



MOTHERS' PERFORMANCE REGARDING CARE OF THEIR CHILDREN WITH THALASSEMIA AT ABO EL-RISH HOSPITAL

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Abstract

Background: Thalassemia is one of the most common genetic blood disorders in the Mediterranean region. Few studies have investigated the beliefs regarding thalassemia, especially in a developing country.

Aim: the study aimed to assess mothers' performance regarding care of their children with thalassemia.

Design: A descriptive research design was used in this study.

Sample: Convenient sample included 286 mothers was used.

Setting: Abo El-Rish Hematology Outpatient Clinics - Egypt.

Tool: Interview questionnaire consisted of five parts. Part I: Demographic characteristics of mothers and their child, Part II: Medical history of children, Part III: Mothers' knowledge regarding thalassemia, Part IV: Assess mothers' attitudes. Part V: Assess mothers' reported practices.

Results: 40.20% of the studied mothers had poor total knowledge regarding thalassemia. 97.2% of the studied mothers had positive total attitude. 95.5% of the studied mothers had adequate total reported practices. There was a highly statistically significant relation between mothers' knowledge and all items of demographic characteristics except residence item.

Conclusion: Two fifths of studied mothers had poor knowledge, majority of them had positive attitude, and adequate total reported practices regarding thalassemia. There was highly statically significant positive correlation between total knowledge, reported practice, and not with attitude.

Recommendation: Performing educational program to mothers who having children with thalassemia on a large scale.

Keywords: Children with thalassemia, mothers' performance

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1. BACKGROUND

Thalassemia is one of the most famous genetic diseases that lead to severe anemia and other complications on the long run. Thalassemia means a heterogeneous group of genetic disorders of hemoglobin (Hg) synthesis, that result from a reduced rate of production of one or more of the globin chains of hemoglobin. It requires a regular blood transfusion every three to four weeks, accompanied by pain to the children and great suffering to their families (Abbood and Liu, 2017) & (El-Wakeel and El-Haddad, 2019).

Thalassemia has 2 main types: Alpha and beta-thalassemia. B-thalassemia is the most common type in Mediterranean region, it divided into: Thalassemia major, thalassemia intermedia and thalassemia minor or trait. Children with thalassemia major usually present within the first two years of life with severe anemia, requiring regular red blood cell (RBC)

transfusions. Children with thalassemia intermedia present later in life with moderate anemia and do not require regular transfusions. Thalassemia minor is clinically asymptomatic, but some children may have moderate anemia (Xiang et al., 2021) & (Ibrahim et al., 2021).

Thalassemia has many effects on the physical health of affected children. It can lead to physical deformity, growth retardation, and delayed puberty. Its impact on physical appearance, e.g., bone deformities and short stature, also contributes to a poor self-image and severe complications such as heart failure, cardiac arrhythmia, liver disease, endocrine complications, and infections are common among thalassemia children. More than 240 million children have thalassemia major in the whole world and 100 thousand children are born with thalassemia major yearly. Beta thalassemia has been reported in more than 60 countries and is more common in countries

that have malaria (Heba et al.,2018) & (Fouad et al., 2019).

Mother performance regarding thalassemia disease is very important in managing and caring of their affected child with the disease so, improvement the health status of children with thalassemia requires increasing mother's knowledge, attitude and practices regarding thalassemia. Mother should be prepared and encouraged to participate in normal routines such as feeding, bathing, playing, reading stories and cuddling while the child at home. The ability of mother to manage and care for their child can affect the child's recovery and development through follow up to prevent complication (Elhalfawy et al., 2017) & (Husain et al.,2018) & (Punaglom et al., 2019).

Community health Nurses play a crucial role in managing the thalassemic children by helping to prevent unnecessary complications and providing treatment aimed at minimizing interference with the demands of school or work. This encompasses., instructing the children 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 medical contact (Khreshah & Brair,2020).

Significance of the study

Worldwide, thalassemia is a serious public health problem due to the high prevalence of the disease that extending from the Mediterranean and parts of Africa, throughout the Middle East, the Indian Sub-continent, and into South-East Asia with carrier rate $5.3 \geq 9\%$, and 1000/1.5 million / year live births born with thalassemia. Thalassemia is the most common hemolytic anemia in children that necessitating frequent blood transfusions and leading to iron overload and endocrine complications. The prevalence rate in Egypt estimated with carrier rates ranging from 9 to 16% (Kermansaravi et al., 2018) & (Abdelmotaleb et al., 2020).

Listening to mothers' experiences of caring for their chronically ill children with thalassemia is essential for the healthcare professional to support and provide a comprehensive care. Increasing mothers' performance play a key factor in solving children health problem, maintaining a healthy lifestyle and provide the best child-care and child-rearing practices (Keshvari et al., 2016). Decrease of mother's performance about care of their child with thalassemia leads to serious complications. So, we need a study to assess mothers' performance regarding care of their children with thalassemia.

Aim of the study.

The aim of this study is to assess mothers' performance regarding care of their children with thalassemia at Abo El- Rish Hospital through the following objectives:

1. Assessing mothers' knowledge, attitude and reported practices regarding care of their children with thalassemia.
2. Determining the relation between mothers' knowledge, attitude and their reported practices.
3. Appraising the relation between mothers' knowledge, attitude and reported practices with demographic characteristics.

Research questions:

1. What are mothers' knowledge, attitude and reported practices regarding care of their children with thalassemia?
2. Is there relation between mothers' knowledge, attitude and reported practices?
3. Is there relation between mothers' knowledge, attitude and reported practices with demographic characteristics.

2. SUBJECT AND METHODS

A descriptive research design was used to conduct the study at Abo El-Rish Hematology Outpatient Clinic-Egypt.

Type of Sample: A convenient sample include 286 of mothers they attended the outpatient clinic to follow-up and treatment for their children diagnosed with thalassemia.

Tools for data collection→: An interviewing questionnaire was used in this study it includes 5 parts

Part I: Demographic characteristics: This data developed by the investigator aimed to assess studied mothers, and children's personal data such as: -

- Mothers characteristics consist of 6 items about age, marital status, educational level, occupation, income, and residence.

- Child characteristics consist of 4 items about gender, age, educational level, and the child's order in the family.

Part II: Medical history: Aimed to assess medical history of studied children which included 12 items about, when did the child get sick, what are the tests that the child done, is there relation between father and mother, is other family member or relative suffer from this disease, if yes, who is the person, what kind of disease, does the child receive a blood transfusion, if yes, how often does the child receive a blood transfusion, has the child ever been hospitalized, if the answer is yes, what was the reason, - if the cause is related to the disease, what is it, are you committed to giving treatment.

Part III: Mothers' knowledge: Aimed to assess knowledge of the studied mothers regarding thalassemia. Questions were prepared by the investigator after reviewing literature review that consist of 9 items such as: Meaning; causes, symptoms, complications, adherence to treatment, basic treatment, complications of blood transfusion, ways to treat complications of blood transfusion, and ways to prevent thalassemia.

Scoring system for knowledge items: Scoring system was followed to assess mother knowledge, regarding thalassemia. Each knowledge question was scored by zero for incorrect answer or don't know, one for correct answer. The total knowledge scores ranged from 0-9. The total knowledge score were summed and converted into a percent score. It was classified as follows:

- Poor knowledge if the score less than 50% (0- 4 grads)
- Average knowledge if the score from 50%-<75% (4.5-6.5 grads)
- Good knowledge if the score $\geq 75\%$ (>6.5- 9 grads.)

Part IV: Mothers' attitude: To assess attitude of the studied mothers regarding thalassemia. Questions were prepared by the investigator after reviewing literature review that consist of 31 items such as: I hope his condition gets better, i have the ability to control, i am thinking to find solution, i face the problem objectively, i eat a lot, i smoke cigarettes, i use my previous experiences, i pray, i become nervous, i become anxious, i solve my problem step by step, i look for comfort, i look for others' help i make goals for myself, i accept what happened, i would to be alone, i leave the problem aside, i drown in daydreaming, i expect the worst, i discuss the issue with others, i commit to giving treatment to the child for the sake of his health, i take responsibility for taking good care of my child, i accept no help from relatives and friends, i feel like i'm going crazy, i run away from the problem, i do different activities, i cast my problem on someone else, i blame others, i hold on to hope, and i am trying to cope with my child's illness.

Scoring system for attitude: Each attitude question was scored by one for a «never», two for a «sometimes» and three for always. The total practices scores ranged from 1-93, they were evaluated as follows:

- Positive attitude if score ($\geq 50\%$) (≥ 46.5 grads)
- Negative attitude if score ($< 50\%$) ($0 < 46.5$ grads).

Part V: Mothers' reported practices: To assess mothers' reported practices regarding care of their children with thalassemia consist of 14 items as check medication and expired date, perform hand hygiene before giving medication, constant hand washing , the medication given as doctor order, medication is given daily at the same time, observe side effects of medication, the mother observes any changes in the child skin color, the mother takes a healthy diet to avoid fatigue, encourage the child to practices exercise, given folic acid, care about foods that contain calcium and vitamin D to the child, give the child an annual flu vaccination, follow the color of the child's urine, and visits the doctor if signs or symptoms of thalassemia appear.

Scoring system for reported practices: Each practices question was scored by one for a «done practices»,

zero for a «not done ». The total practices scores ranged from 0-14, they were evaluated as follows:

- Adequate ($\geq 50\%$) (≥ 7)
- Inadequate ($< 50\%$) (< 7)

Validity:

The validity of the tool was tested through a panel of five experts from Community Health Nursing staff, and pediatric expertise to review relevance of the tools for understanding, and applicability.

Reliability:

The reliability was done by Cronbach's Alpha coefficient test which revealed that tool consisted of relatively homogenous items as indicated by the moderate to high reliability of each tool.

Items	Cronbach alpha
Knowledge items	0.927
Attitude items	0.985
Practices items	0.985

Ethical considerations:

Official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee, Faculty of Nursing. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations was included explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it not be accessed by any other party without taking permission of the participants. Ethics, values, culture and beliefs were respected.

II. Operational item:

The operational item included preparatory phase, pilot study and fieldwork.

Preparatory Phase

It included reviewing of past, current, national and international related literature and theoretical knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to develop tools for data collection.

Pilot study:

The pilot study was done on 10% (29) of the mothers to examine the clarity of questions and time needed to complete the study tools. Based on the results, no modifications were done so the mothers of the pilot study were included in the study sample. The pilot has also served to estimate the time needed for each subject to fill in the questionnaire.

Fieldwork

1. A written approval letter issued from Dean of Faculty of Nursing.
2. The letter directed to manager of Abo El-Rish hospital in Cairo city for conducting the study.
3. The purpose of the study and its procedure explained to mothers to get their informed consent and cooperation.
4. Data collected 2 days/week (Sunday and Tuesday) within 3 months through the academic year 2022-2023 till the needed sample completed.

5. The questionnaire was filled by the investigator who take 15-20 minutes.

III. Administrative item

Approval letter included aim of the study was obtained from the dean of the Faculty of Nursing, to the director of the previously mentioned setting. An official agreement was obtained from hospital manager and to get approval to conduct the study. Collect the necessary data for current study after a brief explanation for the purpose of the study and its expected outcomes. Used proper channels of communication from authorized personnel. After getting written permission. Mothers interviewing was done after obtaining their consent to participate.

IV. Statistical analysis:

The collected data were organized, tabulated and statistically analyzed using SPSS software (Statistical Package for the Social Sciences, version 24, SPSS Inc. Chicago, IL, USA). For quantitative data, the range, mean and standard deviation were calculated. For qualitative data, which describe a categorical set of data by frequency, percentage or proportion of each category, using Chi-square test (χ^2). Correlation between variables was evaluated using Pearson's correlation coefficient (r).

Statistically Significance of the results:

- Highly Statistically significant at p-value < 0.01.
- Statistically significant was considered at p-value < 0.05
- Non-significant at p-value \geq 0.05.

3. RESULTS

Table (1) Displays that 30.2% of studied mothers were between the ages of 27- < 36 years old with mean age \pm SD 32.83 ± 9.39 , while 61.1% of them were married, 45.1% had secondary education, 58.4% of them had insufficient income, 52.1 of them were housewives, and 59.1% were live in rural.

Figure (1): Illustrates that 53.10% of the child with thalassemia were male, while 46.90% of them were female.

Table (2): Reveals that 49.3% of studied children were diagnosed with thalassemia at age less than a year, 51.4% of children had presence of relation between their father and mother, while 71.7% of studied children received blood transfusion, whenever 45.8% were received blood transfusion once every 4 weeks, and 94.1% of the studied child were hospitalized.

Figure (2): Illustrates that 40.20% of the studied mothers had poor total knowledge levels regarding thalassemia, while 21% of them had good knowledge levels.

Figure (3): Illustrates that 97.2% of the studied mothers had positive total attitude level regarding thalassemia, while 2.8% of them had negative total attitude regarding thalassemia

Figure (4): Illustrates that 95.5% of the studied mothers had adequate total reported practices level regarding thalassemia, while 4.5% of them had inadequate total reported practices level regarding thalassemia.

Table (3): Reveals that there were highly statistically significant relation between total knowledge and reported practices (p value = 0.000), and no statistically significant relation between knowledge and attitude (P value= 0.427).

Table (1): Frequency Distribution of Mothers according to Demographic Characteristics (n= 286).

Demographic Characteristics	No.	%
Age of mothers		
18 - < 27	50	50
27 - < 36	86	30.2
36 - < 45	70	70
45 - < 54	55	55
54 - < 63	25	25
Mean \pmSD 32.83 \pm 9.39		
Marital status		
Married	189	66.1
Divorced	35	12.2
Widowed	62	21.7
Educational level		
Doesn't read and Write	36	12.6
Basic Education	50	17.5
Secondary education	129	45.1
University education or more	71	24.8
Occupation		
Employee	137	47.9
House wife	149	52.1
Income		
Insufficient	167	58.4
Sufficient	104	36.4
Sufficient, saving	15	5.2
Residence		
Rural	169	59.1
Urban	117	40.9

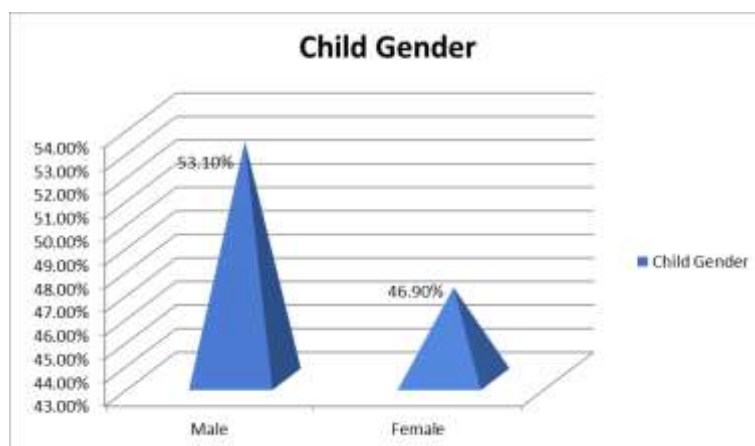


Figure (1): Distribution of Child according Gender (n=286).

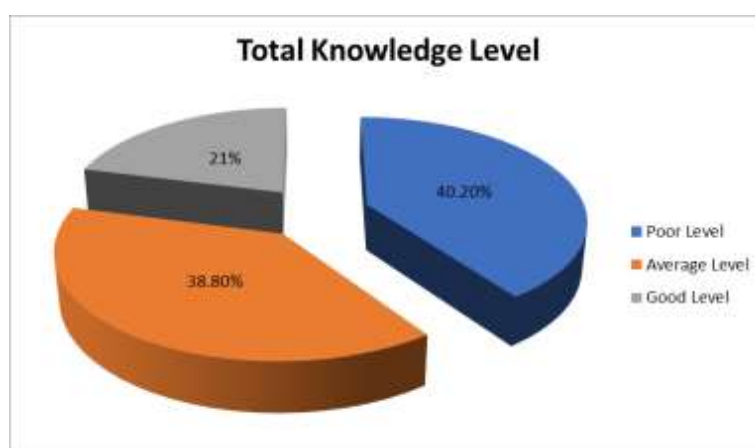


Figure (2): Percentage Distribution of Mothers according Total Knowledge Level (n=286).

Table (2): Frequency Distribution of Child Medical History (n=286).

Medical history	No	%
The age of child to get sick		
less than a year	141	49.3
1 ≤ 3 years	94	32.9
4 ≤ 6 years	50	17.5
7 ≤ 9 years	1	0.3
Tests that the child done		
A complete blood count	140	49
A reticulocyte count	7	2.4
Serum iron level	29	10.1
Hemoglobin electrophoresis	12	4.2
All above	98	34.3
Presence of relation between father and mother		
Yes	147	51.4
No	139	48.6
Family member or relative suffer from this disease		
Yes	167	58.4
No	119	41.6
If yes the person who affected		
Father	68	40.7
Mother	51	30.5
Sibling(s)	1	0.6
Paternal/maternal uncle(s)	8	4.8
Grandparents	39	23.4
kind of disease		
Carrier	159	55.6
Affected	127	44.4

Child receive a blood transfusion		
Yes	205	71.7
No	81	28.3
The frequency the child receive a blood transfusion		
Once a week	18	8.8
Once every two weeks	28	13.7
Once every 3 weeks	54	26.3
Once every 4 weeks	94	45.8
Once every 5 weeks	11	5.4
Child hospitalization		
Yes	269	94.1
No	17	5.9
The reason of hospitalization (n=269)		
A cause related to the disease	238	88.5
A cause not related to the disease	31	11.5
If the cause is related to the disease, what is it (n=238)		
To receive treatment for the disease.	168	70.6
To treat complications of the disease	70	29.4
Committed to giving treatment		
Sometimes	153	53.5
Always committed	88	30.8
Never	45	15.7

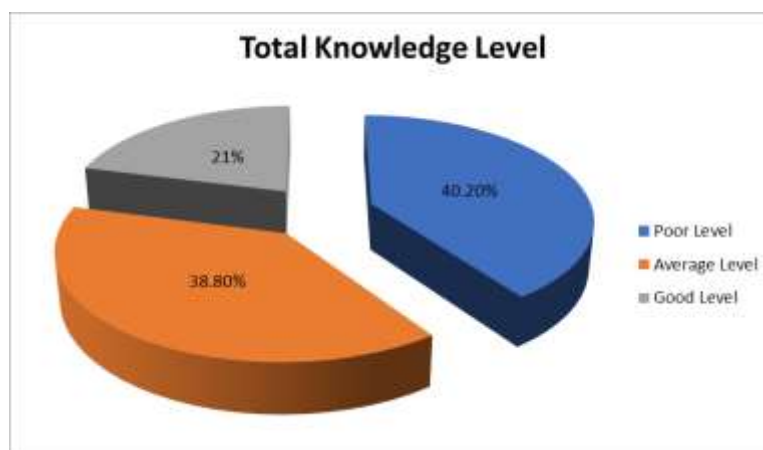


Figure (3): Percentage Distribution of Mothers according Total Knowledge Level (n=286).

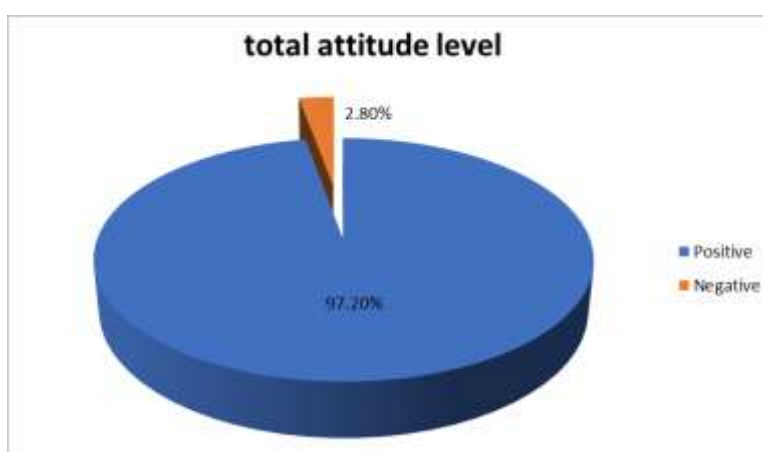


Figure (4): Percentage Distribution of the Mothers' Total Attitude Level regarding Thalassemia (n=286).

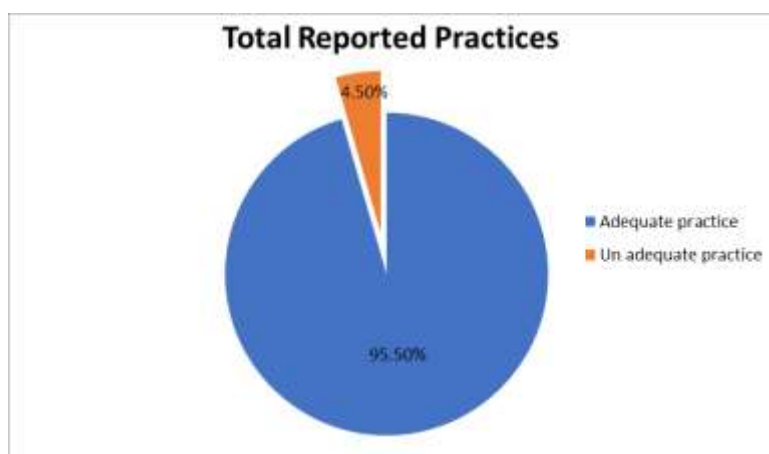


Figure (5): Percentage Distribution of Mothers' Total Reported Practices Level regarding Care of their Children with Thalassemia (n=286).

Table (3): Relation between Total Knowledges, Attitude and Reported Practices of Mothers regarding Care of their Children with Thalassemia (n=286).

Total Knowledge	Total attitude				Total Reported Practices			
	Negative (n= 8)		Positive (n=278)		Adequate (n= 273)		Inadequate (n= 13)	
	No.	%	No.	%	No.	%	No.	%
Poor (n=115)	5	4.3	110	95.7	103	89.6	12	10.4
Average (n=111)	2	1.8	109	98.2	111	100	0	0
Good (n=60)	1	1.7	59	98.3	59	98.3	1	1.7
χ^2	1.704				15.62			
P value	0.427				0.000**			

4. DISCUSSION

Thalassemia is a genetic blood disorder that affects globin chain synthesis with several manifestations. Thalassemia needs regular blood transfusion at an early age especially beta thalassemia. In addition, those children require iron chelation therapy to prevent iron overload. Such as a chronic illness, thalassemia is considered a great burden not only on the children, but also on the parents. This is due to frequent hospital visits for supportive lifelong treatment. Consequently, the principal goal for effective management of thalassemia is to permit children to function with minimal restrictions and enjoy a better life (Elsoudy et al., 2022).

The finding of the current study revealed that more than one quarter of the studied mothers were between the ages 27<36 years with Mean \pm SD 32.83 \pm 9.39. (Table 1) The result is similar with the study performed by Ibrahim et al., (2021) which titled "Relationship between quality of life and social support among mothers of children with thalassemia" in Shebin El-kom City, Menoufya, (n= 87) who stated that 50.6% of studied mothers were between 20-35 years old. The previous results were disagree with Hisam et al., (2018) titled "Perceived stress and monetary burden among thalassemia patients and

their caregivers" in Rawalpindi (n= 87) who reported that caregivers' age was 41.25 \pm 10.17 years. From the investigator point of view, the mothers' age of 27 to 36 is the normal age of having children.

The present study revealed that two thirds of studied mothers were married (table 1). This is in the same line with the study by Mohammed et al., (2022) which titled "The Effect of health coaching intervention on mothers' performance and quality of life of their children with beta thalassemia" in Fayoum (n= 70) which reported that 80% of the studied mothers were married. This in the same line with what was mentioned by Mohammad & Hashem, (2021) in their study which titled "Information and practices of self-administration about injection of Deferoxamine among adolescent thalassemia patients" in al-Najef City who reported that 80.1% of mothers were married. From the investigator point of view this is normal life in Islam culture that the men and women should be marriage.

The current study revealed that the majority of mothers were secondary education (table 1). The result similar with the study performed by Mat et al., (2020) which titled "parental knowledge on thalassemia and factors associated with refusal to screen their children" in Malaysia who stated that most of them had up to secondary school education.

These results in contrast with study performed by Saboula et al., (2019) which titled "Enhancing mother's awareness, attitude and practices about non-prescribed medications through counseling" in Shibin El-kom, Menoufya Governorate, Egypt, (n= 80) who founded that 41.2% had a technical diploma. From the investigator point of view increase in the percentage of secondary education among mothers is due to the most participant mothers were from rural area.

The present study showed that more than half of the studied mothers had insufficient income (table 1). This is in the same line with the study performed by Manzoor & Zakar, (2019) which titled "Sociodemographic determinants associated with parental knowledge of screening services for thalassemia major" in Lahore (n = 186) who reported that 58.6% belonged to a group where monthly income was below Rs 20,000. This also agree with what was studied by Sidra et al., (2019) which titled "Knowledge and beliefs regarding thalassemia in an urban population" in Pakistan (n= 720), who reported that 64.2% belonging to low-income families. This may be due to high cost of treatment and high percentage of non-working mothers.

The current study revealed that more than half of mothers were housewives (table 1). This in the same line with Biswas et al., (2018) in their study which titled "Knowledge of the caregivers of thalassemic children regarding thalassemia: a cross-sectional study in a tertiary care health facility of eastern India" (n= 328), who reported that 53.4% were not working. These results also agree with the study conducted by Mansoor et al., (2018) which titled "A descriptive study on quality of life among adolescents with beta-thalassemia major" in the Maldives (n= 81), who reported that 65.4% of the mothers were housewife. This may be due to a decrease in educational level among participant mothers.

The present study indicated that the majority of studied mother were live in rural area (table 1). This result agrees with study performed by Ghafoor et al., (2016) in a study titled "Level of awareness about thalassemia among parents of thalassemic children" in Pakistan (n=150) who stated that 70% belonged to rural areas. This result disagreement with a study performed by Ishfaq et al., (2021), which titled "Mothers' awareness and experiences of having a thalassemic child: a qualitative approach" in Pakistan (n=64). who reported that 65.6% of studied mothers were live in urban. From the investigator point of view that because of the culture of consanguineous marriage is prevalent in rural areas.

Concerning gender of children, the current study revealed that more than half of the studied children were male (figure 1). This is supported by the study performed by Fazal et al., (2021) which titled "Assessment of level of awareness regarding thalassemia major among parents of affected children" in Rawalpindi, (n= 272) who mentioned

that around 60% of children suffering from thalassemia major were males. Also this is in contrast with Kermansaravi et al., (2018) in their study titled "Coping behavior in parents of children with thalassemia major" in Iran,(n= 103) who reported that 57.3% of children were female. From the investigator point of view this due to thalassemia is an autosomal disease can affect males and females alike since the abnormality is one of the autosomes.

In relation to the onset of disease our results revealed that nearly half of the studied children were get sick at less than a year of life (table 2). This result agrees with study performed by Biswas et al., (2021) which titled "Malnutrition, its attributes, and impact on quality of life: an epidemiological study among β -thalassemia major children" performed at thalassemia day care unit of a medical college, in India (n=328) who reported that 56.5% of the study participants were diagnosed with thalassemia within the first year of their lives with a mean age at diagnosis of 20 months. This also agreed with a study performed by Baruah et al., (2022) which titled "pulmonary function in children with transfusion-dependent thalassemia and its correlation with iron overload" in Assam (n= 66). who stated that 43.9% of children were diagnosed before the age of two years. From the investigator point of view this result is due to the nature of diseases that appear early in life because it is a genetic disease.

As regarding to relation between father and mother our results stated that half of the studied sample were have relation (table 2). This in the same line with study performed by Khalid et al., (2019) which titled "Knowledge of thalassemia and consanguinity: A multicenter hospital based retrospective cohort study from metropolitan City of Karachi, Pakistan" (n= 200) Who reported that out of total study participants 78.5% were relatives, out of these 61% were first relatives and 17.5% were distant relatives. In addition, this result disagreement with Jain et al., (2020) in their study which titled "A cross-sectional study of awareness and practices regarding thalassemia among parents of thalassemic children" in India (n= 118) who stated that 98.30% were outside the family. This may be related to the consanguineous marriage common in Egyptian culture especially in rural area.

As regarding to frequency of child receiving blood transfusion our results stated that 45.8% of children were received blood transfusion onec/4 weeks (table 2). This is in the same line with study performed by Nimkarn et al., (2021) which titled "Age as a major factor associated with zinc and copper deficiencies in pediatric thalassemia" in Thai (n= 209), who reported that blood transfusion was given at an interval of 4 weeks. It is also in accordance with Mettananda et al., (2019) in their study titled "Blood transfusion therapy for β -thalassemia major and hemoglobin E β -thalassemia: Adequacy, trends, and determinants' in Sri Lanka (n=328) who stated 76.5% of children

received blood transfusion every 4 weeks. This is because life span of Red Blood Cells is 120 days.

Concerning to total knowledge regarding thalassemia the present study showed that two fifths of studied mothers had poor knowledge regarding thalassemia (figure 2). This result agrees with the study done by Mohammed et al., (2022), who reported that 67.1% had poor knowledge regarding thalassemia. This disagrees with a study performed by Ebrahim et al., (2019), who reported that 60% were having adequate knowledge. From the investigator point of view this related to individual variation and educational level.

In relation to mothers' attitudes regarding thalassemia, the present study revealed that the majority of studied mothers had positive total attitude regarding thalassemia (figure 3) this study in the same line with the study performed by Wahidiyat et al., (2021) in their study titled "Study protocol for a cross-sectional study on knowledge, attitude, and practices towards thalassemia among Indonesian youth" in Indonesian (n= 480) who clears that 72.9% of respondent showed a positive attitude towards thalassemia. This result disagreement with study performed by Biswas et al., (2022) which titled "Coping styles in parents of children with Thalassemia in West Bengal" (n=96) who stated that 90.5% of studied mothers did not use the coping mechanisms adequately. From the investigator point of view this result is due to the nature of Egyptian mothers to hold on hope, expect the best and trust in Allah.

According mothers' total reported practices regarding thalassemia the present study revealed that the majority of studied mothers had adequate reported practices regarding care of their children with thalassemia (figure 4). This study is in the same line with study performed by Mohammed et al., (2019) titled "Effect of Health Coaching Intervention on Mothers' Performance and Quality of Life of their Children with Beta Thalassemia" in Egypt (n=70) who stated that 77.1% of the participated mothers in the study had adequate practices. This result disagreement with the study performed by Wahidiyat et al., (2021) titled "Cross-sectional study on knowledge, attitude and practices towards thalassemia among Indonesian youth" in Indonesian (n=906) who said that 54.4% of studied mothers had poor practices. From the investigator point of view because the mothers follow health practioner's instructions to keep the health of their children.

The present study reveals that there highly statistically significant relation between knowledge and reported practices (p value = 0.001), and no statistically significant relation between knowledge and attitude (P value= 0.427) (table 3). This is similar to study performed by Mohammed and Abdalla, (2022) titled "Effect of Health Coaching Intervention on Mothers' Performance and Quality of Life of their Children with Beta Thalassemia." in Egypt (n= 70) who reported that there was highly statistically

significant positive correlation between total knowledge, and total practices. From the investigator point of view, this result is due to the individual differences between mothers.

5. CONCLUSION

Based on the findings of the present study results and answered the research questions, it can be concluded that: Two fifths of studied mothers had poor knowledge, majority of them had positive attitude, and adequate reported practices. There were a highly statistically significant relation between mothers' attitude and their demographic characteristics. Also, there were highly statistically significant positive correlation between total knowledge, reported practices, and mother's attitude.

List of abbreviations,

Not applicable

6. RECOMMENDATIONS

In the light of the result of this study, the following recommendations were suggested:

- Performing educational programs about thalassemia to mothers with thalassemia child.
- Dissemination of guideline booklet for mothers in outpatient clinic on thalassemia child care.
- Increase public awareness about the importance of premarital screening and counseling to detect carriers of thalassemia throughout educational campaign.
- Further studies on thalassemia should be conducted in other settings and large scale.

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