

Correlation between Psychological Problems, Quality of Life and Coping Strategies among Parents of Children with Thalassemia

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Abstract

Background: The psychological problems that parents of children with thalassemia typically face have a detrimental impact on all aspects of their quality of life as well as their coping mechanisms with their children. **Aim of the study:** This study aimed to assess the correlation between psychological problems, quality of life and coping strategies among parents of children with Thalassemia. A descriptive correlational research **design** used in this study. **Setting:** This study was conducted at the blood transfusion unit in the blood diseases department at Benha specialized children hospital, Qalyubia Governorate. A purposive **sample** of 100 parents of children with thalassemia chosen from the previous setting. **Instruments:** *instrument (I):* A structured Interviewing Questionnaire Sheet, *instrument (II):* Depression, anxiety and stress (DASS) scale, *instrument (III):* Quality of life scale and *instrument (V):* Brief COPE strategies scale. The research **results** revealed that more than half of the studied parents had moderate level of total psychological problems (depression, anxiety and stress), nearly two thirds of them had a low level of total quality of life and more than half of them had low level of total coping strategies. The study **concluded** that there was a highly statistically significant negative correlation between total DASS, total quality of life and total coping strategies scales. While there was a highly statistically significant positive correlation between total quality of life and total coping strategies scales among the studied parents. According to study findings researchers. **Recommended** application of psycho-educational nursing program for all parents of children with thalassemia to improve their quality of life and, consequently, their coping mechanisms and lessen psychological issues.

Keywords: Psychological problems, Quality of life, coping strategies, Thalassemia.

Introduction:

Thalassemia is a chronic disease starting in childhood and can be defined as a group of chronic, genetic disorders of hemoglobin synthesis that are marked by mild to severe hypochromic and microcytic anemia, result from the partial or complete failure in production of one or more globin chains. This leads to aberrant red blood cell formation and, eventually, anemia, the hallmark symptom of thalassemia. Anemia caused by thalassemia can occur either in mild or severe degree that damage organs and ultimately lead to death, so the usual used treatment for the affected children of thalassemia is continuous blood transfusions to maintain their normal growth up to puberty and help them to perform activities of daily living as much as possible (Merriam-Webster, 2022).

The parents' psychological well-being is significantly impacted by thalassemia diagnosis of their children. As a result, they experience a

wide range of psychological issues, which are conditions marked by abnormal thoughts, feelings, and behaviors. These issues include increased emotional burden, anxiety, stress, depression, sadness, hopelessness, negativity about their own lives, low self-esteem, and difficulties integrating into society. Additionally, frequent transfusion-related hospital stays, financial strains, an inability to manage the illness, the child's odd appearance, bone abnormalities, low height, and a negative self-image can all cause problems for the parents of affected children. Thus, it is essential that they understand how to deal with these issues and control how they affect their quality of life (Baghersalimi et al., 2021).

Quality of Life "QoL," encompasses a broad variety of complex ideas that frequently entail subjective evaluations of both favorable and unfavorable aspects of life. Numerous problems, mostly related to the child's clinical state and possibly fatal sequelae, had a detrimental effect on

the quality of life for parents of children with thalassemia. In addition to affecting parents' social and psychological well-being, thalassemia affects all aspects of their quality of life, which leads to routine changes or the inability to complete daily duties. (Miller et al., 2021).

Coping strategies are very important when facing stressful conditions as a youngster diagnosis with thalassemia. When a child experiences illness or disability and needs care and support, coping mechanisms are an active process that involves using the family's current resources while also observing the development of new resources and behaviors that will strengthen the family, lessen the impact of stressors, and facilitate a return to normal health. This is especially true for parents, who are responsible for helping the sick child. Therefore, applying active coping strategies leads to an increase in well-being and decrease in the level of psychological problems and hence improved quality of life among parents of children with thalassemia (Budimir et al., 2021).

Psychiatric and mental health nurse has a vital role in managing the psychological status, improving quality of life and coping strategies among parents of children with thalassemia not only, before and after the blood transfusion process but also, later at the follow-up periods. They should implement a psycho-educational nursing program for them to reduce stress, depression, anxiety, enhance quality of life and coping abilities to accept the situation of their child. As well as help them to perform stress management techniques and attend group therapy with other parents who have a similar child with thalassemia. Furthermore, they assess dysfunction and evaluate progress, help mothers regain or improve coping abilities, promote their general health and psychological wellbeing (Abu Shosha et al., 2021).

Significance of the study:

According to World Health Organization (WHO) statistics, at least 5.2% of people worldwide were carriers of thalassemia, 1.1% of couples worldwide were at risk of having children with a hemoglobin disorder, and 2.7 out of every 1,000 conceptions were affected. Thalassemia is a chronic and common disorder in children that can cause psychological distress for

both the children and their parents. While children in developing nations die before reaching five, most thalassemia-affected youngsters in high-income nations live with a chronic condition (Apidechkul et al., 2022).

Furthermore, **In Egypt;** An estimated 1000 to 1.5 million live births with thalassemia occur each year, with the carrier percentage ranging from 5.5% to over 9% (Ibrahim et al., 2022). According to statistical records of Benha specialized children hospital, the number of affected children with thalassemia aged from 1 month to -18 years was (252) cases in 2023. Therefore, there was a critical need for researchers to conduct this study to assess the correlation between psychological problems, quality of life and coping strategies among parents of children with Thalassemia.

Aim of the study:

This study aimed to assess the correlation between psychological problems, quality of life and coping strategies among parents of children with Thalassemia.

Research questions:

- 1-What are the levels of psychological problems, quality of life and coping strategies among parents of children with Thalassemia?
- 2- Is there a correlation between psychological problems, quality of life and coping strategies among parents of children with Thalassemia?

Subject and Methods:

Research design: A descriptive correlational design was utilized to achieve the aim of this study.

Research setting: The study was conducted at the blood transfusion unit in the blood diseases department at Benha specialized children hospital, Qalyubia Governorate which is affiliated to ministry of the health. The blood transfusion unit operates 4 days throughout the week. There are (6) nurses, (1) head nurse and (5) physicians in this department. Furthermore, the blood diseases department is located on the fourth floor of the hospital and consists of (3) rooms; (2) rooms specialized for blood transfusion to children with thalassemia **only** and contain

(14) beds. While (1) room specialized for hemophilia and other blood diseases and contains (10) beds.

Subjects:

Sample Size:

Based on the past review of literature that examined the same outcome and found significant differences, a sample size has been calculated using the following equation: $n = (z^2 \times p \times q) / D^2$ At power 80% and CI 95%.

The calculated sample size was 100 parents of children with thalassemia.

Sample Technique:

A purposive sample of 100 parents of children with thalassemia chosen from the previous setting based on these criteria:

Inclusion criteria:

- 1- Parents whose children were 1 month to 18 years and diagnosed with thalassemia.
- 2- Parents aged from 18-65 years
- 3- Both sexes.
- 4- Parents who are interested in taking part in the research.

Exclusion criteria:

- 1- Parents of children with other blood diseases.
- 2- Parents with a history of psychiatric or neurological disorders.
- 3- Parents with auditory or vision impairments.

Data collection instruments:

Data collected by four instruments.

Scoring system for DASS:

Scoring system was different as follow:

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21 and more	15 and more	26 and more

Instrument III: - Quality of Life Scale (QoLS):

This scale was originally constructed by *WHO (1996)* and adapted by the researchers. It was used to assess the level of quality of life among parents of children with thalassemia. This scale consisted

Instrument (I): A Structured Interviewing Questionnaire Sheet:

After examining relevant literature, the researchers created it to accomplish the study's aim. It consists of two sections; **Section (1)** It involved the sociodemographic details of the parents under study, including age, sex, educational level, marital status, occupation, how many children do you have, having other children suffer from the same disease and monthly income of the family. **Section (2)** it included clinical data of the affected children such as duration of disease, the type of thalassemia of the affected child, previous hospitalization, disability caused by thalassemia to the affected child and family history for thalassemia.

Instrument (II): Depression, Anxiety and Stress Scale (DASS):

It was originally developed by **Lovibond & Lovibond, (1995)**, and adapted by the researchers. This scale was used to assess psychological problems among parents of children with thalassemia. The DASS consisted of 21 items, based on three subscales of depression subscale (7 Items) anxiety subscale (7 Items), and stress subscales (7 Items). The three subscale scores of items assessed on a four-point scale are combined to get the DASS total score (did not apply to me at all=0, Applied to me to some degree =1, Applied to me to a considerable degree=2 and applied to me most of the time =3). The total score of the scale was 63 grades. Scores on the DASS-21 will need to be multiplied by 2 to calculate the total score. These scores were converted to percentage score.

of 26 items; it consisted of four domains physical domain (6 items), psychological domain (9 items), social domain (3 items), and environmental domain (8 items). Responses were rated on a 3 – point likert scale ranged from; No (3), Sometimes (2) and Yes (1), but items 1, 2, 11 are reversed.

Higher scores indicate a high level of quality of life.

Scoring system of quality of life scale.

- Less than 60 % (1- <49 grades) indicate low quality of life.
- 60% - <75 % (49- <58 grades) indicate moderate quality of life.
- 75%- \geq 100% (58- \geq 78 grades) indicate high quality of life.

Instrument V: Brief COPE Strategies Scale: -

This scale was originally developed by *Carver et al., (1989)* and adapted by researchers. It was used to assess the coping strategies used by parents of children with thalassemia. This scale consisted of 28 items categorized into four subscales, active avoidance coping subscale (10 Items), problem-focused coping subscale (7items), religious/denial coping subscale (4 items), positive coping subscale (7 items). Answers were arranged in a 3-point likert format (1=never, 2= sometimes, and 3= always). Higher scores indicate high level of coping strategies.

Scoring system of COPE Strategies Scale was as follow:

- Less than 50% (< 42 grades) indicated low coping strategies.
- 50% - < 75% (42- < 63 grades) indicated moderate coping strategies.
- 75% – \geq 100% (63 – \geq 84 grades) score indicate high coping strategies

Methods:

The following procedures were followed in the execution of the study:

Administrative approval:

The director of Benha Specialized Hospital and all other authorized officials were given formal approval from the dean of Benha University's Faculty of Nursing to carry out the proposed study, including the title, goal, and instruments. A thorough explanation of the study's purpose was investigated.

Validity

The content validity of the data collection instruments used in this study were assessed to meet the requirements for accuracy and deservingness. Five professionals in the field of psychiatry and mental health nursing evaluated

the face and content validity. To make it easier for study participants to understand and collect data, various changes were made, such as rephrasing some sentences in the DASS scale, adjusting the Arabic and English translation of the COPE strategies scale, and rearranging some sentences at the quality of life scale.

Reliability:

The researchers used reliability to verify the internal consistency of the instruments, by giving the identical instruments to the same subjects in comparable circumstances on one or more occasions. Alpha Cronbach reliability was used to compare the findings of multiple tests (test-retest reliability). The DASS scale had a reliability of 0.91, the quality of life scale had a reliability of 0.93, and the COPE strategies scale had a reliability of 0.90.

Ethical considerations:

- Prior to data collection ethics committee approvals were received from Benha University's faculty of nursing (REC. PSY. NP47).
- Approvals from the studied parents were obtained prior to data collection and following an explanation of the study's purpose.
- Anonymity of the studied parents was assured as the filled questionnaire sheets were given a code number (not by names).
- The studied parents were ensured that questionnaire sheet will be used only for the purpose of the study and will be discarded at the end of this study.
- There are no detrimental consequences on participation from the study's methods.
- The study's parents were made aware of their freedom to leave the study at any moment and without explanation.

Pilot study:

To evaluate the instruments applicability, clarity, and dependability, a pilot study was carried out by testing the study on 10% of the total sample (10) parents of children with thalassemia. Later, this sample was removed from the study's actual sample.

The results of the pilot study:

- The instruments were clear and applicable; although several sentences were reworded and retranslated to make them more comprehensible for the parents under study.
- There were no difficulties identified to be interfering with the data collection process.
- After pilot study the instruments prepared for use.

Field work:

The actual field work of this current study was carried out within 3 months from the beginning of September 2024 to the end of November 2024. The researchers visited study setting for data collection two days (Saturday & Tuesday) per week at morning shift (10a.m-1p.m). An individual interview was conducted for every parent under study and the interview was held in a private, comfortable room in the blood disease department. The average time needed was around 20-30 minutes for quality of life and cope strategies scale and about 10-15 minutes for DASS scale as the researchers meet 4-5 parents per day. The researcher greeted the parents under study, introduced herself, explained the study's goal, obtained their verbal agreement to participate, and filled out the interview form and data collection instruments before the interview started.

Statistical analysis:

The Microsoft Excel Program and Statistical Package for Social Science (SPSS) version 20 computer program was used to perform the statistical analysis of the data. Data were presented using descriptive statistics in the form of frequencies and percentage of categorical data, the arithmetic mean (\bar{X}) and standard deviation (SD) for quantitative data. Qualitative variables were compared using chi square test (χ^2), P-value to test association between two variables and R- test to the correlation between the study variables.

Results:

Table (1) Reflects number and percentage distribution of the studied parents according to their socio-demographic characteristics. It reveals that less than half (46.0%) of the studied parents their age are ranged between 20-< 30 years with the Mean \pm SD of age is 31.5 ± 5.58 years. As well

as all and more than half of them are females and have secondary education (100.0% & 52.0% respectively). Concerning marital status, the vast majority (95.0%) of the studied parents are married. Furthermore, more than three quarters (80.0%) of them are not working. Also, more than half (57.0%) of them have 1 – 2 children and only (8%) of the studied parents mention they have other children suffering from thalassemia. In addition, three-quarters (75.0%) of them have not enough monthly income.

Table (2) Indicates number and percentage distribution of the affected children according to their clinical data. It reports that, more than half (52.0%) of the affected children have thalassemia from 1-< 3 years with the Mean \pm SD is 2.11 ± 1.34 years. As well, the vast majority (92.0%) of them have Beta thalassemia. Regarding previous hospitalization, more than three quarters (86.0%) of the affected children were previously hospitalized as more than half (53.5%) of them were admitted twice. In addition, more than three quarters (85.0%) of them suffer from disability because of thalassemia as the vast majority (90.6%) of them suffers from stunted growth. Furthermore, more than three-quarter (78.0%) of the affected children have family history for thalassemia as the majority (87.2%) of them are the first-degree relatives.

Figure (1) Represents percentage distribution of the studied parents according to total level of depression, anxiety and stress (DASS) scale. It shows that more than half of the studied parents have moderate levels of total depression, anxiety and stress (52.0%, 53.3% & 56.7% respectively).

Figure (2) Reflects percentage distribution of the studied parents according to total level of quality of life scale. It illustrates that nearly two-thirds (64.7%) of the studied parents have low level of total quality of life. As well, one-quarter (25.3%) of them have moderate level. While the minority (10.0%) of the studied parents have high level of total quality of life.

Figure (3) Explains percentage distribution of the studied parents according to total level of coping strategies scale. It shows that, more than half (57.3%) of the studied parents have low level of total coping strategies. As well, nearly one-third (30.7%) of them have moderate level. While, the minority (12.0%) of the studied parents have high level of total coping strategies.

Table (3) Clarifies relationship between the socio-demographic characteristics of the studied parents and the total level of DASS scale. It represents that, there are a highly statistically significant relation between the studied parents' total level of DASS scale and their socio-demographic characteristics as educational level, number of children and having other children suffer from the same disease at (P-value < 0.001**). As well as there are a statistically significant relation with their age, sex, occupation and family monthly income at (P-value < 0.05*).

Table (4) Shows relationship between the socio-demographic characteristics of the studied parents and the total level of quality of life scale. It explains that there is a highly statistically significant relation between the studied parents' total level of quality of life scale and their socio-demographic characteristics such as age, occupation, number of children do you have, having other children suffering from the same disease and family monthly income at (P-value < 0.001**). While there is no statistically significant relation with the sex, education and marital status at (P-value > 0.05).

Table (5) reveals relationship between the socio-demographic characteristics of the studied parents and the total level of coping strategies scale. It reports that, there are a highly statistically significant relation between the studied parents' total level of coping strategies scale with all items of their socio-demographic characteristics except marital status at (P-value < 0.001**).

Table (6) Illustrates relationship between the clinical data of the affected children and the total level of depression, anxiety and stress (DASS) scale among the studied parents. It reports that,

there are a highly statistically significant relation between the studied parents' total level of DASS scale with all items of clinical data of the affected children except type of thalassemia at (P-value < 0.001**).

Table (7) Illustrates relationship between the clinical data of the affected children and the total level of quality of life scale among the studied parents. It shows that, there are a highly statistically significant relation between the studied parents' total level of quality of life scale with all items of clinical data of the affected children except type of thalassemia at (P-value < 0.001**).

Table (8) Reflects relationship between the clinical data of the affected children and the total level of coping strategies scale among the studied parents. It reveals that, there are a highly statistically significant relation between the studied parents' total level of coping strategies scale with all items of clinical data of the affected children except and type of thalassemia and disability caused by thalassemia at (P-value < 0.001**).

Table (9) Explains correlation between total depression, anxiety and stress (DASS), total quality of life and total coping strategies' scales among the studied parents of children with thalassemia. It reveals that, there is a highly statistically significant negative correlation between total depression, anxiety and stress, total quality of life and total coping strategies' scales while there is a highly statistically significant positive correlation between total quality of life and total coping strategies' scales among the studied parents at (P-value 0.001**).

Table (1): Number and Percentage distribution of the studied parents according to their socio-demographic characteristics (n=100).

Socio-demographic characteristics	Studied parents (n=100)	
	No.	%
1) Age (in years)		
18 -< 20 Years	5	5.0
20 -< 30 Years	46	46.0
30 -< 40 Years	30	30.0
40 -< 50 Years	14	14.0
>50 Years	5	5.0
Mean ±SD	31.5 ± 5.58	
2)Sex		
Male	0	0.0
Female	100	100.0
3)Education Level		
Illiterate	4	4.0
Read and writes	8	8.0
Primary	8	8.0
Preparatory	15	15.0
Secondary (Diplome)	52	52.0
University	13	13.0
4)Marital status		
Married	95	95.0
Divorced	3	3.0
Widowed	2	2.0
5)Occupation		
Work	20	20.0
Not work	80	80.0
- If the answer is work, what is the type of work? (n=20)		
Employee at governmental sector	12	60.0
Employee at private sector	6	30.0
Free business	2	10.0
6)How many children do you have?		
1 – 2 Children	57	57.0
3 – 4 Children	38	38.0
5 – 6 Children	5	5.0
7)Do you have other children suffer from the same disease?		
Yes	8	8.0
No	92	92.0
- If yes. How many affected children do you have? (n=8).		
1-2 children	8	100.0
3-4 children	0	0.0
More than 4 children	0	0.0
2) Monthly income of the family		
Enough	17	17.0
Not enough	75	75.0
Enough and increase	8	8.0

Table (2): Number and percentage distribution of the affected children according to their clinical data (n=100).

Clinical data	Affected children (n=100)	
	No.	%
1)Duration of disease(in years)		
1-< 3 years	52	52.0
3-< 6 years	28	28.0
6-< 9 years	10	10.0
9 years or more	10	10.0
Mean ±SD		2.11 ± 1.34
2) Type of thalassemia of the affected children		
Beta thalassemia	92	92.0
Alpha thalassemia	8	8.0
3)Previous hospitalization		
Yes	86	86.0
No	14	14.0
- If yes. How many times of previous hospitalization? (n=86)		
One time	18	20.9
Two times	46	53.5
Three times	14	16.3
Four- or More times	8	9.3
4) Disability caused by Thalassemia to affected child?		
Yes	85	85.0
No	15	15.0
*If yes. What is the type of this disability? (n=85)		
Physical disability	48	56.5
Mental disability	6	7.1
Stunted growth	77	90.6
5)Family history for thalassemia		
Yes	78	78.0
No	22	22.0
-If yes. What is the degree of relationship?(n=78)		
First degree relatives	68	87.2
Second degree relatives	10	12.8

(* select more than one answer

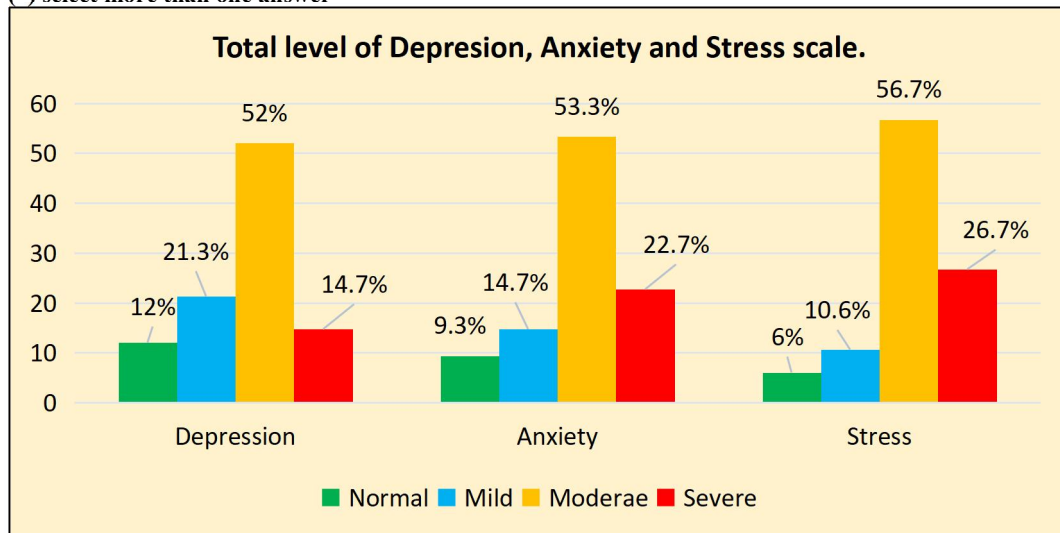


Figure (1): Percentage distribution of the studied parents according to total level of depression, anxiety and stress scale (n=100).

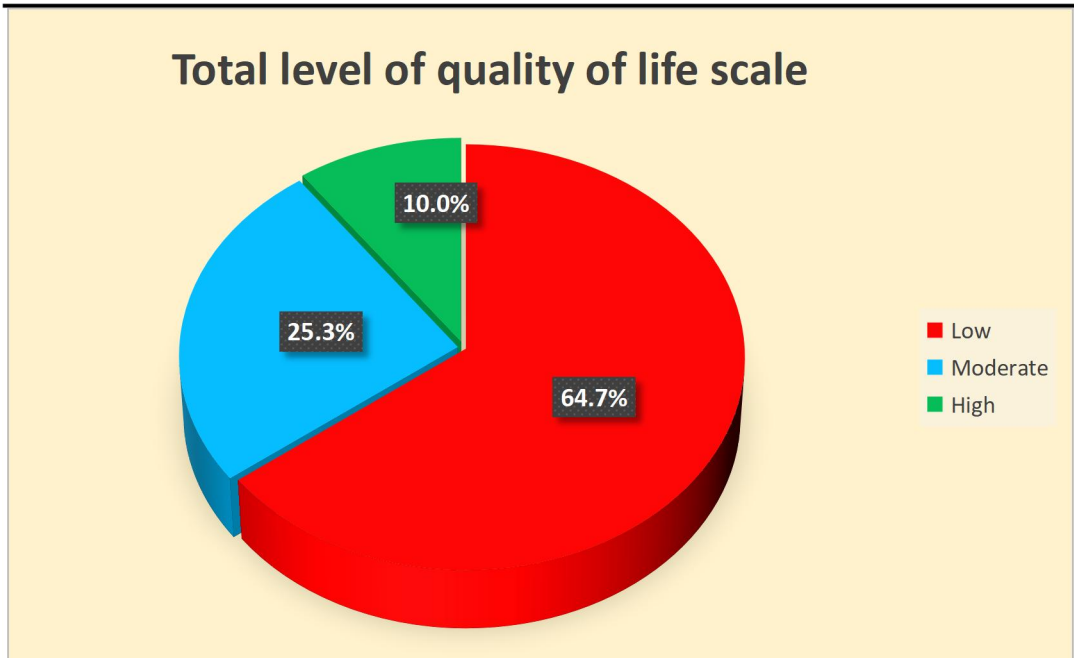


Figure (2): Percentage distribution of the studied parents according to total level of quality of life scale (n=100).

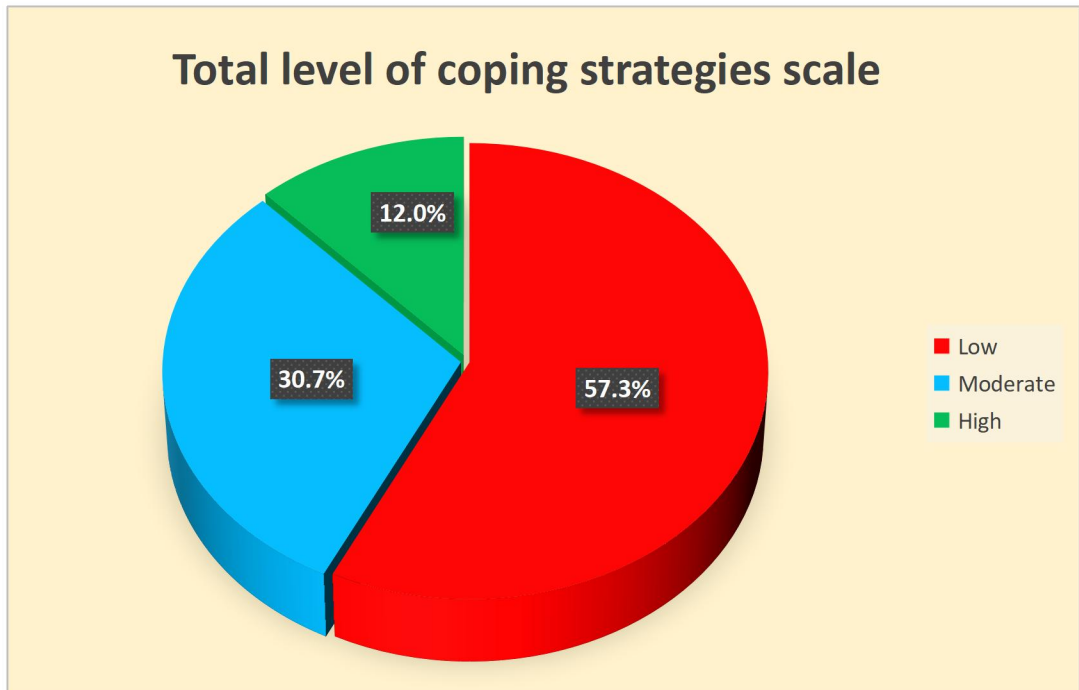


Figure (3): Percentage distribution of the studied parents according to total level of coping strategies scale (n=100).

Table (3): Relationship between the socio-demographic characteristics of the studied parents and the total level of depression, anxiety and stress scale (n=100).

Socio-demographic characteristics of the studied parents		Parents' total level of DASS scale (n=100)								X ²	P-Value
		Normal (n=7)		Mild (n=11)		Moderate (n=52)		Severe (n=30)			
		No.	%	No.	%	No.	%	No.	%		
Age (in years)	18-< 20 Years	1	14.3	4	36.4	0	0.0	0	0.0	13.97	<0.05*
	20-< 30 Years	5	71.4	5	45.4	31	59.6	5	16.7		
	30-< 40 Years	1	14.3	2	18.2	19	36.5	8	26.7		
	40-< 50 Years	0	0.0	0	0.0	2	38.5	12	40.0		
	> 50 Years	0	0.0	0	0.0	0	0.0	5	16.7		
Sex	Male	0	0.0	0	0.0	0	0.0	0	0.0	12.33	<0.05*
	Female	7	100	11	100	52	100	30	100		
Educational level	Illiterate	0	0.0	0	0.0	0	0.0	4	13.3	27.63	<0.001**
	Read and writes	0	0.0	0	0.0	0	0.0	8	26.7		
	Primary	0	0.0	0	0.0	0	0.0	8	26.7		
	Preparatory	0	0.0	0	0.0	7	13.5	8	26.7		
	Secondary (Diplome)	0	0.0	5	45.5	45	86.5	2	6.7		
University	7	100	6	54.5	0	0.0	0	0.0			
Marital status	Married	7	100	11	100	50	96.2	27	90.0	5.937	>0.05
	Divorced	0	0.0	0	0.0	2	3.8	1	3.3		
	Widowed	0	0.0	0	0.0	0	0.0	2	6.7		
Occupation	Work	0	0.0	2	18.2	5	9.6	13	43.3	8.570	<0.05*
	Not work	7	100	9	81.8	47	90.4	17	56.7		
Number of children do you have	1 – 2	7	100	9	81.8	24	46.2	17	56.7	18.57	<0.001**
	3 – 4	0	0.0	2	18.2	28	53.8	8	26.7		
	5 – 6	0	0.0	0	0.0	0	0.0	5	16.7		
Have other children suffer from the same disease	Yes	0	0.0	0	0.0	0	0.0	8	26.7	25.93	<0.001**
	No	7	100	11	100	52	100	22	73.3		
Monthly income of the family	Enough	1	14.3	9	81.8	7	13.5	0	0.0	15.74	<0.05*
	Not enough	0	0.0	0	0.0	45	86.5	30	100		
	Enough and save	6	85.7	2	18.2	0	0.0	0	0.0		

X² = Chi square test.

n.s No significant at p > 0.05.

*Significant at p < 0.05.

**highly significant at p < 0.001.

Table (4): Relationship between the socio-demographic characteristics of the studied parents and the total level of quality of life scale (n=100).

Socio-demographic characteristics of the studied parents		Parents total level of quality of life scale (n=100)						X ²	P-Value
		High (n=12)		Moderate (n=28)		Low (n=60)			
		No.	%	No.	%	No.	%		
Age (in years)	18-< 20 Years	0	0.0	0	0.0	0	0.0	14.94	<0.001**
	20-< 30 Years	10	66.7	15	50.0	21	38.2		
	30-< 40 Years	2	13.3	10	33.3	18	32.7		
	40-< 50 Years	0	0.0	3	10.0	11	20.0		
	>50 Years	0	0.0	0	0.0	10	9.1		
Sex	Male	0	0.0	0	0.0	0	0.0	13.87	>0.05
	Female	12	100	28	100	60	100		
Educational level	Illiterate	0	0.0	0	0.0	4	7.3	19.37	>0.05
	Read and writes	0	0.0	0	0.0	8	14.5		
	Primary	0	0.0	0	0.0	8	14.5		
	Preparatory	0	0.0	3	16.7	10	18.2		
	Secondary (Diplome)	2	13.3	25	83.3	25	45.5		
University	10	86.7	0	0.0	5	9.1			
Marital status	Married	12	100	27	90.0	53	87.4	10.09	>0.05
	Divorced	0	0.0	1	10.0	2	3.6		
	Widowed	0	0.0	0	0.0	5	9.0		
Occupation	Work	0	0.0	3	16.7	25	42.5	14.04	<0.001**
	Not work	12	100	25	83.3	35	58.5		
Number of children do you have	1 – 2	12	100	14	50.0	28	50.9	15.26	<0.001**
	3 – 4	0	0.0	14	50.0	22	40.0		
	5 – 6	0	0.0	0	0.0	10	9.1		
Have other children suffer from the same disease	Yes	0	0.0	0	0.0	13	14.5	13.77	<0.001**
	No	12	100	28	100.0	47	85.5		
Monthly income of the family	Enough	7	46.7	8	33.3	0	0.0	14.33	<0.001**
	Not enough	0	0.0	20	66.7	60	100		
	Enough and save	5	53.3	0	0.0	0	0.0		

X²= Chi square test

n.s No significant at p > 0.05.

**highly significant at p < 0.001.

Table (5): Relationship between the socio-demographic characteristics of the studied parents and the total level of coping strategies scale (n=100).

Socio-demographic characteristics of the studied parents		Parents total level of coping strategies scale (n=100)						X ²	P-Value
		High (n=15)		Moderate (n=30)		Low (n=55)			
		No.	%	No.	%	No.	%		
Age (in years)	18-< 20 Years	3	20.0	2	6.7	0	0.0	18.96	<0.001**
	20-< 30 Years	10	66.7	15	50.0	21	38.2		
	30-< 40 Years	2	13.3	10	33.3	18	32.7		
	40-< 50 Years	0	0.0	3	10.0	11	20.0		
	>50 Years	0	0.0	0	0.0	5	9.1		
Sex	Male	0	0.0	0	0.0	0	0.0	14.45	<0.001**
	Female	15	100	30	100	55	100		
Educational level	Illiterate	0	0.0	0	0.0	4	7.3	21.37	<0.001**
	Read and writes	0	0.0	0	0.0	8	14.5		
	Primary	0	0.0	0	0.0	8	14.5		
	Preparatory	0	0.0	5	16.7	10	18.2		
	Secondary (Diplome)	2	13.3	25	83.3	25	45.5		
	University	13	86.7	0	0.0	0	0.0		
Marital status	Married	15	100	27	90.0	53	96.4	11.07	>0.05
	Divorced	0	0.0	1	3.3	2	3.6		
	Widowed	0	0.0	2	6.7	0	0.0		
Occupation	Work	0	0.0	5	16.7	25	45.5	18.01	<0.001**
	Not work	15	100	25	83.3	30	55.5		
Number of children do you have	1 – 2	15	100	14	46.7	28	50.9	16.22	<0.001**
	3 – 4	0	0.0	16	53.3	22	40.0		
	5 – 6	0	0.0	0	0.0	5	9.1		
Have other children suffer from the same disease	Yes	0	0.0	0	0.0	8	14.5	15.15	<0.001**
	No	15	100	30	100.0	47	85.5		
Monthly income of the family	Enough	7	46.7	10	33.3	0	0.0	17.33	<0.001**
	Not enough	0	0.0	20	66.7	55	100		
	Enough and save	8	53.3	0	0.0	0	0.0		

X²= Chi square test

n.s No significant at p > 0.05.

**highly significant at p < 0.001.

Table (6): Relationship between the clinical data of the affected children and the total level of depression, anxiety and stress (DASS) scale among the studied parents (n=100).

Clinical data of the affected children		parents' total level of DASS scale (n=100)								X ²	P-Value
		Normal (n=7)		Mild (n=11)		Moderate (n=52)		Severe (n=30)			
		No.	%	No.	%	No.	%	No.	%		
Duration of disease	1-< 3 years	2	28.6	5	45.5	35	67.3	10	33.3	24.71	<0.001**
	3-< 6 years	3	42.8	2	18.2	15	28.8	8	26.7		
	6-< 9 years	2	28.6	4	36.4	2	3.9	2	6.7		
	9 years or more	0	0.0	0	0.0	0	0	10	33.3		
Type of thalassemia that the child suffer from	Beta thalassemia	5	71.4	10	90.9	49	94.2	28	93.3	4.558	>0.05
	Alpha thalassemia	2	28.6	1	9.1	3	5.8	2	6.7		
Previous hospitalization	Yes	0	0.0	6	54.5	50	96.2	30	100.0	23.97	<0.001**
	No	7	100.0	5	45.5	2	3.8	0	0.0		
Disability caused by thalassemia	Yes	0	0.0	4	36.4	51	98.1	30	100.0	30.01	<0.001**
	No	7	100.0	7	63.6	1	1.9	0	0.0		
Family history for thalassemia	Yes	0	0.0	0	0.0	48	92.3	30	100.0	21.74	<0.001**
	No	7	100.0	11	100.0	4	7.7	0	0.00		

X² = Chi square test

n.s No significant at p > 0.05.

**highly significant at p < 0.001.

Table (7): Relationship between the clinical data of the affected children and the total level of quality of life scale among the studied parents (n=100).

Clinical data of the affected children		Parents total level of quality of life scale (n=100)						X ²	P-Value
		High (n=12)		Moderate (n=28)		Low (n=60)			
		No.	%	No.	%	No.	%		
Duration of disease	1-< 3 years	8	73.3	16	53.3	25	45.5	13.83	<0.001**
	3-< 6 years	4	26.7	10	33.3	19	25.5		
	6-< 9 years	0	0.0	4	6.7	8	14.5		
	9 years or more	0	0.0	0	0.0	8	14.5		
Type of thalassemia that your child suffers from	Beta thalassemia	9	80.0	28	93.3	52	90.5	3.33	>0.05
	Alpha thalassemia	3	20.0	0	0.0	8	9.5		
Previous hospitalization	Yes	1	6.7	28	100.0	60	100.0	22.55	<0.001**
	No	11	93.3	0	0.0	0	0.0		
Disability caused by thalassemia	Yes	0	0.0	28	100.0	60	100.0	24.40	<0.001**
	No	12	100.0	0	0.0	0	0.0		
Family history for thalassemia	Yes	10	66.7	14	50.0	52	90.5	21.31	<0.001**
	No	2	33.3	14	50.0	8	9.5		

X² = Chi square test

n.s No significant at p > 0.05.

**highly significant at p < 0.001.

Table (8): Relationship between the clinical data of the affected children and the total level of coping strategies scale among the studied parents (n=100).

clinical data of the affected children		Parents total level of coping strategies scale (n=100)						X ²	P-Value
		High (n=15)		Moderate (n=30)		Low (n=55)			
		No.	%	No.	%	No.	%		
Duration of disease	1-< 3 years	11	73.3	16	53.3	25	45.5	15.93	<0.001**
	3-< 6 years	4	26.7	10	33.3	14	25.5		
	6-< 9 years	0	0.0	2	6.7	8	14.5		
	9 years or more	0	0.0	2	6.7	8	14.5		
Type of thalassemia that your child suffers from	Beta thalassemia	12	80.0	28	93.3	52	94.5	4.501	>0.05
	Alpha thalassemia	3	20.0	2	6.7	3	5.5		
Previous hospitalization	Yes	1	6.7	30	100.0	55	100.0	25.07	<0.001**
	No	14	93.3	0	0.0	0	0.0		
Disability caused by thalassemia	Yes	0	0.0	30	100.0	55	100.0	27.80	>0.05
	No	15	100.0	0	0.0	0	0.0		
Family history for thalassemia	Yes	10	66.7	16	53.3	52	94.5	22.71	<0.001**
	No	5	33.3	14	46.7	3	5.5		

X² = Chi square test

n.s No significant at p > 0.05.

**highly significant at p < 0.001.

Table (9): Correlation between total depression, anxiety and stress (DASS), total quality of life and total coping strategies scales among the studied parents of children with thalassemia (n= 100).

Variables	R.	P.value
Total DASS and total coping strategies	-0.324	0.001**
Total DASS and total quality of life	-0.543	0.001**
Total quality of life and total coping strategies	0.645	0.001**

(**) highly statistically significant at p<0.01.

Discussion:

Thalassemia is a chronic blood disorder that usually needs frequent hospital stays and routine blood transfusions to be controlled. This complicated, prolonged, and unpleasant treatment plan frequently has a detrimental impact on the kid's psychological and physical well-being. Additionally, caregiving obligations during treatment had a detrimental impact on the psychological health of who parenting kids with thalassemia. In addition, they experience anxiety, worry regarding their child's future health, and financial difficulties because of the lifetime medical therapy. All of these have a detrimental impact on their coping mechanisms for their children's condition as well as all aspects of their quality of life (Hesham et al., 2021 & Ibrahim et

al., 2022). Therefore, the researchers implemented this research because of its importance to identify challenges facing parents of thalassemia children.

Concerning the socio-demographic characteristics of parents under study, the current study's findings revealed this, just under half of the parents in the study were between the ages 20-< 30 years. According to the researchers, this result may be because of the early marriage that considered the most common tradition in rural communities in Egypt. The findings of this research were like those of Bakthavatchalam & Vetrisevi, (2021) investigations who disclosed that the parents in their study were between the ages of 20 and 30. However, the findings of this study were in conflict with those of a study

conducted in 2021 by **Alizadeh et al.**, which found that the ages of the parents under observation ranged from 45 to 50 years.

In terms of sex, the results of the current study clarified that all the parents under investigation were female. According to the researchers, this finding might be because of women are the direct support of their children and assume all responsibilities toward their children all the time especially disease responsibilities and follow up. This outcome was consistent with the research of **Mohiuddin et al., (2021)**, which revealed that every member of his sample was female.

In terms of educational attainment, the current study's findings clarified that over 50% of the parents under investigation had a diploma. According to the researchers, this may have resulted from the widespread perception in Egypt's rural areas that girls' marriage is preferable to their education. The findings of this survey were similar to those of a study conducted in 2021 by **Hisam et al.**, which found that over half of the parents of the study had completed secondary school.

According to the current study's findings, almost all the parents under investigation were married. According to the researchers, this could be due to marriage in rural areas at a young age. Additionally, they view marriage as chaste and safeguarding for women. This outcome aligned with the research conducted by **Monem et al., (2021)**, which demonstrated that nearly all of parents under study were married.

Concerning occupation, the research findings showed that over three quarters of the parents under investigation were not working. According to the researchers, this finding might be because the greater percentage of the population under study came from rural areas, where women focused more on their sick children and gave less attention to working outside the home for pay. This finding agreed with a research by **El Sayed & Ahmad (2022)** indicated that almost three-quarters of the parents they surveyed were housewives.

According to the research's findings over half of the parents in this research had one or two children. Furthermore, the minority of them had other children suffer from thalassemia. Similarly, **Ibrahim et al., (2022)** demonstrated that just 8%

of the participants had additional children complaining of thalassemia, whereas over half had children aged one to three. Regarding family income of the studied parents, the present study findings revealed that three-quarters of the studied parents said that their monthly income was not enough. According to the researchers, this result could be due to financial requirements for treatment and follow up. This finding aligned with a study conducted by **Septyana et al., (2022)** which showed almost three-quarters of the parents being assessed had inadequate incomes. However, this conclusion contradicted the findings of **Biabani et al., (2022)**, who found that most of the moms in their study possessed intermediate family incomes.

According to the children's clinical data, almost half of the afflicted children had thalassemia between the ages of one and three. Moreover, the vast majority of them have Beta thalassemia. Also, more than three quarters of the affected children were previously hospitalized and more than half of them were admitted twice. According to the researchers, these results might be due to thalassemia is chronic illness that causes anemia, pallor, fatigue and stunted growth, so the affected children need blood transfusions to give their body healthy hemoglobin to support their growth and development which require frequent hospitalization. This contradicted the findings of **Mohamed & Hassan (2021)** who presented that nearly three-quarter of children under study get Beta thalassemia from three years and admitted frequently to hospital.

Moreover, more than three quarters of the affected children said that they had disability as a complication from thalassemia and the vast majority of them had stunted growth. Furthermore, more than three-quarters of the affected children had family history for thalassemia as the majority of them were first-degree relatives. According to the researchers, these results could be due to many research and studies reported that thalassemia is genetic disease that runs in first degree relatives more than second degree relatives. These findings coincided with the research of **El Sayed and Ahmed (2022)**, who showed that over three-quarters of the children in their study had a first-degree family history and experienced stunted growth due to thalassemia.

According to the current study's findings, over half of the parents under investigation showed moderate levels of total depression, anxiety, and stress. The researchers suggested these results might be due to the parents of children had many difficulties in caring of their children with thalassemia and frequent worries from their children disease and its complications later and fear of loss their children at any time, other than bearing financial pressures for treatment. The parents experienced emotional strains including guilt or shame, depression, anxiety, and stress because of all of these. Furthermore, they encounter more difficulties that necessitate their involvement in exceptional care, providing routines and specific assistance and services during hospitalization. These findings aligned with a study by **Karakul et al., (2022)** that found over half of the parents in the study experienced moderate psychological problems (stress, anxiety, and depression).

Approximately two-thirds of the parents under study had a bad overall quality of life. According to the researchers, this might be because of financial pressure of the parents were associated with significantly poorer quality of life in areas vitality and emotional well-being. Anxiety, stress, and depression in parents can have a detrimental impact on the care of a child with a chronic illness as well as the general mental health and well-being of the parents under study and their quality of life. These findings coincided with those of a study conducted by **Lisanti et al., in 2022**, which demonstrated that almost two-thirds of the parents under study exhibited poor overall quality of life. The study by **Lee et al., (2021)**, however, showed that three-quarters of his parents had an excellent quality of life, which contrasted with these findings.

As far as overall strategies for coping go, over half of the parents in the study had total low levels of coping. According to the researchers, this might be due to parental stress that was significantly related to other causes that may be due to ambiguity, lack of clarity and lack of information. Also, other causes may be due to frequent hospitalization, burden of caring for other siblings as well as caring for their sick child. All of these have a detrimental impact on their coping mechanisms for dealing with their kids' illnesses. These outcomes agreed with a study by

Biswas et al., (2022) significantly indicated that over half of the parents in the study showed low levels of overall strategies for coping. However, these findings contradicted the findings of the **Abhilasha et al., (2021)** study, which found that fewer than three-quarters of the parents in the study had a greater level of overall strategies for coping.

Regarding the association between the sociodemographic traits of the parents under investigation and their overall DASS score, the current study's findings demonstrated a highly statistically significant relationship between the parents' sociodemographic traits—such as educational attainment, the number of children they had, and whether having other children had the same illness—and their overall DASS score. The researchers hypothesize that this outcome might be the result of parents from higher socioeconomic backgrounds having greater access to health information about illnesses, better housing, better diet, and better medical care, all of which enhanced their psychological well-being and coping mechanisms. This outcome was consistent with a study by **Shafie et al., (2021)** that showed a substantial positive correlation between the parents' demographic information, including their level of education, the number of children they had, and whether additional children had the same illness, and their overall DASS score.

Regarding the association between the sociodemographic traits of the parents under study and their overall quality of life score, these factors were found to be highly statistically significant: age, education, number of children, having other children with the same illness, and family income. According to the researchers, this might be because of more than half of parents under study had a low income and only completed secondary school. Additionally, families may find it difficult to manage their affected child's chronic disease, which exposes them to serious declines in their biological, psychological, and social lives, resulting in a reduced quality of life. They also face the weight of thalassemia diagnosis and its stressful aspects. These results were gone in agreement with the study of **Lisanti et al., (2022)**, which showed that there was a highly statistically significant relation between the studied parents' total quality of life and their age, age, education and monthly income.

Regarding the relation between the sociodemographic features of the parents under study and their overall level of coping strategies, the results of this study showed that, with the exception of marital status, there was a highly statistically significant relation between the parents' total level of coping strategies and all of their sociodemographic characteristics. The researchers hypothesized that, these outcomes could be because mothers have a better ability to deal with the situation and greater flexibility to adopt coping strategies with good demographic factors. In addition, most of them aged from 20-30 years, less young and females and they experienced wide range of emotions and resistance in the adaptation process, they result from the child condition, the possibility of death and uncertainty for family structure, so, parents' coping abilities affected.

These findings were comparable to those of the study by **Kermansaravi et al., (2021)** which concluded there was a highly statistically significant connection between demographic data of the participants and overall coping, however, research by **Biswas et al., (2022)** disputed this finding, explaining that there was no significant correlation between the parents' total score of methods of coping and their demographic information.

Regarding the relation between the clinical information of the impacted children and the total DASS score of the parents under study, there was a highly statistically significant correlation between the parents' DASS score and every clinical data item of the impacted children, except for the thalassemia type. According to the researchers, this might be due to, the medical and current history of thalassemia and its impact on the children health play an important and vital role on level of stress, anxiety and depression among parents toward their kids. This finding was consistent with a study by **Andriani et al., (2022)** that found a highly statistically significant connection between the clinical history of the impacted children and the parents' overall levels of stress, anxiety, and depression. Additionally, this result agreed with a study by **Rayhan et al., (2022)** that indicated a strong association between the parents' DASS and the clinical history of thalassemia in offspring.

Regarding the relation between the clinical information of the impacted children and the overall quality of life score of the parents under study this research indicated that all clinical data items of the affected children, except for the type of thalassemia, showed a highly statistically significant relation with the parents' overall quality of life score. According to the researchers, this could be due to most of the affected children had disease from 1-< 3 years, and hospitalized frequently which made their parents didn't have the time to perform activities of daily living because of care burden toward their children. These outcomes agreed with a study by **Khoshhal et al., (2021)** that found a highly significant connection between the clinical data of affected children and the parents' overall quality of life.

Concerning the relationship between the total level of coping strategies scale among the parents under study and the clinical data of the affected children the study showed a highly statistically significant relationship with all items of the clinical data of the affected children, apart from the type of thalassemia and the disability brought on by it. According to the researchers, this result might be due to the clinical history of thalassemia among children might lead to social, financial burden, dissatisfaction, mental upset of their parents that hampering adaptation of their coping strategies and patterns. This finding was comparable to that of a study by **Biswas et al., (2022)**, which shown a highly significant relation between the age at which children were diagnosed with thalassemia, the duration and complications of the disease, and the parents' overall coping mechanisms.

The current study findings revealed that, there was a highly statistically significant negative correlation between total depression, anxiety and stress, total quality of life and total coping strategies' scales while there was a highly statistically significant positive correlation between total quality of life and total coping strategies' scales among the studied parents. According to the researchers, this might be due to failure of those parents in adaptation to their child illness and use effective coping strategies to cope with it led to increase level of parents' psychological distress such as depression, anxiety and stress due to burden from their children or lack of support, so impaired their quality of life.

This result was in the same line with Lal et al., (2022) who reflected that a highly statistically significant negative correlation between total psychological problems, total quality of life and total coping strategies.

Furthermore, there was a highly statistically significant positive correlation between total quality of life and total coping strategies among the studied parents. According to the researchers, this might be due to low level of coping with their children condition and not understanding of the disease, frequent follow-up and admission to hospital affecting to all domains of quality of life. These results were in accordance with the study of Othman et al., (2022) which represented that there was a highly statistically significant positive correlation between total quality of life and total coping strategies among the studied parents.

Conclusion:

Based on the findings of this research the researchers concluded that; there was a strong relationship between psychological problems, quality of life and coping strategies among the studied parents as over half of them had moderate level of total psychological problems (depression, anxiety and stress). Also, nearly two thirds of them had a low level of total quality of life and more than half of them had low level of total coping strategies. Furthermore, there was a highly statistically significant negative correlation between total depression, anxiety and stress, total quality of life and total coping strategies scales. While there was a highly statistically significant positive correlation between total quality of life and total coping strategies scales among the studied parents.

Recommendations:

The following suggestions are made considering the results of this study:

- Application of psycho-educational nursing program for all parents of children with thalassemia to improve their quality of life and, consequently, their coping mechanisms and lessen psychological issues.
- Implementation of counseling program to all units' staff to raise awareness and promote the bio psychological approach to the disease.

- Work brochures for all available parents of children with thalassemia to increase their knowledge about the disease, how to treat it, emergence of any complication, how to deal with child and his psychological condition.

Further research: To generalize the findings, the study should be repeated with a bigger sample in various correctional settings.

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References:

- Abhilasha, T., Deepika, I., Navjot Kaur, P., Das, K., Sharma, R. & Trehan, A. (2021): Health promotion practices and coping behaviors among caregivers of children suffering from thalassemia major. *IP International Journal of Medical Pediatrics and Oncology*, 7(3):125–133.
- Abu Shosha, G. M., Al-Kalaldehy, M. & Shoqirat, N. (2021). Nurses' experiences of psychosocial care needs of children with thalassaemia and their families in Jordan: A phenomenological study. *Nursing Open journal*, 20;9(6):2858–2866. doi: 10.1002/nop2.992.
- Alizadeh, M., Chehrzad, M., Mirzaee, M. & Leyli, E. (2021): Caregiver burden and related factors in parents of children with Thalassemia. *Journal of Advanced Pharmacy Education & Research*, 9(S2).
- Andriani, R., Nurhaeni, N. & Safariyah, E. (2022): Mother's Fortitude in Taking Care of Children with Thalassemia in Indonesia. *KnE Life Sciences journal*, 574-584.
- Apidechkul, T., Yeemard, F., Chomchoei, C., Upala, P., & Tamornpark, P. (2022): Epidemiology of thalassemia among the hill tribe population in Thailand. *Plos one journal*, 11;16(2). <https://doi.org/10.1371/journal.pone.0246736>.

- Baghersalimi, A., Darbandi, B., Kazemnezhad, E., Kamran, Z., Ahmad, M. & Rezasefat, A. (2021): Evaluation of self-efficacy in children and adolescents with thalassemia major. *Journal of Pediatric Hematology/Oncology*; 43(6):e754-e8.
- Bakthavatchalam, P. & Vetrivelvi, P. (2021): assessment of quality of life among mothers of children with thalassemia. *Int. J. of Adv. Res.* 7, 1074-1083, (ISSN 2320-5407).
- Biabani, A., Kermansaravi, F. & Navidian, A. (2022): The Effect of Group Education on Adaptive Behaviors and Caregiver Burden in Mothers of Children with Thalassemia Major: A Trial Clinical Study. *Medical-Surgical Nursing Journal*, 9(1).
- Biswas, D., Lo, S., Sarkar, P., Mondal, T., Haldar, D. & Saha, I. (2022): Coping styles in parents of children with Thalassemia in West Bengal. *Indian Journal of Social Psychiatry*, 38(2), 131.
- Budimir, S., Probst, T., & Pieh, C. (2021): Coping strategies and mental health during COVID-19 lockdown. *Journal of Mental Health* (Abingdon, England), 30 (2), 156–163. <https://doi.org/10.1080/09638237.2021.1875412>.
- Carver, C., Scheier, M. & Weintraub, J. (1989): Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*; 56(2), 267.
- El Sayed, I., & Ahmed, H. (2022): Effect of Nursing Care Protocol on Nurses' Competency regards Children with Thalassemia. *International journal of novel research in health care and nursing*, 9(2), 40-85.
- Hesham, A., Beshar, R., & Khalifa, A. (2021). Screening for b-thalassemia carrier among students in A secondary School in Diarb Negm, Sharkia. *Zagazig University Medical Journal*, 24(1), 72-79.
- Ibrahim, E., Al Nagar, M., Eita, L. & Alam, F. (2022): Relationship between Quality of Life and Social Support among Mothers of Children with Thalassemia. *International Journal of Novel Research in Healthcare and Nursing*, 8(2) Pp: (75-87).
- Karakul, A., Oymak, Y. & Karapinar, T. (2022). The Experiences of mothers of Children with Thalassemia Major in Turkey: *International Journal of Caring Sciences*, 15 (1) 424-434.
- Kermansaravi, F., Najafi, F. & Rigi, S. (2021): Coping behaviors in parents of children with Thalassemia major. *Medical-Surgical Nursing Journal*, 7(1).
- Khoshhal, S., Al-Harbil, K., Al-Mozainy, I. & Al-Ghamdi, S. (2021): Assessment of quality of life among parents of children with thalassemia using WHOQOL-BREF: a cross-sectional study from Northwest Saudi Arabia, 1Pediatric Team, Department of Pediatrics, Faculty of Medicine, Taibah University, Al-Madinah Al-Munawarah, Saudi Arabia;16 ,233-239.
- Lal, K., Bala, N. & Singh, G. (2022): Stress, Anxiety, Depression and Burden in caregivers of Beta thalassemia Major. *European Journal of Molecular & Clinical Medicine*, 9(6), 1000-1006.
- Lee, M.H., Matthews, A.K. & Park, C. (2021): Determinants of health-related quality of life among mothers of children with thalassemia. *J Pediatr Nurs*, 44: 1-8.
- Lisanti, A., Golfenshtein, N. & Medoff-Cooper, B. (2022): The pediatric cardiac intensive care unit parental stress model. *Advances in Nursing Science*, 40(4):319–336.
- Lovibond, S., & Lovibond, P. (1995): The structure of negative emotional states: comparison of the Depression, anxiety and Stress Scale (DASS) with the Beck Depression and Anxiety Inventories, *Behavioral Research Therapy*, 33(3):335-43. Doi: 10.1016/0005-7967(94)00075-u.
- Merriam-Webster, (2022): Merriam-Webster dictionary, definition of thalassemia.

- Available at <https://www.merriam-webster.com/dictionary/thalassemia>. Accessed on 9 Jun. at 5 pm.
- Miller, V., Newcombe, J., Radovich, P., Johnston, F., Medina, E., Jr. & Nelson, A. (2021): The healing hearts at home @Mobile application usability and influence on parental perceived stress: A pilot study. *International Journal of E-Health and Medical Communications (IJEHMC)*; 12(3), 90–105.
- Mohamed, A., & Hassan, E. (2021): Effect of Empowerment Program on Self-efficacy among Children with Thalassemia. *Indian Journal of Psychiatry*, 66(Suppl 3), S522.
- Mohiuddin, Z., Haque, M. & Ahmad, S. (2021): Parenting Stress of Mothers Having Children with Thalassemia. *Journal of Preventive and Social Medicine*, 38(2), 22-29.
- Monem, A. A., Shehata, S., Elsayed, M. & Ayad, A. (2021). Descriptive clinical study of children with beta-thalassemia at Damanhour Medical National Institute. *Alexandria Journal of Pediatrics*, 34(1), 67.
- Othman, A., Ghani, M. S. A. A., Taib, F. & Mohamad, N. (2022). Psychological distress and coping strategies among the caretakers of children with transfusion-dependent thalassemia. *frontiers in Pediatrics*, 10, 941202. doi: 10.3389/fped.2022.941202.
- Rayhan, G., Nurunnabi, M., Kabir, S. & Alam, B. (2022): Mental Stress of Parents Having Thalassemic Children. *KYAMC Journal*, 13(2), 102-107.
- Septyana, G., Mardhiyah, A. & Widianti, E. (2022): The mental burden of parents of children with Thalassemia. *Jurnal Keperawatan Padjadjaran*, 7(1), 94-102.
- Shafie, A., Chhabra, K., Wong, Y., Mohammed, S., Ibrahim, M. & Alias, H. (2021): Health-related quality of life among children with transfusion-dependent thalassemia: a cross-sectional study in Malaysia. *Health and quality of life outcomes*, 18(1), 1-11.
- World Health Organization (WHO), (1996): WHOQOL: Measuring quality of life. Available at. <https://www.who.int/healthinfo/survey/whoqol>.