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Self-Efficacy of Adolescents with Thalassemia Major

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Abstract

Background: Adolescents suffering from chronic disease as thalassemia major are more susceptible for social, psychological, and physical barriers. Those barriers are generally more likely to be overcome if affected adolescents have a high level of self-efficacy. This study **Aimed to** assess self-efficacy of adolescents with thalassemia major. A descriptive research **Design**: was used to perform this study. A convenience sampling of (80) adolescents with thalassemia major attending the Thalassemia Center at Assiut University Children Hospital was selected. Data were collected by utilizing **Two Tools**: **Tool (1)**:- A structured Questionnaire Interview Sheet, **Tool (2)**:- The Self-Efficacy Scale. **Results** of this study revealed that the majority of the studied adolescents (80.0%) had low self-efficacy levels. The study results indicated that there was a statistically significant difference as regards self-efficacy levels and number of siblings (p= 0.02). **Conclusion**: The present study emphasized low self-efficacy levels among adolescents with thalassemia major. So the study **recommended** that health education programs for adolescents with thalassemia major are indicated to increase their knowledge about the disease and how to cope with it.

Keywords: Adolescents- Self-efficacy & Thalassemia Major.

Introduction

Thalassemia major is one of the commonest hereditary blood disorders in the world that results from absence of or decreased globin chain production. β-Thalassemia major is the most common chronic hemolytic anemia among adolescents worldwide. The total annual incidence of symptomatic patients is estimated at 1 in 100,000 throughout the world. Major factors affecting the disease progression are ineffective hematopoiesis, hemolysis and anemia **(Bonjar, 2018).**

Control of thalassemia depends on certain preventive health services. Premarital counseling**,** education about the risks of conceiving a child with thalassemia combined with screening and genetic counseling are associated with numerous health benefits which include decreasing the chance of having a child affected with thalassemia major **(Basu, 2015)**.

Self-efficacy is defined as the trust on one's ability to perform self-care behaviors and activities in certain conditions. It is an effective factor in promoting adolescents' quality of life. The concept of self-efficacy in the patient with thalassemia is also important, and it is related to the capability to achieve some important goals together with their psychological well-being **(Platania et al., 2017).**

Similar to other chronic diseases**,** thalassemia imposes serious physical**,** socio-mental**,** congenital and economic effects to the adolescents and their families. Physical problems such as chronic anemia, bone deformation, growth change, short height and delayed physical maturing on one hand and unpleasant and long and repetitive therapies on the other hand affect different life aspects of the adolescents (**Moghadam, et al., 2016).**

Thalassemia major have a significant negative impact on social and educational activities of children and adolescents as children cannot attend school because of hospitalization**,** frequent blood transfusions and treatment. These factors results in greater dependence on others. Chronic nature of thalassemia causes changes in different aspects of adolescents' life, including their self-efficacy **(Borimnejad et al., 2017)**.

Thalassemia major is a chronic hemolytic anemia; therefore the nurse needs to build a close bond with the adolescent as he would require a continued care. The nurse must consider both psychological as well as medical needs of the family **(Gupta, 2017)**.

Significance of the study

Disease duration, treatment period, increased hospitalization and therapy costs, mental status and social harms are among complexities affecting adolescents with thalassemia major and their families. As an influential factor of the quality of life**,** self-efficacy emphasizes adolescents' perception of their abilities in successfully performing a competent performance.

Researches show that those adolescents who trust their abilities actively participate in health programs promoting healthy living. Better drug compliance and better relations with therapy team are among the positive outcomes of self-efficacy programs. Adolescents with maximum self-efficacy levels are more probable to start or maintain a specific function even in the face of existing barriers (**Moghadam, et al., 2016)**.

Aim of the study

The aim of this study was to assess self-efficacy of adolescents with thalassemia major.

Study question

Does thalassemia major have an effect on self-efficacy?

Subjects & Method

Research design

A descriptive research design was utilized to conduct this study.

Setting

This study was conducted at Assiut University Children Hospital.

Subjects

A convenience sample composed of 80 adolescents with thalassemia major attending the Thalassemia Center at Assiut University Children Hospital was included in the study. All adolescents who were able to read and write and willing to participate in the study were recruited into the study.

Tools of data collection

Two tools were used for this study.

Tool (1): A structured Questionnaire Sheet

It was divided into two parts

Part I: Demographic characteristics of the studied adolescents as age, sex, birth order, number of siblings, residence and educational level.

Part II: - Adolescents' clinical data as age at onset of the disease, duration of the disease, onset of chelation therapy, frequency of blood transfusion, whether splenectomy had been done or not, family history of the disease and parental degree of consanguinity.

Tool (2): The Self-Efficacy Scale

The Self-Efficacy Scale (SCSES) was adapted from **(Edwards et al., 2001).** It was the first instrument validated to test self-efficacy in adolescents and adults with sickle cell disease (SCD) and thalassemia major. The scale contained nine questions that measured self-efficacy in adolescents with sickle cell disease and thalassemia major, indicating adolescents' confidence in controlling routines as well as their ability to manage the disease and control symptoms caused by the disease.

Scoring system

Responses were scored in a 5 point likert scale ranging from "not at all sure" to "very sure" and the scores ranged from 9-45. Higher scores indicated greater self-efficacy associated with the disease. Scores 9-20**,** 21-32**,** and 33-45 indicated low self-efficacy**,** moderate self-efficacy and high self-efficacy, respectively.

Validity and reliability

The Self-Efficacy Scale was reviewed by the expert panel and modified to accommodate the difference in nature of the sickle cell disease and thalassemia major eg. deletion of two question revolving around the pain and addition of question about school absentism and another question about fear of rejection due to facial changes.

The researcher translated the Self-Efficacy Scale items into Arabic form. The content validity of tool (2) was estimated by five experts in Pediatrics and Pediatric Nursing Field. The content validity index was 90% and internal consistency was tested by using the Cronbach's alpha and it was r= 0.83.

Method of data collection

1- An official Permission was obtained from the chairman of Pediatric Department for approval to collect data from the Thalassemia Center at Assiut University Children Hospital.
2- A pilot study was carried out on 10 % (8) adolescents. It was conducted to assess the clarity of the study tools and to estimate the time required to fulfill the questionnaire. Based on the results of the pilot study, modifications were done. The adolescents included in the pilot study were excluded from the study sample.
3- The tools used for the study were ensured to be valid and reliable before the beginning of data collection.

Ethical considerations

A written informed consent was taken from the adolescents and their parents. The adolescents were informed that they were under no obligations to participate in the study and the study would not affect their education or assessment. Confidentiality and anonymity were assured. Adolescents had the right to withdraw from the study at any time without any rationale.

Field of the work

The study was conducted over a period from the beginning of November 2018 to the end of April 2019. Data were collected two days each week. 2-3 adolescents/ day were interviewed. The study was conducted in the morning shift. Each adolescent was individually interviewed using the questionnaire sheet. The researcher first introduced herself to them

and gave them a complete background about the study. Throughout the interview, related information was recorded in the designed sheet depending upon the response of the participant. The time used for filling each sheet ranged between 15: 25 min.

Statistical Analysis

All the statistical analysis was performed using SPSS package version 20. The collected data were coded and analyzed. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables and mean and standard deviations for quantitative variables. Qualitative variables were compared using Chi-square. Statistical significance was considered at P. value < 0.05.

Results

Table (1): Demographic characteristics of the studied adolescents with thalassemia major.

Items	Studied adolescents (n= 80)	
	No	%
Age		
12 - <15 years	60	75.0 %
15 - 18 years	20	25.0 %
Mean± SD	14.03 ± 1.79	
Sex		
Male	38	47.5 %
Female	42	52.5 %
Birth order		
First child	12	15.0 %
Second child	44	55.0 %
Third child	22	27.5 %
Fourth or more	2	2.5 %
Number of siblings		
One	8	10.0 %
Two	30	37.5 %
Three or more	42	52.5 %
Residence		
Rural	40	50.0 %
Urban	40	50.0 %
Educational level		
Basic education	52	65.0 %
Secondary	24	30.0 %
University	4	5.0 %

Table (2): Percentage distribution of the studied adolescents according to their clinical data (n= 80).

Items	Studied adolescents n=80	
	No.	%
Age of onset of the disease		
< 6 months	6	7.5 %
6 < 12 months	58	72.5 %
12 < 18 months	14	17.5 %
≥18 months	2	2.5 %
Duration of the disease since first symptoms		
5 < 10 years	2	2.5 %
10 < 15 years	64	80.0 %
≥ 15 years	14	17.5 %

Items	Studied adolescents n=80	
	No.	%
Onset of chelation therapy		
1 ≤ 3 years	4	5.0 %
3 ≤ 5 years	42	52.5 %
≥ 5 years	34	42.5 %
Frequency of blood transfusion		
Less than 3 weeks	12	15.0 %
3 weeks	38	47.5 %
More than 3 weeks	30	37.5 %
Splenectomy		
Yes	52	65.0 %
No	28	35.0 %
Family history		
Yes	56	70.0 %
No	24	30.0 %

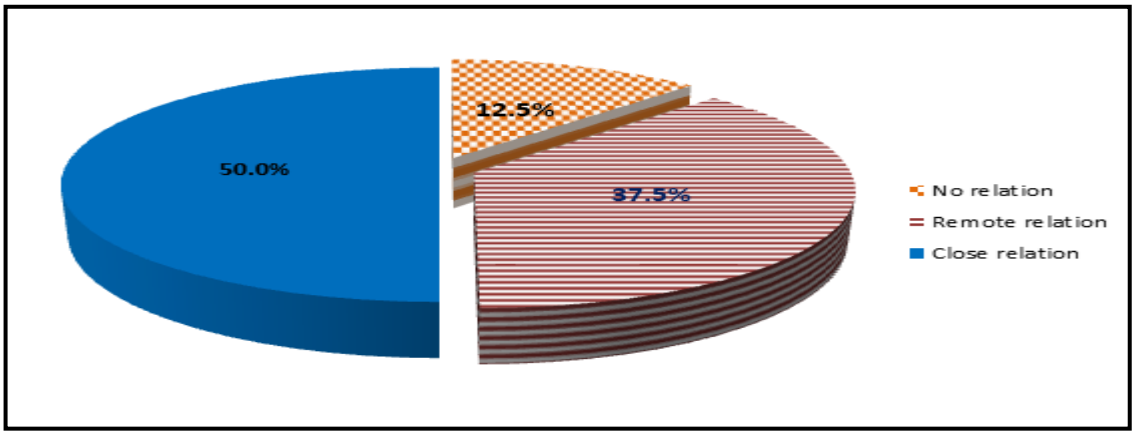

Figure (1): Percentage distribution of parental degree of consanguinity among the studied adolescents.

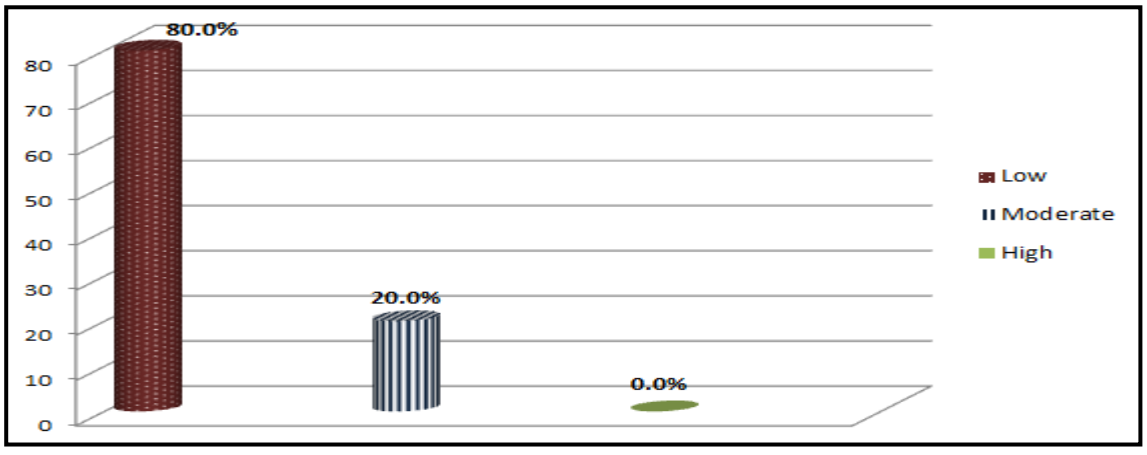

Figure (2): Percentage distribution of self-efficacy levels among the studied adolescents.

Table (3): Relation between the studied adolescents' self-efficacy levels and their demographic characteristics.

Item	Self-efficacy level						P. value
	Low		Moderate		High		
	No	%	No	%	No	%	
Age							
12-15	51	63.8 %	9	11.2 %	0	0.0 %	0.054
16-18	13	16.2 %	7	8.8 %	0	0.0 %	
Gender							
Male	28	35.0 %	10	12.5 %	0	0.0 %	0.18
Female	36	45.0 %	6	7.5 %	0	0.0 %	
Birth order							
1st child	12	15.0 %	0	0.0 %	0	0.0 %	
2nd child	33	41.2 %	11	13.8 %	0	0.0 %	0.18
3rd child	18	22.5 %	4	5.0 %	0	0.0 %	
4th or more	1	1.2 %	1	1.2 %	0	0.0 %	
Number of siblings							
One	4	5.0 %	4	5.0 %	0	0.0 %	0.02*
Two	28	35.0 %	2	2.5 %	0	0.0 %	
Three or more	32	40.0 %	10	12.5 %	0	0.0 %	
Residence							
Rural	33	41.2 %	7	8.8 %	0	0.0 %	0.58
Urban	31	38.8 %	9	11.2 %	0	0.0 %	
Level of child's education							
Basic education	45	56.2 %	7	8.8 %	0	0.0 %	0.09
Secondary	17	21.2 %	7	8.8 %	0	0.0 %	
University	2	2.5 %	2	2.5 %	0	0.0 %	

**Statistically significant difference (p≤ 0.05).*

Table (4): Relation between the studied adolescents' self-efficacy levels and their clinical data.

Item	Self-efficacy level						P. value
	Low		Moderate		High		
	No	%	No	%	No	%	
Age of disease onset							
< 6 months	5	6.2 %	1	1.2 %	0	0.0 %	
6 – <12 months	46	57.5	12	15.0 %	0	0.0 %	0.69
12 -18 months	12	15.0 %	2	2.5 %	0	0.0 %	
≥ 18 months	1	1.2 %	1	1.2 %	0	0.0 %	
Duration of the disease since first symptoms							
5 ≤ 10 years	1	1.2 %	1	1.2 %	0	0.0 %	0.13
10 ≤ 15 years	54	67.5 %	10	12.5 %	0	0.0 %	
≥ 15 years	9	11.2 %	5	6.2 %	0	0.0 %	
Onset of chelation therapy							
1 ≤ 3 years	1	1.2 %	3	3.8 %	0	0.0 %	0.008**
3 ≤ 5 years	37	46.2 %	5	6.2 %	0	0.0 %	
≥ 5 years	26	32.5 %	8	10.0 %	0	0.0 %	
Frequency of blood transfusion							
Less than 3 weeks	10	12.5 %	2	2.5 %	0	0.0 %	0.06
3 weeks	34	42.5 %	4	5.0 %	0	0.0 %	
More than 3 weeks	20	25.0 %	10	12.5 %	0	0.0 %	
Splenectomy							
Yes	39	48.8 %	13	16.2 %	0	0.0 %	0.13
No	25	31.2 %	3	3.8 %	0	0.0 %	

*** Highly statistically significant difference (p≤ 0.01).*

Table (1): Indicates demographic characteristics of the studied adolescents with thalassemia major. The results showed that 75.0 % of the studied adolescents aged from 12- <15 years old with a mean ± SD 14.03 ± 1.79 years. According to their gender**,** more than half (52.5 %) of the studied adolescents were females. As well, more than half (55.0 %) of them were the second child in their family. The results revealed that more than half (52.5%) of adolescents had three or more siblings. Exact equal proportions of the studied adolescents were from both rural and urban areas. Regarding level of education, less than two thirds (65.0 %) of them had basic education.

Table (2): Illustrates percentage distribution of the studied adolescents according to their clinical data. The disease onset in the highest percentage (72.5 %) of the studied adolescents was between 6- <12 months. As regards the disease duration, the majority (80.0 %) of the studied adolescents had disease symptoms since 10< 15 years ago. More than half (52.5 %) of the studied adolescents started the chelation therapy when they were 3- <5 years old. The results indicated that 47.5 % of them had blood transfusion every three weeks. Also, 65.0 % of the studied adolescents had splenectomy. The study results presented that most of the studied adolescents (70.0%) had positive family history of thalassemia major.

Figure (1): Shows percentage distribution of parental degree of consanguinity among the studied adolescents. The study results indicated that an exact half of the studied adolescents' parents were closely related.

Figure (2): Represents percentage distribution of self-efficacy levels among the studied adolescents. This result illustrated that the majority of them (80.0%) had low self-efficacy levels.

Table (3): Shows the relation between the studied adolescents' self-efficacy levels and their demographic characteristics. The study results indicated that there was a statistically significant relation as regards self-efficacy levels and number of siblings (p= 0.02) as the highest percentage (40.0 %) of the studied adolescents with three or more siblings had low self-efficacy level. While no statistically significant relations were detected as regards other variables.

Table (4): Reveals the relation between the studied adolescents' self-efficacy level and clinical data. A highly statistically significant relation (P= 0.008) between self-efficacy levels and the onset of chelation therapy was present as the highest percentage (46.2 %) of the studied adolescents who started chelation therapy between 3 up to 5 years old had low self-efficacy level. There was no statistically significant difference as regards the other items.

Discussion

Adolescents with thalassemia major have difficulties adjusting to their illness which predispose them for poor longitudinal outcome. One potentially modifiable construct that may be important to adolescent adjustment is self-efficacy. Coping with the illness is best when the individual demonstrates self-efficacy, takes charge of life situations, and has a strong expectation of being successful with the outcome **(Parhiz et al., 2016)**.

The current study revealed that disease onset in the highest percentage of the studied adolescents was between six up to twelve months. This goes in the same line with results of **Hussein & Mansour (2015)**, whose results showed that (65%) of the sample were infant at the age of diagnosis of thalassemia. This can be attributed with the fact indicating that thalassemia major are highly to be recognized during the latter half of the first year due to high tendency of the disease to be more symptomatic.

More than half of the studied adolescents started their chelation therapy when they were 3-< 5 years old. This is different from results of **Shareef & Obaid (2015)**, who indicated that the majority of the studied adolescents started having iron chelating therapy after five years old.

In addition, less than half of the studied adolescents had blood transfusion every three weeks, as indicated by the current study. Also the study conducted by **Hussein & Mansour (2015)**, whose results showed that (78%) was taking blood transfusion 1-2 times monthly. This result indicates the essentiality of regular blood transfusion for the survival of affected children with thalassemia major.

The current study showed that more than two thirds of the studied adolescents had splenectomy. This contradicts results of **Hussein & Mansour (2015)**, who showed that (34%) of those patients had splenectomy.

As regards consanguinity degree, an exact half of the studied adolescents' parents were closely related as noted from the results of the current study. Consanguineous marriages and avoiding pre-marital and antenatal screening are common due to cultural, and economic factors which support relative marriages.

Unsurprisingly, results of the current study revealed that the majority of the studied adolescents had low self-efficacy levels. These results are in line with results of **Sheibani et al., (2015),** who showed that

the mean score of self-efficacy in adolescent with major thalassemia is low.

Moreover, the study results indicated that there was a statistically significant relation between self-efficacy levels and number of siblings (p= 0.02). From the researcher's point of view, having an increased number of siblings somehow limits both the adolescent's options and parental support and encouragement in achieving his goals hence decreases personal beliefs regarding his capabilities to carry out a specific task to achieve a desired outcome; in other words, decreases his self-efficacy.

In addition, a highly statistically significant relation between self-efficacy levels and onset of chelation therapy was noted from the study results. From the researcher's point of view, receiving iron chelation therapy affects the symptoms severity of blood transfusion and hence affects the adolescents' self-efficacy.

Conclusion

The present study results add to the growing body of evidence that supports low self-efficacy levels among adolescents with thalassemia major.

Recommendations

Based upon findings of the current study, the following recommendations are suggested;

1- Training programs for nurses on how to help caregivers to cope appropriately with their adolescents needs.
2- Health education programs for adolescents with thalassemia major are indicated to increase their knowledge about the disease and how to cope with it.

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