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Knowledge of Thalassemic Children about Their Pain and The used Coping strategies

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Abstract: **Thalassemia is the most common genetic disorder in Egypt, with an estimated carrier rate of 9-10%. Pain is a subjective symptom whose prevalence can be grossly underestimated. Chronic pain often necessitates new coping skills. Children coping with their pain will help their body and mind. Aim: assess the knowledge of Thalassemic Children about Their Pain and The used Coping strategies Design: A descriptive cross- sectional design was utilize. Setting: the study was carried out at the heamatology outpatient clinics affiliated to Mansoura University Children Hospital(MUCH) and heamatology department of elabour hospital affiliated to Health Insurance Organization at kafer el-sheikh city, Egypt. Subjects: A purposive sample of Pediatric patient 132 (66 of them from hematology outpatient clinic at Mansoura university children hospital MUCH and 66 from hematological department at elabour hospital at kafr elsheikh city) their age from 8-18 years, free from other complain, and Accept to participate in the study. Tools: Data collection lasted 3 months by using structured questionnaire sheet, Brief pain inventory and Children Coping strategies checklist. The study Results revealed average children' knowledge regarding thalassemia and associated pain, children had mild pain and no children had higher level of coping. Recommendations: Health educational program for children about thalassemia and pain associated with the disease at outpatient clinics to improve their knowledge toward thalassemia and pain.**

Keywords: **Thalassemia, Children, pain, Coping strategies.**

1. INTRODUCTION

Thalassemia like the mainly prevalent genetic disorder worldwide is considered as a critical trouble in general health matters in the Mediterranean area[1]**.** Thalassemia is a Greek term that taken from two terms, Thalassa means Sea and Emia means blood, thus called Mediterranean anemia or Cooley's anemia[2]. Thalassemia is a hereditary, autosomal recessive, persistent hemolytic anemia because of a partial or total deficiency in the synthesis of α-globin chains (α-thalassemia) or β-globin chains (β-thalassemia) which form the main adult hemoglobin[3.]

It is rated that 1.5% of the world's population are carriers of β- thalassaemia with an estimated 60,000 new carriers born every year. Southeast Asia considers for about 50% of the world's carriers while Europe and the Americas jointly regard for 10-13% of world carriers[4]. β-thalassemia in Egypt is the most prevalent kind of hereditary anemia, having a carrier rate of around 10%.**El-Hashemite** stated which of 1.5 million yearly live births, around 1000 babies are born with β-thalassemia. The ailment is complexes by a high mutation ratio and the existence of genetic modifiers. Furthermore 200 mutations are recognized to reason β-thalassemia[5].

The thalassemias are categorized along with which chain of the hemoglobin molecule is influenced. In α thalassemias, manufacture of the α globin chain is affected, whilst in β thalassemia manufacture of the β globin chain is affected. α globin chains are encoded by two closely linked genes on chromosome 16; β globin chains are encoded by a single gene on chromosome 11. So in a normal person with two copies of every chromosome, there are four loci encoding the α-chain, and two loci encoding the β chain**[6].**

Thalassemia is the most prevalent inherited hemolytic anemia. Children with Thalassemia request lifelong adherence to distressing treatment regimens, including regular blood transfusions and daily chelation therapy. Therefore, preserving hemoglobin target levels as well as a suitable chelation therapy has been particularly confirmed in the care of children with Thalassemia[7].

Present management advances have prolonged life spans for children with thalassemia, which has uncovered previously unknown troubles, including persistent ache. A lot of doctors looking after for children with thalassemia have faced with children with persistent ache that is at times excessive and intractable[8]**.** Although, pain is not a symptom commonly linked with thalassemia, it has been recently reported as an emerging complication and a major reason of morbidity in thalassemia[9]**.**

It has been proved that age was an independent predictor of pain frequency and intensity in pediatric thalassemia pediatric patients, irrespective of transfusion status, gender, iron overload, type of administration of iron chelator regimen, and bone density. The most repeated location of pain was the lower back followed by the leg, head and mid-back. As repeated by children, the nature of pain was aching, throbbing, sharp, and tiring[10]**.**

The exact mechanism of pain in thalassemia has not yet been fully explained; however, low hemoglobin level, iron overload, and low bone mass have been proposed as potential causes. It is supposed that lower hemoglobin levels, which happen at the end of a transfusion cycle, are possibly connected with worsening of pain in thalassemia children. In addition, because skeletal changes and bone marrow expansion, the risk of extending pain increases in children who delay the blood transfusion[8].

Chronic pain impacts Thalassemic children emotionally, cognitively, physically, and socially, and their medical treatment often happens in healthcare settings that may have little understanding of their many requirements. When working with children who experience chronic pain, counselors must address the developmental level so that children are able to understand the complex concerns they are facing[11] **.**

Coping expresses purposeful cognitive and behavioral efforts to reject the negative impact of pain. To calculate pain coping is to differentiate the ongoing cognitive, emotional and behavioral processes linked to pain in Thalassemic children and adolescents with chronic or recurrent pain[12]**.** The development of the capability to cope to pain and stress is an important asset, which explores by coping research. Coping has been known as "conscious, volitional efforts to adjust emotion, behavior, cognition, physiology, and the surroundings in reply to stressful occasions"[13]**.**

As a healthcare provider, nurses may play an important and unique role in helping Thalassemic children to perform healthy behavior in the context of treatment adherence and attaining better clinical outcomes[14]**.** Nurses also play a critical role in managing the children's chronic pain by helping to avoid unnecessary complications and giving treatment aimed at reducing interference with the demands of activity or school[15]**.**

Aim of the study:

The study was aimed to assess the knowledge of Thalassemic Children about Their Pain and The used Coping strategies .**Research Question:**

1- What are the level of Thalassemic children knowledge about their pain?

2- What are the level of severity of pain among Thalassemic children?

3- What are the strategies used by Thalassemic children to cope with their pain?

2. SUBJECTS & METHOD

Design: A descriptive cross sectional research design was used to accomplish this study.

Setting: This study was carried out in the Hematology outpatient clinics number 3and 9(Saturday, Monday& Wednesday) at Mansoura university Children Hospital (MUCH) which serve whole children's age from birth to 18 years. average number of children 25/ day and Hematology department at elabour hospital at kafr elsheikh city affiliated to health insurance organization. This department located at elabour hospital and provided care for thalassemia children during they receive Blood transfusion, other forms of treatment and also when they come for hospitalization due to serious complication. Average number of Thalassemic children receiving blood transfusion 6/ day, while average number of hospitalized Thalassemic children one child per week.

Samples: A purposive sample of Pediatric patient 132 (66 of them from hematology outpatient clinic at Mansoura university children hospital MUCH and 66 from hematological department at elabour hospital at kafr elsheikh city) their age from 8-18 years, free from other complain, and Accept to participate in the study.

Tools and techniques of data collection:

Three tools were used to collect data for current study.

Tool (I)-: Interview Questionnaire: this questionnaire will be developed by the researcher after reviewing of the related literature in Arabic language to suit the level of children understanding . This tool will compromise the following parts**:**

Part I: Characteristics of the studied children: Like: Children age, gender, education level and birth order.

Part II: Children's clinical data, which includes: types of thalassemia, duration of disease or treatment, regularity of blood transfusion, number of blood transfusion per month and family history of Thalassemia.

Part III: Children knowledge about thalassemia and its associated pain such as definition, causes, symptoms, complication and treatment of thalassemia – pain definition, causes and associated risk factors .

Tool (II):- Brief pain inventory tool: this tool was developed by **Charles, 1991, Cleeland, 2009** and **Haines, 2013** and this tool will be developed by the researcher in Arabic form . brief pain inventory tool were designed to assess pain severity, location, duration and interference with daily life. participants rates the level that interfere with daily living in seven areas : general activity, mood, walking ability, school performance, peer relation, sleep and enjoyment of life .

Tool (III):- Children Coping strategies checklist: Children Coping strategies checklist developed by **Alo, 2008 and Camisasca, 2012** and this tool will be translated to Arabic version by the researcher after making some modification to be suitable for our community**.** It consists of 32 items were used to measure the extent to which modes of coping were used by children. The items on questionnaire divided in to six empirically constructed scales (problem focused coping, positive cognitive restructuring, distracting action, avoidant action, Support seeking coping strategies and aggressive actions.

The preparatory phase:

This phase include a review of the past and current related literature and studies using available books, periodicals, magazines and articles, to get acquainted with the various aspect of the study problem and develop the study tool. The structured questionnaire was developed in an Arabic language by the researcher after reviewing of the related literature, then revised and adjusted by supervisors. The developed tool was submitted to a jury of five experts (four experts in the nursing field and one experts in the medical field from el-ebour hospital at kafr elsheikh city, hematology department) for its content validity. According to their suggestions, the required modifications were done. The developed tools were tested for their reliability using Alpha Cronbach's test to measure its internal consistency to evaluate how well the tool consistency measure. The Alpha reliability for tool (1) was 0.844, the alpha reliability for tool (2) was 0.891 and the alpha reliability for tool (3) was 0.814.

Pilot study:

A pilot study was carried out on 13 child (10%of the sample), to ascertain the feasibility , applicability and clarity of the tool and minor modifications were made consequently: those children were excluded from the final study sample.

Field work:

- Once the necessary approval were granted to protocol with proposal study. The subjects who agree to participate in the study, were interviewed and observed by researcher to collect the necessary data.
- The researcher started by introducing herself to the child and his relative and giving them a brief idea about the aim and nature of the study.
- Oral consent approval was obtained from each participating child or their caregiver prior to his/ her participation in the study. Clarification of the nature and purpose of the study was done on interview with each child or his caregiver.

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- Each child was met individually by the researcher to collect the necessary data. The time consumed to answer questionnaire sheet ranged from 25-30 minutes .The researcher was available three days per week from 9.00 am to 12.00 pm
- Data collection extended from the first of July to the first of October 2017 (3 months).

Ethical consideration:

The researcher followed ethical research principles as the following: Actual official permission from the Researcher Ethics Committee of the Nursing Faculty at Mansoura University to get an approval for conducting the study.

Informed oral consent was obtained from each child and his / her relative for his/ her participations after explaining the aim of the present study. Anonymity and singularity of the data collected by the researcher in the present study were confirmed and the children were informed that they can able to withdraw from the present study at any time freely without any responsibilities.

IV. statistical design:

The collected data were coded and entered in a data based file using the excel program for windows. Frequency analysis and manual revision were used to detect any error. Data were analyzed with SPSS version 17.0 by applying frequency tables with percentages. Data were revised, coded and analyzed. Qualitative data was presented as number and percentage. Quantitative data were described as mean SD (standard deviation). Association between categorical variables was tested using chi- square test. Significance occurred when the probability of error is less than 5% (P< 0.05) and highly significant occurred when the probability of error is less than 0.1% (p< 0.001).

3. RESULTS

Table (1): Clinical data of the Thalassemic children in percentage distribution (no=132)

Variable	No	%
Age at onset of the disease		
>1 year	88	67.2
1 :3 years	26	19.8
<3 years	17	13.0
Mean ±SD(months)	14.9 ±13.1	
Type of thalassemia		
Minor	10	7.6
Intermediate	19	14.5
Major		
Disease duration		
From 6 to <9	39	29.8
From 9 to <12	35	26.7
From 12 to <15	31	23.7
>15		
Mean ±SD	11.3 ±3.6	
Family history of thalassemia		
No	60	45.8
First degree relatives	58	44.3
Second degree relatives	13	9.9
The number of Thalassemic siblings in the family		
None	62	47.3
One	48	36.6
Two	17	13.0
Three or more	4	3.1
Frequency of blood transfusion		
1-2 time/year	11	8.4
Once / month	105	80.2
Two times or more / month	15	11.5

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Regulatory of blood transfusion		
Regular	112	85.5
Irregular	19	14.5
1-2 time/year	11	8.4

Table 1: This table presented that, 67.2% 0f the studied Thalassemic children were diagnosed as Thalassemic children in the first year of age. About 77.9% of them were diagnosed as thalassemia major. About 45.8% of them had no family history of thalassemia and 47.3% of them had none Thalassemic siblings. As regard number of blood transfusion per month, 80.2% were transfused once per month. According to regularity of blood transfusion, 85.5% of them were irregular.

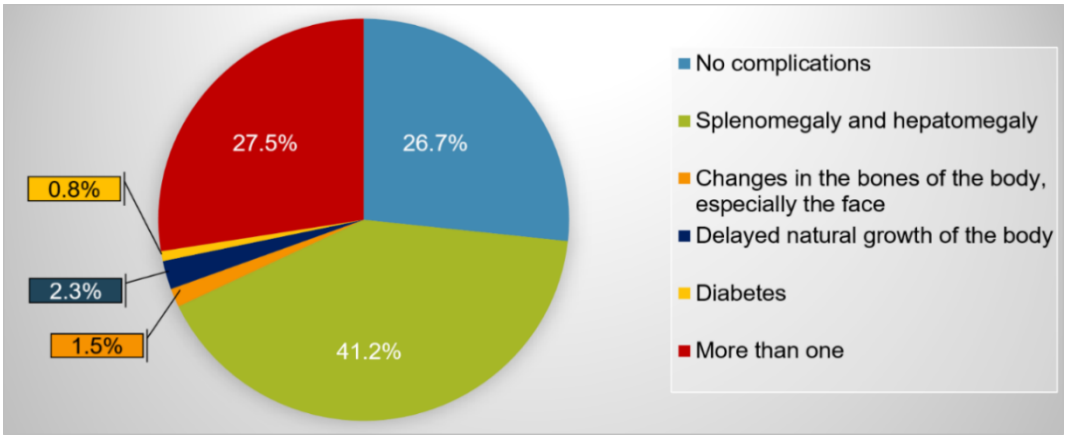

Figure 1: Associated complication with thalassemia among studied children

Fig (1). Associated complication with thalassemia among studied children, it was illustrated from this figure that the majority of children were complicated as (41.2%) had splenomegaly and hepatomegaly and (27.5%) of them had more than one complication. While, the minority of them (0.8%) of them had diabetes.

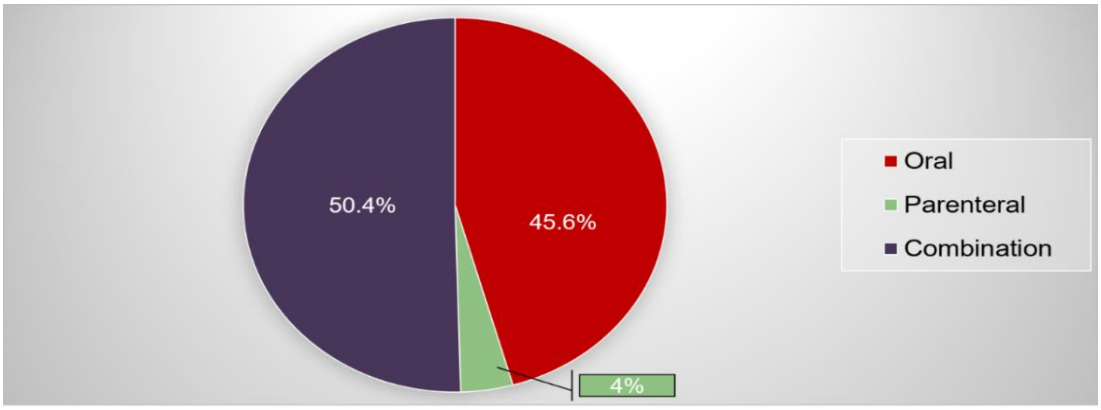

Figure 2: Distribution of treatment modalities used among Thalassemic children

Fig (2). Distribution of treatment modalities used among Thalassemic children, it was clarified from this figure that approximately (50.4%) of the studied children depend on both oral and parental treatment modalities, while only (4%) were received parental treatment.

Table (2): Percentage distribution of level of knowledge of the Thalassemic children (n0=132).

Total knowledge	**No**	**%**
Poor	25	19.1%
Average	56	42.7%
Good	50	38.2%
M ± SD	11.7 ± 3.5	

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Table (2) reflects Percentage distribution of level of knowledge of the Thalassemic children. It was found that, approximately more than one third of the studied children (42.7%) have average level of knowledge. While, the minority (19.1%) of them were poor level of knowledge.

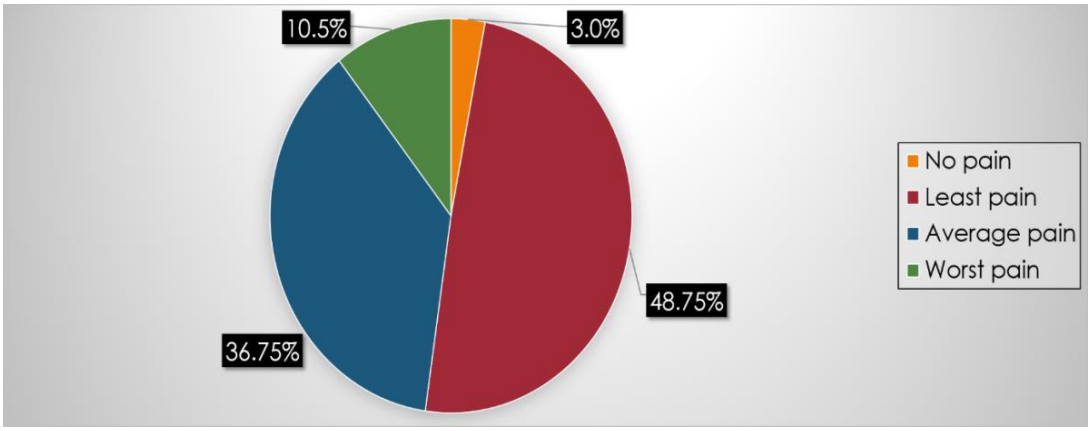

Figure 3: Intensity of pain among Thalassemic children in the last seven day

Fig (3). Intensity of pain among Thalassemic children in the last seven day. It was clear from that figure that approximately half of the studied children (48.75%) have least pain in the last seven day. While the minority of them (10.5%) have worst pain.

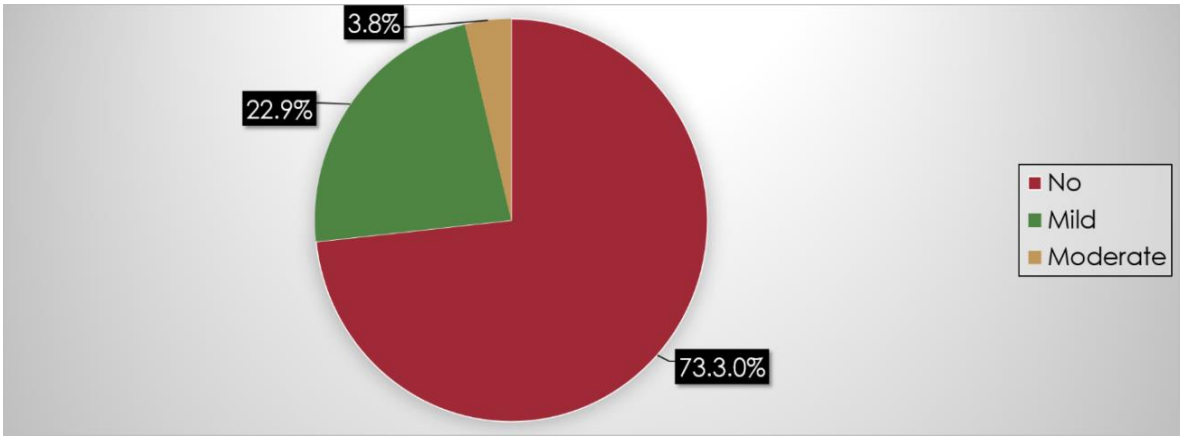

Figure 4: Severity of pain among Thalassemic children at the time of study

Fig (4). Severity of pain among Thalassemic children at the time of study. It was clear from that figure that approximately two third of the studied children (73.3%) have no pain at the time of study. While the minority of them (3.8%) have moderate pain.

Table (3): Interference level of pain with daily living areas in percentage distribution (no=132).

Variable	No		Mild		Moderate		Severe	
	No	%	No	%	No	%	No	%
General activity	0	0	26	19.8	70	53.4	35	26.7
Mood	3	2.3	39	29.8	70	53.4	19	14.5
Walking ability	1	0.8	23	17.6	43	32.8	64	48.9
School performance	5	3.8	43	32.8	65	49.6	18	13.7
Peer and family relation	19	14.5	82	62.6	27	20.6	3	2.3
Sleep	50	38.2	69	52.7	11	8.4	1	0.8
Life enjoyment	9	6.9	75	57.3	40	30.5	7	5.3

Table 3: This table clarifies that, 48.9% of the studied children pain severe interference with their walking ability. And about 38,2% of them pain no interfere with their sleep.

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Table (4): Percentage distribution of pain nature, frequency, duration and frequency of pain medication used(no=132).

Items	No	%
Pain nature		
Don't know	7	5.3
Throbbing	3	2.3
Compression	49	37.4
Colic& aching	15	11.5
Sharp	2	1.5
More than one feeling	55	42.0
Frequency of pain in the last 4 weeks		
Don't know	4	3.1
No pain	3	2.3
Times a day	30	22.9
Times a week	60	45.8
Times a month	34	26.0
Duration of pain		
Less than one year	69	52.7
2-3 years	31	23.7
4-5 years	20	15.3
More than 5 years	11	8.4
Medication frequency in the last 4 weeks		
Never use it	62	47.3
times daily	13	9.9
Once a week	40	30.5
Once a month	16	12.2
Action of pain medications		
No pain relief	71	54.2
50% pain relief	3	2.3
80% pain relief	2	1.5
100% pain relief	55	42.0

Table 4: This table presented that according to pain nature 42.0% of the studied children experience more than one feeling. In relation to frequency of pain in the last 4 weeks about 45.8% of them had pain time a week. As well as about 52.7% of them had pain for less than one year.

Table (1): Level of coping strategies used by Thalassemic children toward their pain in percentage distribution (no=132).

Items	Low coping		Moderate coping		High coping		Mean ±SD
	No	%	No	%	No	%	
Problem Focused Coping	111	84.7	18	13.7	2	1.5	3.5 ±3.7
Positive Cognitive Restructuring	113	86.3	16	12.2	2	1.5	4.1 ±3.7
Distracting Action	100	76.3	29	22.1	2	1.5	8.3 ±3.4
Avoidant Action	101	77.1	23	17.6	7	5.3	7.3 ±2.7
Support Seeking Coping Strategies	93	71.0	34	26.0	4	3.1	3.9 ±2.7
Aggressive Action	63	48.1	45	34.4	23	17.6	3.1 ±1.8
Total coping items							30.2 ±13.6

It was obvious from **table (5)** that the lowest coping strategies used by more than two third of Thalassemic children (86.3%) is positive cognitive restructuring. While, the moderately used coping strategies were aggressive action. At the last, The mean score of coping strategies is (30.2 ±13.6), which indicate moderate coping strategies used by Thalassemic children.

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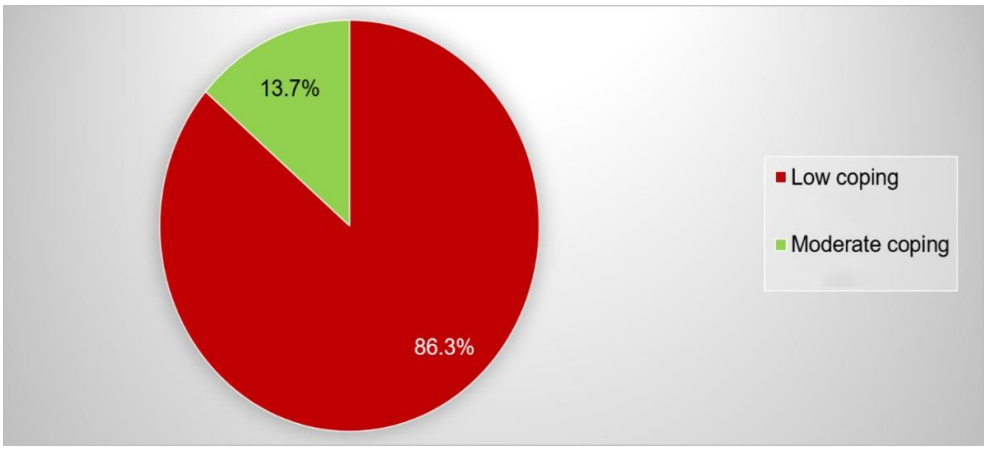

Figure 5: Total coping level among Thalassemic children

Fig (5). Total coping level among Thalassemic children**.** It was obvious that, the majority (86.3%) of the studied children had low coping with pain. Compared to only (13.7%) of them had moderate coping**.**

4. DISCUSSION

Pain in Thalassemia, make the child and his parents Suffer from many problems. To improve the quality of life of children with thalassemia and their families must follow a good coping method **(Salehi& Morovati, 2016)**[17]. The current study showed that, approximately two thirds of the studied Thalassemic pediatric patients age of onset of disease were in the first year of their life **(Table 1**). This finding agrees with **NHLBI (2010)**[18] who conducted a study "What are thalassemia?" and mentioned that, signs and symptoms of thalassemia disease appear early in the child life this is because occurrence of anemia. Similarly, **Nigam (2017)**[19] who conducted a study "B- Thalassemia: from clinical symptoms to the management" and found that manifestation of Thalassemia happen between six and twenty four months.

Ishaq (2012)[20] ; who conducted a study about " Parents awareness about prenatal diagnosis, who have children with thalassemia" Among Parents of B- Thalassemia Major Patients, Regarding Prenatal Diagnosis and Premarital Screening " and reported that most children with thalassemia found that one of his relative had thalassemia and therefore Thalassemia is an inherited disease. One of the most important causes of thalassemia is the relatives marriage. There is a large proportion of our society doing this habits "relatives marriage" due to the traditions and customs of society and people who prefer to marry from the same family without good knowledge of the consequences of that. Similarity, this finding goes in harmony with **Gharaibeh, Barqawi, Al-awamreh & Al Bashtawy (2018)**[21]; carried out a study about "Clinical burdens of B- Thalassemia Major in affected children" and stated that the majority of studied Thalassemic children had a family history of thalassemia.

Regarding the pediatric children knowledge about the complications of thalassemia, the present study showed that, more than half of them replied complete correct answer (**figuer1**), This result come in correspondent with **Chonat, 2017**[22] who studied "Management of Thalassemia" and mentioned that; the complications of thalassemia are; iron over load, infection, especially if the spleen removed, hepatitis B and hepatitis, bone deformities due to expansion of bone marrow, osteoporosis, enlarged spleen (splenomegaly), slowed growth rates, short stature, complication of endocrine (diabetes) and heart problems.

In addition, regarding the studied Thalassemic pediatric patient knowledge about the treatment about thalassemia it was noticed that approximately more than half of the pediatric patient in the present study answered completely correct answer such as blood transfusion, chelation therapy, splenectomy and bone marrow transplantation (**figure2)**. This result come in agreement with **Makis, 2017**[23] who study " Clinical trials update in new treatments of β-thalassemia " and mentioned that the effective therapy of children with thalassemia includes blood transfusion therapy, iron chelation, spleen removal, and bone marrow transplantation. Similarity, this finding goes in harmony with **Chonat et al., 2017** who studied "Management of Thalassemia" and reported that the treatment of thalassemia need regular blood transfusion, chelation therapy (by using desferrioxamine and deferiprone that are effective in maintaining Thalassemic pediatric patient life by preventing serious complication result from the disease of thalassemia) splenectomy and bone marrow transplantation.

Concerning the knowledge level of Thalassemic children toward their disease and pain **table (2)**, the result of the current study showed that approximately one third of the pediatric patient in the present study had average level of knowledge and the minority of them had poor level of knowledge. This study come in agreement with **Miri-Moghaddam, Motaharitabar & Houshvar 2014**[24] who conducted a study "High school knowledge and attitude towards thalassemia in southeastern Iran" and mentioned that more than half of our sample study had acceptable knowledge (average) and only 14.7% of them had poor knowledge. Moreover, **Przybelinski, 2015**[25] who conducted a study "Pediatric Patient knowledge about thalassemia and associated pain " and added that the Thalassemic pediatric patients in the study have moderate level of knowledge about disease and associated pain. This finding goes in contradicted with **Kourorian, 2014**[26] who conducted a study " Thalassemic pediatric children knowledge, attitude and practice toward disease and accompanied pain " and founded that thirty nine percentage of Thalassemic pediatric patients had poor information about thalassemia and twenty eight point five percentage of thalassemic pediatric patient had satisfying information

As regard the severity of pain of the studied children, it was observed that, more than half of the studied pediatric patient have mild pain **(Figure 3).** This result come in agreement with **Haines& Oliveros 2013**[27] who study "pain severity and frequency in thalassemia" and state that Thirty-nine percent rated worst pain as severe {seven–ten/ten} while forty two percentage reported their worst pain as moderate {four–six/ten}. 63% of the pediatric thalassemic patients in the study rated their average pain over the last seven days to be at least moderate.

The current study revealed that, pain interfere with daily living activity as walking ability, general activity, mood and school performance respectively **(Table 3).** This study come in agreement with **Gharaibeh, et al., (2018)** who founded that when children get older they experience more leg ulcers, as well as bone and joint pain, which impact on their daily activities, especially attending school regularly. Similarity, this finding goes in harmony with **Kumar, 2017**[28] who studied " Impact of pain in thalassemic pediatric patients daily routine" and reported that Increased pain severity significantly interfered with daily life activity. Approximately one third of thalassemic pediatric patients pain decrease their ability to practice daily activities as walking, twenty nine point two percentage pain affected school performance and concentration in lessons and forty point two percentage had difficulty in practicing their hobbies.

In relation to the pain nature of the thalassemic pediatric patients **Table (4)**, it was observed that, the natural of pain was more than one feeling, followed by compression, aching, and throbbing. This finding goes in harmonies with **Haines, 2010**[29] who studied "Phenomenon of pain in thalassemia" and who mentioned that, as described by participants, the nature of pain was aching {seventy nine percentage}, throbbing{sixty one percentage}, sharp {fifty percentage}, and tiring {fifty five percentage}.

As regard the frequency of pain of the studied children, it was observed that, more than one third of the studied pediatric patient have pain one time per a week, followed by one time per a month ,then the minority of them have one time a day **(Table 4).** This result come in agreement with **Kuşkonmaz, 2014**[30] who conducted a study about "Endocrinological Problems in Adult Thalassemia Patients" and demonstrated that the majority of β-TM children experienced pain in the past month and 22% of the minority reported pain on a daily basis. In addition, 81% and 31% of all patients experienced pain for one to five year or longer, respectively.

In relation to level of coping strategies used by Thalassemic children toward their pain, it was observed from **Table (5)** that, the moderately used coping strategies are aggressive action, support seeking, distracting and avoidant action respectively. This study come in agreement with **Kraaimaat, 2018**[31] who conducted a study about " The way in which chronic pain patients as thalassemia used to cope with their pain and characteristic of pain- coping"and indicated that patient with chronic pain used active pain coping as pain transforming and distraction more than the use of passive pain coping as treating and worrying active. This study doesn't come in agreement with **Esteve, Ramírez, & López, 2007**[32] who conducted a study about "Methods used by thalassemic pediatric patients as a result of pain and stress " and indicated that active coping is associated with a better social relation and school performance while passive coping lead to increase maladjustment.

5. CONCLUSION AND RECOMMENDATIONS

Based on the findings of the current study, it is concluded that More than one third of the studied children had average knowledge about thalassemia. Also, more than one third of the studied children had least pain followed by average pain and the majority of them pain interfere with their walking ability. As well as, more than two third of the studied children had moderate level of coping..

Accordingly, the study recommended that:

1- Health educational program for children about thalassemia and pain associated wlth the disease at outpatient clinics to improve their knowledge toward thalassemia and pain.

2- Regular and continuous health educational programs are essential for nurses working with thalassemia about thalassemia and its associated pain.

REFERENCES

[1] Ansari, S. H., Baghersalimi, A., Azarkeivan, A., Nojomi, M., & Rad, A. H. (2014). Quality of life in patients with thalassemia major. Iranian journal of pediatric hematology and oncology, 4(2), 57.

[2] Tari, K., Valizadeh Ardalan, P., Abbaszadehdibavar, M., Atashi, A., Jalili, A., & Gheidishahran, M. (2018). Thalassemia an update: molecular basis, clinical features and treatment. International Journal of Biomedicine and Public Health, 1(1), 48-58.

[3] Fibach, E., & Rachmilewitz, E. A. (2017). Pathophysiology and treatment of patients with beta-thalassemia–an update. F1000Research, 6.

[4] Al-Mosawy, W. F. (2017). The beta-thalassemia. Scientific Journal of Medical Research, 1(1), 24 – 30.

[5] El Mezayen, A., Sadek, N. A.,Kotb, S. M., & Abdalla, E. (2015). Globin Mutations in Egyptian Patients With –Thalassemia. Laboratory Medicine, 46(1):8-13available at www.labmedicine.com.

[6] Malakar, R., Kour, M., Malviya, S. N., and Dangi, C. B. S. (2018). A REVIEW ON: B-THALASSEMIA . Department of Biotechnology, RKDF University Bhopal (M.P.) India, 6(5), 432-445.

[7] Darvishi-Khezri, H., Salehifar, E., Kosaryan, M., Karami, H., Mahdavi, M., Alipour, A., & Aliasgharian, A. (2018). Iron-chelating effect of silymarin in patients with β-thalassemia major: A crossover randomised control trial. Phytotherapy Research, 32(3), 496-503.

[8] Lal, A. (2016). Assessment and treatment of pain in thalassemia. Annals of the New York Academy of Sciences, 1368(1), 65-72.

[9] Haines, D., Martin, M., Carson, S., Oliveros, O., Green, S., Coates, T., ... & Gerstenberger, E. (2013). Pain in thalassaemia: the effects of age on pain frequency and severity. British journal of haematology, 160(5), 680-687.

[10] Zeydi, A. E., Heydari, A., & Karimi Moonaghi, H. (2018). Pain in β-thalassemia major patients: an important yet neglected issue. The Korean journal of pain, 31(1), 58-59.

[11] Marttinen, M. K., Santavirta, N., Kauppi, M. J., Pohjankoski, H., & Vuorimaa, H. (2018). Validation of the Pain Coping Questionnaire in Finnish. European Journal of Pain, 22(5), 1016-1025.

[12] Donnelly, T. J., & Jaaniste, T. (2016). Attachment and chronic pain in children and adolescents. Children, 3(4), 21.

[13] Pender, R. R., Webber, J., & Mascari, J. B. (2015). Using Play to Help Children Cope With Chronic Pain: A New Role for Counselors.

[14] Camisasca, E., Caravita, S., Milani, L., & Di Blasio, P. (2012). THE CHILDREN'S COPING STRATEGIES CHECKLIST-REVISION1: A VALIDATION STUDY IN THE ITALIAN POPULATION. TPM: Testing, Psychometrics, Methodology in Applied Psychology, 19(3).

[15] Aycicek, A., Koc, A., Bayram, C., & Abuhandan, M. (2016). The Impact of Patient and Parents' Education by Nurses on Serum Ferritin Levels in Children with Beta-Thalassemia Major. Global Journal of Hematology and Blood Transfusion, 3, 48-53.

[16] Kelsey, J. A., Azize, P. M., & Tahir, F. A. (2015). Nurses' knowledge and role in the management of thalassemic disease in the Sulaimania Thalassemia Centre.

[17] Salehi, S., & Morovati, S. (2016). Coping behaviors in families with children suffering from thalassemia major and evaluating the implementation effect of nursing intervention on these behaviors. International Journal of Medical Research and Health Sciences, 5(2), 58-63.

[18] NHLBI (2010): National Heart, Lung, and Blood Institute. What are thalassemias? Available at: http://www. nhlbi.nih.gov/health/dci/Disease/Thalassemia-All.html.

[19] Nigam, N., Nigam, S., Agarwal, M., & Singh, P. K. (2017). β-Thalassemia: From Clinical Symptoms to the Management.

[20] Ishaq, F., Hasnain Abid, F. K., Akhtar, A., & Mahmood, S. (2012). Awareness Among Parents of ββ-Thalassemia Major Patients, Regarding Prenatal Diagnosis and Premarital Screening. Journal of the College of Physicians and Surgeons Pakistan, 22(4), 218-221

[21] Gharaibeh, H., Barqawi, M. A., Al-Awamreh, K., & Al Bashtawy, M. (2018). Clinical Burdens of β-Thalassemia Major in Affected Children. Journal of pediatric hematology/oncology, 40(3), 182-187.

[22] Chonat, S., & Quinn, C. T. (2017). Current Standards of Care and Long Term Outcomes for Thalassemia and Sickle Cell Disease. In Gene and Cell Therapies for Beta-Globinopathies (pp. 59-87). Springer, New York, NY.

[23] Makis, A., Hatzimichael, E., Papassotiriou, I., & Voskaridou, E. (2016). 2017 Clinical trials update in new treatments of β-thalassemia. American journal of hematology, 91(11), 1135-1145.

[24] Miri-Moghaddam, E., Motaharitabar, E., Erfannia, L., Dashipour, A., & Houshvar, M. (2014). High school knowledge and attitudes towards thalassemia in southeastern Iran. *International journal of hematology-oncology and stem cell research*, *8*(1),24.

[25] Przybelinski, K. M., & Ball, L. S. (2015). Patients' knowledge of pain agreements. The Nurse Practitioner, 40(9), 39-46.

[26] Kourorian, Z., Azarkeivan, A., Hajibeigi, B., Oshidari, A., & Shirkavnd, A. (2014). The effect of knowledge, attitude and practice on the function of Thalassemic patients. Iranian Journal of Blood and Cancer, 6(4), 177-181.

[27] Oliveros, O., Trachtenberg, F., Haines, D., Gerstenberger, E., Martin, M., Carson, S., ... & Vichinsky, E. (2013). Pain over time and its effects on life in thalassemia. American journal of hematology, 88(11), 939-943

[28] Kumar, G., Chhabra, A., Dewan, V., & Yadav, T. P. (2017). Idiopathic musculoskeletal pain in Indian children–Prevalence and impact on daily routine. Revista brasileira de reumatologia, 57(1), 8-14.

[29] Haines, D., Carson, S., Green, S., Martin, M., Coates, T. D., Vega, O. O., ... & Giardina, P. (2010). Phenomenon of pain in thalassemia: a prospective analysis by the thalassemia clinical research network (TCRN).

[30] Kuşkonmaz, Ş. M. (2014). Endocrinological Problems in Adult Thalassemia Patients. Gazi Medical Journal, 25(4A).

[31] Kraaimaat, F. W., & Evers, A. W. (2018). Pain-coping strategies in chronic pain patients: psychometric characteristics of the pain-coping inventory (PCI). International journal of behavioral medicine, 10(4), 343-363.

[32] Esteve, R., Ramírez-Maestre, C., & López-Martínez, A. E. (2007). Adjustment to chronic pain: the role of pain acceptance, coping strategies, and pain-related cognitions. *Annals of Behavioral Medicine*, *33*(2), 179-188.