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Mothers' Knowledge and Practices regarding care of their children suffering from Thalassemia in Beni -Suef Governorate

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ABSTRACT

Background: Thalassemia is one of the most common genetic disorders worldwide. Mothers of children with thalassemia usually experience many suffering and challenges in caring of their children. ***Aim:*** Assess the mother's knowledge and practices regarding care of their children suffering from thalassemia in Beni-Suef Governorate. ***Design:*** Across sectional descriptive research design. ***Setting:*** The study was conducted at outpatient clinics of Beni–Suef University hospital. ***Sample:*** A convenience sample was used for selection of mothers (n=100). **Tools**: One tool used to achieve the aim of this study: Structural interviewing questionnaire Part I: Socio demographic data of mothers, personal data of the child and medical history of the child. Part II: Mothers' knowledge regarding care of their children suffering from thalassemia. Part III: Mothers' reported practices regarding care of their children suffering from thalassemia. ***Results:*** 35.0% of the studied mothers had inadequate total knowledge regarding thalassemia.While, 58.0% of the studied mothers had incompetent total reported practices regarding the care of their children suffering from thalassemia. ***Conclusion:*** There are highly statistically significant relation between age, kinship, education, job, income, number of their family members and total knowledge at (p value <0.01) .There are highly statistically significant relation between education, income and total mothers' reported practices at (p value <0.05). ***Recommendations:*** Health education programs on knowledge and care practices about thalassemia for mothers of thalassemia children in every public hospital in Egypt.

Keywords: Children, Knowledge, Mothers, Practices, Thalassemia.

INTRODUCTION

Thalassemia is a genetic blood disorder. The public suffering from this disease cannot make sufficient hemoglobin in the body, which leads to severe anemia. In people with alpha thalassemia, the hemoglobin does not produce sufficient alpha protein. In beta thalassemia, low levels of hemoglobin lead to a lack of oxygen in many parts of the body.

Some people with thalassemia intermediate present later than thalassemia major, have milder anemia and by definition do not require or only occasionally require transfusion **(Emami et al., 2022)**.

The causes of thalassemia are inheriting abnormal and mutated genes involved in hemoglobin production from the parents, if one of the parents is a carrier for thalassemia, the child may become a carrier of the disease,

though the child will not have any symptoms. High levels of iron can result in damage to the heart, liver, and endocrine system **(Abolghasemi et al., 2021)**.

Birth of thalassemia major children can only be prevented by knowing the thalassemia status of the parents before the child is conceived. If both parents test positive for the carrier state, they need to be counseled for prenatal diagnosis in the first trimester of pregnancy to know whether the index fetus is affected or not. If affected, medical termination is advised for the couple **(Ishfaq et al., 2023)**.

Children and adults with the condition will be supported by a team of different healthcare professionals working together in a specialist thalassemia center. Treatment to remove excess iron caused by regular blood transfusions is known as chelation therapy. It's very important because high levels of iron in the body can damage organs. Stem cell or bone marrow transplants are the only cure for thalassemia, but they're not done very often because of the significant risks involved **(Shosha & Kalaldeh, 2021).**

Thalassemia is a genetic blood disorder. People with thalassemia disease are not able to make enough hemoglobin, which causes severe anemia. Hemoglobin is found in red blood cells and carries oxygen to all parts of the body. When there is not enough hemoglobin in the red blood cells, oxygen cannot get to all parts of the body. Organs then become starved for oxygen and are unable to function properly **(Jajormaneh et al., 2022)**.

These polymers are used for modified release. Modified release systems are designed to reduce the frequency of dosing by modifying the rate of drug absorption has been available for many years. This type of release dosage form is far better than the conventional release dosage form. Mucoadhesives are synthetic or natural polymers that will interact with the mucus layer which is present in the body at the buccal cavity, and gastric mucosal layers. Antibiotics can be used for the preparation of tablets. The specific approach to their use is dependent on the individuals affected and the stage of the disease **(Khaledi et al., 2022).**

Antibiotics are also used to treat this disease. Oral modified drug delivery systems can be classified into two broad groups Single Unit dosage forms and multiple unit dosage forms. The advances and progress made by the pharmaceutical industry have greatly contributed in terms of the treatment of disease, thereby enhancing the quality of life. Mucilage and Gums are hydrophilic polysaccharides. Smoking is bad for health **(Mashayekhi et al., 2022).**

A drug is any substance (other than food that provides nutritional support) that, when inhaled, injected, smoked, consumed, absorbed via a patch on the skin, or dissolved under the tongue causes a temporary physiological (and often psychological) change in the body The impact of this disorder can range from mild, to severe; to life-threatening. Around 100,000 newborns are delivered each year with severe forms of thalassemia. It is most common in Mediterranean, South Asian, and African ancestry **(Biswas et al., 2021).**

Nurses play an essential role in promoting healthy outcomes for individual patients. In some cases, nurses may also advocate for the health and well-being of entire communities, supporting not only individuals but whole demographics. One example of this role is that of a community health nurse. Community health nurses are an integral part of public health initiatives. The American Nurses Association (ANA) defines public health nursing as the practice of promoting and protecting the health of populations using knowledge from nursing, social, and public health sciences **(Kirch, 2022).**

Significance of the study

Thalassemia is one of the most widespread genetic disorders worldwide . It estimates that there are 270 million carriers in the world and 300000 up to 400000 are annually born with thalassemia in the world . Therefore, children afflicted with thalassemia suffer from a conciderable range of developmental disorders with slow growth speed and poor body mass index that could occur as aresult of low haemoglobin ,anemia and increased levels of body ferritin .In Egypt , thalassemia is the most common form of thalassemia , with acarrier rate varying

from 5.3% to ≥ 9% and agene frequency of 0.03 .it has been estimated that 1000 /1.5 million per year live births are estimated to suffer from thalassemia ,creating a social and financial burden for the patient's family and the Egyptian government . **(world health organization , 2023).**

AIM OF THE STUDY

The current study aims to assess the mother's knowledge and practices regarding care of their children suffering from thalassemia through assessing :

1. Knowledge of the mothers regarding care of their children suffering from thalassemia.
2. Practices of the mothers regarding care of their children suffering from thalassemia.

Research questions

1. What is the level of mothers' knowledge regarding care of their children suffering from thalassemia?
2. What is the level of the mothers' reported practices regarding care of their children suffering from thalassemia?
3. Is there a relationship between total knowledge scores, total reported practice scores and socio-demographic characteristics of the mothers?

SUBJECTS AND METHODS

I- Technical Item:

The technical item includes research design, setting, subject and tools for data collection.

Research design:

Across sectional descriptive research design was applied to achieve the aim of the current study. The design helps us to provide an accurate description of observation of phenomenon of interest.

Setting:

The study was conducted at outpatient clinics of Beni-Suef University hospital. It was a teaching hospital. It located on Mohammed Hassan street, El shamela, Beni-suef inside the faculty of medicine .The hospital consists of (5) floors. Outpatient clinics are located on the first and second above floors, it consist of (16) clinics.

Sample type

A convenience sample was used for selection of mothers.

Sample size:

100 mothers were included in the study.

Tools for data collection:

One tool used to achieve the aim of this study.

A: Structural interviewing questionnaire sheet:

It was developed by investigator after reviewing the national and international related literature. It was contain 3 parts:

I : Demographic characteristics of the participants in the study: This part include: mothers' age, kinship, marital status, residence, education, job, number of rooms, income and numbers of family members.

II : Personal data of the child suffering from thalassemia: This part include: child's age, gender, ranking, weight, length and blood group.

III: Medical history of the child suffering from thalassemia: This part include: family history of thalassemia, time where thalassemia was discovered, effect of thalassemia on vital activities, type of activity affection, blood transfusion needs, time where the blood transfusions take place, place where the blood transfused to the child, commitment to giving treatment to the child and commitment to doing medical tests for the child.

B: Mothers' knowledge regarding care of their children suffering from thalassemia:

I : Mothers' knowledge regarding thalassemia such as: functions of the blood , function of red blood cells, definition of the blood hemoglobin, definition of thalassemia, causes of thalassemia, symptoms of thalassemia, thalassemia diagnostic tests, complications of thalassemia, methods to reduce or limit the complications of

thalassemia and methods of treating thalassemia.

II : Mothers' knowledge regarding the sports activities of the child with thalassemia such as: importance of sports for a child who suffers from thalassemia and sports allowed for a child who suffers from thalassemia.

III : Mothers' knowledge regarding the nutrition of the child suffering from thalassemia such as: foods that allowed for a child suffering from thalassemia and foods are forbidden for a child who suffering from thalassemia.

IV: Mothers' knowledge regarding blood transfusion for the child suffering from thalassemia such as: definition of blood transfusion, importance of blood transfusion, tests are required before a blood transfusion and precautions must be followed to prevent blood transfusion complications.

Scoring system for mothers' knowledge:

- Knowledge of mothers regarding care of their children with thalassemia was classified as :
  - Complete correct answers was scored as (2)
  - Incomplete correct answers was scored as (1)
  - Don't know was scored as (0)

Total knowledge scores were classified as the follows:

Adequate knowledge = ≥ 60 %

In adequate knowledge = < 60

C: Mothers' reported practices regarding care of their children suffering from thalassemia: (Bowden& Greenberg , 2017)

1. **Questionnaire to evaluate hand washing**

Such as: wet hands with water, apply an amount of soap to cover the surface of the hand, rub the palm of the hand with the palm of the other hand, rub the palm of the right hand on the back of the left hand, overlapping fingers and vice versa, rub the palm of the hand against the palm of the other hand, interlacing the fingers, rub the back of the fingers with the palm of the other hand with the fingers together, circular rubbing of the left thumb, then the right, circular rubbing with the end of the fingers of the right hand and the palm of the left hand and vice versa, washing the wrists by moving the palm of one hand over the other in a sliding motion, rinse hands well with running water from the fingertips until the end of the forearm in one direction and make the hands up and dry the hands using a clean towel or paper tissues.

2. **Questionnaire to measure the child's temperature (oral and axillary)**

Oral temperature such as: wash hands routinely, take the thermometer out of its case and disinfect it with an alcohol swab, ensure that the thermometer temperature is lowered to less than 35°C, the child is placed in sitting position, gently place the thermometer under the child's tongue, make the child close his mouth using his lips only not by his teeth, maintain the thermometer for 3 minutes, remove the thermometer and wipe it with a piece of cotton, the thermometer reads correctly, wash the thermometer with soap and water, disinfect it with alcohol, and place it in the cover and record the child's temperature.

Axillary temperature such as: wash hands routinely, take the thermometer out of its case and disinfect it with an alcohol swab, ensure that the thermometer temperature is lowered to less than 35°C, the child is placed lying on his back, expose axillary area, wipe it with a piece of cotton with warm water, then dry it, place the tip of the thermometer vertically in the middle of axillary and fix the arm, maintain the thermometer for 3-5 minutes, remove the thermometer and wipe it with a piece of cotton, the thermometer reads correctly, wash the thermometer with soap and water, disinfect it with alcohol, and place it in the cover and record the child's temperature.

3. **Questionnaire to measure the child's pulse.**

Such as: wash hands routinely, warming stethoscope with the palm of the hand, wipe the surface of stethoscope with an alcohol swab, place the stethoscope on the top of the heart, directly under the left nipple , the pulses are counted for a full minute, for the

strength, regularity, rate, and speed and record the pulse count.

4. **Questionnaire to measure the child's breathing**

Such as: wash hands routinely, approach the child calmly and observe the breathing rate without warning, count your breaths for a full minute by observing the movement of the abdomen and record the breath count.

5. **Questionnaire to measure flexibility exercises of the child**

Such as: place the child on his back, place his arms next to his body, slowly raise the child's legs with the knees slightly bent, maintain this position for 15 second and return the legs to the front and repeat the movement 3 times.

6. **Questionnaire to evaluate the child's height**

Such as: stand as tall and straight as possible, make the head level in the midline of the child's body, the child's back should be to a vertical flat surface with heels, buttocks touching the surface and the legs are spread, make a mark using a pen or place a book above the child's head and take the correct reading by using a tape measure.

7. **Questionnaire to evaluate the child's weight**

Such as: place the scale on a flat surface, set the scale to zero, remove the child's clothes except underwear, place the child on the scale, the mother advises the child not to move from the scale and takes the correct reading

8. **Questionnaire to evaluate eye care**

Such as: wash hands routinely, place a clean towel under the child's head, bring a clean, dry piece of cotton, bring a small bowl of warm water, place a piece of cotton in the water and squeeze it, gently wipe the child's eyes from the inside to the out without going back, repeat this process in the other eye and get rid of dirty tools and cotton and wash hands.

9. **Questionnaire to evaluate dental care**

Such as: place the child in a sitting or sleeping position on his side, place a clean towel around the child's neck and chest, put the paste on the brush, brush the child's teeth in all directions, place a bowl under the child's chin to receive the used water, give the child a little water to rinse his mouth, or the mother rinses the child's mouth with a piece of gauze or cotton soaked in water and dry the child's mouth well with a towel.

10. **Questionnaire to evaluate the role of the mother during blood transfusion**

Such as: observe the child well during the blood transfusion, fix the child's hand so that he does not remove the cannula during the blood transfusion, ensure blood flow normally, observe any changes that occur to the child during the blood transfusion, inform the nurse or doctor of any changes that occur to the child during the blood transfusion, wait with the child throughout the blood transfusion and knowing the child's blood type.

11. **Questionnaire to evaluate the role of the mother when giving their children tablets (Desferral)**

Such as: check medication and expired date, perform hand hygiene, check the ferritin level before and after giving the medication, check the creatinine level before and after taking the medication, medication should be given when ferritin levels are more than 1000 mg/ml or after taken 20 blood cells, the dose is given only one tablet daily according to the doctor's orders (Dosage: 125 mg, 250 mg, 500 mg), observe side effects of the medication, such as abdominal pain, diarrhea, nausea, vomiting, hearing and vision disturbance), give the medicine 30 minutes before eating and must not be destroyed, give the medicine at the same time every day, dissolve the medicine in 100-200 ml of water or orange juice and vitamins C and E should be given with the medication.

Scoring system for mothers' reported practices:

- Reported practices of mothers regarding care of their children with thalassemia was classified as:
  - Done answers was scored as (1)
  - Not done answers was scored as (0)

Total reported practices scores were classified as the follows:

Competent reported practices= ≥ 60 %

In competent reported practice= < 60 %

Tool Validity:

Validity of the study tool was assessed by panel of five experts from faculty of nursing, Beni-Suef University (3in the field of community health nursing department and 2 in the field of pediatric nursing department). The experts reviewed the tool for clarity of sentences, relevance, accuracy, comprehensiveness, simplicity and applicability.

Reliability:

The study tool was tested for its internal consistency using Cronbach's Alpha test. It was (0.803) for knowledge questionnaires and (0.939) for reported practices tool.

Ethical Considerations:

A written ethical approval was obtained from the Research Ethics Committee of the Faculty of Medicine , Beni-Suef University in 6th of June ,2023 under approval No:FMBSUREC/06062023.Official permission was taken from the Director of Beni-Suef University hospital. Oral consent was obtained from all mothers (participants). The aim and purposes of study were explained through direct personal communication with the mothers. The purpose and nature of the study were explained to them before the interview. The investigator was confirming that participation in the study is entirely voluntary and mothers have the right to withdraw at any time. Ethics, value, culture and believes was respected. Mothers in the study were given complete information about the study and their role before signing the informed consent.

II. Operational item

The operational item includes preparatory phase, pilot study and field work.

Preparatory phase:

This phase include reviewing of current and past national and international related literature concerning the subjects of the study, using textbooks, articles, journals and websites. This review was helpful to the investigator in reviewing and developing the data collection tool.

Pilot Study:

The pilot study has been conducted to test the clarity of questions, applicability and understanding of the tool. It has been conducted on 10 % (10) of mothers. The results of the pilot study helped in refining the interview questionnaire and to schedule the time framework. The participants of the pilot were included in the main study sample since no fundamental modifications were made.

Field work:

Data collection for the study takes six months. The study data collection began at the beginning of June 2023, and ended at the end of November 2023. Data collection done 2 days/week (Saturday and Tuesday) by the investigator in outpatient clinics at Beni-Suef University hospital from 9 am - 12 pm.

Duration of the study:

The study was conducted in six months.

At the beginning , the investigator explained the purpose of the study to the mothers and reassured them that the collected information is strictly confidential and that it is used only for the purpose of the research.

III. Administrative item:

Approval to conduct this study was obtained from the dean of the Faculty of Nursing, Beni-Suef University, and official permission was obtained from the Director of Beni-Suef University hospital regarding mothers that were included and agreed to participate in the study. This approval included a permission to collect the necessary data and explain the purposes and nature of the study.

IV. Statistical item:

Data analysis of the collected information was performed with the help of a statistical package for social sciences (SPSS) software version 25. The variables were analyzed descriptively where continuous variables were analyzed and presented using means and standard deviations. Qualitative variables were compared using qui square

test (X^2) as the test of significance, independent (t) test were used to compare mean score between two and more groups respectively.

Significance of the results:

- P-value ≤0.05 was considered significant.
- P-value ≤0.001 was considered as highly significant.
- P-value >0.05 was considered no significant.

RESULTS

Table (1) displays that, 64.0 % of studied mothers were in age group from 20 −<30 years old. Also, 42.0% of them had first degree kinship. Moreover, 92.0% of them were married. Also, 60.0% of them were lived in rural areas and 54.0% of them had secondary education. While, 82.0% of them were house wives and 52.0% of them had three rooms in their houses. In addition, 60.0% of them had not enough income and 40.0% of them had four members of their families.

Table (2) displays that, 54.0% and 62.0% of the studied mothers don't know the function of red blood cells and the definition of blood hemoglobin, respectively. While, 60.0 % and 84.0% of them had incomplete correct knowledge regarding the definition and causes of thalassemia, respectively. Also, 68.0% of them had complete correct knowledge regarding symptoms of thalassemia.

Figure (1) shows that, 35.0% of the studied mothers had inadequate knowledge regarding thalassemia. While, 65.0% of them had adequate knowledge regarding thalassemia.

Table (3) displays that, 38.0 % of the studied mothers had incomplete correct knowledge regarding the importance of sports for a child who suffers from thalassemia. While, 60.0% of them had complete correct knowledge regarding sports allowed for a child who suffers from thalassemia.

Figure (2) shows that, 29.0% of the studied mothers had inadequate knowledge regarding activities of their children suffering from thalassemia. While, 71.0% of them had adequate knowledge regarding activities of their children suffering from thalassemia.

Table (4) displays that, 72.0 % of the studied mothers had incomplete correct knowledge regarding foods that allowed for a child suffers from thalassemia. Also, 40.0% of them had complete correct knowledge regarding foods are forbidden for a child who suffers from thalassemia.

Figure (3) shows that, 27.0% of the studied mothers had inadequate knowledge regarding nutrition of their children suffering from thalassemia. While, 73.0% of them had adequate knowledge regarding nutrition of their children suffering from thalassemia.

Table (5) displays that, 44.0% of the studied mothers had complete correct knowledge regarding the definition of blood transfusion. Also, 46.0 % of them had incomplete correct knowledge regarding the importance of blood transfusion. While, 50.0% of them don't know tests are required before a blood transfusion.

Figure (4) Shows that, 56.0% of the studied mothers had inadequate knowledge regarding blood transfusion for their children suffering from thalassemia. While, 44.0% of them had adequate knowledge regarding blood transfusion for their children suffering from thalassemia.

Figure (5) Shows that, 58.0% of the studied mothers had incompetent total reported practices regarding the care of their children suffering from thalassemia. While, 42.0% of them had competent total reported practices regarding the care of their children suffering from thalassemia.

Table (6) Displays that, there are highly statistically significant relation between age, kinship, education, job, income, number of their family members and total knowledge at (p value <0.01). While, there are no statistical significant relation between marital status, residence, number of rooms and total knowledge at (p >0.01).

Table (7) displays that, there are highly statistically significant relation between education, income and total mothers' reported practices at (p value <0.05). While,

there are no statistical significant relation between age, kinship, marital status, residence, job, number of rooms, number of their family members and total mothers' reported practices at ($p > 0.05$).

Table (1): Frequency distribution of demographic characteristics of the studied mothers (n=100).

Variables	Category	No	%
Age (years)	20-	30	30.0
	30-	**64**	64.0
	40+	6	6.0
Kinship	1st Degree	**42**	42.0
	2nd Degree	28	28.0
	No	30	30.0
Marital status	Married	**92**	92.0
	Divorced	8	8.0
Residence	Urban	40	40.0
	Rural	**60**	60.0
Education	Illiterate	14	14.0
	Basic	16	16.0
	Secondary	**54**	54.0
	University	16	16.0
Job	Works	18	18.0
	Housewife	**82**	82.0
No. of Rooms	Two	28	28.0
	Three	**52**	52.0
	More than Three	20	20.0
Income	Enough	32	32.0
	Not-Enough	**60**	60.0
	Enough and saving	8	8.0
No. of Family members	Three	10	10.0
	Four	**40**	40.0
	Five	38	38.0
	More than five	12	12.0
Total		100	100.0
Data are expressed as frequency and percentage			

Table (2): Frequency distribution of mothers' knowledge about thalassemia (n=100).

	Complete correct		Incomplete correct		Don't know	
Knowledge items	**No**	**%**	**No**	**%**	**No**	**%**
Functions of the blood	28	28.0	38	38.0	34	34.0
Function of red blood cells	24	24.0	22	22.0	**54**	**54.0**
Definition of the blood hemoglobin	16	16.0	22	22.0	**62**	**62.0**
Definition of thalassemia	32	32.0	**60**	**60.0**	8	8.0
Causes of thalassemia	10	10.0	**84**	**84.0**	8	8.0
Symptoms of thalassemia	**68**	**68.0**	32	32.0	0	0.0
Thalassemia diagnostic tests	44	44.0	38	38.0	18	18.0
Complications of thalassemia	36	36.0	52	52.0	12	12.0
Methods to reduce or limit the complications of thalassemia	34	34.0	50	50.0	16	16.0
Methods of treating thalassemia	34	34.0	44	44.0	22	22.0
Data are expressed as frequency and percentage						

Figure (1): Percentage distribution of the studied mothers according to their total knowledge regarding thalassemia.

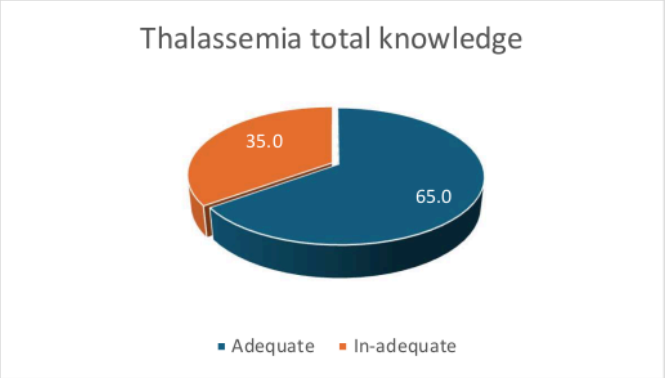

Table (3): Frequency distribution of mother's knowledge about the sports activities of the child with thalassemia (n=100).

Knowledge items	Complete correct		Incomplete correct		Don't know	
	No	%	No	%	No	%
Importance of sports for a child who suffers from thalassemia	48	48.0	**38**	**38.0**	**14**	**14.0**
sports allowed for a child who suffers from thalassemia	**60**	**60.0**	34	34.0	6	6.0
Data are expressed a frequency s No and percentage						

Figure (2): Percentage distribution of the studied mothers according to their total knowledge regarding activities.

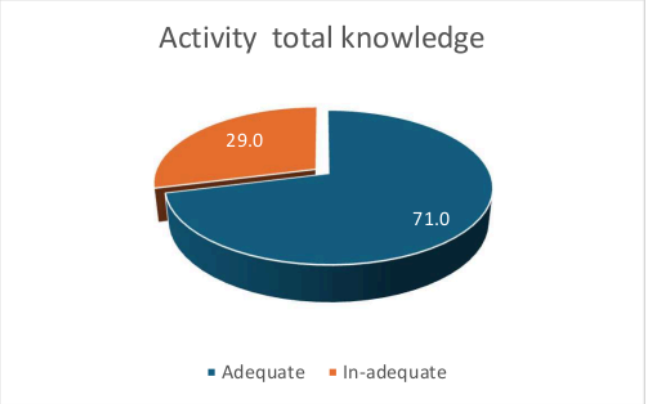

Table (4): Frequency distribution of mother's knowledge about the nutrition of the child with thalassemia (n=100).

Knowledge items	Complete correct		Incomplete correct		Don't know	
	No	%	No	%	No	%
foods that allowed for a child suffers from thalassemia	28	28.0	**72**	**72.0**	0	0.0
foods are forbidden for a child who suffers from Thalassemia	**40**	**40.0**	50	50.0	**10**	**10.0**
Data are expressed as frequency No and percentage						

Figure (3): Percentage distribution of the studied mothers according to their total knowledge regarding nutrition.

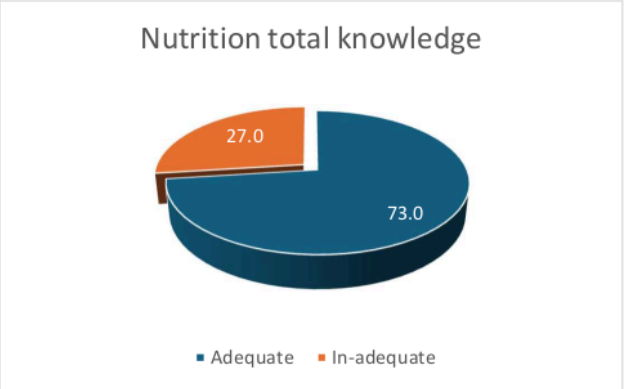

Table (5): Frequency distribution of mother's knowledge about blood transfusion for the child with thalassemia (n=100)

	Complete correct		Incomplete correct		Don't know	
Knowledge items	**No**	**%**	**No**	**%**	**No**	**%**
Definition of blood transfusion	**44**	**44.0**	40	40.0	16	16.0
Importance of blood transfusion	36	36.0	**46**	**46.0**	18	18.0
Tests are required before a blood transfusion	28	28.0	22	22.0	**50**	**50.0**
Side effects that can appear during a blood transfusion	32	32.0	26	26.0	42	42.0
Precautions must be followed to prevent blood transfusion complications	24	24.0	34	34.0	42	42.0
Data are expressed a frequency s No and percentage						

Figure (4): Percentage distribution of the studied mothers according to their total knowledge regarding blood transfusion

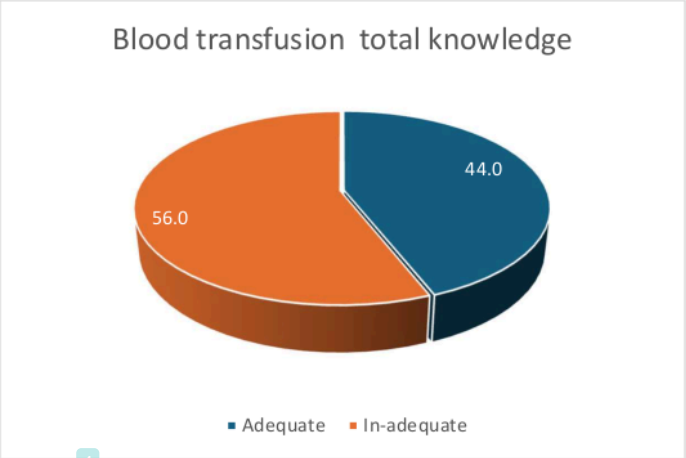

Figure (5): Percentage distribution of the studied mothers according to their total reported practices regarding care of their children suffering from thalassemia (n=100).

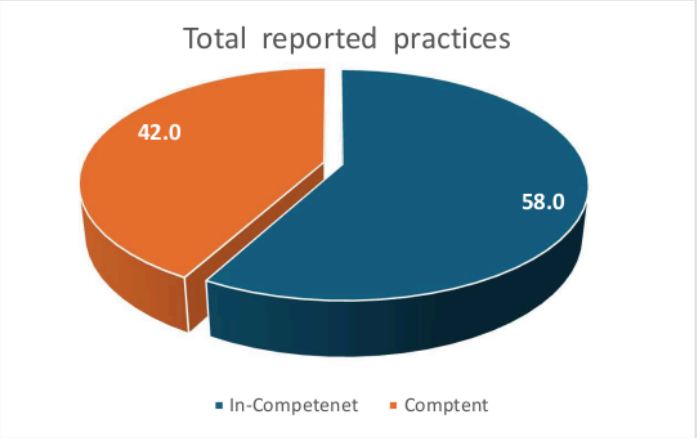

Table (6): Relation between demographic characteristics and mothers' total knowledge (n=100) answer research question (3)
Is there a relationship between total knowledge scores, total reported practice scores and socio-demographic characteristics of the mothers?

Variables	Category	Total knowledge				X Square	P-value
		In-adequate		Adequate			
		No	%	No	%		
Age	**20-**	14	14.0	16	16.0	13.377	0.001**
	30-	8	8.0	56	56.0		
	40+	2	2.0	4	4.0		
Kinship	**1st Degree**	6	6.0	36	36.0	14.421	0.001**
	2nd Degree	14	14.0	14	14.0		
	No	4	4.0	26	26.0		
Marital status	**Married**	20	20.0	72	72.0	3.223	0.073
	Divorced	4	4.0	4	4.0		
Residence	**Urban**	10	10.0	30	30.0	.037	0.848
	Rural	14	14.0	46	46.0		
Education	**Illiterate**	8	8.0	6	6.0	15.972	0.001**
	Basic	6	6.0	10	10.0		
	Secondary	10	10.0	44	44.0		
	University	0	0.0	16	16.0		
Job	**Works**	0	0.0	18	18.0	6.932	0.008**
	Housewife	24	24.0	58	58.0		
No. of Rooms	**Two**	8	8.0	20	20.0	1.364	0.506
	Three	10	10.0	42	42.0		
	More than Three	6	6.0	14	14.0		
Income	**Enough**	2	2.0	30	30.0	13.332	0.001**
	Not-Enough	22	22.0	38	38.0		
	Enough and saving	0	0.0	8	8.0		
No. of Family members	**Three**	8	8.0	2	2.0	22.409	0.000**
	Four	10	10.0	30	30.0		
	Five	6	6.0	32	32.0		
	More than five	0	0.0	12	12.0		
** statistically significant at the 0.01 level							

Table (7): Relation between demographic characteristics and mothers' total reported practice (n=100)

Variables	Category	Total reported Practices				X Square	P-value
		Competent		In-Competent			
		No	%	No	%		
Age	**20-**	8	8.0	22	22.0	3.088	0.213
	30-	10	10.0	54	54.0		
	40+	0	0.0	6	6.0		
Kinship	**1st Degree**	10	10.0	32	32.0	1.665	0.435
	2nd Degree	4	4.0	24	24.0		
	No	4	4.0	26	26.0		
Marital status	**Married**	16	16.0	76	76.0	.289	0.591
	Divorced	2	2.0	6	6.0		
Residence	**Urban**	4	4.0	36	36.0	2.891	0.089
	Rural	14	14.0	46	46.0		
Education	**Illiterate**	6	6.0	8	8.0	8.456	0.037*
	Basic	4	4.0	12	12.0		
	Secondary	6	6.0	48	48.0		
	University	2	2.0	14	14.0		
Job	**Works**	2	2.0	16	16.0	0.706	0.401
	Housewife	16	16.0	66	66.0		
No. of Rooms	**Two**	6	6.0	22	22.0	0.518	0.772
	Three	8	8.0	44	44.0		
	More than Three	4	4.0	16	16.0		
Income	**Enough**	10	10.0	22	22.0	6.448	0.040*
	Not-Enough	8	8.0	52	52.0		
	Enough and saving	0	0.0	8	8.0		
No. of Family members	**Three**	4	4.0	6	6.0	6.873	0.076
	Four	6	6.0	34	34.0		
	Five	4	4.0	34	34.0		
	More than five	4	4.0	8	8.0		
* statistically significant at the 0.05 level							

DISCUSSION

School-age children experience significant growth and development across multiple domains. During these years, they continue to refine their physical abilities, improve coordination, and develop greater strength and endurance. Cognitively, they enhance their problem-solving skills, logical thinking, and ability to concentrate for longer periods, which supports academic success. Language skills become more advanced, allowing them to express complex thoughts and engage in meaningful conversations. Socially, school-age children form stronger friendships, develop teamwork skills, and learn important values such as empathy and responsibility. Emotionally, they begin to understand and manage their feelings more effectively, gaining greater self-control and resilience **(Centers for Disease Control and Prevention, 2023).**

During the school-age years, children may face various health challenges and developmental concerns. Common issues include respiratory infections, allergies, and asthma, which can be triggered by environmental factors and increased social interactions. Nutritional deficiencies, such as anemia especially in cases like thalassemia may persist and require proper dietary management. Behavioral and learning difficulties, including attention deficits, dyslexia, and other academic challenges, often become more noticeable as children engage in structured education. School-age children are also prone to injuries from sports or playground activities as they develop their physical skills. Emotional and mental health challenges, including anxiety, stress, or difficulties with peer relationships, can become more pronounced as children navigate social expectations **(World Health Organization, 2023).**

Regarding to age of the studied mothers, the results of the current study showed that, less than two thirds of studied mothers were in age group from 20 – <30 years old **(Table 1).** This result was in agreement with the study carried out by **(Youssef et al., 2020)**, which examined "Mothers' knowledge and practices regarding the care of children with thalassemia in Upper Egypt, n=120", where (62.5%) of the participating mothers were also in the same age range. Similarly, **(Kumar et al., 2022)** in their study on " Caregivers of children with chronic blood disorders in India, n=345", reported that 65% of the participants were young mothers aged between 20 and 30 years **(Table1).** From the investigator point of view, this age group represents a period when women are more likely to have young children, aligning with societal norms and childbearing patterns in many regions.

In relation to marital status of the studied students, the results of the current study revealed that, the majority of them were married, also, three fifths of them lived in rural areas. These findings are consistent with the study conducted by **(Ali et al., 2021),** which explored "Socio-demographic factors influencing students' health-related practices, n=270" and reported that a significant proportion of married participants were from rural regions. Similarly, **(Al-Mahdi & Morsy, 2020)** who examined "Knowledge, attitudes, and practices of parents of children with thalassemia in Jazan region, Saudi Arabia, n=300 " found that most of their participants were married and lived in rural communities. From the investigator point of view, this result might be due to cultural norms and traditions in rural settings, where early marriage is more prevalent and higher education often coincides with marital responsibilities **(Table1).**

Concerning education and number of rooms of the studied mothers, the results of the current study clarified that, more than half of them had secondary education and had three rooms in their houses respectively, while the majority of them was house wives. These results were similar **(Hassan & Mahmoud, 2024)** who studied " Effect of educational program on mothers' knowledge and practices regarding care of children with beta-thalassemia in Egypt, n=275" which reported that (56%) of the participants had secondary education and a similar proportion were housewives. From the investigator point of view, this result might be alignment might

reflect the educational and occupational norms prevalent among mothers in similar socioeconomic settings **(Table1).**

In contrast, the results differ from the study by **(Kumar et al., 2021),** who investigated "The demographic profile of mothers caring for children with thalassemia in urban areas, n=75 ". That study revealed that (38%) of mothers had secondary education, and (32%) were housewives, as many were engaged in small businesses or part-time jobs to support their families. From the investigator point of view, these differences could be attributed to variations in urban versus rural settings, where mothers in urban areas might have access to higher education and employment opportunities.

In relation to family income and number of family members of the studied mothers, the results of the current study illustrated that, three fifths of them had not enough income and two fifths of them had four members of their families **(Table1).** These findings are consistent with the study conducted by **(Hassan et al., 2020),** who examined "The socioeconomic status of mothers caring for children with chronic illnesses as thalassemia, n=320", revealing that (63%) of participants struggled with insufficient income, particularly in households with multiple dependents. Limited income often impacts access to healthcare services and the ability to manage chronic conditions like thalassemia effectively.

However, these results differ from the findings of **(Singh et al., 2022),** who investigated "Parental awareness and management practices for children with thalassemia in rural settings in Indian regions, n=430", which focused on urban mothers caring for children with blood disorders. This study found that (45%) of mothers reported insufficient income, likely due to higher employment rates and better socioeconomic opportunities in urban areas. From the investigator point of view, the variation might stem from differences in rural versus urban living conditions, as well as the availability of social and financial support systems. These findings emphasize the need for targeted financial support and educational programs to help families in low-income settings better manage the challenges of caring for children with chronic conditions. Regarding to mothers' knowledge regarding the care of their children suffering from thalassemia, the current study illustrated that more than half and more than two thirds of the studied mothers don't know the function of red blood cells and the definition of blood hemoglobin, respectively, while, three fifths and more than four fifths of them had incomplete correct knowledge regarding the definition and causes of thalassemia, respectively. Also, more than two thirds of them had complete correct knowledge regarding symptoms of thalassemia **(Table 2).**

These results were in the same line with **(Khalil et al., 2020),** who examined the "Knowledge of mothers in Egypt about thalassemia, n=335". They found (56%) of mothers lacked a clear understanding of the function of red blood cells, and (65%) were unaware of the role of hemoglobin, similar to the results of this study. Moreover, they reported that while many mothers had limited understanding of the causes and definition of thalassemia, less than (72%) demonstrated adequate knowledge of its symptoms.

From the investigator point of view, these results might be associated that low level of knowledge regarding the function of red blood cells and the causes of thalassemia highlights a critical gap in education for mothers of children with the disease. While most mothers were aware of the symptoms, which are more apparent and observable, the lack of understanding of the underlying biology of the disease could affect their ability to fully support the medical care of their children **(Table 2).**

These results weren't similar to **(Patel et al., 2022),** which clarified that (70%) of mothers correctly understood the causes and definition of thalassemia, and (20%) had incomplete knowledge, which is higher than the findings in the current study. This difference could be attributed to differences in educational interventions and access to healthcare resources in urban versus rural areas.

The study indicates that more than one third of the studied mothers had inadequate knowledge regarding thalassemia, while, about two thirds of them had adequate knowledge regarding thalassemia **(Figure 1).** These findings are consistent with previous research. For instance, **(Youssef et al., 2020)** in a study about "Mothers knowledge and practices about thalassemia and its management in Egypt, n=145" found that while many mothers demonstrated adequate knowledge about thalassemia, a portion still faced challenges in comprehending the disease and its management.

Similarly, in a study by **(Kumar et al., 2022)**, about "Awareness about thalassemia and its management among the caregivers of the thalassemia patients of Punjab and Chandigarh, India, n=325" and reported a significant percentage of caregivers in India showed gaps in understanding chronic blood disorders, including thalassemia. This may be due to that the level of knowledge may be influenced by factors such as geographic location, healthcare access, and educational outreach initiatives. Concerning mother's knowledge about the sports activities of the child with thalassemia, the result of the present study clarified less than two fifths of the studied mothers had incomplete correct knowledge regarding the importance of sports for a child who suffers from thalassemia, while, three fifths of them had complete correct knowledge regarding sports allowed for a child who suffers from thalassemia **(Table 3).**

These findings are consistent with the study by **(Khaled et al., 2021),** who investigated "The understanding of caregivers regarding physical activity for children with thalassemia, n=290". They found that (40%) of mothers had limited knowledge about the benefits of exercise for children with chronic conditions like thalassemia, while (63%) correctly identified suitable sports that could help maintain physical health without exacerbating the condition. This suggests that while caregivers may be aware of the importance of physical activity, they often lack sufficient knowledge about its specific benefits and limitations for children with thalassemia.

From the investigator point of view , the finding that a majority of mothers knew which sports were appropriate for children with thalassemia but lacked full understanding of the benefits of physical activity suggests a need for more comprehensive education on the holistic role of exercise in managing the condition. Educating mothers not only about suitable physical activities but also about how these activities can improve overall health, muscle strength, and quality of life for children with thalassemia is essential for fostering better health outcomes.

In contrast, **(Suresh et al., 2020),** in a study focused on "The knowledge of caregivers in urban India, n=325", reported that (75%) of the participants had an incomplete understanding of the importance of sports for children with thalassemia, but nearly 90% knew which sports were safe for these children. This discrepancy could be due to differences in educational outreach and healthcare advice provided to parents in different regions, highlighting the importance of culturally and contextually relevant education programs.

The result of the present study also revealed that less than one third of the studied mothers had inadequate total knowledge regarding activities of their children suffering from thalassemia, while, less than three quarters of them had adequate total knowledge regarding activities of their children suffering from thalassemia **(Figure 2).** These findings are consistent with the study by **(Ahmed et al., 2020),** which assessed "The knowledge of caregivers about appropriate activities for children with chronic illnesses like thalassemia, n=100". Their study showed that (72%) of mothers' demonstrated adequate knowledge regarding safe and beneficial activities for their children, while (28%) had inadequate understanding.

From the investigator point of view, the higher proportion of mothers with adequate knowledge suggests a positive outcome in terms of educational interventions. However, inadequate knowledge indicates a need for further efforts in educating caregivers. Providing targeted information about safe

physical activities, the impact of exercise on disease management, and how to adjust activities based on the child's health status could help improve the quality of life and overall health of children with thalassemia.

Regarding to mother's knowledge about the nutrition of the child with thalassemia, the current study also demonstrated that less than three quarters of the studied mothers had incomplete correct knowledge regarding foods that allowed for a child suffers from thalassemia. Also, two fifths of them had complete correct knowledge regarding foods are forbidden for a child who suffers from thalassemia **(Table 4).**

These findings are in the same line with the study by **(Abdel-Rahman & Fawzy, 2020),** which explored "The nutritional knowledge of mothers of children with thalassemia in Egypt, n=280". They found that (68%) of mothers had incomplete knowledge about the dietary requirements of children with thalassemia, particularly in relation to foods that support iron absorption and those that should be avoided due to the risk of iron overload. Furthermore, (45%) of mothers in their study demonstrated complete knowledge about foods to avoid, especially iron-rich foods and those that can increase the absorption of iron, such as vitamin C-rich foods.

From the investigator point of view, the relatively high proportion of mothers with incomplete knowledge regarding allowable foods suggests that further efforts are needed to improve education on the specific dietary needs of children with thalassemia. Ensuring that mothers understand not only what foods to avoid but also what types of foods can support their children's health is crucial in managing iron overload and other complications associated with the disease.

Conversely, **(Zhang et al., 2021),** in a study conducted in China entitled "The impact of knowledge on health of children with thalassemia, n=650", reported a higher level of knowledge among mothers regarding the dietary restrictions for children with thalassemia. Their study found that (60%) of the mothers had accurate knowledge of both the foods allowed and forbidden for children with the condition, which was attributed to more widespread educational campaigns and nutritional counseling provided in healthcare settings.

The result of the present study also showed that, more than one quarter of the studied mothers had inadequate total knowledge regarding nutrition of their children suffering from thalassemia. While, less than three quarters of them had adequate total knowledge regarding nutrition of their children suffering from thalassemia **(Figure 3).** These findings align with the study by **(El-Shafie & Mostafa, 2021),** which investigated "The nutritional knowledge of mothers caring for children with thalassemia, n=160". Their study revealed that (75%) of mothers demonstrated adequate understanding of the dietary needs of their children, particularly concerning foods to limit due to iron overload. However, about (25%) of the mothers had inadequate knowledge, often lacking understanding about managing iron intake and the role of specific foods in preventing complications such as organ damage.

In contrast, **(Khan et al., 2022),** in their study of caregivers "Experiences of family caregivers of children living with thalassemia-major in Karachi in Pakistan, n=320", reported (60%) of mothers with adequate knowledge regarding the nutrition of children with thalassemia, while(40%) of mothers had inadequate knowledge. This discrepancy could reflect differences in healthcare access, the availability of educational programs, and socioeconomic factors that influence mothers' understanding of medical advice.

Moreover, the current study results displayed that, more than two fifths of the studied mothers had complete correct knowledge regarding the definition of blood transfusion. Also, less than half (46.0 %) of them had incomplete correct knowledge regarding the importance of blood transfusion. While, half of them don't know tests are required before a blood transfusion **(Table 5).**

These findings supported **by (Rashed et al., 2020)**, which assessed the "Knowledge of caregivers about blood transfusion procedures for children with thalassemia,

n=150". Their study showed that (45%) of mothers had complete knowledge about the definition of blood transfusion, while (48%) had an incomplete understanding of its importance. Furthermore, (52%) of caregivers were unaware of the specific tests needed before blood transfusions, similar to the findings in the current study.

This gap in knowledge can affect the safety and efficacy of transfusions and overall disease management. From the investigator point of view, the moderate level of knowledge about blood transfusion definitions and its importance, combined with the high percentage of mothers unaware of the necessary pre-transfusion tests, highlights a critical area for improvement in caregiver education.

In contrast, **(Bari et al., 2022),** "Assessing parental knowledge about thalassemia in a thalassemia center of Karachi, Pakistan, n=172", reported that (60%) of mothers had a clear understanding of both the definition and the importance of blood transfusions. However, (65%) still lacked knowledge about pre-transfusion testing, indicating a need for further education on this critical aspect of care.

The present study results clarified that more than half of the studied mothers had inadequate knowledge regarding blood transfusion for their children suffering from thalassemia. While, more than two fifths of them had adequate knowledge regarding blood transfusion for their children suffering from thalassemia **(Figure 4).** These results align with the findings of a study by **(Raza et al., 2021),** which examined "The knowledge of caregivers regarding blood transfusions for children with thalassemia in Pakistan, n=300" and reported that more than half of mothers lacked comprehensive knowledge about blood transfusions, particularly regarding the frequency, complications, and the importance of iron chelation therapy to prevent iron overload.

However, the results of the present study differ from those of a study by which investigated "Caregiver knowledge in urban areas of India, n=250", found that (65%) of mothers had adequate knowledge about blood transfusion practices, possibly due to better access to healthcare education, regular medical consultations, and the availability of support groups in urban settings.

From the investigator point of view, the inadequate knowledge observed in over half of the studied mothers could be attributed to limited educational initiatives and insufficient healthcare support in rural or less-developed areas. Many mothers may not receive comprehensive guidance on blood transfusion protocols or the importance of regular transfusions in preventing complications such as iron overload. The current study results also revealed that less than three fifths of the studied mothers had incompetent total reported practices regarding the care of their children suffering from thalassemia, while , more than two fifths of them had competent total reported practices regarding the care of their children suffering from thalassemia **(Figure 5).** These results are in agreement with **(Dewi et al., 2024)** in a study "Exploring experiences of mothers of children with thalassemia major in Indonesia, n=75" found that despite receiving information about thalassemia, many mothers struggled with the daily practices required to manage the disease effectively. The study emphasized the need for continuous support and training to improve the practical care provided by parents.

In contrast, the results of the current study differ from a study by (**Patel et al., 2021**), which examined "The practices of mothers caring for children with thalassemia in urban areas of India, n= 154". Patel's research revealed that (55%) of the mothers reported competent care practices due to better access to healthcare resources, including specialized care and continuous follow-up support. These differences might be attributed to the availability of resources, healthcare infrastructure, and education levels in urban settings. Mothers in urban areas typically have more access to medical information, healthcare professionals, and support groups, which contribute to better management of thalassemia.

From the investigator point of view, the observed differences between the two studies can be explained by the urban versus rural

context. In rural areas, where healthcare access and education may be more limited, mothers might face additional barriers in implementing competent care practices, such as travel distance to healthcare centers, limited availability of specialists, and a lack of specialized programs. Urban areas, however, tend to have better healthcare facilities and educational opportunities, which can empower mothers to provide more effective care. Concerning relationship between demographic characteristics of the studied mothers and total knowledge , the result of the present study showed that, there were highly statistically significant relation between age , kinship, education , job, income , number of their family members and total knowledge at (p value <0.01). While, there were no statistical significant relation between marital status, residence, number of rooms and total knowledge at (p >0.01) **(Table 6).**

These findings are consistent with those of **(Said et al., 2020),** who examined "Factors influencing the knowledge of mothers of children with chronic illnesses, including thalassemia, n=75", found that maternal education, income, and family size were significantly correlated with higher levels of health knowledge. From the investigator point of view, this result may be due to that educated mothers are more likely to seek out information about managing their child's condition, while those with higher income may have better access to healthcare resources, both of which can contribute to a better understanding of medical conditions like thalassemia.

These results were dissimilar **(Abdel-Monem & Farouk, 2021)** who examined " Relationship between Knowledge of Patients with Thalassemia and Their Quality of Life in South Africa, n=305" ,found that while education and income had a significant impact on knowledge scores, other factors such as marital status and number of family members were less influential. These results support the findings of the present study that there was no significant relation between marital status, residence, and total knowledge. In rural settings, despite lower educational and income levels, social support networks such as extended family members can sometimes help compensate for lack of formal education, though this did not significantly impact knowledge in this study.

The lack of significant findings related to marital status and residence might be due to the homogeneity of the sample or other unmeasured factors that influence knowledge, such as access to healthcare facilities or cultural beliefs. While it is often assumed that urban areas and married women may have better access to information, the present study suggests that these demographic characteristics did not show a significant relationship with the total knowledge score in this case.

Concerning relationship between demographic characteristics of the studied mothers and total reported practices , The results of the current study showed that there were highly statistically significant relation between education , income and total mothers' reported practices at (p value <0.05) . While, there are no statistical significant relation between age, kinship, marital status, residence, job, number of rooms, number of their family members and total mothers' reported practices at (p >0.05) **(Table 7).**

These results were in the same line with **(Hassan et al., 2021),** who investigated " Beyond mothers: the crucial role of family caregivers' knowledge on exclusive breastfeeding in rural China, n=132", which found that maternal education and income were significant predictors of better caregiving practices, as mothers with higher education levels were more likely to follow medical advice and engage in health-promoting behaviors. Additionally, mothers with higher income had greater access to healthcare resources, which could support better caregiving practices.

On the other hand, **(Zayed & Ali, 2020)** "Associations of maternal resources with care behaviors differ by resource type and care behavior in Jordan, n=80" ,found that despite the lack of significant relationships with variables like marital status or job, maternal education and income were strongly correlated with more accurate and consistent caregiving behaviors. Their study also noted that factors such as kinship or family size did

not significantly affect the quality of care provided, consistent with the findings in the present study.

The lack of significant relationships between demographic factors such as age, kinship, marital status, and residence with the total reported practices suggests that while these characteristics might influence attitudes toward care, they do not necessarily translate into actual caregiving behaviors. This may imply that caregiving practices are more closely linked to the mother's education and income, which determine their ability to access information and resources for the proper care of children with thalassemia.

CONCLUSION

Based on findings of the present study, it can be concluded that:

About more than one third of the studied mothers had inadequate total knowledge regarding thalassemia. While, more than half of the studied mothers had inadequate knowledge regarding blood transfusion for their children suffering from thalassemia. More ever, more than half of the studied mothers had incompetent total reported practices regarding the care of their children suffering from thalassemia. There are highly statistically significant relation between age, kinship, education, job, income, number of their family members and total knowledge at (p value <0.01). Finally, there are highly statistically significant relation between education, income and total mothers' reported practices at (p value <0.05) .The findings of the current study achieved the study aim and supported the research questions.

RECOMMENDATIONS

- **Based on the findings of the present study, the following can be recommended:**

Recommendations to mothers:

- Health education programs on knowledge and care practices about thalassemia for mothers of thalassemia children in every public hospital in Egypt.
- Simple booklet written in Arabic language should be developed for mothers regarding care of their children suffering from thalassemia includes all needed information.
- Continuous encouragement of parents to continue follow up, early detection and early management of thalassemia.
- Using different health education methods such as videos, pictures, TV, internet, face book, books and magazines.

Recommendations to researchers:

- Replication of the study on a large sample selected from different geographical areas in Egypt is recommended to obtain more generalized data.
- Further research studies are needed to focus on studying factors affecting health of children with thalassemia

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