Family Management and Its Relation to Health-related Quality of Life among Thalassemic Children

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Abstract

Background: Children with thalassemia are more exposed to physical, psychological, environmental and social problems and the families have a crucial role in caring for thalassemic children. **Aim:** To assess family management and its relation to health-related quality of life among thalassemic children. **Research design:** A descriptive research design was used to fulfill the aim of the study. **Sample:** A purposive sample included 103 of families with thalassemic children. **Data Collection Tools: Tool (I):** A structured interviewing questionnaire includes two parts. **Part 1**: Demographic characteristics: **A:** Background information of parent. **B:** Background information of the child. **Part 2**: Family Management Measure (FaMM). **Setting:** This study was performed at a hematology clinic in the Minia Regional Blood Bank.**Tool (II):** Pediatric Quality of Life Inventory Version 4.0™ parent proxy-report (PedsQL™ 4.0). **Results:** 62.2% of the studied families have a poor level of family management measures toward thalassemic children with Mean of 74.44±12.70 and also 60.2% of the studied families reported that have a poor quality of life for their children with mean of 65.1±10.20. **Conclusion:** a positive correlation was found between the total family management and the total level quality of life, some sociodemographic characteristic such as residence, education, income and number of family members were associated with family management measures and also with the parents' perception of their children's quality of life among families of thalassemic children. **Recommendations:** health education programs should be given about family management and its relation to health-related quality of life among thalassemic children. Community health nurses should collaborate with other health team members to implement comprehensive educational sessions about endogamy mirage and its significant relation to thalassemic disease.

***Keywords*:** Family Management, Health-related Quality of Life, Thalassemic Children

Introduction:

Thalassemia is a genetic hematological disease that is inherited due to impaired synthesis of hemoglobin (Hb), especially in the production of globin chains. Thalassemia generally consists of 2 types, namely α-thalassemia and β-thalassemia. Clinically, thalassemia consists of transfusion-dependent and non-transfusion-dependent **(Ayukarningsih et al., 2022).**

Thalassemia is generally asymptomatic in trait and carrier states. Alpha-thalassemia major results in hydrops fetalis and is often fatal at birth. Beta-thalassemia major requires lifelong transfusions starting in early childhood (often before two years of age). Alpha- and beta-thalassemia inter-media have variable presentations based on gene mutation or deletion, with mild forms requiring only monitoring but more severe forms leading to symptomatic anemia and requiring transfusion **(Baird et al., 2022)**.

Clinical features of thalassemia vary depending on disease severity, severe symptoms include failure to thrive, progressive jaundice, and skeletal changes secondary to bone marrow expansion including frontal bossing, prominent malar eminence, maxillae hypertrophy, and long bone deformities while the milder form of thalassemia is subtler and more present with fatigue and weakness. Patients suffering from mild to severe anemia often require regular blood transfusions which results in an increased risk of developing clinical manifestations of iron overload creating highly reactive oxygen species ensuing to organ damage **(Chaudhry et al., 2022).**

The absence of treatment can result in anemia, splenomegaly, and severe bone deformations and by the age of twenty, the disease has progressed to the point of death. Blood transfusions are administered on an as-needed basis; splenectomy is performed if splenomegaly is evident **(Numan& Ali ., 2022).**

Family is the main source of children support. Families of children with thalassemia may become exhausted due to the frequent hospitalizations of the child for blood injections and because of spending a great deal of time learning about and managing the child condition. Parents of children with thalassemia often tend to recite their stories and in fact, these stories reveal their feelings, challenges, and medical experiences, family with a child with thalassemia has to deal with many challenges and experiences **(Heidari& Ahmadi, 2022).**

Thalassemia affects the physical and mental health of sufferers and causes physical problems such as chronic anemia, bone deformities, impaired growth and puberty and heart failure and in addition, severe forms of thalassemia cause suffering to parents as well, they may experience psychosocial problems e.g., fear anxiety and despair after receiving the diagnosis. The other problems that may challenge the parents are probable separation from the child, lack of knowledge of the prognosis of the disease, long-term care, and the society's reactions to the disease **(Lotfi et al., 2023)**.

Community nurses have essential roles and responsibilities in carrying out promotive and preventive efforts against thalassemia cases. Promotive measures that can be carried out include education about thalassemia disease, prevention efforts, and diagnostic tests that can be taken. The preventive efforts that can be made are screening, tracing, and

genetic counseling. Thalassemia screening can be done in public hospitals by examining MCV (mean corpuscular volume), MCH (mean corpuscular hemoglobin), and MCHC (mean corpuscular hemoglobin concentration). This screening is very important, especially for couples who are about to get married (premarital screening), so nurses need to collaborate with the Office of Religious Affairs, which has authority over the marriage process. **(Setiawan et al., 2023)**.

Significance of the Study

Thalassemia is considered the most common single-gene disorder worldwide with high prevalence in the Mediterranean basin through Middle East, Indian subcontinent, Burma, Southeast Asia and Pacific Islands. According to the Thalassemia International Federation, over 3, 30,000 diseased with blood transfusion disorder are born annually, of which 83% are sickle cell disorders and 17% have thalassemia (around 56,000) **(Sonkawade et al., 2022)**.

It has been estimated that 5% to 7% of the world's population carries a mutated gene affecting the production or function of the hemoglobin molecule and about 56,000 new born are affected by beta thalassemia syndromes annually **(Soteriades et al., 2023).**

Carriers of hemoglobin disorders may be asymptomatic or have only mild anemia and may thus be unaware of their condition. Furthermore, if two carriers have a child, there is a 25% chance that the child will suffer from a more severe condition requiring transfusion and iron chelation therapies**. (Wendt et al., 2023).**

Beta thalassemia major is considered the most common chronic hemolytic anemia in Egypt with an estimated carrier rate of 9–10.2% .The disease represents a significant psychological and financial burden on the affected families and the Egyptian government **(Nassim et al., 2022)**

Parents of thalassemic children face social, cultural, economic, psychological challenges and family dimensional problems while taking care of their children. Including a lack of services available for early diagnosis and treatment, difficulty in arranging donors regularly for blood transfusion, and the very high cost of chelation therapy which leads poor parents to non-compliance with the child treatment. The disease negatively affected their socioeconomic conditions. **(Amin et al., 2022)**.

Aim of the study:

The aim of the present study is to assess family management and its relation to health-related quality of life among thalassemic children.

Research questions :

- **Q1**- What is the family management's level among families of thalassemic children؟
- **Q2**- What is the quality of life's level among thalassemic children ؟
- **Q3**- Is there a relation between family management and children quality of life among families of thalassemic children?

Subjects and Method: -

Research design: This study used a descriptive research design to fulfill the aim of the current study.

Setting of the study:

This study was performed at a hematology clinic in the Minia Regional Blood Bank. It is located in Minia governorate and serves all its centers and contains three floors. The health care team working in the Minia Regional Blood Bank includes five physicians, sixteen pharmacists and forty-four nurses. It provides blood donation and blood transfusion services to patients suffering from blood disorders such as thalassemia, hemophilia and Glucose-6-phosphate dehydrogenase. The clinic works six days a week for all blood disease from 8 A.m. to 2 P.m.

Study Sample:

A purposive sampling technique was used for the current study, the participating families who have children with thalassemia and who were attending a hematology clinic at Minia Regional Blood Bank, they visited the clinic during the Study period from October to December 2022.

Inclusion criteria:

1. Families who have only one child affected by thalassemia.
2. Child aged from 6 to 18 years.

Exclusion criteria:

1. Children who have more than one chronic disease.

Sample size:

According to Minia Regional Blood Bank census, the yearly average of patients with thalassemia is 400 children, the sample size was determined according to the statistical equation in which the sample proportion ranged between (10% to 30%) of the total population size **(Bartlett et al., 2001)**. The calculation was as the following formula:

$$n = \frac{\frac{z_\alpha^2\ p\ (1-p)}{m^2}}{1+\frac{z_\alpha^2\ p\ (1-p)}{m^2\ N}} = \frac{\frac{(1.96)^2\ \ (0.3)\ (0.7)}{(0.05)^2}}{1+\frac{(1.96)^2\ \ (0.3)\ (0.7)}{(0.05)^2\ 400}} = 103$$

Description:

n = required sample size.

z = is the Z score at 0.025 (1.96).

p = Prevalence of patients with thalassemia at Minia University Hospitals 2021 (0, 3).

m = Margin of error at 5 % (standard value of 0.050).

Tools of data collection:

Data collection tools were developed by the investigator after extensive reviewing of the related literature and two tools were used and developed by investigator to collect the necessary data from parents who have thalassemic children.

Tool (I): structured interviewing questionnaire

This tool was divided into two parts.

Part 1: Demographic characteristics:

A: Background information of parent: It consists of six questions about parental age, gender, educational level, residence, family income as well as a question about number of family members. **(Lubna et al., 2021)**

B: Background information of the child consists of three questions: age, sex, duration of disease.

Part 2: Family Management Measure (FaMM)

Adapted by **Knafl (2021)** to assess parental perspectives on how the family is managing the care of the child with thalassemia and the extent to which they are able to incorporate thalassemia into everyday life. FaMM consists of 43 items and 5 domains as follows: 1) child's daily life (5 items), 2) condition management ability (12 items), 3) condition management effort (4 items), 4) family life difficulty (12 items), and 5) view of condition impact (10 items).

Scoring system:

The three-point Likert scale was used. The parent was given the options of agree (3), neutral (2), and disagree (1) with regard to each item. The total score of items response is 129. These scores were summed and converted into a percent score **(Chusri et al., 2019)**.

It was classified into 3 categories:

- Good management level if score > 75 %
- Average management level if score 60 – 75%.
- Poor management level if score < 60%.

Tool (II): Pediatric Quality of Life Inventory Version 4.0™ parent proxy-report (PedsQL™ 4.0):

It was adapted by **Verni** (**2001**) to assess parents' perception of their child's HRQOL in children and adolescents aged 6 to 18 years. Get included 23-item: 1) physical functioning (8 items), 2) emotional functioning (5 items), 3) social functioning (5 items), and 4) school functioning (5 items). Parents were asked to indicate how much of a problem each item was for their child during the past month.

Scoring system:

Parent proxy-report (3 = never a problem; 2 = sometimes a problem; 1 = almost always a problem). The total score of items response is 69. These scores were summed and converted into a percent score. **(Verni et al., 2001**)

It was classified into 3 categories:

- Good quality level if score > 75 %
- Average quality level if score 60 – 75%.
- Poor quality level if score < 60%.

The Validity:-

Expert evaluation was used to determine the tool's content authenticity. For content coverage, language, length, format, and overall look, the questionnaire was examined by five community health nursing experts. Rephrasing and reordering of sentences were among the changes performed in response to expert comments and recommendations.

Reliability:-

Internal consistency was evaluated using Cronbach's Alpha coefficient test which revealed that the tools of the study were reliable as indicated by the value of 0.86. and 0.93 respectively Family Management Measure (FaMM) and Pediatric Quality of Life Inventory Version 4.0™ parent proxy-report (PedsQL™ 4.0).

Pilot Study:

The pilot study was done for 11 families (10%) before the actual work began to test the clarification of the tools and to calculate the time required to fill the sheets after obtaining permission from the director of Minia Regional Blood Bank. There were no modifications done to the study tools based on the pilot study; 10% of the parents in the pilot study were included in this study sample.

Procedure*:*

Agreement to conduct the study was obtained from the Ethical Committee and the Nursing Faculty Dean at Minia University. The jury committee gave their agreement for the tool to be used to collect study data, and required modifications were made to the tool.

Approval was taken from the director of National Blood Bank in Cairo and the director of Regional Blood Bank in Minia governorate. After obtaining permission from the director of the regional blood bank in Minia, the investigator proceeded by introducing herself to the director of the hematology unit, physicians and nursing staff. Then discussed the aim and purpose of the study with them to get their help.

The investigator went to the hematology unit from 9 A.m. to 2 P.m. and from Saturday to Monday because the number of children was more within these days. While the children begin the blood transfusion session in the Hematology Unit the families sit in the waiting room and the investigator begins the assessment. At the begging the investigator introduced herself to them and explained the aim of the study, and verbal consent was taken to fill out the questionnaire.

A pilot study was conducted to ensure that the data collection tools were clear and applicable. The tools were given to all the families. The investigator administered the tools immediately and supervised the process. Families were given between 20 and 40 minutes to complete the questionnaires. In the case of illiterate parents, the investigator would have helped them fill out. Any inquiries that families have were answered by the investigator.

The real field work for data collection began on 15 October 2022 and ended on 31 December 2022. The investigator interviewed the families according to the hematology clinics' timetables; the investigator spent 20-40 minutes with each parent and interviewed (1-4) parent every day for only one time.

Ethical Consideration:

The Research Ethics Committee of Minia University's Faculty of Nursing gave their initial clearance in writing. After discussing the study's nature and benefits, participants gave their oral informed permission. For the sake of privacy and secrecy, each sheet was coded and the participant's names were not printed on the sheets. Participants were informed that they might leave the present study if they wanted at any moment without affecting their treatment. Participants were interviewed and data were collected by the investigator. Families and children's privacy and confidentiality were protected during participation in the research.

Statistical Analysis

The data was tabulated, analyzed and computerized by using SPSS (statistical package for the social science version 20). Data were presented using descriptive statistics in

the form of frequencies and percentages for qualitative variables, mean and standard deviations for quantitative variables. Categorical variables were presented as numbers and percentages and intergroup differences were compared using Chi-squared test for trend (for ordinal data), and the r-test was used for investigate Correlation. Statistical significance difference was considered when p-value ≤ 0.05, and high significance when P-value ≤ 0.001 and no statistically significant difference was considered when p-value > 0.05.

Results

Table (1): Frequency distribution of studied family regarding their demographic data (N= 103).

Socio-demographic data	Study sample N= 103	
	No	%
parents age / years		
20-<30	12	11.7
30-<40	48	**46.6**
40-<50	32	31.0
50 +	11	10.7
Mean ± SD	35.05 ± 9.90	
Sex		
Male	34	33.0
Female	69	**67.0**
Residence		
Urban	21	20.4
Rural	82	**79.6**
Education Level		
Illiterate	47	**45.6**
Read and write	11	10.7
secondary education	35	34.0
University education	10	9.7
Occupation		
Not-working	78	**75.7**
Manual Work	10	9.7
Professional	15	14.6
Income		
just meet expenses	63	**61.2**
meet expenses	24	23.3
Emergencies	9	8.7
Able to save	6	6.8
Number of family members		
3	10	9.7
4-6	28	27.2
6+	65	**63.1**

Table (1) shows that 46.6% of studied parents in age ranged from 30: <40 with mean age (Mean ± SD 35.05 ± 9.9), 67.0% of participants were female, 79.6% of the studied parents live in a rural area, 45.6% of them were Illiterate, regarding their occupation 75.7% were not-working, concerning parents' income 61.2% of them just meet expenses, and 63.1% of them had more than 6 family members.

Table (2) Frequency distribution of studied children regarding their personal data (N= 103).

Child data	No	%
Age		
6-9 years.	29	28.1
9-13 years	35	34.0
13-18 years.	39	**37.9**
Sex		
Male	60	**58.3**
Female	43	41.7
Duration of disease		
Less than one year	2	1.9
1-3years	4	3.9
3-5 years	6	5.8
More than 5 years.	91	**88.4**

Table (2) reveals that **37.9 %** of studied children's ages ranged from **13 <18**, **58.3%** of children were male and regarding their duration of disease **88.4%** were more than 5 years.

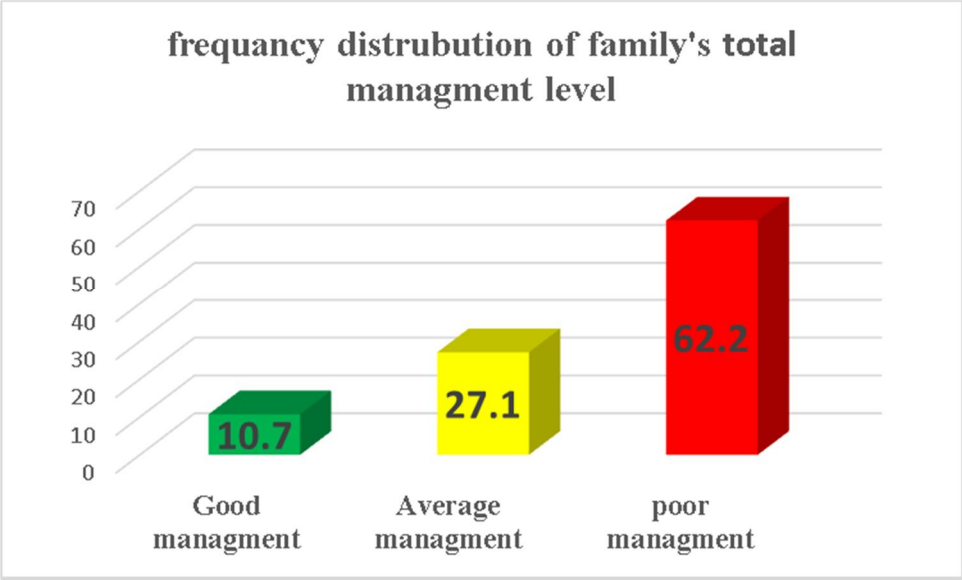

Fig 1: Frequency distribution of total management level of the studied families (N=103).

Fig 1: shows that **(62.2%)** of the studied families have poor level of family management measures toward their thalassemic children with **(Mean%± SD 74.44±12.70),** and only **(10.7%)** of them have good level of family management measures toward their thalassemic children **(Mean%± SD 11.47±8.9).**

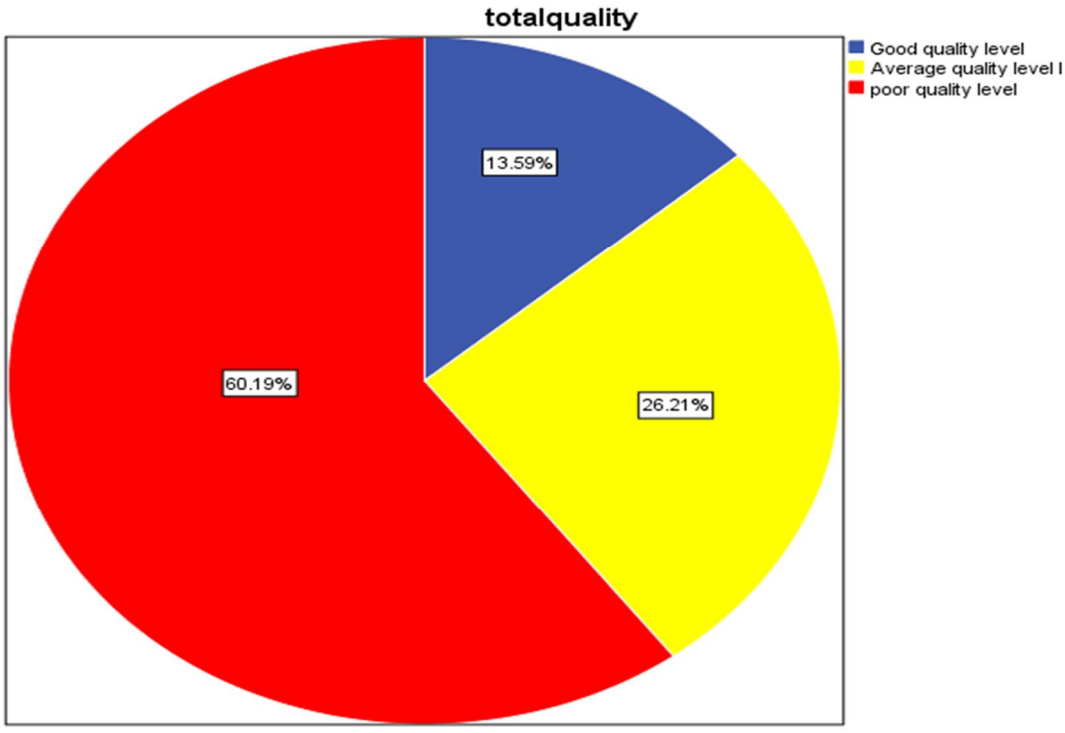

Fig 2: Total level of parent perception about their children's quality of life of the studied families (N=103).

Fig 2: illustrates that (60.2%) of the studied families reported that having a poor quality of life level for their children with (Mean%± SD 65.1±10.20), and only (13.6%) of their children had a good quality of life level with (Mean± SD 14.11±4.27).

Table (3) Relation between demographic characteristics and total family management level of the studied families (N=103).

Socio-demographic data	Family management measures						χ^2	p- value
	Good management level		Average management level		Poor management level			
	No	%	No	%	No	%		
parents age / years								
20-<30 (12)	1	9.1	7	25.0	4	6.3	12.489	.050
30-<40 (48)	6	54.5	6	21.4	36	56.3		
40-<50 (32)	3	27.3	11	39.3	18	28.1		
50 + (11)	1	9.1	4	14.3	6	9.4		
Sex								
Male (34)	6	54.5	8	28.6	24	31.3	2.646	.266
Female (69)	5	45.5	20	71.4	44	68.8		

Socio-demographic data	Family management measures						χ^2	p- value
	Good management level		Average management level		Poor management level			
	No	%	No	%	No	%		
parents age / years								
Residence								
Urban (21)	6	54.5	11	39.3	4	6.3	21.578	.001*
Rural (82)	5	45.5	17	60.7	60	93.7		
Education Level								
Illiterate (47)	1	9.1	10	35.7	36	56.3	21.790	.001*
Read and write (11)	3	27.3	1	3.6	7	10.9		
secondary education (35)	4	36.4	11	39.3	20	31.3		
University education (10)	3	27.3	6	21.4	1	1.6		
Occupation								
Not-working (78)	5	45.5	19	67.9	54	84.4	12.457	.014
Manual Work(10)	1	9.1	4	14.3	5	7.8		
Professional(15)	5	45.5	5	17.9	5	7.8		
Income								
just meet expenses(63)	2	18.2	8	28.6	53	82.8	51.270	.001*
meet expenses(24)	3	27.3	14	50.0	7	10.9		
Emergencies(9)	2	18.2	4	14.3	3	4.7		
Able to save(7)	4	36.4	2	7.1	1	1.6		
Number of family members								
3 members (10)	6	54.5	3	10.7	1	1.6	20.351	.001*
4-6 (28)	4	36.4	21	75.0	3	4.7		
6+ (65)	1	9.1	4	14.2	60	93.7		
Child age								
6-9 yrs. (29)	2	18.2	9	32.1	18	28.1	1.049	.902
9-13(35)	4	36.4	10	35.7	21	32.8		
13-18(39)	5	45.5	9	32.1	25	39.1		
Duration of disease								
Less than one year	0	0.0	1	3.6	1	1.6	5.956	.428
1-3years	0	0.0	3	10.7	1	1.6		
3-5 years	1	9.1	1	3.6	4	6.3		
More than 5 years.	10	90.9	23	82.1	58	90.6		

$\chi 2$ Chi-square test * Statistical significant difference ($P < 0.05$) * *P*- value is significant

Table 3: reports that the place of residence, level of education, income and number of family members were highly associated with family management measures among families of thalassemic children with (P= 0.001*), Other demographics did not show any significant association with family management measures

Table (4) Relation between demographic characteristics and total level of parent perception about their children's quality of life of the studied families (N=103).

Socio-demographic data	Parent perception about their children' quality of life						χ^2	p- value
	Good quality level		Average quality level		Poor quality level			
	No	%	No	%	No	%		
parents age / years								
20-<30 (12)	1	7.1	5	18.5	6	9.7	5.204	.518
30-<40 (48)	4	28.6	11	40.7	33	53.2		
40-<50 (32)	7	50.0	8	29.6	17	27.4		
50 + (11)	2	14.3	3	11.1	6	9.7		
Sex								
Male (34)	8	57.1	6	22.2	20	32.3	5.124	.077
Female (69)	6	42.9	21	77.8	42	67.7		
Residence								
Urban (21)	8	57.1	4	14.8	9	14.5	13.486	.001*
Rural (82)	6	42.9	23	85.2	53	85.5		
Education Level								
Illiterate (47)	2	14.3	14	51.9	31	50.0	18.870	.002*
Read and write (11)	0	0.0	6	22.2	5	8.1		
secondary education (35)	8	57.1	5	18.5	22	35.5		
University education (10)	4	28.6	2	7.4	4	6.5		
Occupation								
Not-working (78)	7	50.0	21	77.8	50	80.6	10.519	.033
Manual Work(10)	1	7.1	3	11.1	6	9.7		
Professional(15)	6	42.9	3	11.1	6	9.7		
Income								
just meet expenses(63)	6	42.9	17	63.0	40	64.5	7.202	.515
meet expenses(24)	4	28.6	6	22.2	14	22.6		
Emergencies(9)	3	21.4	1	3.7	5	8.1		
Able to save(7)	1	7.1	3	11.1	3	4.8		
Number of family members								
3 members (10)	6	42.8	2	7.4	2	3.2	11.354	.003*
4-6 (28)	4	28.6	15	55.6	9	14.5		

Socio-demographic data	Parent perception about their children' quality of life						χ^2	p- value
	Good quality level		Average quality level		Poor quality level			
	No	%	No	%	No	%		
parents age / years								
6+ (65)	4	28.6	10	37.0	51	82.3		
Child age								
6-9 yrs. (29)	2	14.3	10	37.0	17	27.4	2.782	.595
9-13(35)	6	42.9	9	33.3	20	32.3		
13-18(39)	6	42.9	8	29.6	25	40.3		
Duration of disease								
Less than one year(2)	0	0.0	0	0.0	2	3.2	7.684	.262
1-3years(4)	2	14.3	1	3.7	1	1.6		
3-5 years(6)	0	0.0	1	3.7	5	8.1		
More than 5 years.(90)	12	85.7	25	92.6	54	87.1		

$\chi 2$ Chi-square test * Statistical significant difference ($P < 0.05$) * *P*- value is significant

Table 4: indicates that the place of residence, level of education, and number of family members were associated with Parents' perception of their children's quality of life among families of thalassemic children with (P= 0.001*), (0.002*) and (0.003*) respectively. Other demographics did not show any significant association with parents' perception of their children's quality of life.

Table (5) Correlation between participants' total family management and total quality of life level regarding thalassemic children (n=103).

Variable	Total quality of life	
	R	P-value
Total family management	0.404	0.0001*

** Correlation is significant at the 0.01 level (2-tailed).

Table (5) demonstrates that there was a positive correlation (p value = < 0.001) between total family management and total quality of life level.

Discussion: -

Concerning demographic characteristics of the studied sample, the current study showed that the **mean age** for the studied parent was 35.05 ± 9.9, this result in accordance with **Atiye et al., (2022)** who studied "The Experiences of Parents of Children with Thalassemia Major in Turkey: A Qualitative Study". The sample size was fourteen and reported that the mean age of the parents was 36.64 ±8.18.

In addition, this result was supported by **Sahu et al., (2022)** who studied "Quality of Life among Parents of Children Having Thalassemia versus leukemia". The sample size was fifty participants and found that the mean age of parents was 38 ± 6.5. This result disagreed with **Thiyagarajan et al., (2019)** who studied "Assessing the Role of Family Well-being on the Quality of Life of Indian Children with Thalassemia". The sample size was one hundred and twenty-five participants and reported that the mean age among parents was 26 ± 4.86.

Regarding parent's **gender**, two-thirds of the study sample was female and almost half of parents were **illiterate**, these results agreed with **Manzoor& Zakar (2019)** who studied "Sociodemographic Determinants Associated with Parental Knowledge of Screening Services for Thalassemia Major in Lahore". The sample size was one hundred and eighty-six parents and reported that more than two-thirds of parents were female and the major proportion belonged to the illiterate group. This finding was in line with **Mediani et al.,(2019)** who studied "Factors Related to the Needs of Parents Having School Age Thalassemic Children". The sample size was one hundred and thirty-six parents and reported that the majority of the studied sample was female and illiterate.

From the investigator`s point of view, Thalassemia spreads in less educated societies where endogamy marriage is prevalent, and they are not interested in premarital tests. This agrees with Egypt statistics of illiteracy rate which 24.6%. The illiteracy rate is higher among females than males **Countrymeters,.(2023).** The mothers are bearing the burden of treatment, care and follow-up of children's disease so the majority of the studied sample was female.

In contrast to the current results, **Khalid et al., (2019)** who studied "Knowledge of Thalassemia and Consanguinity: A Multicenter Hospital Based Retrospective Cohort Study from Metropolitan City of Karachi, Pakistan". The sample size was two hundred and found that a quarter of the studied sample was illiterate. This study was done in Buahira governorate.

According to the investigator`s point of view, the level of education differs from Lower Egypt to Upper Egypt, where the level of education is higher in Lower Egypt. This study was carried out in the city of Bahria in Lower Egypt.

The current study revealed that the majority of studied parents lived in a rural area concerning **residence**, this result consistent with **Akram& Khan (2022)** who investigated "Implementation, Patient Satisfaction and Usability of Telemedicine Services for Pediatric Thalassemia Cases in Balochistan during COVID-19 Pandemic and beyond". The sample size was three hundred and forty- seven participants and reported that the majority of participants were residing in rural areas. On the other hand, this result was disagreed by **Wali & Barakat (2022)** who studied "Current Situation of Thalassemia in Paktia Regional Hospital Afghanistan". The sample size was one hundred and found that the majority of cases were from urban areas.

According to the investigator`s point of view, it may be due to the lack of health education about thalassemia and how to prevent it, so thalassemia is widespread in urban and rural areas.

Regarding **income,** almost two thirds of parents were just meet expenses, this result was supported by **Abd Elaty et al., (2023)** who studied "Mothers' Performance Regarding Care of Their Children with Thalassemia at Abo El-Rish Hospital". The sample size was two hundred and eighty-six and reported that almost two third of participants had insufficient income. This finding in agreement with **Biswas et**

al., (2022) who studied "Coping Styles in Parents of Children with Thalassemia in West Bengal". The sample size was one hundred participants and found that the majority of the sample was from lower socioeconomic strata.

According to the investigator`s point of view, the poverty rate reached 27.9% in Egypt as of 2022 **Statista,.(2023).** Therefore, treating thalassemia exposes families to a large financial burden on the Egyptian family.

Regarding **occupation** three-quarters of the studied sample were not-working, this result consistent with **Karakul& Senol, (2022)** who studied "Effectiveness of Individualized Empowerment Education on Children with Beta-Thalassemia Major". The sample size was thirty participants and found that the majority of studied sample was not working.

In the same line, this result in accordance with **Khresheh& Brair, (2020)** who studied "Knowledge and Practices among Mothers about Care of their Children with Beta Thalassemia Major: A Descriptive Study". The sample size was forty-five and stated that the majority of participants were not employed. **From the investigator`s point of view**, Arab countries suffer from the same pressure in the availability of jobs, which leads to a financial burden.

The present study revealed that two-thirds of the studied sample had more than six **family members**, this result disagreed with **Zolaly et al., (2020)** who studied "Depression, Anxiety, and Stress Symptoms in Patients with Beta Thalassemia Major in Almadinah Almunawwarah, Saudi Arabia". The sample size was sixty-two participants and reported that one fourth of the participants had more than five members. **From the investigator`s point of view**, the number of children within the family varies according to the culture of the society in which the family lives.

Concerning **children's age**, more than one third of studied children ranged from13 <18 and **more than half of the children were male,** these results agreed with **Mettananda et al., (2022)** who studied " Maternal knowledge on Curative Therapies and Its Impact on Medical Care And Psychological Health among Children with Thalassemia in Sri Lanka". The sample size was three hundred and four and found that one third of children ranged from 13 <18 years, near of half were male. This result disagreed with **Ali et al.,(2018)** who studied "Coping Strategies among Children with Thalassemia" .The sample size was three hundred children and reported that two thirds of studied sample ranged from 12 years to 18 years and more than half of the studied thalassemic children were females.

The present study noted that there was a high percentage of studied children who had more than five years of **duration of disease**. This result was supported by **Suryawan et al.,(2021)** who studied "Determinant Factors of Depression in Beta Major Thalassemia Children". The sample size was fifty-six children and found that the duration of illness of thalassemic children was more than five years for the vast majority of studied children. **According to the investigator`s point of view**, diagnosis of thalassemia occurs in the first year of child`s life so thalassemia is a lifelong disease.

Concerning the **total family management level**, the current study showed that **more than half of** the studied families **had poor level of family management measures toward their thalassemic children**, this result run against **Chusri et al., (2016)** who assessed "The Styles of Management in Families Having a Child with Thalassemia". The sample size was three hundred and nine parents and reported that Parents' scores in every dimension of family management were at the moderated level. **From the investigator`s point of view**, the family management level differs in developing countries from the developed ones, as in developed countries the capabilities are available for the family to take care of the thalassemic child.

The present study illustrated that **more than half of the studied families reported that had a poor quality of life level with their children** concerning the **total quality of life level**. This result agreed with **Naderi et al., (2023)** who studied "Evaluation of Quality of Life in Children and Adolescents with Thalassemia Major". The sample size was one hundred and thirty-six and stated that the children with thalassemia required special attention to various aspects of their lives as their lower quality of life negatively impacted them. Providing more and better medical and rehabilitation services to this group seems to be necessary.

In addition, this result was advocated by **Fatkuriyah& Hidayati (2022)** who studied "Factors Related to Quality of Life among Children with Thalassemia Major: A Literature Review" and reported that there were 6 articles reviewed according to the inclusion criteria. All the studies showed that the score of quality of life among children with thalassemia was lower than that of healthy children. In the same line, this result was supported by **Jay et al., (2017)** who studied "A Study to Compare Quality of Life of Healthy Children and Children with Thalassaemia". The sample size was twenty-eight children and found that the scores of all four PedsQL domains (Physical, Emotional, Social and School functioning) of thalassemic children were lower than those of the healthy children.

Furthermore, a parallel finding was reported by **Ogaz, (2017)** who studied "Health Related Quality of Life in Lebanese Children with Thalassemia". The sample size was eighty children and reported that children with thalassemia had significantly lower HRQOL scores in all dimensions. **According to the investigator`s point of view**, although the countries of the world differ in customs, traditions, culture and availability of possibilities for treatment, thalassemia negatively affects all dimension of child's quality of life.

The current study reported that the **place of residence, level of education ,income and number of family members were associated with family management measures** among families of thalassemic children, this result in accordance with **Jaide (2019)**who studied "Testing a Model of Family Management of Childhood Asthma in Thailand" and found that financial status ,family employment status, number of family members, education and community (rural or urban)influence management behaviors of management of children with chronic disease. In the same line, this result consistent with **Sheng et al.,(2018)** who studied "Family Management affecting Transition Readiness and Quality of Life of Chinese Children". The sample size was fifty-six participants and found that the family characteristics included geographical location, income, number of children, parental education, and employment status associated with management the child condition.Higher maternal education, and higher family income predict high levels of easy family management.

The current study indicated that **the families' place of residence, level of education, and number of family members were associated with children's quality of life**, this result in accordance with **Biswas et al.,(2023)** who

studied "An Epidemiological Study of the Quality of Life of Children with Beta-Thalassemia Major (B-TM) and Its Correlates in Kolkata", and reported that place of residence, the mother's educational level as significant influencers of the quality of life of a thalassemic child .

In addition, this result comes consistent with **Thiyagarajanetal et al., (2019**) who studied "Assessing the Role of Family Well-being on the Quality of Life of Indian Children with Thalassemia" and stated that parent's education status was found to have a significant influence on children's HRQoL. Educated parents bring a warm and pleasing social climate at home compared to non-educated parents. Children with educated parents are more inclined to have educational support, moral advice, economic background, nutritional support, assistance in taking the right decisions, and help to face a problem with a positive attitude.

Furthermore, a parallel finding was reported by **Ibrahim et al., (2021)** who studied "Relationship between Quality of Life and Social Support among Mothers of Children with Thalassemia".The sample size was eighty-five and reported that there was a significant relation between quality of life, educational level and socioeconomic level. The mean quality of life is high at high educational and socioeconomic levels.

The present study demonstrated that there was a **positive correlation (p value = < 0.001) between total family management and total quality of life level**, this result was supported by **Sutthisompohn &Kusol (2021)** who studied "Association between Caregivers' Family Management and Quality of Life in Children with Chronic Disease in Southern Thailand ". The sample size was two hundred participants and found that easy family management positively correlated with the overall quality of life and difficult family management had a negative correlation with the quality of life.

Conclusion:

Based on the findings of the present study, it can be concluded that most families of thalassemic children had poor level of family management measures toward their thalassemic children and had a poor quality of life for their children. Also, there was a positive correlation between total family management and total quality of life score . Furthermore, the place of residence, level of education, income and number of family members were highly associated with family management measures among families of thalassemic children. The place of residence, level of education, and number of family members were associated with Parents' perception of their children's quality of life among families of thalassemic children.

Recommendations

Based on the finding of the current study, the following points are suggested:

- Provide health education programs about Family Management and Its Relation to Health-related Quality of Life among Thalassemic Children.
- Community health nurses should collaborate with other health team members to implement comprehensive educational sessions about endogamy marriage and its significant relation to thalassemia disease.
- Newborn and pregnancy screening for thalassemia.

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