Caregivers' Empowerment regarding Care of their Children with Thalassemia

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Abstract

Background: Thalassemia is a group of autosomal recessive genetic diseases caused by mutations in globin. **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 at Benha Specialized Pediatric Hospital at 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 thalassemia children, **b):** Medical characteristics of children, **c):** Knowledge of caregivers regarding thalassemia and empowerment and, **D):** Reported practices of caregivers regarding care of their children **II):** Family empowerment scale to assess how cregivers deal with children problems, utilize services and participate in the community. **Results:** 56.5% of caregivers aged from 28 -38 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 thalassemia children, and 46.8% of the studied caregivers had low total family empowerment level regarding thalassemia. **Conclusion:** There was a highly positive correlation between studied caregivers' total knowledge, total empowerment and their total reported practices regarding thalassemia. **Recommendations:** Health educational programs should be developed and implemented for studied caregivers to increase their awareness regarding prenatal counseling, early detection of thalassemia and care of thalassemia children.

Keywords: Thalassemia, Children, Caregivers, Empowerment.

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, βthalassemia 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).**

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 the children. The term “empowerment” is derived from the verb empower meaning to give someone the power or authority to do something. 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 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 their caregiving responsibilities **(Hood et al., 2024).**

Community health nurses had a role of care where the first role of nurses is promotive where nurses are able to provide health education to caregivers with hematological disorders, especially in thalassemia. The second role of the nurse is preventive where the role is being able to take actions that can prevent new problems from occurring, such as infection. The third role of the nurse is curative where the nurse is able to provide nursing services by collaborating with other health teams to provide pain relief. The fourth role of the nurse is rehabilitative where the nurse is able to make the children independent so that the children can recover and be able to do activities as before being admitted to the hospital **(Mardhiyah et al., 2023).**

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 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 **(Elaasar et al., 2023).**

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, given the prevalence of consanguineous unions. 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 relation between knowledge, practices and empowerment regarding thalassemia and demographic characteristics?
5. 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.

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 haven't 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 caregivers' of children with thalassemia: It include 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: It include 3 closed end questions as : (Age, sex and child order).

Part II: Medical history of children with thalassemia: It included of 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: It included 10 closed ended questions.

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

Scoring system of students' knowledge

Scoring system is graded according to the items of questionnaire. The scoring system for caregiver knowledge 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= (28 points) which further categorized into 3 levels as the following.

Good→ if the total score of knowledge ≥75% (≥ 21 points).

Average→ if the total score equals 50<75% (14-21 points).

Poor→ if the total score was < 50% (<14 points).

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

Scoring system of reported practices

Scoring system is graded according to the items of questionnaire. The scoring system for caregivers reported practices 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 questions was summed-up and the total divided by the number of the questions, which converted into a percent score. The total reported practices scores (88points) which further categorized: 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 it 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) questions, child services (12) questions and community (10) questions.

Scoring system for total family empowerment scale was:

Scoring system was graded according to the items of questionnaire. The scoring system for family empowerment was calculated as (5) scores for always, (4) scores for often, (3) scores for somtimes, (2) scores for rarly and (0) 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 scores (165) which further categorized into 2 levels as following:

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

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

Low→ if the total score of family empowerment scale < 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 was applied by the researchers for testing the internal consistency of the tools, by administration of the same tools to the same subject under similar condition on one or more occasion. The 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 =0.818, practice was =0.746 and empowerment =0.701.

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 introduce herself for each caregiver then explain 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 caregivers 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 coefficient 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 28- <38 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. Regarding the educational level, 66.1% of the studied caregivers had secondary education, also 74.2% of them were married and 54.8% of them were working, moreover 47.1% of them were working at private sector and 51.6% of them had enough monthly income.

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

Table (3): Shows that; 53.2% of studied children had disease onset <6months and 67.7% of them had disease duration ≥2 years. Regarding type of thalassemia, 82.3% of them have beta thalassemia also, 100.0% of them had previous hospitalization moreover, 43.5% of them admitted to hospital 4 times or more. Concerning complications of thalassemia, 32.3% of 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 children had family history of thalassemia, 60.5% of them had 1st degree family history (father-mother) and 96.7% of children take blood transfusion once per month.

Figure (1): Demonstrates that; 54.8% of the studied caregivers had average total knowledge level, 30.7 % of them had poor total knowledge and 14.5% of them had good total knowledge level regarding thalassemia and family empowerment.

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.

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

Table (4): Represents that; there were highly positive correlations between studied caregivers' total knowledge, total empowerment and their total reported practices at p<**0.001***. While there was positive correlations between studied caregivers' total family empowerment and total knowledge about thalassemia **p≤0.05**.

Table (1): Frequency distribution of studied caregivers regarding their demographic characteristics (N= 62).

Demographic characteristics	No.	%
Age/ years		
28>-18	27	43.5
38>-28	**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**	**74.2**
Divorced	12	19.4
Widowed	4	6.5
Job		
Working	**34**	**54.8**
Not working	28	45.2
Type of Job (n=34).		
Governmental sector	10	29.4
Private sector	**16**	**47.1**
Freelancing	8	23.5
Monthly income		
Enough	24	38.7
Not enough	**32**	**51.6**
Enough and save	6	9.7

Table (2): Frequency 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): Frequency distribution of studied children regarding their medical history (N= 62).

Medical history	**No.**	**%**
Onset of disease		
< 6 months	**33**	**53.2**
1<2 years	29	46.8
Duration of the disease		
1< 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
If yes (n=62).		
Once	16	25.8
Twice	14	22.6
Three times	5	8.1
4 times or more	**27**	**43.5**
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
Enlarged spleen	2	10.0
Platelets Deficiency	2	10.0
Family history of thalassemia		
Yes	**38**	**61.3**
No	24	38.7
Degree of family history of thalassemia (n=38)		
1st degree (father-mother)	**23**	**60.5**
2nd degree (Aunt-Uncle-grandfather-grandmother)	15	39.5

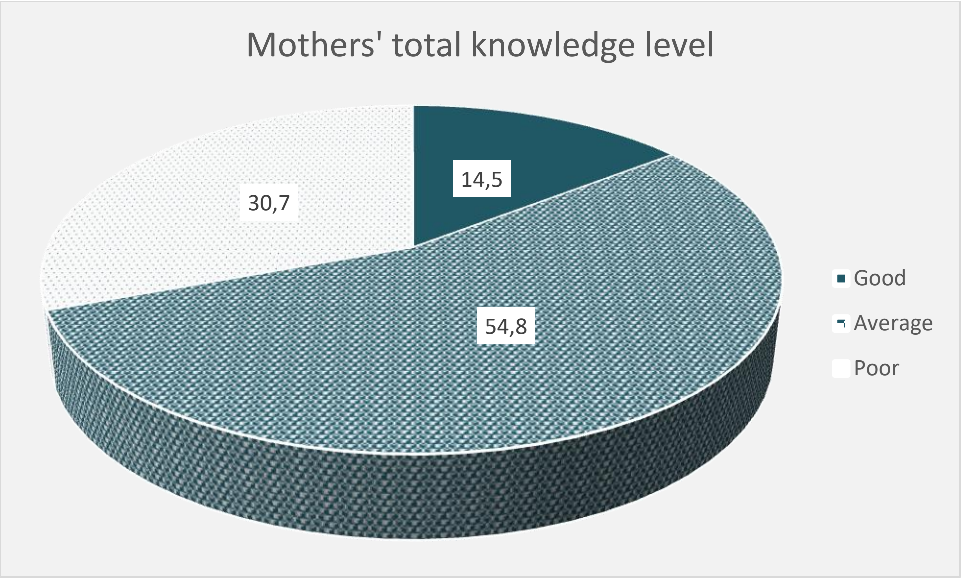

Figure (1): Percentage distribution of studied caregivers regarding their total knowledge level about thalassemia and family empowerment (N= 62).

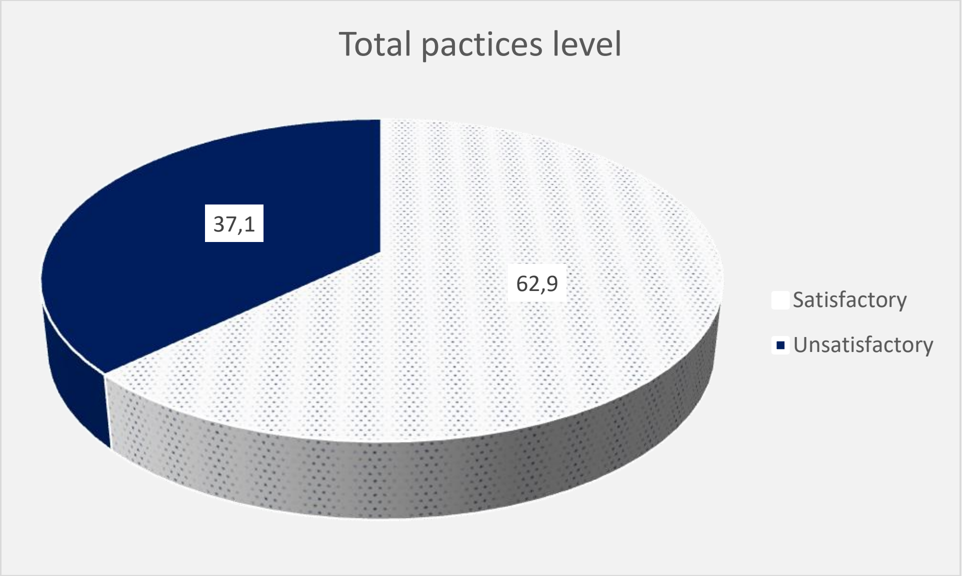

Figure (2): Percentage distribution of studied caregivers regarding their total reported practices level about care of their children with thalassemia (N= 62).

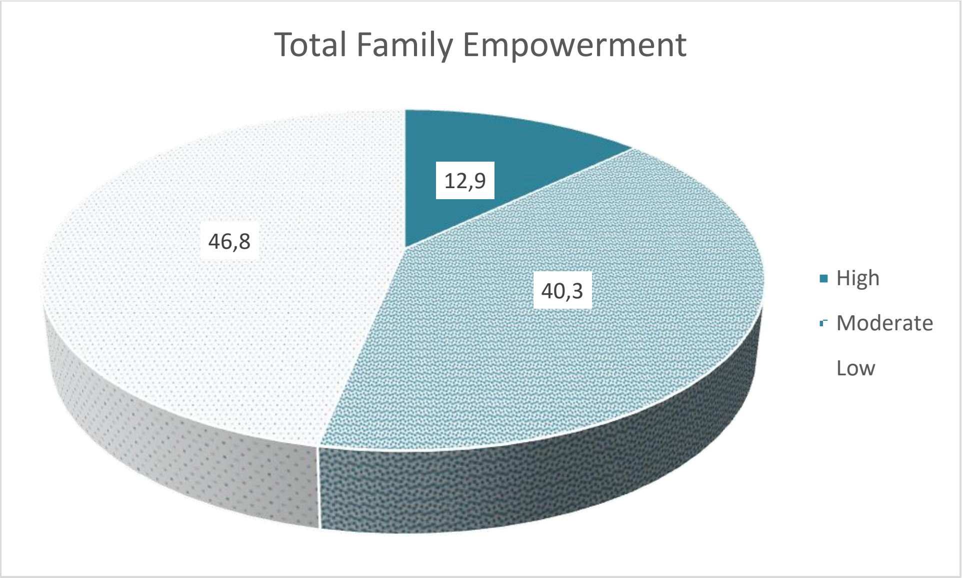

Figure (3): Percentage distribution of studied caregiver regarding their total family empowerment level regarding thalassemia (N= 62).

Table (4): Correlation matrix between total knowledge, total reported practices and total family empowerment among studied caregivers regarding thalassemia (N= 62).

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

Discussion

Thalassemia is one of the world's most frequent diseases, particularly in the Mediterranean. Many countries are currently dealing with the high and rising incidence of thalassemia, which has become a primary public health concern and significant source of disability and mortality around the world. Early detection of thalassemia can aid in the reduction of death rates. As a result, healthcare practitioners are responsible for making the right decisions. When distinguishing between ordinary children and patients. Thalassemia is a genetic blood disorder characterized by insufficient production of hemoglobin. Hemoglobin plays a crucial role in the child body by transporting oxygen from the lungs to the rest of the body and returning carbon dioxide to the lungs **(Ibrahim et al., 2024).**

According to demographic characteristic of studied caregivers, the finding of present study showed that; more than half of studied caregivers aged from 28 and less than 38 years old with mean age were 35.64±6.41 (table 1). This finding agreed with **Adly et al. (2023),** who studied "Family Management and its Relation to Health-Related Quality of Life among Thalassemia Children at A Hematology Clinic in the Minia Regional Blood Bank, n=103" and reported that 46.6% of studied parents aged 30 and less than 40 years old with mean age was 35.05 ± 9.9, on the other hand, this finding disagreed with **Abhilasha et al. (2021),** who studied **"**Health Promotion Practices and Coping Behaviors among Caregivers of Children Suffering from Thalassemia Major at Advanced Pediatric Centre in PGIMER, Chandigarh, n=70"and reported that 45.7% of studied caregivers aged 41 and less than 50 years old.

The findings of the current study showed that; more than three quarter of studied caregivers was female (table 1). This finding was in agreement with **Sa'd et al. (2023),** who studied "Knowledge of Parents about Beta Thalassemia Patients at the Thalassemia Center of Children Hospital PIMS, Islamabad, n=250" and reported that 77.6% of studied sample was female. Moreover, on the opposite side, this study finding was in disagreement with **Dhanwadkar et al. (2024),** who studied "A Study on Awareness among Parents with Beta Thalassemia Major Children in Government District Hospital, at Department of Pediatrics, Gulbarga institute of Medical sciences, Kalaburagi, n=65" and showed that, 44.6% of studied caregivers was female. From the investigator point of view, these results might be due to the traditions in Egypt that female caregiver has family and house responsibilities, activity of daily living such as preparing food, shopping and arranging the house, caring of thalassemia children as going to treatment sessions as blood transfusion and iron chelation therapy and caring of other children in the family. As well as; this might due to care mother for her children than father.

Regarding to residence of studied caregivers, the finding of current study showed that; more than half of studied caregivers lived in rural areas (table 1). This finding was in the same line with **Sikandar et al. (2024),** who studied "Perceived Physical, Emotional and Monetary Burden among Caregivers of Thalassemia Patients: An Evidence-Based Study from District Gujarat, Pakistan at thalassemia care institute of Gujarat city, n=360" and showed that 60.5% of studied participants lived in rural area. However this finding was different with **Shahzad et al. (2024),** who studied "Socio-Economic Vulnerabilities of the Families of Beta-Thalassemia Children in Rawalpindi and Islamabad, Pakistan at Thalassemia Centre of SZABMU-PIMS, Islamabad and Jamila Sultana Foundation, Rawalpindi, Pakistan, n=410" and showed that 69% of studied caregivers lived in rural area.

Regarding to educational level of caregivers, the finding of current study showed that; two thirds of studied caregivers had secondary education (table 1). This study agreed with **Shrestha et al. (2024),** who studied "Psychological Burden Faced by Parents Having Children with Thalassemia in a Teaching Hospital at Pediatric OPD, National Medical College, n= 88" and showed that 52.3% of studied caregivers had secondary educational level. This study objected to **PV& Pujari. (2020),** who studied "Knowledge, Attitude, Practices among Parents of β

Thalassemia Children regarding Thalassemia at a Pediatric Unit of Government Medical College/Hospital of Anantapuram district of Andhra Pradesh, n=260” and found that; 50.7% of studied caregivers had bachelor or master’s degree. From the investigator point of view; due to lower level of education among Egyptian mothers in rural area.

The finding of current study revealed that; three quarters of caregivers were married (table 1). This study agreed with **Mahfouz et al. (2024),** who studied “Effect of Stepwise Program on Mothers' Care of Their Children with Beta Thalassemia at the Hematology Outpatient Clinic affiliated to Assiut University Children Hospital, n=115” and showed that 85.7% of studied caregivers were married. From the investigator point of view, this finding might be due to the fact that marriage in Egyptian culture is better for female. From the investigator point of view; the thalassemia children require more efforts giving by caregivers so mothers must have husband to carry out some responsibilities and financial burden with mothers.

Regarding to occupation of caregivers, the finding of current study showed that; more than half of studied caregivers worked (table 1). This study was consistent with **Othman et al. (2022),** who studied “Psychological Distress and Coping Strategies among the Caretakers of Children with Transfusion Dependent Thalassemia at Three Hospitals in East-Coast Malaysia, n=68” and showed that 60.3% of studied caregivers were employee. This finding of disagreed with **Apriani et al. (2024),** who studied “Quality of Life and Social Support among Parents of Adolescence with Thalassemia at Dr. Slamet Garut Regional Hospital, n=64” and showed that 62.5% of studied caregivers weren’t working. From the investigator point of view; the caregivers must worked to accomplish frequent medical expenses and financial burden.

Regarding to type of job of caregivers, the finding of current study showed that; slightly less than half of studied caregivers worked in a private sector (table 1). This finding was consistent with **Arzu et al. (2023),** who studied “Epidemiological Factors of Thalassemia in Patients Reporting to the Thalassemia Centre in Islamabad at the Thalassemia Center of the Pakistan Institute of Medical Sciences, n=200” and showed that 42% of studied caregivers worked in a private sector. From the investigator point of view; the caregivers worked in a private sector to fulfillment the needs of thalassemia children.

Regarding to monthly income of caregivers, the finding of current study showed that; more than half of studied caregiver hadn’t enough monthly income (table 1). This finding was congruent with **Al-sayed et al. (2022),** who studied “Caregivers Burnout of Their Children with Thalassemia at Mustafa Hassan University Hospital for Pediatric Al-fayoum, Egypt, n=116” and found that 51.7% of studied caregiver monthly income not enough. This study disagreed with **Eidan& Aldoori. (2022),** who studied “Physical Wellness among Adolescents with Hemoglobinopathic Disorders at Babylon Teaching Hospital for Women and Children, n=150” and showed that, 47.3% of economic state enough some of extent. From the investigator point of view, this finding might be due to that increase number of family members, majority of caregivers were private job and increase expenditures on treatment sessions of thalassemia children, and periodic follow-up for the thalassemia children.

From the investigator point of view; due to medical expenses and frequent hospital visit for blood transfusion and regular medical checkup.

According to personal data of children with thalassemia, the finding of current study found that; more than half of thalassemia children less than three year (table 2).This study had a different opinion 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; 54.69% of thalassemia children from six to twelve years old. Moreover this study objected to **Mahfoz et al. (2024),** who studied "Effect of Stepwise Program on Mothers' Care of their Children with Beta Thalassemia at the Hematology Outpatient Clinic Affiliated to Assiut University Children Hospital, n=115" and found that; 47.8% of children aged ranged from eight to twelve years old.

The finding of the current study revealed that; more than half of studied children were female (table 2). This finding consistent with **Tsagkou et al. (2024),** who studied "Quality of Life in Children and Adolescents with Beta Thalassemia at the Greek Public Children's Hospital, n=41" and showed that 51.2% of children were female. However this study finding disagreed with **Mediani et al. (2021),** who studied "Predicting Factors Impact to Quality of Life of School Age Thalassemia Children in Indonesia at a District Hospital in Sumedang Indonesia, n=55" and revealed that 56.4% of studied children were males.

The finding of current study found that; more than half of studied children were the first child of family (table 2). This study was in accordance with **Humaira et al. (2024),** who studied "Exploring Caregiver Burden of Thalassemia Major Patients at Transfusion Centers in Pakistan, n=83"and found that 60.2% of studied children were the first children of family. Moreover, this study supported by **Mitra et al. (2021),** who studied "Psychological Problems and Quality of Life among Transfusion Dependent Thalassemia Children: Sharing Experience from a Thalassemia Care Center in West Bengal, India, n=100" and found that; 48% of studied children were the first child of family. From the investigator point of view; parents had lower level of awareness regarding prenatal examination and counseling.

The finding of current study approved that; more than half of children diagnosed less than six months (table 3). This study finding was compatible with **Prajapati et al. (2021),** 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 less than one years of age. From the investigator point of view; appearing sign and symptoms of thalassemia on the children as jaundice, stunt growth and anemia.

The current study found that: almost two third of children suffered from thalassemia more than two years ago (table 3). This study was opposed with **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 held 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 (table 2).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 investigator point of view; as beta thalassemia most common type prevalence than alpha thalassemia in Egypt.

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 (figure 1). 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),** and 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 (figure 1). 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 investigator point of view this is due to the lack of health education programs dedicated to mothers of thalassemia children in the selected centers.

According to caregivers total reported practices level regarding care of their children with thalassemia, the finding of current study found that; more than three fifth of studied caregivers had satisfactory total reported practices regarding care of their children with thalassemia (figure 2). 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.

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 (figure 3). 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 correlations between studied caregivers’ total knowledge, total empowerment and their total reported practices. (table 4). This finding was compatible with **Ibrahim et al. (2024),** 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 found that; there were significant positive correlations between caregivers' total knowledge, total empowerment and their total reported practices.

Conclusion

More than half of studied caregivers had average knowledge about thalassemia and family empowerment, more than three fifth of studied caregivers had satisfactory reported practices regarding care of their children with thalassemia while more than two fifth of studied caregivers had low total family empowerment level regarding thalassemia. There were statistically significant relations between caregivers’ total knowledge regarding thalassemia and family empowerment and their educational level and monthly income. There were highly statistically significant relations between caregivers’ total reported practices regarding care of their children with thalassemia and their educational level and monthly income. There was a highly statistically significant relation between caregivers’ total family empowerment and their place of residence. There were highly positive correlations between studied caregivers’ total knowledge, total empowerment and their total reported practices.

Recommendation

- Health educational program should be developed and implemented for caregivers to educate them the importance of prenatal screening, thalassemia, prevention of complications and physical activity and psychological practices which include (social, spiritual) health for caregivers’ children with thalassemia.
- Booklets should be available and distributed in all thalassemia hematology unit of hospital to all caregivers about the disease and health-related practices.
- Creating an integrated system to support people with thalassemia by providing specialists, treatments and necessary examinations.
- Mass media should emphasize the physical, psychological, and social needs of children with thalassemia and their caregivers to raise society's awareness regarding this disease.
- Further research studies about thalassemia needed to be carried out

with different larger samples in different setting of health care.

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