

Relationship between Quality of Life and Social Support among Mothers of Children with Thalassemia

¹Eman S. Ibrahim., ²Mona A. Al Nagar., ³Lamiaa H. Eita., ⁴Faten H. Alam

¹Clinical Instructor of Psychiatric and Mental Health Nursing, Faculty of Nursing, Menoufia University, Egypt

²Professor of Psychiatric and Mental Health Nursing, Faculty of Nursing, Menoufia University, Egypt

³Assistant Professor of Psychiatric and Mental Health Nursing, Faculty of Nursing, Menoufia University, Egypt

⁴Assistant Professor of Psychiatric and Mental Health Nursing, Faculty of Nursing, Menoufia University, Egypt

Corresponding authors: Emansobhy5657@gmail.com, Lamy20012002@yahoo.com

Abstract: Mothers of children with thalassemia are often confronted with stressful life associated with the illness of the child as well as other related stressors. Consequently, these mothers' quality of life is impacted. Previous researches have shown that perceived social support is a part of coping strategies that can help mothers to cope with their stressful life and increase their health status. The purpose of this study was to explore the relationship between quality of life and social support among mothers of children with thalassemia. **Design:** A descriptive correlational design was utilized. **Setting:** The study was conducted at pediatric department in University units at the Menoufia University Hospital at Shebin El-kom city, Menoufia Governorate, Egypt. **Sample:** A Convenient sample of 87 mothers of children with thalassemia who met inclusion and exclusion criteria were selected: **Three instruments were used to collect data:** Structured Interview Questionnaire to assess socio demographic characteristics of the studied subjects, a structured interview questionnaire, Quality of life Scale and Perceived social support scale. **Results:** The findings of this study revealed that less than half of studied mothers (42.4) have average and bad quality of life and more than one third of mothers (37.60%) have moderate social support. There was a positive correlation between total quality of life and total social support among the studied mothers. The study concluded that there was a positive correlation between total quality of life and total social support among the studied mothers. It was recommended that, an educational program should be given for the mothers of children with thalassemia to maintain their psychological and physical health, as well as improve their quality of life as a whole.

Keywords: Thalassemia, quality of life, social support, Mother.

1. INTRODUCTION

Thalassemia is a group of genetic disorders characterized by quantitative defects in globin chain synthesis with subsequent absence of hemoglobin production leading to variable degree of microcytic anemia. The Beta-thalassemia is inherited in an autosomal recessive manner. The parents of an affected child are obligate heterozygotes and carry a single copy of a disease causing beta globin gene mutation. Beta-thalassemia major is a chronic disorder of blood, having an extensive impact on life and presenting with hemolytic anemia, growth retardation, hepato-splenomegaly and skeletal abnormalities. It often requires regular blood transfusions, iron chelation therapy and sometimes splenectomy for its management. Thus, the therapeutic regime is complex, lifelong and inconvenient, requiring repeated hospitalizations and blood transfusions, which often affects the child's physical and mental health negatively [1].

Psychological well-being among mothers of children with Thalassemia was affected because of caregiving responsibilities during the treatment process. Besides that, they feel worried, uncertainty about their child's health status in the future and also financial issues arise during the lifelong treatment. Furthermore, mothers showed the symptoms of anxiety and depression what make these mothers need more emotional and psychological support as they play a more active role in the caregiving process. Moreover, the level of quality of life among mothers is lower than fathers because of their frequently involvement in the physical and psychological problem of children with thalassemia and have a higher rate of psychiatric problem [2].

The quality of life of mothers of children with thalassemia is affected by the long time. As they the main caregivers, encounter numerous challenges in coping with various and complicated problems due to the disease of their children. Mothers reported feelings of anxiety, distress and hopelessness regarding the condition of their children, especially blood change and disease progress. Also they have concern regarding their children's bone deformities, short stature, poor self – image, frequent hospital visits for transfusion, delay development and infertility and other associated complications such as heart disease, bone disease, diabetes and infection [3].

Social support can help mothers to cope with various crises caused by the children illness and its treatment. Family, friends and significant others are the sources of support perceived by mothers who have children with thalassemia. Most of mothers have significant psychological impact and difficulty with social integration. They have severe psychosocial problems due to their inability to cope up with painful situation that leads to worsening of relationship amongst family members and isolation [4].

The psychiatric nurse has important role in the therapeutic approaches delivered by trained therapists or health professionals. Humor therapy, mindfulness and stress reduction, reminiscence group therapy and cognitive and social support interventions which are all successful in significantly reducing loneliness and had a positive impact on a range of other outcomes including social support, happiness and life satisfaction. A common feature of these interventions was that they all involved facilitated group based activities [5]. Also the psychiatric nurse should help mothers in identifying a wide variety of stress management techniques such as meditation, progressive muscle relaxation, breathing exercises, guided imagery, focused state ,yoga and stretching, light exercising are relaxation techniques used frequently in daily life to help them regulate their reactions to stress, achieve overall well-being making a person healthier in mind, body and spirit and also beneficial in the prevention and control of common health and emotional problems that linked with children such as anxiety symptoms [6; 7].

Significance of the study

Thalassemia is the most common monogenic disorder in the world. Thalassemia major (beta-thalassemia) affects a significant segment of the population in certain areas of the world. Alterations in migration patterns have changed the geographic distribution of this disease and made it a worldwide health problem with a high frequency in Africa, India, Southeast Asia and the Mediterranean area. Beta Thalassemia is the most common chronic hemolytic anemia in Egypt. The carrier rate varies between 5.5% to $\geq 9\%$; it is estimated that there are 1000/1.5 million per year live births born with b-thalassemia [8]. Thalassemia imposes a significant intrusion in the lives of children and their mothers. The effects are many, sweeping from financial hardships and absence from school and work to significant problems with self – image and self – esteems [9].

Theoretical and Operational Definitions:

1- Quality of life is as defined the general well-being of individuals and societies, outlining negative and positive features of life. It observes life satisfaction, including everything from physical health, family, education, employment, wealth, religious beliefs, finance and the environment [10]. In the current study it is operationally defined as the degree to which mothers experience satisfaction among four domains of life (physical health, Psychological, Social relationships and environment) which will be measured by quality of life scale developed by WHO [11].

2- Perceived social support: is defined as the financial and moral support from people close to the person who is in a stressful situation or in a hardship (12). In the present study it is operationally defined as the extent to which mothers feel they have support from their family, friends and a special person and the obtained score will be measured by perceived social support scale developed by (13)

2. SUBJECTS AND METHODS

2.1 The purpose of the study: The present study was carried out to assess the relationship between quality of life and social support among mothers of children with thalassemia.

2.2 Research questions:-

- What are the levels of quality of life and social support among mothers of children with thalassemia?
- Is there a relationship between quality of life and social support among mothers of children with thalassemia?

2.3 Research Design: The descriptive co-relational design was utilized to achieve the aim of the study.

2.4 setting: This study was conducted at pediatric department in University units at the Menoufia University Hospital at Shebin El-kom city, Menoufia Governorate, Egypt.

2.5 Subjects

A Convenient sample of 87 mothers of children with thalassemia who had the following criteria: absence of any psychiatric disorders, having the responsibility regarding the child treatment and his / her follow- up, read and write, having a child with thalassemia major below the age of 18 years, willingness to participate in the study.

Sample size was calculated according to the study design and the objectives of the study. Based on review of past literatures (14) "Stress and quality of life among mothers with thalassemic children in Malaysia" The results showed significant negative correlation between stress and quality of life ($r = - 0.296$ $P < 0.001$). Based on this results sample size was calculated at power 80%, margin of error 5% and confidence interval 95%. By the following equation where $Z = Z$ statistic for a level of confidence, Z statistic (Z): For the level of confidence of 95%, which is conventional = 1.96.

- Total sample size = $N = [(Z\alpha + Z\beta)/C]^2 + 3$
- The standard normal deviate for $\alpha = Z\alpha = 1.960$
- The standard normal deviate for $\beta = Z\beta = 0.842$
- $C = 0.5 * \ln[(1+r)/(1-r)] = 0.305$

2.6 Tools of the Study: Three tools were utilized to accomplish the purpose of the study.

Tool (1): A structured interviewing questionnaire: This questionnaire was developed by the researcher after reviewing literature to assess socio demographic characteristics of the mothers as age, educational level, number of children you have, child age, housing, number of rooms, income, marital status, occupational status, presence chronic diseases and questions about health status and quality of life.

Tool (2): quality of life scale: This scale was developed by WHO (11), to provide a brief profile of the level the prevailing quality in an individual's life, it was used for assessing the quality of life. This scale consists of 26 items. It includes two items for general quality of life and for public health, and only one of the twenty-four items that make up the original image World Health Organization (1995), consisting of 100 Phrase) to make the shortened image comprehensive and integrated. It was translated into Arabic by researcher. Furthermore, it consists of four domains (physical health, Psychological health, Social relationships and environment). Original scale contains 26 items, but items 1,2 assess mother opinion about their quality of life but not assess quality of life domains itself, and items 3 to 26 assess quality of life domains and so on the statistician excluded 1& 2 items from the scale to become 24 items, and made the validity and reliability for it. Responses were rated on a 3-point Likert scale labeled from No (1), Sometimes (2) and Yes (1), but 1, 2, 24 items are reversed, it mean No (3), Sometimes (2) and Yes (1). The scoring system; less than 60% of total score indicated bad quality of life, from 60% - 75 % of total score indicate average quality of life, ≥ 75 % of total score indicate good quality of life. It was tested for its validity by a panel of experts. The reliability of the tool was done using test - retest reliability and proved to be strongly reliable at 0.927.

International Journal of Novel Research in Healthcare and Nursing

Vol. 8, Issue 2, pp: (75-87), Month: May - August 2021, Available at: www.noveltyjournals.com

Tool (3): Perceived Social Support scale(PSS): This scale originally developed by (13), It was used for assessing perceived social support, it will translated into Arabic and validated by the researcher, It is a measure of how much support mothers feel they get from family, friends and significant others. It consists of three subscales:

- Significant Other Subscale: 1, 2, 5, & 10
- Family Subscale: 3, 4, 8, & 11
- Friends Subscale: 6, 7, 9, & 12

It contains 12 items in the form of 3-point likert scale ranging from No (1), sometimes (2) and Yes (3). Scoring system: less than 60% of total score indicate low social support, from 60-75% of total score indicate moderate social support, $\geq 75\%$ of total score indicate high social support. It was tested for its validity by a panel of experts. The reliability of the tool was done using test - retest reliability and proved to be strongly reliable at 0.893.

2.6.1 Ethical consideration:

A written approval will be obtained from ethical and research committee of the Faculty of Nursing, Menoufia University. The researcher will clarify the purpose of the study to every participant in the study, take her informed consent for participation, and assure maintaining anonymity and confidentiality of the subjects' data. The mothers will be informed that participation in this study is voluntary and they have the right to participate to withdraw from it at any time.

2.6.2 Data Collection:

Before starting any step in the study, an official letter was addressed about the purpose of study from the Faculty of Nursing, Menoufia University to pediatric department in University units at the Menoufia University Hospital at Shebin El-kom city, Menoufia Governorate, Egypt to obtain the official approval to collect data of the study.

- All of the authorized personnel provided by the needed information about the study from the researcher.
- All mothers who fit in the inclusion criteria were approached by the researcher to fill the questionnaires according to the following steps: The researcher started data collection by introducing herself to the participant. Informed consent was obtained from each mother. Then brief description of the purpose of the study and the type of the questionnaire required to fill was given to each mother. Data collected were done through interviewing with the mothers at the hall or their room in the pediatric department. Each interview lasted for 20-30 minutes for each questionnaire, depending on the response of the mother. The researcher collected the data during the morning at two days/week. The researcher began to collect data from pediatric department in University units at the Menoufia University Hospital at Shebin El-kom city, Menoufia Governorate, Egypt with approximately 9-12 daily. The data collected within 4 days weekly, for 3-4 weeks. The process of data collection took a period of one month from 15 November to 15 December.

2.6.3 Statistical Analysis

Data were collected, tabulated, statistically analyzed using an IBM personal computer with Statistical Package of Social Science (SPSS) version 19 (SPSS, Inc, Chicago, Illinois, USA). where the following statistics were applied: descriptive statistics: in which quantitative data were presented in the form of mean, standard deviation (SD), range, and qualitative data were presented in the form numbers and percentages. Analytical statistics: used to find out the possible association between studied factors and the targeted disease. The used tests of significance included: Chi-square test (χ^2): was used to study association between two qualitative variables. Kruskal-Wallis test (nonparametric test): is a test of significance used for comparison between three or more groups not normally distributed having quantitative variables. Pearson correlation: Used for correlation of two quantitative variables. P value of >0.05 was considered statistically non-significant. P value of <0.05 was considered statistically significant. P value of <0.001 was considered statistically highly significant.

3. RESULTS

Table (1): This table shows that half of studied mothers (50.6%) age are between (20-35) years old. Majority of the mothers (94.1%) are married. Nearly half of the mothers (42.4%) have secondary education. Majority of the mothers (90.6%) are house wife. While more than half of mothers (57.6%) stay with relatives. More than three quarter of the mothers (83.5%) have moderated socioeconomic level. While more one third of mothers (29.4%) have chronic disease.

International Journal of Novel Research in Healthcare and Nursing

Vol. 8, Issue 2, pp: (75-87), Month: May - August 2021, Available at: www.noveltyjournals.com

Table (2): This table shows that there is a significant relation between quality of life, educational level and socioeconomic level. Mean quality of life is high in high educational and socioeconomically level and absence of disease. While there is no significant relation between quality of life and marital state, occupation, housing, number of children and age of children.

Table (3): This table shows that: There is a significant relation between social supports, socioeconomic level. Mean that mothers with high level of socioeconomic state have high social support, while there is no significant relation between social support and marital status, educational level, occupation, housing, number of children and age of children.

Figure (1): This figure shows that less than half of studied mothers (42.4) have average and bad quality of life.

Figure (2): This figure shows that more than three quarter of the mothers (83.7%) who haven't chronic illness have good quality of life. While more than two thirds of mothers (66.7%) who have chronic illness have bad quality of life.

Figure (3): Figure shows that more than one third of subjects (37.60%) have moderate social support.

Figure (4): Figure shows that there is a positive correlation between total quality of life and total social support among the studied mothers. This means that when social support increase quality of life increase.

Table (1): Socio demographic characters of the studied mothers (N= 85)

Socio demographic characters	No.	%
Age / years		
20 – 35	43	50.6
35 – 50	40	47.1
More than 5	2	2.40
Educational level		
Illiterate	15	17.6
Primary	26	30.6
Secondary	36	42.4
University & Post graduate	8	9.50
Marital state		
Married	80	94.1
Divorced	4	4.70
Widow	1	1.20
Occupation		
Work	8	9.40
Housewife	77	90.6
Housing		
Rent	2	2.40
Owner	34	40.0
With relatives	49	57.6
Socioeconomic level		
Low	13	15.3
Moderated	71	83.5
High	1	1.20
Chronic illness		
Yes	25	29.4
No	60	70.6
Number of children		
Mean ±SD		3.05±0.9
Range		1.00 – 6.00
Age of children		
Mean ±SD		9.12±3.0
Range		1.00 – 16.0
Number of rooms		
Mean ±SD		2.60±0.67
Range		1.00 – 4.00

Table (2): Relation between quality of life and socio demographic characters of the studied mothers (N= 85)

Socio demographic characters	Quality of life						Test of sig.	P value
	Good (N=49)		Average (N=18)		Bad (N=18)			
	No.	%	No.	%	No.	%		
Age / years							X ² 4.98	0.289
20 – 35	26	53.1	11	61.1	6	33.3		
35 – 50	22	44.9	6	33.3	12	66.7		
More than 5	1	2.00	1	5.60	0	0.00		
Educational level							X ² 27.1	0.001**
Illiterate	6	12.2	0	0.00	9	50.0		
Primary	18	36.7	5	27.8	3	16.7		
Secondary	17	34.7	13	72.2	6	33.3		
University& Postgraduate	8	16.2	0	0.00	0	0.00		
Marital state							X ² 1.91	0.752
Married	45	91.8	17	94.4	18	100		
Divorced	3	6.10	1	5.60	0	0.00		
Widow	1	2.00	0	0.00	0	0.00		
Occupation							X ² 6.69	0.153
Work	3	6.10	3	16.7	2	11.1		
Housewife	46	93.9	15	83.3	16	88.9		
Housing							X ² 7.31	0.120
Rent	2	4.10	0	0.00	0	0.00		
Owner	23	46.9	8	44.4	3	16.7		
With relatives	24	49.0	10	55.6	15	83.3		
Socioeconomic level							X ² 37.6	0.001**
Low	1	2.00	1	5.60	11	61.1		
Moderated	47	96.0	17	94.4	7	38.9		
High	1	2.00	0	0.00	0	0.00		
Number of children							K 2.14	0.343
Mean ±SD	3.10±1.00		2.83±0.78		3.10±0.85			
Range	1 - 6		1 – 6		2 – 5			
Age of children							K 1.26	0.531
Mean ±SD	9.44±4.09		9.05±2.70		8.33±3.98			
Range	1.50 - 16		4 - 13		1 – 13			

Table (3): Relation between social support and socio demographic characters of the studied mothers (N= 85)

Socio demographic characters	Social support						Test of sig.	P value
	Low (N=31)		Moderate (N=32)		High (N=23)			
	No.	%	No.	%	No.	%		
Age / years							X ² 6.64	0.156
20 – 35	12	40.0	15	46.9	16	69.6		
35 – 50	17	56.7	17	53.1	6	26.1		
More than 5	1	3.30	0	0.00	1	4.30		
Educational level							X ² 10.3	0.242
Illiterate	8	26.7	4	12.5	3	13.0		
Primary	10	33.3	10	31.3	6	26.1		
Secondary	11	36.7	14	43.8	11	47.8		
University& Post graduate	1	3.30	4	12.5	3	12.100		

Marital state							X^2	
Married	28	93.3	32	100	20	87.0	5.47	0.242
Divorced	2	6.70	0	0.00	2	8.70		
Widow	0	0.00	0	0.00	1	4.30		
Occupation							X^2	
Work	4	13.3	0	0.00	4	17.4	5.58	0.061
Housewife	26	86.7	32	100	19	82.6		
Housing							X^2	
Rent	0	0.00	1	3.10	1	4.30	5.13	0.273
Owner	10	33.3	17	53.1	7	30.4		
With relatives	20	66.7	14	43.8	15	65.2		
Socioeconomic level							X^2	
Low	10	33.3	1	3.10	2	8.70	14.5	0.006**
Moderated	20	66.7	31	96.9	20	87.0		
High	0	0.00	0	0.00	1	4.30		
Number of children							K	
Mean \pm SD	3.06 \pm 0.91		3.28 \pm 0.92		2.73 \pm 0.91		3.92	0.141
Range	1 - 5		2 - 6		1 - 5			
Age of children							K	
Mean \pm SD	9.35 \pm 3.74		9.73 \pm 3.80		8.00 \pm 3.81		2.61	0.272
Range	2 - 16		1.50 - 14		1 - 16			
Number of rooms							K	
Mean \pm SD	2.43 \pm 0.72		2.65 \pm 0.65		2.73 \pm 0.62		2.88	0.236
Range	1 - 4		2 - 4		1 - 3			

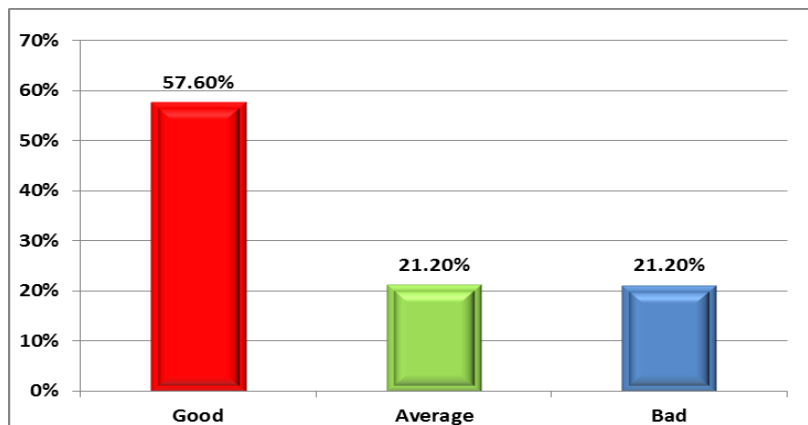


Figure 1. Percentage distribution of total quality of life among the studied mothers

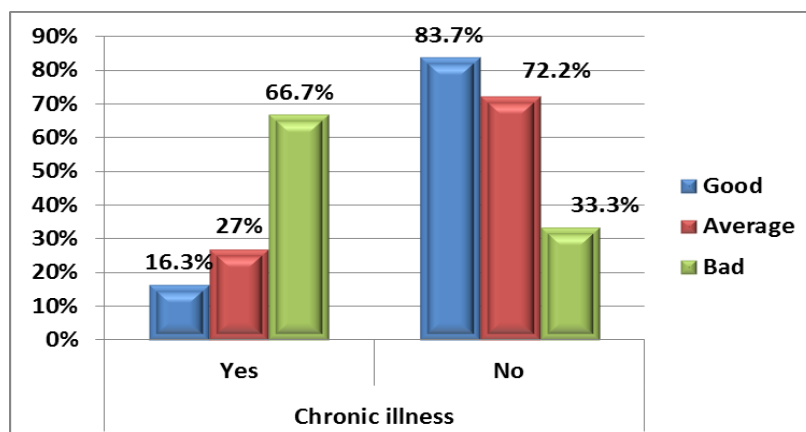


Figure 2. Relationship between total quality and chronic illness among the studied mothers

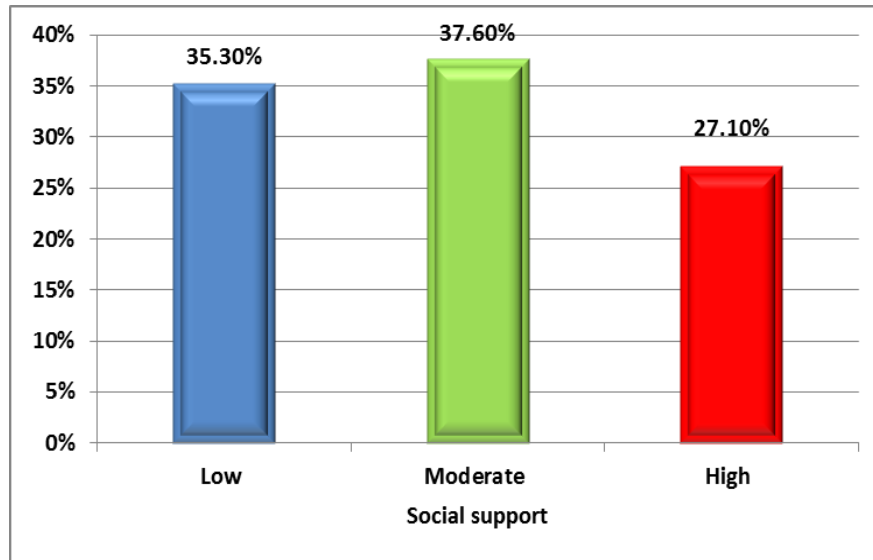


Figure 3. Percentage distribution of total social support among the studied mothers

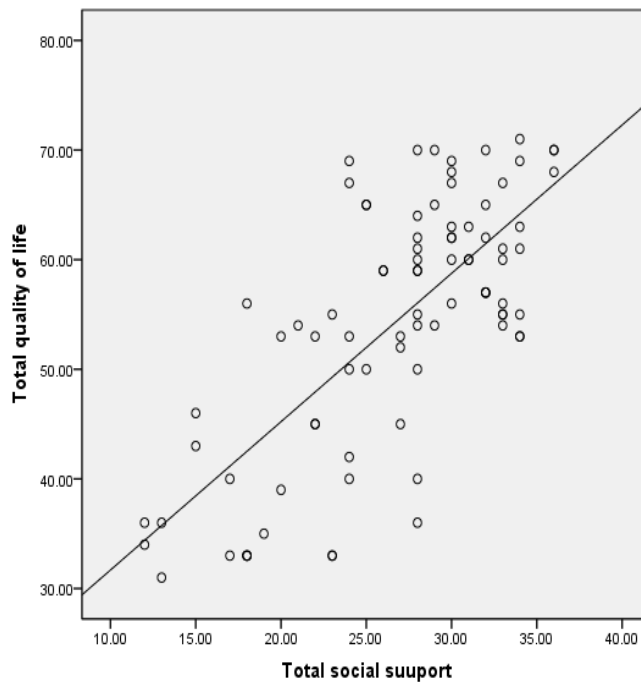


Figure 4. Correlation between total quality of life and total social support among the studied mothers

4. DISCUSSION

Regarding the socio-demographic characteristics of the mothers, the results of this study revealed that the age of the studied mothers was ranged from 20-35 years. This is may be due to that they married in young age as the marriage age in Egypt is ranged between 20-29years old. This result was in agreement with [15] who studied "assessment of quality of life among parents of children with thalassemia". They found that age for studied mothers was ranged between 25-35 years old. The study was in disagreement with the result by [16] who studied "Caregiver burden and related factors in parents of children with Thalassemia ". They stated that the studied parents' ages was ranged from 41-50 years.

Regarding the marital state, the present study revealed that the majority of studied mothers were married. This may be due to the fact that marriage in Egyptian culture is better for female. Also they consider that marriage to be chastity and protect for woman. This result was in agreement with the study which done by [17] who studied "Parenting stress of

mothers having children with thalassemia". They stated that majority of studied mothers (95%) were married. Also it was consistent with [9] who studied "parenting stress in Malaysian parents of children with thalassemia". They found that majority of parents were married (91%).

Concerning the level of education nearly half of the mothers have secondary education (42.2%). This is may be due to the fact that female in Egyptian culture is married younger or may be because there was a common belief that in Egypt marriage is better than education for girls or due to lower economic status. This result was consistent with [17] who studied "parenting stress of mothers having children with thalassemia". They stated that majority of studied mothers (64%) were secondary education, and the study was on the same line with [18] who studied "Perceived stress and monetary burden among thalassemia patients and their caregivers". They found that caregiver were 19 (48.7%) having secondary education. As well as the study was in agreement with [14] who studied "Mediating role of perceived social support on the relationship between stress and quality of life among mothers with thalassemia children in Malaysia". They showed that majority of studied mothers have a secondary school background (62.6%).

Regarding to the occupation, the majority of the mothers are house wife (90.6%). This may be due to mother chosen not to work outside the home for money but rather devotes all times, energy and love to her ill child and all family what help her to do that their adequate income, as well as lack of occupational chances and unemployment problem in Egypt. This result was in the same line with the result by [17] who studied "Parenting stress of mothers having children with thalassemia". They stated that majority (87%) of studied mothers were house wife. It was also consistent with [19] who studied "Quality of Life among Caregiver of Children with Thalassemia in Al-Najaf Governorate". He found that mother occupation was more than half (61.3%) of studied mothers were house wife.

Regarding having chronic diseases, the results of the present study found that one third of mothers (29.4%) have chronic disease. This is may be due to absence of physical activity, poor nutrition, psychological distress and child's illness that effects on mothers health. This result was similar to the study which done by [20] who studied "effect of child thalassemia on the mental health of their caregivers". They found that 30% were suffering from a disease. But was inconsistent with [21] who studied "Quality of life in caregivers with and without chronic disease" they found that more than three quarters of studied subjects (78.8%) had chronic illness.

Concerning the socioeconomic state the current study showed that majority of the study mothers have moderate degree of socioeconomic level (83.3.5%). This may be due to presence of good opportunity for free jobs, Mage in the money and health, presence of financial support from government as well as the state bears the expenses for the child's treatment. This result was congruent with the study which conducted by [19] who studied "Quality of Life among Caregiver of Children with Thalassemia in Al-Najaf Governorate". He found that family socio-economic status was barely sufficient about half of caregiver (52.5%). Also the study was consistent with [22] who studied "the mental burden of parents of children with thalassemia". They found that parents' income was barely adequate.

Regarding the level of quality of life of studied mothers, the current study showed that the majority of the mothers has good quality of life (57, 6%). This is may be due to that they satisfied with everything from God, trusting in God and they contact with religious men at the time of crisis. The result of study was consistent with [23] who studied "Quality of Life of Caregivers of Hematopoietic Cell Transplant Recipients". They found that most caregivers are experiencing physical and mental quality of life equivalent to or better than that of the general population and, on average, caregivers report better physical but similar mental quality of life versus recipients. But the study was in consistent with the study done by [24] who studied "Stress level among caregivers of thalassemia patients". They reported that the quality of life was affected adversely among 50% of caregivers of Thalassemia patients. As well as was in disagreement with the study which done by [25] who studied "quality of life in children with thalassemia and their caregivers in India". They illustrated that the total quality of life score on parent- proxy report was significantly lower among cases as compared with controls in all age groups.

Concerning to the level of total social support among the studied mothers. The present study found that more than one third of mothers (37.60%) have moderate social support. This may be due to being supported by family; being supported by community, closer family members, increased frequency of seeing others or feeling not the only one on their problem, increase feeling of being connected, building of new friendships. The result of the study was in agreement with [26] who studied "Factors associated with the quality of life of family caregivers for leukemia patients in China". They found that

the majority (73.8%) of family caregivers received a moderate level of social support. While these findings were inconsistent with research conducted by [27] who studied "Caregiver Burden and Social Support in Mothers with β -Thalassemia Children". Their results demonstrated that about half of (51.5%) of mothers of major β -thalassemic children have low level of social support. As well as it was consistent with [17] who studied "parenting stress of mothers having children with thalassemia". They found that majority of the studied mothers (84%) had high financial support and one quarter of the mothers had low social support (28%).

According to the results of this study, there was a significant relation between social support and socioeconomic state (p value 0.006). Mean social support score was higher in high socioeconomic class level than low socioeconomic class level. This may be due to when income increase, life welfare improved that provides time for interpersonal relationship with family members and others. This result was identical with the outcomes of a study which done by [28] who studied "Social support of parents of children with leukemia". Who found that the family income was a risk factor of parent social support. The higher family income, the more social supports perceived by parents. It was also consistent with [6] they studied "Caregiver Burden and Social Support in Mothers with β -Thalassemia Children" Who found that the mother's low level of income and living alone could significantly affect their social support.

Regarding the relation between quality of life and educational level, the present study showed that there was a significant positive relation between quality of life and educational level. This is may be due to education is the source of knowledge that helps the mother to create awareness by removing misconception caused by illness. The study was consistent with [29] who studied "Care-Related Quality of Life of Caregivers of Beta-Thalassemia Major Children: An Epidemiological Study in Eastern India". The findings of the present study were contradicted with study conducted by [24] who studied "Stress level among caregivers of thalassemia patients". They reported no relation between difference levels of education and psychosocial burden of the caregiver, an educated caregiver is likely to be more resilient, thus have more capabilities to cope up with the stress and strain the disease of his/her child puts onto him/her. As well as the study was consistent with the study of [30] who studied "Quality of life, depression, anxiety and stress in over-18-year-old patients with beta thalassemia major and their caregivers". They found that people with higher education have always tended to have higher socioeconomic status and income as well as higher life satisfaction and quality of lived experiences of Iranian parents of beta-thalassemia children life.

The current study showed that there was a positive correlation between quality of life and health status among the studied mothers. This may be due to illness affect mobility and consequently their physical and functional status and this preventing them from providing optimum care to their children what's make them feel delinquent and depressed. This result matched with [25] who studied "Quality of Life in Children with Thalassemia and their Caregivers in India". They found that parent-proxy report [84.2 (11.9) $p < 0.001$] was significantly lower in cases as compared with controls. It was found that a significantly higher proportion of caregivers of cases reported poor health compared with caregivers of controls (29.2% vs. 2.5%, $p < 0.001$). As well as the study was consistent with [31] who studied "Health-related Quality of Life for Children with Leukemia: Child and Parental Perceptions". They found that the presence of maternal chronic disease was significantly related to the total score of the parent-proxy report (mother) ($P < 0.05$).

According to the result of current study, there was a positive correlation between quality of life and socioeconomic status among the studied mothers. This may be due to mothers with higher socioeconomic state have access to more health knowledge, better housing, nutrition and health care which increase quality of life. This result was consistent with [4] who studied "Experience of parents caring for their children with thalassemia: challenges and issues for integrative review". They found that financial problems seemed to be a universal cause of suffering of parents with children with thalassemia since the disease requires prolonged care and treatment and frequent hospitalization. It was the greatest problem seen, especially among parents in the lower socio-economic group. Also it was consistent with [32] who studied "Quality of Life among Caregivers of children with Autism Spectrum Disorders, Intellectual Disability, and Typical Development". They found that there was a direct relationship between higher income and quality of life because low income appears to be a risk factor for poor quality of life, particularly in the psychological and environment domains.

Concerning the correlation between quality of life and social support the present study demonstrated that there is a positive correlation between total quality of life and total social support among the studied mothers with high statistical significant (P value, 0.001). This may be due to presence of support from health care providers, friends, siblings and

family especially partner. This result was on the same line with a study done by [33] who studied "Mediating role of perceived social support on the relationship between stress and quality of life among mothers with thalassemia children in Malaysia". They demonstrated that there was the positive correlation between perceived social support and quality of life indicates that mothers who receive social support experience higher levels of quality of life because they get the adequacy of support in their life. It was also the same line with [34] who studied "Self-efficacy, social support, and quality of life among primary family-member caregivers of patients with leukemia in Thailand" who found that Perceived social support also significantly predicted quality of life, and caregivers with greater social support enjoyed a better quality of life, in total, 56.7 percent of primary family-member caregivers reported high levels of perceived social support, which may be related to the strong relationships between family-member caregivers.

5. CONCLUSION

The current study concluded that there was a positive correlation between total quality of life and total social support among the studied mothers

6. RECOMMENDATIONS

This study recommended that an educational program should be given for the mothers of children with thalassemia to maintain their psychological and physical health, as well as improve their quality of life as a whole.

REFERENCES

- [1] Hesham, A.M., Beshar, R.M., & Khalifa, A.N. (2018). Screening for B thalassemia carrier among students in asecondary school in diarb negm, sharkia.Z.U.M. J;24(1):72-9.
- [2] Singh, P., & Seth, A. (2017). Growth and endocrine issues in children with thalassemia. *Pediatric Hematology Oncology Journal*, 2(4), 98-106.
- [3] Ali, 2019
- [4] Punaglom, N., Kongvattananon, P., & Somprasert, C. (2019). Experience of parents caring for their children with Thalassemia: Challenges and issues for integrative review. *The Bangkok Medical Journal*, 15(1), 100-100.
- [5] Gardiner, C., Geldenhuys, G., &Gott, M. (2018). Interventions to reduce social isolation and loneliness among older people: an integrative review. *Health & social care in the community*; 26(2): 147-57.
- [6] Fradelos, E., Komini A. (2015). The use of essential oils as a complementary treatment for anxiety. *American Journal of Nursing Science*. 4(2):1-5.
- [7] Daniels, K., Gedikli, C., Watson, D., Semkina, A., & Vaughn, O. (2017). Job design, employment practicesand well-being: a systematic review of intervention studies. *Ergonomics*; 60 (9): 1177- 96.
- [8] Al-Kherbash, H. A., Al-Awdi, A., & Hasan, N. S. (2017). Pattern and clinical profile of thalassemia among pediatric patients attending the Yemeni Society Centers for Thalassemia and Genetic Blood Disorders in Yemen. *The Scientific Journal of Al-Azhar Medical Faculty, Girls*, 1(2), 43.
- [9] Mohamed, M., Lau, D. S. C., Loh, C. K., Zakaria, S. Z. S., Alias, H., Jamal, A. R. A., & Latiff, Z. A. (2017). Parenting Stress In Malaysian Parents Of Children With Thalassaemia. *Malaysian Journal of Paediatrics and Child Health*, 23(1), 31-41.
- [10] Abd- Elhamead, M.M. (2017). Effect of social Support and Hope on Quality of Life among Patients with Bladder Cancer. Department of Family and Community Health Nursing. Faculty of Nursing. Menoufia University.2
- [11] World Health Organization. (1996). *WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996* (No. WHOQOL-BREF). World Health Organization.
- [12] Maheri, A., Sadeghi, R., Shojaeizadeh, D., Tol, A., Yaseri, M., & Rohban, A. (2018). Depression, anxiety, and perceived social support among adults with beta-thalassemia major: cross-sectional study. *Korean journal of family medicine*, 39(2), 101.

International Journal of Novel Research in Healthcare and Nursing

 Vol. 8, Issue 2, pp: (75-87), Month: May - August 2021, Available at: www.noveltyjournals.com

- [13] Canty-Mitchell, J., & Zimet, G.D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. *American Journal of Community Psychology*; 28: 391-400.
- [14] Hazlina, M. M., Rumaya, J., & Nor, S. (2017). Mediating role of perceived social support on the relationship between stress and quality of life among mothers with thalassemia children in Malaysia. *International Journal of Public Health and Clinical Sciences*, 4(1), 103-123.
- [15] Bakthavatchalam, P., & Vetrisevi, P., (2019); ASSESSMENT OF QUALITY OF LIFE AMONG PARENTS OF CHILDREN WITH THALASSEMIA. *Int. J. of Adv. Res.* 7 (Aug). 1074-1083] (ISSN 2320-5407). www.journalijar.com
- [16] Alizadeh, M., Chehrzad, M. M., Mirzaee, M., & Leyli, E. K. N. (2019). Caregiver burden and related factors in parents of children with Thalassemia. *Journal of Advanced Pharmacy Education & Research/ Apr-Jun.*, 9(S2).
- [17] Mohiuddin, Z., Haque, M. M., & Ahmad, S. A. (2019). Parenting Stress of Mothers Having Children with Thalassemia. *Journal of Preventive and Social Medicine*, 38(2), 22-29. <https://doi.org/10.3329/jopsom.v38i2.47861>
- [18] Hisam, A. (2018). Perceived stress and monetary burden among thalassemia patients and their caregivers. *Pakistan journal of medical sciences*, 34(4), 901.
- [19] Shaker, W. H. (2019). Quality of Life among Caregiver of Children with Thalassemia in Al-Najaf Governorate. *Indian Journal of Public Health Research & Development*, 10(6).
- [20] Haq, F.U., Khan, A. M.M., Yaqoob, U., Sheikh, R. J., Salam, O., & Zubair, U. (2017) Effect of Child Thalassemia on the Mental Health of their Caregivers. *International Journal of Mental Health & Psychiatry*, 3(3).
- [21] Shiue, I., & Sand, M. (2017). Quality of life in caregivers with and without chronic disease: Welsh Health Survey, 2013. *Journal of Public Health*, 39(1), 34-44.
- [22] Septyana, G., Mardhiyah, A., & Widiyanti, E. (2019). The Mental Burden of Parents of Children with Thalassemia. *Jurnal Keperawatan Padjadjaran*, 7(1).
- [23] Jamaniet al., (2018)
- [24] Inamdar, S., Inamdar, M., & Gangrade, A. (2015). Stress level among caregivers of thalassemia patients. *Community Med*, 6(4), 579-578.
- [25] Sharma, S., Seth, B., Jawade, P., Ingale, M., & Setia, M. S. (2017). Quality of Life in Children with Thalassemia and their Caregivers in India. *The Indian Journal of Pediatrics*, 84(3), 188-194.
- [26] Yu, H., Li, L., Liu, C., Huang, W., Zhou, J., Fu, W., & Wu, Q. (2017). Factors associated with the quality of life of family caregivers for leukemia patients in China. *Health and quality of life outcomes*, 15(1), 1-11.
- [27] Mashayekhi, F., Jozdani, R. H., Chamak, M. N., & Mehni, S. (2016). Caregiver burden and social support in mothers with β -thalassemia children. *Glob J Health Sci*, 8(12), 206-212.
- [28] Nursyamsiyah, N. (2019). Social support of parents of children with leukemia. *Belitung Nursing Journal*, 5(4), 155-161.
- [29] Biswas, B., Naskar, N. N., Basu, K., Dasgupta, A., Basu, R., & Paul, B. (2020). Care- Related Quality of Life of Caregivers of Beta-Thalassemia Major Children: An Epidemiological Study in Eastern India. *Journal of Epidemiology and Global Health*, 10(2), 168.
- [30] Poormansouri, S., Ahmadi, M., Shariati, A. A., & Keikhaei, B. (2016). Quality of life, depression, anxiety and stress in over-18-year-old patients with beta Thalassemia major. *Scientific Journal of Iran Blood Transfus Organ*, 13(1), 72-82.
- [31] Ocak et al., (2020)

International Journal of Novel Research in Healthcare and NursingVol. 8, Issue 2, pp: (75-87), Month: May - August 2021, Available at: www.noveltyjournals.com

- [32] Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbati, M. M., Al-Adawi, S., Cucchi, A., Essa, M. M., & Qoronfleh, M. W. (2020). Quality of Life among Caregivers of children with Autism Spectrum Disorders, Intellectual Disability, and Typical Development. *Applied Research in Quality of Life*, 1-17.
- [33] Hazlina, M. M., Rumaya, J., & Nor, S. (2017). Mediating role of perceived social support on the relationship between stress and quality of life among mothers with thalassemia children in Malaysia. *International Journal of Public Health and Clinical Sciences*, 4(1), 103-123.
- [34] Warapornmongkholkul, A., Howteerakul, N., Suwannapong, N., & Soparattanapaisarn, N. (2018). Self-efficacy, social support, and quality of life among primary family-member caregivers of patients with cancer in Thailand. *Journal of Health Research*.
- [35] Ali, S., Mumtaz, S., Shakir, H. A., Tahir, H. M., & Mughal, T. A. (2019). Current Perspective of Beta Thalassemia and Its Treatment Strategies
- [36] Jamani, K., Onstad, L. E., Bar, M., Carpenter, P. A., Krakow, E. F., Salit, R. B., & Lee, S. J. (2018). Quality of life of caregivers of hematopoietic cell transplant recipients. *Biology of Blood and Marrow Transplantation*, 24(11), 2271-2276.
- [37] Ocak, E., Yozgat, A. K., Kacar, D., Sucakli, I. A., Ozbek, N. Y., Uneri, O. S., & Yarali, N. (2021). Health-related Quality of Life for Children With Leukemia: Child and Parental Perceptions. *Journal of Pediatric Hematology/Oncology*, 43(1), e56-e63.