 and P value <0.05

The present study proved 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 for all items**.** In the patients with thalassemia, complications usually begin to appear after 1st decade and increase with age. In this study, complications were more frequent among patient with major thalassemia than children with intermedia thalassemia and significantly increased with age ($p< 0.05$).

Conclusion

The current study indicated that, more than have of studied children with thalassemia were female, less than one quarter of them had many complications from the medications used. Majority of mothers had unsatisfactory knowledge about thalassemia and its treatment, as well as less than two thirds of them, had inadequate level of total practices about the care provided for their children with thalassemia. Also, there were most of studied children always adhering to the treatment plan and conduct follow up regularly to the especial clinic. Also, the result of study proved that there was insignificant negative correlation between the complications of thalassemia among studied

children and their total mothers' knowledge about thalassemia and their total reported mothers' practices toward health care of thalassemia.

Recommendations

Based on the findings of this study, the following recommendations were suggested:

- Periodic counseling program should be done to all mothers of children suffer from thalassemia who attended to the outpatient clinics about diseases treatment, prevention and control measures.
- Continuous preconception counseling to consanguinity couples to prevent heredity disease of thalassemia.
- Encourage support group of mothers having children with thalassemia to work as a volunteer in the consulting unites to help the mothers of children with thalassemia newly diagnosed cases to be oriented with the health needs and problems of their children and how to care with them.
- Further research is needed in other areas especially rural areas to implement counseling program about management of thalassemia and evaluate its effect.

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