Caregivers' Empowerment regarding Care of their Children with Thalassemia

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Abstract

Background: Empowering caregivers of children with thalassemia is essential for enhancing the quality of care and overall well-being of both the children and caregivers. **The aim** of this study was to assess caregivers' empowerment regarding care of their children with thalassemia. **Research design:** Descriptive research design was utilized in this study. **Setting:** This study was carried out at Out-Patient Clinic of Benha Specialized Pediatric Hospital in Benha City. **Sample:** Purposive sample was used in this study; the total sample included 62 caregivers. **Tools: Two tools** were used **I):** An interviewing questionnaire which consisted of four parts to assess **a):** Demographic characteristics of caregivers and personal data of children with thalassemia **b):** Medical history of children, **c):** Knowledge of caregivers regarding thalassemia and empowerment, **d):** Reported practices of caregivers regarding care of their children. **II):** Empowerment scale that included three dimensions: Family, child services and community that include social and political services. **Results:** 56.5% of caregivers aged from 30 -40 years, 66.1 % of them had secondary education. 54.8% of the studied caregivers had average total knowledge regarding thalassemia and empowerment, 62.9% of caregivers had satisfactory reported practices regarding care of their children with thalassemia and 46.8% of the studied caregivers had low total empowerment level regarding thalassemia. **Conclusion:** There was a positive statistically significant correlation between the studied caregivers' total knowledge, total reported practices and total empowerment regarding thalassemia. **Recommendations:** Health educational programs should be developed and implemented for caregivers to increase their awareness about importance of prenatal screening, thalassemia, managing symptoms and prevention of complications and care of children with thalassemia..

Keywords: Caregivers, children, empowerment, thalassemia.

Introduction

Thalassemia is autosomal recessive disorders with reduced the production of α- or β-globin chains leading to unbalanced globin chain ratio and consequently to ineffective erythropoiesis, increased hemolysis, and altered iron homeostasis **(Ferraresi et al., 2023).** Thalassemia is chronic disease that affect children's long-term health and can have significant sequel. The global prevalence of thalassemia varies by region. According to World Health Organization 2019 data, approximately 5% of the world's populations are carriers, with 300,000 to 400,000 new cases diagnosed yearly **(Dewi et al., 2024).**

Thalassemia can be divided into alpha and beta types. In the Mediterranean area, β-thalassemia is the predominant form, further distinguished as thalassemia major, thalassemia intermediate, or thalassemia minor. Thalassemia major typically emerges in early childhood characterized by severe anemia requiring frequent red blood cell transfusions. In contrast, thalassemia

intermediate presents as moderate anemia later in life and does not mandate regular transfusions. While some children may exhibit signs of moderate anemia, thalassemia minor generally remains asymptomatic **(Mahfoz et al., 2024).**

Children with thalassemia face numerous health challenges that can significantly impact lives; children often require regular blood transfusions and medical treatments to manage the condition. Despite that hardships, many children with thalassemia show remarkable resilience and courage, due to support of the families, medical professionals, and communities to navigate the daily lives. With proper care and treatment, children with thalassemia can lead fulfilling lives and participate in many of the same activities as peers **(Tsagkou et al., 2024).**

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 affected with thalassemia suffer from a considerable range of developmental disorders with slow growth speed and poor body mass index that could occur as a result of low hemoglobin, anemia and increased levels of body ferritin **(Elaaser et al., 2023).**

Empowerment makes children cope with the new status, increases the participation of both the children and the caregivers in care practices, and results in a better life for children. Empowerment is also a positive and dynamic process focusing on caregiver power, competence, capabilities, and self-capacity. Empowerment seeks to attract society's participation and create environmental changes; therefore, the children become self-efficient and has experience the change. Empowerment program is necessary to prevent dependency and disability in children **(Dehkordi et al., 2023).**

Caregivers of children with thalassemia could have more psychosocial stressors than the children due to a greater understanding of the disease severity, organization of treatment appointments and hospital visits, and other caregiving and social responsibilities. Caregivers experiences of social isolation, feelings of despair and anger. Caregivers of children with thalassemia have reported feeling worried about child's physical health and future, as well as experiencing increased anxiety and stress related to the caregiving responsibilities **(Hood et al., 2024).**

Community Health Nurses (CHNs) play a vital role in the care of children with thalassemia. CHNs provide experienced, support skills and encouragement throughout and often standardized treatment regimes. CHNs should be sure that children and families are educated about the disease and the treatment options available, also CHNs provides continuing education and monitors compliance with chelation therapy and provide support regarding the diagnosis and therapy. CHNs identify all necessary resources for the family and counsel all family members on preventive treatment and significant squeals **(Mohammed& Abdulla, 2022).**

Significance of the study:

Prevalence of thalassemia major in the populations in the Middle East and North Africa (MENA region) a significant indicator of risk in the case of major thalassemia found that Saudi Arabia had a higher rate of β-thalassemia, with 1–15% of the overall population carrying β-thalassemia and 5–10% carrying α-thalassemia. In Jordan, the prevalence of β-thalassemia carriers was 3 to 5.9%, whereas the same area showed a prevalence of 2 to 3.5% for α-thalassemia

carriers. In Egypt, 4.5% of β thalassemia carriers were found, but Kuwait reported a 5–10% incidence of α thalassemia carriers. Compared to Bahrain, the UAE exhibited a greater prevalence of carriers of both β and α thalassemia. In Bahrain and the United Arab Emirates, the prevalence of β- and α-thalassemia is 49.2% and 2.9%, respectively **(Mahmoud et al., 2024).**

In Egypt, thalassemia is the most common form of thalassemia, with a carrier rate varying from 5.3% to ≥ 9%, and a gene 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 **(Mohamed et al., 2023).**

Aim of the study:

This study aimed to assess caregivers' empowerment regarding care of their children with thalassemia.

Research questions:

1. What is the caregivers' knowledge regarding thalassemia, and empowerment?
2. What are the caregivers' reported practices regarding care of child with thalassemia?
3. What is caregivers' empowerment level regarding care of their children with thalassemia?
4. What is the correlation between total knowledge, practices and empowerment of caregiver regarding thalassemia?

Subjects and method:

Research design:

A descriptive research design was utilized to conduct this study.

Setting:

This study was conducted at Pediatric Hematology Out patient at Benha Specialized Pediatric Hospital at Benha City, Egypt.

Sampling:

Purposive sample of caregivers' of children with thalassemia who visited the previously mentioned setting through six months with the following inclusion criteria: Children age from one to six years and children don't have any other blood disease. The total was 62 caregivers.

Tools for Data Collection:

Two tools were used for data collection.

Tool I: A structured interviewing questionnaire: It was consisted of four parts:

Part I (A): Demographic characteristics of studied caregivers' of children with thalassemia, which included 8 closed ended questions as (Age, sex, place of residence, educational level, marital status, job, type of job and monthly income).

Part I (B): Personal characteristics of children with thalassemia and included 3 closed end questions as : (Age, sex and child order).

Part II: Medical history of children with thalassemia and included 7 closed ended questions as: (Onset of disease, duration of the disease, type of thalassemia, previous hospitalization, complications of thalassemia, family history of thalassemia, degree of family history of thalassemia and frequency of blood transfusion per month).

Part III (A): Knowledge of caregivers of children with thalassemia regarding thalassemia which included 10 closed ended questions.

Part III (B): Knowledge of caregivers of children with thalassemia regarding empowerment and included 2 closed ended questions.

Scoring system:

Scoring system is graded according to the items of questionnaire and was calculated as follows 2 score for correct and complete answer, 1 score for correct and incomplete answer, and 0 for don't know answer. For each area of knowledge, the score of the questions was summed-up and the total divided by the number of the questions, which

converted into a percent score. The total knowledge scores was= 24 points, which further categorized as the following.

Good→ if the total score of knowledge was ≥75% (≥ 18 points).

Average→ if the total score equaled 50<75% (12 < 18 points).

Poor→ if the total score was < 50% (<12 points).

Part IV: Was concerned with reported practices of caregivers' regarding care of their children with thalassemia **(Abhilasha et al., 2021),** and included 9 categories as (personl hygiene involved 8 items, nutrition involved 7 items, treatment and follow up involved 8 items, physical activity involved 4 items, defecation involved 3 items, body image involved 4 items, psychological and emotional health involved 3 items, social health involved 4 items and spiritual health involved 3 items).

Scoring system:

Scoring system is graded according to the items of questionnaire and was calculated as follows 2 score for and always answer, 1 score for sometimes answer, and 0 for never. For each area of reported practices, the score of the items was summed-up and the total divided by the number of the items, which converted into a percent score. The total reported practices scores 88points which further categorized as: Satisfactory and unsatisfactory.

Satisfactory→ if the total score of reported practice was ≥60% (≥52 points).

Unsatisfactory→ if the total score of reported practice was < 60% (<52 points).

Tool II: Family empowerment scale adapted from **(Koren et al., 1992),** and was used to assess caregivers' ability to deal with their children problems and how to utilize services and participate in the community, consisted of three areas: Family (11) items, child services (12) items and community (10) items.

Scoring system:

Scoring system was graded according to the items of questionnaire and was calculated as 5 scores for always, 4 scores for often, 3 scores for somtimes, 2 scores for rarly and 1 for never. For each area of scale, the score of the questions was summed-up and the total divided by the number of the questions, which converted into a percent score. The total scale was 165 which further categorized as following:

High→ if the total score of family empowerment was ≥75% (≥123 points).

Moderate→ if the total score of family empowerment was 50<75% (82 < 123 points).

Low→ if the total score of family empowerment was < 50% (<82 points).

Tools validity:

The tools validity was done by three of Faculty's Staff Nursing Experts from the Community Health Nursing Specialties, Benha University who reviewed the tools for clarity, relevance, comprehensiveness, applicability and easiness for implementation and according to their opinion minor modifications were carried out.

Tools Reliability:

Reliability of the tools were done by Cornbrash's Alpha coefficient test which revealed that each of the two tools consisted of relatively homogenous items as indicated by the moderate to high reliability of each tool. The internal consistency of knowledge was =0.92, practices was =0.89 and empowerment was=0.93.

Ethical consideration:

Approval was obtained from the Research Ethical Committee at Faculty of Nursing Benha University to conduct the study and oral consent from all study participants was obtained after explaining the purpose of the study to gain their trust and cooperation. Each caregiver had a choice to

continue or withdraw from the study. Privacy and confidentiality was assured. Ethics, values, culture, and beliefs were respected. The data collected was stored in confidential manner.

Pilot study:

The pilot study was carried out on 10% (6 caregivers) of the studied sample to test the clarity, objectivity, feasibility and applicability of tools, as well as to estimate the time needed for data collection. Based on pilot study, the modification as the tools included rephrasing and rearrangement of some questions. This study was carried out in two months before starting. The pilot study sample excluded from the study and total sample.

Field work:

Data was collected at a period of 6 months which started from beginning February 2024 to end of August 2024. The study was conducted by researchers for studied sample visited hematology unit at specialized pediatric hospital in Benha City two days (Sunday &Thursday) in every week for six months from 10am to 12pm. To conduct data oral approval obtained from caregivers after the researchers introduced themselves for each caregiver then explained the purpose of the study. The researchers collected data from each caregiver; the average numbers of interviewing caregivers was between 1-2 caregivers/day depending on their response, each caregiver taken about 40-45 minute to fill the sheet depending on their understanding and response. Study collected through face to face by questionnaire and the researchers checked each filled questionnaire to ensure its completion.

Statistical analysis:

All data collected were organized, tabulated and analyzed by using the Statistical Package for Social Science (SPSS version 21), which was used frequencies, and percentages for qualitative descriptive data, and chi-square x^2 was used for relation tests, and mean and standard deviation was used for quantitative data.

- Highly statistically significant $P \leq 0.001$**.
- Statistically significant $P \leq 0.05$* .
- Not significant $P > 0.05$.

Results:

Table (1): Shows that; 56.5% of the studied caregivers aged from 30 <40 years old with mean age was 35.64±6.41, 77.4% of them were female and 53.2% of them lived in rural residence. 66.1% of the studied caregivers had secondary education, also 74.1% of them were married and 51.6% of them hadn't enough monthly income.

Table (2): Indicates that; 51.6% of studied children aged less than 3 years with mean age was 3.44±1.22, 51.6% of them were girls and 56.5% of them were the 1st child.

Table (3): Shows that; 53.2% of studied children aged <1year at onset of disease and 67.7% of them had disease duration ≥2 years. 82.3% of studied children had beta thalassemia and 100.0% of studied children had previous hospitalization. 32.3% of studied children had complications, 30.0%, 20.0% and 20.0% of them had cardiovascular diseases, chronic liver diseases and splenectomy respectively. The current table also reveals that, 61.3% of studied children had family history of thalassemia, 60.5% of them had 1st degree family history (father-mother) and 96.7% of children recieve blood transfusion once per month.

Figure (1): Demonstrates that; 14.5% of studied caregivers had good total knowledge level regarding thalassemia and family empowerment and 30.7% of them had poor total knowledge level regarding thalassemia and family empowerment.

Table (4): Shows that; 67.7% of studied caregivers had satisfactory reported practices about personal hygiene, however; 43.5% of them had unsatisfactory total reported practices about physical activities.

Figure (2): Indicates that; 62.9% of studied caregivers had satisfactory total reported practices regarding care of their children with thalassemia and 37.1% of them had unsatisfactory total reported practice regarding care of their children with thalassemia.

Table (5): Reveals that; 62.9% of studied caregivers had high total empowerment regarding thalassemia, 50.0% of them had moderate total child services empowerment and 61.3% of them had low total social and political empowerment.

Figure (3): Indicates that; 46.8 % of studied caregivers had low total empowerment level regarding thalassemia, 40.3 % of them had moderate total empowerment level and 12.9% of them had high total empowerment level regarding thalassemia.

Table (6): Represents that; there were positive statistically significant correlation between caregivers' total knowledge, total reported practices and total empowerment regarding thalassemia.

Table (1): Distribution of studied caregivers regarding their demographic characteristics (n= 62).

Demographic characteristics	No.	%
Age/ years		
20>30	27	43.5
30>40	**35**	**56.5**
Mean ±SD= 35.64±6.41		
Sex		
Female	**48**	**77.4**
Male	14	22.6
Place of residence		
Rural	**33**	**53.2**
Urban	29	46.8
Educational level		
Can't read or write	4	6.5
Secondary education	**41**	**66.1**
University education or more	17	27.4
Marital status		
Married	**46**	**74.1**
Divorced	12	19.4
Widowed	4	6.5
Monthly income		
Enough	24	38.7
Not enough	**32**	**51.6**
Enough and save	6	9.7

Table (2): Distribution of studied children regarding their personal data (n=62).

Personal data	No.	%
Age/ years		
< 3	**32**	**51.6**
3≤6	30	48.4
Mean ±SD= 3.44±1.22		
Sex		
Female	32	**51.6**
Male	30	48.4
Child order		
1st	**35**	**56.5**
2nd	20	32.3
3rd	6	9.7
4th	1	1.6

Table (3): Distribution of studied children regarding their medical history (n= 62).

Medical history	No.	%
Age of child at onset of disease		
< 1 year	**33**	**53.2**
<1 years	29	46.8
Duration of the disease		
< 2 years	20	32.3
≥2 years	**42**	**67.7**
Type of Thalassemia		
Thalassemia Beta	**51**	**82.3**
Thalassemia Alpha	11	17.7
Previous hospitalization		
Yes	**62**	**100.0**
Occurring complications of thalassemia		
Yes	**20**	**32.3**
No	42	67.7
***Complications of thalassemia (n=20)**		
Cardiovascular diseases	**6**	**30.0**
Chronic liver diseases	**4**	**20.0**
Gland diseases	2	10.0
Osteoporosis	2	10.0
Splenectomy	**4**	**20.0**
Splenomegaly	2	10.0
Platelets deficiency	2	10.0
Family history of thalassemia		
Yes	**38**	**61.3**
No	24	38.7
Kinship of child with the family member have thalassemia (n=38)		
1st degree (father-mother)	**23**	**60.5**
2nd degree (aunt-uncle-grandfather-grandmother)	15	39.5
Frequency of blood transfusion/month		
Once	**60**	**96.7**
Twice	2	3.3

***Results aren't mutually exclusive.**

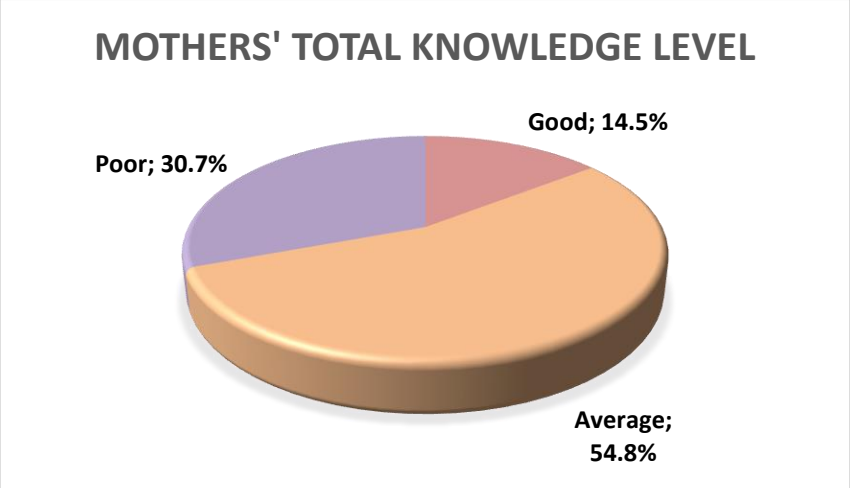

Figure (1): Percentage distribution of studied caregivers regarding their total knowledge level about thalassemia and family empowerment (n= 62).

Table (4): Distribution of studied caregivers regarding their total reported practices` dimensions about care of their children with thalassemia (n= 62).

Total reported practices` dimensions	Satisfactory		Unsatisfactory	
	No.	%	No.	%
Personal hygiene	42	67.7	20	32.3
Nutrition	34	54.8	28	45.2
Treatment and follow-up	38	61.3	24	38.7
Physical activity	35	56.5	27	43.5
Defecation	42	67.7	20	32.3
Total physical	38	61.3	24	38.7
Body image	32	51.6	30	48.4
Psychological and emotional health	53	85.5	9	14.5
Total psychological	36	58.1	26	41.9
Social health	53	85.5	9	14.5
Spiritual health	48	77.4	14	22.6

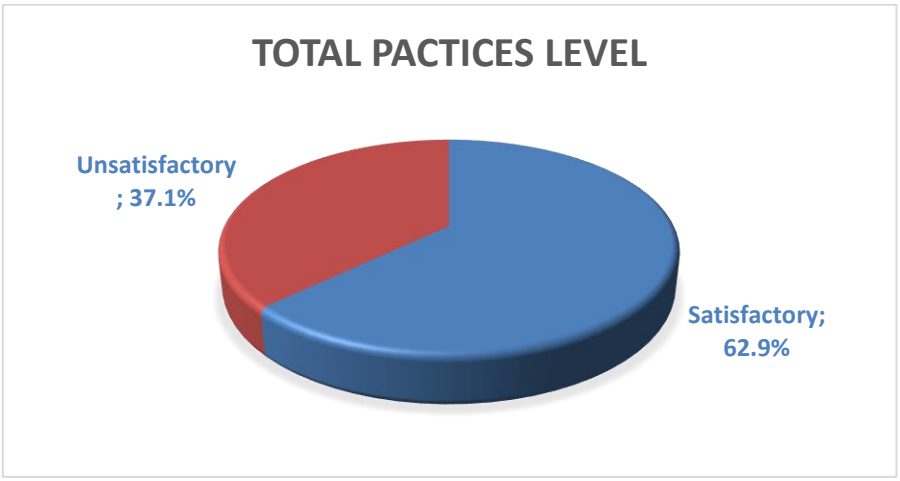

Figure (2): Percentage distribution of studied caregivers regarding their total reported practices level about care of their children with thalassemia (n= 62).

Table (5): Distribution of studied caregivers regarding their total empowerment dimensions for children with thalassemia (n= 62).

Total empowerment dimensions	High		Moderate		Low	
	No.	%	No.	%	No.	%
Total family empowerment	**39**	**62.9**	16	25.8	7	11.3
Total child services	8	12.9	**31**	**50.0**	23	37.1
Total social and political services	8	12.9	16	25.8	**38**	**61.3**

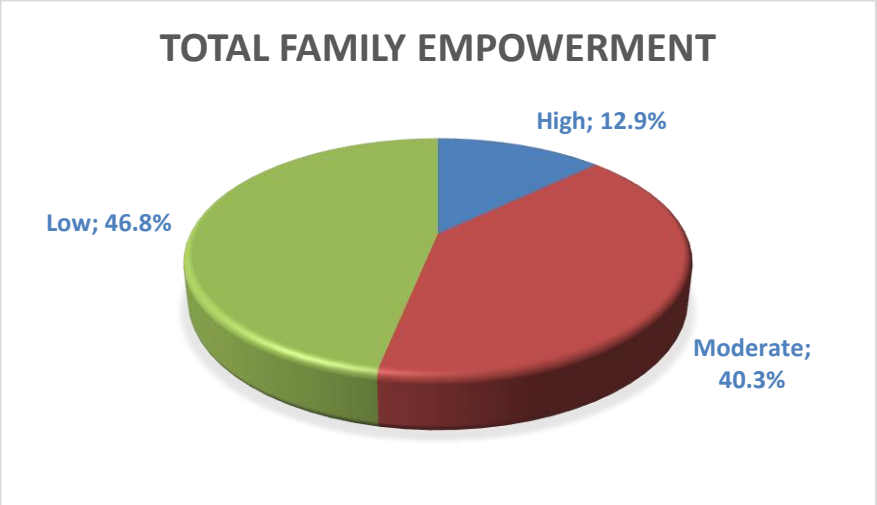

Figure (3): Percentage distribution of studied caregivers regarding their total family empowerment level regarding thalassemia (n= 62).

Table (6): Correlation matrix between total knowledge, total reported practices and total empowerment among studied caregivers regarding thalassemia (n= 62).

		Total knowledge	Total reported practices	Total empowerment
Total knowledge	r.		.420	.357
	p-value		.001**	.004*
Total reported practices	r.	.420		.602
	p-value	.001**		.000**
Total empowerment	r.	.357	.602	
	p-value	.004*	.000**	

Discussion:

Thalassemia is a genetic blood disorder characterized by insufficient production of hemoglobin which plays a crucial role in transporting oxygen from the lungs to the rest of the body and returning carbon dioxide to the lungs. Early detection of thalassemia can aid in the reduction of death rates **(Ibrahim et al., 2024)[a].** Caregivers' empowerment plays a pivotal role in the comprehensive care of children with thalassemia. Empowered caregivers should well-informed about importance of regular blood transfusions, iron chelation therapy, and maintaining optimal nutrition, which are critical during thalassemia care **(Abualrahi et al., 2024).**

The finding of current study approved that; more than half of children diagnosed with disease on less than one year. This study

finding was compatible with **Prajapati et al. (2021),** who studied "Caregiver Burden and Psychiatric Morbidity among Caregivers of Children with Thalassemia Major at the Pediatric Department of a Tertiary Care Hospital, Rajkot, n=245" and showed that; 48.97% of children diagnosed within one year of life. As well as, the study finding was congruent with **Mardhiyah et al. (2024),** who studied "Factors Associated with Quality of Life among Adolescent with Beta Thalassemia in Indonesia at Thalassemia Center in Bandung, West Java, Indonesia, n=240" and found that; 76% of children diagnosed at less than one years of age. From the researchers point of view; diagnosis of thalassemia occur in the first two year of child life.

The current study found that: more than two third of children suffered from thalassemia more than two years ago. This study was opposed to **Elaaser et al. (2023),** who studied "Effect of Educational Program Based on the Precede-Proceed Planning Model on Quality of Life of Children with Thalassemia at Pediatric Hematology Unit and Pediatric Hematology Out-Patient Clinic at Benha Specialized Pediatric Hospital at Benha City, n=125" and found that; 36% of them suffering from thalassemia 5- < 10 years ago. This study finding hold contrasting view with **Atia et al. (2021),** who studied "The Effectiveness of Positive Psychotherapy on the Self-Efficacy and Psychological Wellbeing of Children with Thalassemia at an Outpatient Clinic at Menoufia University Hospital in Shebin Elkom in Egypt, n=60" and found that; children suffered from disease with duration between 7-11.5 years old.

According to type of thalassemia, the finding of current study showed that: majority of studied children had beta thalassemia.This finding was in the same line with **Ahmed et al. (2023),** who studied "Psychological Problems and Coping Patterns among Mothers of Children with Thalassemia at the Blood Disorders Department of Benha Specialized Children Hospital in Qaliubiya Governorate, n=100" and found that; 92% of studied children had beta thalassemia. Moreover, this study finding was congruent with **Mohamed et al. (2022),** who studied "Barriers to Adherence to Iron Chelation Therapy among Adolescent with Transfusion Dependent Thalassemia at Pusat Perubatan Universiti Kebangsaan Malaysia (PPUKM), Cheras, and Hospital Tengku Ampuan Afzan, Kuantan, n=70" and revealed that; 91.5% of studied children had beta thalassemia. From the researchers` point of view; this was because beta thalassemia is the most common type prevalence than alpha thalassemia in Egypt.

The finding of current study approved that; less than third, one fifth of thalassemia children had cardiovascular diseases and chronic liver diseases respectively. This finding was symmetrical with **Naderi et al. (2023),** who studied "Evaluation of Factors Influencing the Birth of Thalassemia in Family Members with Thalassemia Major in Southeast Iran at Ali Asghar Children Hospital in Zahedan, n=48" and revealed that; 50%, 25% of studied thalassemia children had heart disease and liver disease respectively. From the researchers` point of view; this might be due to long term of blood transfusion can cause iron overload in the heart and liver and cause heart complications.

According to family history of thalassemia, the finding of current study found that; more than three fifths of studied caregivers had family history with three fifth of them was first degree (father and mother). This study finding agreed with **Saad et al. (2022),** who studied "Determining Self-Efficacy and its Related Factors in Adolescents with Major Beta-Thalassemia

Referring to Selected Hospital in Tehran at Shohadaye Tajrish Hospital depended to Shahid Beheshti University of Medical Sciences and their Pediatric Wards in Tehran, n=100" and showed that; 89% of studied sample had family history and 71% were parental consanguinity. Moreover, this finding supported by **Ahmed et al. (2023),** who found that; 78% of studied caregivers had family history, and 87.2% of them were first degree relatives (father and mother).

The finding of current study showed that; most of studied children recieve blood transfusion once monthly. This study finding had a different opinion with **Nurhidayah (2022),** who studied "Quality of Life of Preschool-Age Children with Thalassemia Major at Sumedang and Garut areas, n=63" and found that 50.8% of studied children recieved blood transfusion once per month. In addition, this study finding disagreed with **Rathaur et al. (2020),** who studied "Growth Pattern in Thalassemia Children and their Correlation with Serum Ferritin, n=70" and found that 35.71% of studied children recieved blood transfusion once per month. From the researchers` point of view, blood transfusion is more effective treatment of thalassemia.

According to total knowledge of studied caregivers about thalassemia and family empowerment, the finding of current study showed that; less than fifth of studied caregivers had good total knowledge level about thalassemia and family empowerment. This study was in accordance with **Begum et al. (2024),** who studied "Knowledge, Attitude and Practice of Prevention of Thalassemia of the Parents of Children with Thalassemia Attending in a Tertiary Care Hospital in Bangladesh at inpatient and outpatient department of pediatrics, Rajshahi Medical College Hospital, n=45" and found that; 10% of studied parents had adequate knowledge regarding thalassemia. Also, this study was congruent with **Elaaser et al. (2023),** who found that; 15.2% of caregivers had good knowledge about thalassemia.

Also, the finding of current study showed that; more than half of studied caregivers had average total knowledge level about thalassemia and family empowerment. This study was in agreement with **Rahat et al. (2023),** who studied "Knowledge, Attitudes and Practices Regarding the Prevention of Thalassemia in Parents of Thalassemia Children in Swat at conducted in district Swat, KP, Via Three regional Thalassemia Centers, n=200" and found that; 62% of parents had a moderate level of knowledge about thalassemia and family empowerment. From the researchers` point of view this is due to the lack of health educational programs dedicated to mothers of thalassemia children in the selected centers.

The finding of current study showed that; two fifths of studied caregivers had unsatisfactory total reported practices regarding physical activities and three fifth of them had satisfactory total reported practices regarding treatment and follow-up. These study findings were symmetrical with **Knoth et al. (2023),** who studied "Understanding the association between Red Blood Cell Transfusion Utilization and Humanistic and Economic Burden in Patients with β-Thalassemia from the Patients' Perspective at Cooley's Anemia Foundation, n=100" and found that; 39% of studied caregivers had unsatisfactory total reported practices about physical activity while 62% of them had satisfactory total reported practices about treatment and follow-up.

According to caregivers total reported practices level regarding care of their children with thalassemia, the finding of current study found that; more than three fifths of studied caregivers had satisfactory total reported

practices regarding care of their children with thalassemia. This study was congruent with **Shaker et al. (2024),** who studied "Exploring Patients' Perspectives about Thalassemia and its Treatment Modalities at Thalassemia centre of AL Zahraa teaching hospital in Al Najaf governorate, n=220" and found that; 78.9% of studied caregivers had satisfactory practices level towards care of their children with thalassemia.

The finding of current study showed that; more than three fifths of studied caregivers had high total family empowerment regarding thalassemia. This study was congruent with **Humaira et al. (2024),** who studied "Exploring Caregiver Burden of Thalassemia Major Patients at Transfusion Centers in Pakistan, n=83" and they revealed that; 67.5% of studied parents had family support regarding thalassemia. However, this study was incongruent with **Sinaga& Purike. (2022),** who studied "Analysis of Family Empowerment Level in Rural and Urban Area at Two Sub-Districts, Namely Duren Sawit District as an Illustration of Urban Areas and Jasinga District as an Illustration of Rural Areas, n=225" and found that; 24.9% of studied population had high total family empowerment regarding thalassemia.

According to total family empowerment level regarding thalassemia, the finding of current study showed that; less than half of studied caregivers had low total family empowerment level regarding thalassemia. From the investigator point of view; this is due to lack of educational programs toward supporting, empowerment of caregivers towards thalassemia and how to caring their affected children.

The finding of current study found that; there were highly positive correlation between studied caregivers' total knowledge, total empowerment and their total reported practices.. This finding was compatible with **Ibrahim et al. (2024)[b],** who studied "Assessment of Family Empowerment in the Care of Patients with Sickle Cell disease in Siwa Oasis at the Outpatient Clinic, n= 112" and they found that; there were significant positive correlation between caregivers' total knowledge, total reported practices and their total empowerment, moreover this study finding agreed with **Ezaat et al. (2024),** who studied "Effect of Educational Program on Mothers' Knowledge and Practices regarding their Children with Splenomegaly at the Pediatric Medical Department and Hematology Department of Tanta University Hospital, n=60" and showed that; there were significant positive correlation between caregivers' total knowledge, total reported practices and their total empowerment. From the researchers point of view, this might be due to knowledge play important role in affecting practices and empowerment.

Conclusion:

More than half of studied caregivers had average knowledge about thalassemia and family empowerment, more than three fifths of them had satisfactory reported practices regarding care of their children with thalassemia, and more than two fifths of studied caregivers had low total family empowerment level regarding thalassemia. There were highly positive correlations between studied caregivers' total knowledge, total empowerment and their total reported practices regarding thalassemia.

Recommendations:

- Health educational programs should be developed and implemented for caregivers to increase their awareness about importance of prenatal screening, thalassemia, managing symptoms and prevention of complications and care of children with thalassemia.

- Booklets should be available and distributed in all thalassemia Hematology Units of Hospitals to all caregivers about the disease and health-related practices.
- Establishing an integrated system to empower children with thalassemia by providing specialists, treatments and necessary examinations.
- Further studies would be recommended to assess the impact of the empowerment program on self-efficacy and coping strategies among caregivers of children with thalassemia.

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دعم مقدمي الرعاية فيما يتعلق برعاية أطفالهم المصابين بأنيميا البحر المتوسط

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يعد دعم مقدمي الرعاية للأطفال المصابين بمرض أنيميا البحر المتوسط أمر ضروري لتحسين جودة الرعاية والرفاهية العامة لكل من الأطفال والأسروذلك من خلال برامج التعليم والتدريب التي تزود مقدمي الرعاية بالمعلومات اللازمة لكيفيه التعامل مع المرض. لذا هدفت الدراسة إلى تقييم دعم مقدمي الرعاية فيما يتعلق برعاية أطفالهم المصابين بأنيميا البحر المتوسط. تم استخدام تصميم البحث الوصفي. وقد أجريت هذه الدراسة في العيادة الخارجية بمستشفى الأطفال التخصصي ببنها التابع لوزارة الصحة والسكان المصرية وأمانة المراكز الطبية المتخصصة بمدينة بنها على عينة غرضيه من مقدمي الرعاية للأطفال المصابين بانيميا البحر المتوسط وبلغ عددهم ٦٢. وقد أظهرت الدراسة أن ١٤,٥٪ من مقدمي الرعاية لديهم مستوى جيد من المعلومات الكلية فيما يتعلق بمرض أنيميا البحر المتوسط والدعم الأسري ،٦٢,٩٪ من مقدمي الرعاية لديهم مستوى مرضي من الممارسات الكلية تجاه رعاية أطفالهم المصابين بأنيميا البحر المتوسط ، كما كان لدى ٤٦,٨٪ من مقدمي الرعاية مستوى منخفض من الدعم فيما يتعلق بمرض أنيميا البحر المتوسط ، كما كان هناك أرتباط إيجابي ذو دلاله إحصائيه بين معلومات مقدمي الرعاية وممارساتهم والدعم فيما يتعلق بمرض أنيميا البحر المتوسط . وقد أوصت الدراسة إلى تطوير وتنفيذ برامج التثقيف الصحي لمقدمي الرعاية لزيادة وعيهم عن أهمية الفحص قبل الولادة، أنيميا البحر المتوسط والوقاية من المضاعفات وكيفية رعاية الأطفال المصابين بأنيميا البحر المتوسط.