Effect of Health Instructions on Improving Knowledge and Practices of Thalassemic Adolescents at Zagazig University Hospital

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Abstract:

Background: Thalassemic adolescents need information about their disease in order to provide appropriate care, to decrease uncertainty, and to hold realistic expectations for their selves.**Aim of the study:** the present study aimed to identify the effect of health instructions on improving knowledge and practices of thalassemic adolescents at Zagazig university hospital. **Subjects and Methods:** a quasi-experimental study was conducted. **Setting & Sample:** sample of 50 thalassemic adolescents at the Pediatric Hematology Outpatient Clinic at Zagazig University Hospital in Sharkia Governorate, Egypt. **Tools:** Three tools were used in the present study as follows; structured interview questionnaire, clinical checklist and health instructions to educate the studied adolescents about β thalassemia major and its management. **Results:** the studied adolescents did not have satisfactory knowledge about their disease and its management before implementation of the health instructions. Thalassemic adolescent's knowledge, and practices scores had been improved significantly after implementation of health instructions either immediately or 2 months later ($P<0.01$). **Conclusion:** health instructions had improved thalassemic adolescents' knowledge and practices. **Recommendations:** Based on the results of the present study continuous health instructions and educational programs should be conducted for thalassemic adolescents about the disease, its treatment regimen and care practices. Further researches are needed to study the impact of health instructions on thalassemic children's compliance with their treatment regimen.

Key words: Thalassemia; thalassemic adolescents; health instructions; patient education

Introduction:

Thalassemias are hereditary hemolytic diseases in which an imbalance occurs in the synthesis of globin chains. As a group, they are the most common human single gene disorders. [(1)] β-thalassemia is an autosomal hematological disorder that is the result of genetically deficient synthesis of the β-globin chains of hemoglobin. [(2)] In β-thalassemia, the excessive α-globin chain precipitates and leads to damage to the red blood cell membrane. Ineffective erythropoiesis leads to anemia, bone marrow expansion, extramedullary hematopoiesis and increased intestinal iron absorption. [(3)]

The world health organization has estimated that as many as 80 million carriers for, β-thalassemia, exist worldwide. [(4)] There is a high prevalence of β-thalassemia in countries of the Middle East including Iraq, Lebanon, Egypt and Morocco, with an average carrier rate of ~1:30. Among Egyptians, β-thalassemia is the most common cause of chronic hemolytic anemia and represents a major health concern. [(2)]

Individuals with β-thalassemia major usually present within the first two years of life with severe anemia, requiring regular red blood cell transfusions. Findings in untreated or poorly transfused individuals with thalassemia major are growth retardation, pallor, jaundice, poor musculature, hepatosplenomegaly, leg

ulcers, development of masses from extramedullary hematopoiesis, and skeletal changes that result from expansion of the bone marrow. Regular transfusion therapy leads to iron overload-related complications including endocrine complication, dilated myocardiopathy, liver fibrosis and cirrhosis. (5)

Children with thalassemia usually are not aware of the gravity of their disease but, as they mature, they become more aware of the nature of thalassemia, either by their own accord or through their health care provider. This realization may create a level of denial and cause distress, but we cannot deny children's rights to knowledge regarding their own physical state. (6)

Although the information is needed, it may be overwhelming. Pediatric nurse needs to assess the readiness of the child and his caregivers to learn and will need to adjust the pace and the amount of information based on that assessment. In addition, nurses should be sensitive to the responses of the child and his care givers to the teaching and to assess their understanding of the information by asking appropriate questions or by having them demonstrate a newly acquired skill. (7) The patients may then accept the seriousness of their disease and its implications. (6)

Aim of the Study

The aim of the present study was to:

Identify the effect of health instructions on improving knowledge and practices of thalassemic adolescents at Zagazig university hospital.

Research Hypothesis:

- Thalassemic adolescents will have better knowledge about beta thalassemia major and its care after health instructions.
- Thalassemic adolescents will give themselves better care after health instructions.

Significance of the Study:

The way in which the patient come to terms with thalassemia and its treatment will have a critical effect on the patient's survival and quality of life. Without an understanding and acceptance of the disease and its implications, the difficulties of lifelong transfusion and chelation therapy will not be faced, leading to an increased risk of disease complications and poorer survival. A key role for the pediatric nurse is to help patients to face up the difficult demands of treatment, while maintaining a positive role through proper health education and instructions.

Subjects and methods:

Research Design:

A quasi experimental design was used in carrying out the present study.

Setting:

The present study was conducted at Pediatric Hematology Outpatient Clinic at Zagazig University Hospital (Outpatient Clinics Hospital).

Sample:

The study was conducted on a sample of 50 adolescents with confirmed diagnosis of β-thalassemia major who fulfilled the following criteria:-

- Age: from 12-18 years.
- Both sexes.
- Free from any other chronic disease except complications of thalassemia.

Tools of data collection:

Three tools were used to collect the necessary data as follows:

Tool (I): A structured Interview Questionnaire: A structured interview questionnaire was developed by the researchers to collect the required data and consisted of three main parts:

Part 1: Characteristics of the studied thalassemic adolescents

Part 2: Adolescents' knowledge about β thalassemia major and its care

Part 3: Adolescents' knowledge about chelation therapy

Part 2 and part 3 of tool (I) were used as pretest (before implementation of health instructions), post-test (after implementation of health instructions), and follow up (2 months later) format.

The scoring system of tool (I):

A scoring system of adolescents' knowledge was developed by the researchers as follows: 1grade for correct answer and zero for wrong answer or if the answer was (I do not know) Knowledge score in part 2 and part 3 was divided into:

A. Total knowledge score was 129 grades**.** These grades were classified to five main knowledge items as follow:

- Knowledge about blood and blood components summed 11 grades.
- Knowledge about the disease; 42 grades.
- Knowledge about disease's complications; 25 grades.
- Knowledge about diet and premarital genetic counseling 20 grades.
- Knowledge about chelation therapy and chelating agents; 31 grades.

Each knowledge item was divided into satisfactory and unsatisfactory as follows; unsatisfactory if < 50% and satisfactory if ≥ 50% of the item grades.

B. Total knowledge about care practices score totaled 46 grades and dealing with adolescents' knowledge about care practices such as measures taken to lower disease complications, investigations that should be done at follow up, sites of desferal subcutaneous infusion, measures to reduce local skin reactions of desferal, and precautions that should be taken to avoid side effects of iron chelators.

Total knowledge and knowledge about care practices scores were divided into satisfactory and unsatisfactory as follows:

Total Score	%	Corresponding Score
Total Knowledge Score		
Unsatisfactory	< 50%	< 64
Satisfactory	≥ 50%	≥ 64
Total Knowledge about Care Practices Score		
Unsatisfactory	< 50%	< 23
Satisfactory	≥ 50%	≥ 23

Tool (II): Clinical Checklist:

Clinical checklist was developed by the researchers to evaluate adolescents during administration of deferoxamine (desferal) subcutaneously with infusion pump. The clinical checklist was used as pretest, post-test, and follow up format.

The scoring system of tool (II):

Each step of the clinical checklist was given 1 grade if done correctly and zero if not done or done incorrectly, with total practice score of 43 grades.

Total practice score was divided into satisfactory and unsatisfactory as follows:

Total Score	%	Corresponding Score
Total Practice Score		
Unsatisfactory	< 50%	< 21
Satisfactory	≥ 50%	≥ 21

Tool (III): Health Instructions:

Health instructions were developed to educate adolescents about beta thalassemia major and its management and aimed to improve thalassemic adolescents' knowledge and practices to provide proper care for their selves.

The content of the health instructions was selected and the health instructions were planned and developed according to careful study of thalassemic adolescents' educational needs revealed from the assessment phase, and reviewing the relevant literature. Teaching methods were selected to suit teaching small groups' learners in the form of lectures, group discussion, demonstration, and redemonstration. Teaching materials were prepared as booklet, brochures and colored posters that covered theoretical and practical information. The health instructions have been implemented through five sessions. The length of each session ranged about 35-45 minutes. The thalassemic adolescents were divided into small groups; each group consisted of five to seven patients.

Evaluation of the health instructions' success was based on the improvement of the thalassemic adolescents' knowledge and practices. This evaluation was initiated before the health instructions, immediately after the health instructions and then after 2 months.

Field Work:

The tools of data collection were developed by the researchers after thorough detailed review of literature. Jury was done to assess the tools by 5 experts (two professors of pediatric nursing, two professors of pediatrics and one professor of community health nursing). The researchers attended the Pediatric Hematology Outpatient Clinic four days/week for data collection and implementation of health instructions. Each adolescent was individually interviewed to complete tool I and tool II (pretest/assessment phase). The health instructions (tool III) were developed on the basis of the results of the assessment phase and reviewing the relevant literature. The health instructions were implemented through five sessions, and were given in small groups; each group consisted of five to seven patients. After implementation of the health instructions, the studied adolescents were individually re-interviewed to assess their knowledge and practices (posttest) using tool I and tool II. Adolescents' knowledge and practices were reassessed again after two months of health instructions implementation (follow up) using the same tools. Data was collected during7 months, starting from January 2012 to July 2012.

Pilot Study:

A pilot study was conducted on 5 thalassemic adolescents to test the clarity of questions and to estimate the time required for using the tools. No modification was done to the tools; accordingly adolescents' who shared in the pilot study were included in the study sample.

Administrative and ethical Considerations:

An official permission for collection of data was obtained by submission of an official letter issued from the director of the faculty of nursing at Zagazig University to the director of Out-Patient Clinics Hospital "Pediatric Hematology Outpatient Clinic" at Zagazig University Hospital. Oral consent was obtained from the studied thalassemic adolescents after clarification of the aim and process of the study, as well as assurance of

maintaining anonymity and confidentiality of subjects' data, and emphasis on the patient's right to withdraw from the study at any phase.

Statistical Design:

The collected data was coded and entered in a data base file using the FoxPro for windows program. After complete entry, data was transferred to the SPSS version 19.0 program by which the analysis was conducted applying frequency tables with percentages and cross tabulations. Wilcoxon Rank Test was used to determine whether the studied thalassemic adolescents' knowledge and practices scores were significantly changed after repeated measurements. Cochran test was used to assess the significant change in the studied thalassemic adolescents' knowledge and practice throughout the three phases of implementing the health instructions (before, after, and 2 months later).

- P value was statistically significant at < 0.05
- P value was highly statistically significant at < 0.01

Results:

Table (1) shows the socio-demographic characteristics of the studied thalassemic adolescents. Regarding the adolescents' age, 38% were at the age group from 14 to 16 years. Males represented 60% of the studied adolescents. Those who ranked the first birth order constituted 44% of the studied sample. It is revealed from the same table that 82% of the studied adolescents were from rural areas. It was also found that 56% of the studied thalassemic adolescents had positive mother-father consanguinity, in which 82.14% and 17.86 were 2nd degree and 3rd degree relatives respectively. Moreover positive family history of the disease was found among 60% of the studied adolescents, 66.67% of them had a thalassemic brother or sister.

Effect of health instructions on thalassemic adolescents' total knowledge items score was represented in **table (2)**. The results showed that only 2% of the studied thalassemic adolescents had satisfactory knowledge scores regarding to blood and blood components and chelation therapy and chelating agents before implementation of health instructions, compared to 98% of them after health instructions. During follow up phase the previous percentage decreased to 58% and 34% for knowledge about blood and blood components and knowledge about chelation therapy and chelating agents respectively. The differences were highly statistically significant.

Satisfactory score of thalassemic adolescents' knowledge about disease had changed from 4% to 100% and then to 94% throughout the three phases of implementing health instructions with highly statistically significant difference.

The same table revealed that no one of the studied adolescents had satisfactory knowledge score about disease's complications before health instructions, but 100% of them had satisfactory score after health instructions and 90% in follow up phase. The difference was highly statistically significant. On the other hand, satisfactory total score of knowledge about diet and premarital genetic counseling represented the highest knowledge score among knowledge items throughout the three phases of implementing health instructions. It had changed from 42% to 100% and then to 98% in before, after and follow up phases, with highly statistically significant difference.

Table (3) clarifies the effect of health instructions on adolescents' total knowledge and knowledge about care scores. Regarding to total knowledge score, the results revealed that only 4% of the studied thalassemic adolescents have satisfactory total knowledge score before health instructions. This percentage increased to 100% after health instructions, and slightly decreased to 90% in the follow up phase. The difference was highly statistically significant.

As observed from the same table satisfactory total adolescents' knowledge about their care score had been changed from 42% to 100% and then to 96% respectively before, after and after 2 months of implementing the health instructions. The difference was highly statistically significant.

Effect of health instructions on thalassemic adolescents' practices in administration of deferoxamine subcutaneously with infusion pump during preparatory phase was represented in **table (4)**. It was found that only 6% of the studied adolescents clean their work area with antibacterial soap or alcohol before implementation of health instructions. This percentage increased to 100% and 94% after implementation of health instructions and in follow up phase respectively. It was also found that, 48% of the studied adolescents were washing their hands (before preparing desferal) before health instructions, compared to 100% after health instructions and 94% in the follow up phase. The differences were statistically significant.

Table (5) shows the effect of health instructions on thalassemic adolescents' practices in administration of deferoxamine subcutaneously with infusion pump during desferal preparation. It was found that there was statistically significant improvement throughout the three phases of implementing the health instructions regarding to all steps of desferal preparation.

Effect of health instructions on thalassemic adolescents' practices in administration of deferoxamine subcutaneously with infusion pump during desferal administration was shown in **table (6)**. The results showed that only 16% of the studied adolescents cleaned the injection site with alcohol or betadine (Iodine) using friction and let it dry before health instructions. The previous percentage improved to 94% after health instructions then to 96% during follow up phase, with statistically significant difference.

Pinching a small area of skin with fat tissue by thumb and index finger was done by 36%, 96% and 98% of the studied adolescents in before, after and follow up phase respectively. The difference was statistically significant. On the other hand, pulling back slightly on the plunger to see if blood comes into the syringe was done by only 2% of the studied adolescents before health instructions, this percentage improved to 86% after health instructions and then to 90% during follow up phase. The difference was statistically significant.

Table (7) clarifies the effect of health instructions on thalassemic adolescents' practices in administration of deferoxamine subcutaneously with infusion pump (after procedure). It was found that there was statistically significant improvement throughout the three phases of implementing the health instructions (before, after, and follow up) regarding to all steps of (after procedure) phase.

Effect of health instructions on thalassemic adolescents' total practices score was shown in **table (8)**. It was

found that 74% of the studied adolescents had satisfactory total practice score (regarding administration of deferoxamine subcutaneously with infusion pump) before health instructions, compared to 100% after health instructions. The later percentage decreased to 86% in the follow up phase. The difference was highly statistically significant.

Discussion:

Patient's education is an essential component in nursing care and an indispensable element of an effective treatment for any chronic disease. There is a probable agreement that teaching the chronically ill child about his disease is a vital part of meeting his total needs and has many direct benefits that include improving patient's care, cost containment of health services, better patient's compliance, decrease use of emergency room and reduction of hospital admission.(8)

Concerning the socio-demographic characteristics of the studied thalassemic adolescents, the results of the present study showed that more than one third of the studied adolescents were at the age group (14-16years), this is may be due to that they were more interested and more easily convinced to join the study than the other two age groups (12-14 & 16-18). Males constituted three fifths (60%) of the sample size. Similar, male preponderance was reported by other studies. (9-11) On the contrary, a study done at Karachi reported a slight female preponderance which accounted for more than half (57.5%) of the studied thalassemic patients.(12)

The present study showed that more than two fifths (44%) of the studied adolescents was the first born child in the family. This result goes in line with an Iranian study which reported that slightly more than half (53.3%) of the studied sample was the first born child in the family.(13) The results of another study conducted at Faisalabad city showed that the incidence of β-thalassemia among the studied sample was the highest in the 1st birth order and the lowest in 8th birth order.(14) Increased number of thalassemic adolescents in 1st birth order may reflect parents' unawareness about disease and consanguinity.

The majority of thalassemic adolescents in the present study were from rural areas. The exact opposite was found in a study carried out in specific units of thalassemia at various hospitals of Faisalabad city which revealed that the incidence of β-thalassemia was significantly ($P<0.001$) higher in urban population (80.66%) than rural (19.33%). (14) This contrast may prove that thalassemia may be presented in urban as in rural when premarital screening and genetic counseling is neglected. In addition, the data was collected from Pediatric Hematology Outpatient Clinic at Zagazig University Hospital that represents the only center serving thalassemic patients all over Sharkia Governorate for free and attracts patients from all villages of the governorate.

The results of the present study revealed that more than half (56%) of the studied thalassemic adolescents had positive mother-father consanguinity and the majority (82.14%) of adolescents' parents were first cousins. This goes in line with the results of a survey conducted to study the association between education and thalassemia in Peshawar, Pakistan in which, inter family marriages was one of the main reasons of the disease and more than half (56.9%) of the patient 'parents were first cousins. (15)

The results of the present study revealed a positive family history of the disease among nearly two thirds (60%) of the studied adolescents, amongst those, two thirds had a thalassemic brother or sister. This result goes in line with a study conducted at Zagazig city to assess the quality of life of school-age children with thalassemia major, where more than half (57%) of the studied sample had sick relatives with thalassemia. [16] These findings and the previous one could be explained by the fact that consanguineous marriages are encouraged and practiced in Egypt especially in rural areas and that the closer the relation between the parents, the greater the risk that many children might be born with a hereditary disorder such as thalassemia.

To better understand what happens to the blood when one has a hematological disease; it is helpful to know about normal blood components and their functions. [17] The results of the present study showed that only 2% of the studied thalassemic adolescents had satisfactory knowledge scores regarding to blood and blood components before the health instructions. Nearly all thalassemic adolescents (98%) and about three fifths (58%) had satisfactory knowledge score about the same knowledge item after the health instructions and during follow up phase respectively. These findings were supported by other studies where, the studied patients' knowledge score about blood functions and blood components improved significantly after implementation of the educational programs [8,18]

The results of the present study revealed that, only 4% of the studied adolescents had satisfactory total knowledge score about the disease before implementation of health instructions. This is contradicted with the findings of Taiwanese study in which most of the studied patients had fairly correct knowledge about their disease. [19] Poor thalassemic adolescents' knowledge about the disease, observed in the present study, may return to lack of health education about the disease itself and that the health team either doctors or nurses tend to give more health instructions about the care practices than the disease itself. After implementation of the health instructions and during follow up phase, adolescents' knowledge about the disease (thalassemia) improved significantly.

In a study conducted to explore the relationships among illness knowledge, social support and self-care behavior in adolescents with β-thalassemia major in Taiwan, it was found that, the worst knowledge score was the knowledge of complications. [20] This goes in line with the findings of the present study where, no one of the studied adolescents had satisfactory total knowledge score about disease's complications before implementation of health instructions, but all of them and more than four fifths (90%) respectively had satisfactory score immediately after implementation of health instructions and 2 months later. This bad knowledge score about disease's complications may be explained through the fact that, many patients avoid receiving complications-related information owing to distress about an uncertain future.

On the other hand, the findings of the present study revealed a significant improvement in total adolescents' knowledge about diet and genetic counseling after implementation of the health instructions. This is congruent with the findings of another study conducted at Ain Shams University in which the studied thalassemic children

gained more knowledge about diet after implementation of the educational program than before. [21] In a study conducted to assess knowledge and attitude of unmarried female students in Jeddah towards premarital screening program, and to improve their knowledge about premarital screening through conduction of an educational campaign the researchers also supported the previous findings and reported that, Students' knowledge about premarital genetic counseling was generally low before the educational campaign and improved significantly after it. [22]

As regards the studied adolescents' total knowledge about chelation therapy and chelating agents, the results showed that, only 2% of the studied adolescents had satisfactory total knowledge score regarding to this knowledge item before implementation of the health instructions. The same knowledge deficit about chelation therapy was reported by another study where, the studied thalassemic children lacked the essential knowledge in this area before implementation of the educational program.[23] Lack of knowledge observed among thalassemic adolescents in the current study may be due to two reasons (i) inadequate explanation from health-care providers and/or (ii) most of the studied adolescents believed that medications and treatment issues are the responsibility of the physicians and they do not need to know a lot about it. Moreover, the pamphlets of all iron chelating agents were written in English language, that the studied adolescents cannot read or understand.

Nevertheless, after implementation of the health instructions, thalassemic adolescents' knowledge improved significantly regarding all aspects of chelation therapy and iron chelating agents. These findings were supported by the results of a study conducted at Cairo University to evaluate the effectiveness of health teaching for children on adherence with iron chelation therapy in which, there was a highly statistically significant difference between mean scores of pre and post tests of the experimental group in relation to iron chelation therapy.

In continuous subcutaneous infusion (CSQI) the nurse should assess client's knowledge regarding medication to be received and use of the medication pump in order to determine client's ability to problem solve and manage pump. [24] In the present study, most of the studied adolescents had done the majority of the required steps for desferal subcutaneous infusion with the pump, correctly before health instructions. This may be due to the fact that, deferoxamine subcutaneous infusion is an integral part of the daily life routine of the studied adolescents since they were young children and they become familiar with its process. In spite of this, they have some defect in doing a number of the required steps. For example; cleaning the work area with antibacterial soap or alcohol was done only by three of the studied adolescents before the health instructions compared to all and more than four fifths of them in both after and follow up phase.

When teaching the patient the necessary skills to use CSQI, the nurse must focus on safe and effective administration of medication with minimal anxiety and discomfort. She should also stress the importance of keeping the needle insertion site free from infections. [24] As revealed from the results of the present study, all the steps belonging to infection and safety precautions were not done by the majority of the studied adolescents

before health instructions and improved significantly after the health instructions and two months later. This may be returned to inadequate guidance by nurses regards these precautions.

To maximize compliance, one of the practical interventions that can be helpful is, properly training the patient to ensure that subcutaneous, rather than intradermal, infusions are achieved. [25] In the present study, before implementation of health instructions, a large number of the studied adolescents did not make sure that subcutaneous, rather than intradermal, infusions are achieved. Where, pinching a small area of skin with fat tissue with thumb and index finger was done by slightly more than one third of the studied adolescents. While only one patient pulled back slightly on the plunger to see if blood comes into the syringe. These findings may be returned to inadequate guidance by nurses in teaching the patient and his parents how to achieve subcutaneous, rather than intradermal, infusions.

Generally, this study reflected significant improvement in thalassemic adolescents' total knowledge, knowledge about care practices and practices scores after implementation of the health instructions. All knowledge items, knowledge about care practices and practices scores of the studied adolescents increased significantly immediately after implementation of health instructions. During the follow up phase (2 months later) some knowledge items slightly decreased and others dropped a great deal depending on the difficulty of the information. Even though, their knowledge scores were still significantly higher than they were before the health instructions. This is may be due to lack of continued education and reinforcement during the follow up period.

Another researcher agreed with the findings of the present study and reported that, there was a significant increase in thalassemic children knowledge about the disease after implementation of the educational program. However, they did not seem to keep their knowledge level at the end of the program. At the same time, their knowledge after six months was extremely higher than they were before the educational program. [23]

Conclusion:

Health instructions had improved thalassemic adolescents' knowledge and practices.

Recommendations:

Further health instructions and educational programs for thalassemic children at different age groups are needed. Also, further researches are needed to study the impact of health instructions on thalassemic children's compliance with their treatment regimen.

Table (1): Socio-demographic Characteristics of the Studied Thalassemic Adolescents

Socio-demographic Variables	No. = (n=50)	%
Age in years		
▪ 12 -	16	32.0
▪ 14 -	19	38.0
▪ 16-18	15	30.0
$\bar{x} \pm SD$	14.63 ± 1.96	
Sex		
▪ Male	30	60.0
▪ Female	20	40.0
Birth order		
▪ The first	22	44.0
▪ The middle	18	36.0
▪ The last	9	18.0
▪ Only child	1	2.0
Residence		
▪ Rural	41	82.0
▪ Urban	9	18.0
Positive mother and father consanguinity		
▪ Yes	28	56.0
▪ No	22	44.0
If the answer was yes, what is the degree of consanguinity?	n=28	
▪ 2nd degree	23	82.14
▪ 3rd degree	5	17.86
Family history of the disease		
▪ Positive	30	60.0
▪ Negative	20	40.0
Degree of consanguinity	n=30	
▪ Brothers or sisters	20	66.67
▪ Uncles	2	6.67
▪ Cousins	7	23.33
▪ Others	1	3.3

Table (2): Effect of Health Instructions on Thalassemic Adolescents' Total Knowledge Items Score

Adolescents' Knowledge	Before		After		Follow Up		Cochran Test
	No	%	No	%	No	%	
Knowledge about blood and blood components							
Satisfactory	1	2.0	49	98.0	29	58.0	72.840**
Unsatisfactory	49	98.0	1	2.0	21	42.0	
Knowledge about the disease							
Satisfactory	2	4.0	50	100.0	47	94.0	92.367**
Unsatisfactory	48	96.0	0	0.0	3	6.0	
Knowledge about disease's complications							
Satisfactory	0	0.0	50	100.0	45	90.0	91.000**
Unsatisfactory	50	100.0	0	0.0	5	10.0	
Knowledge about diet and premarital genetic counseling							
Satisfactory	21	42.0	50	100.0	49	98.0	56.069**
Unsatisfactory	29	58.0	0	0.0	1	2.0	
Knowledge about chelation therapy and iron chelating agents							
Satisfactory	1	2.0	49	98.0	17	34.0	75.796**
Unsatisfactory	49	98.0	1	2.0	33	66.0	

(**)P value is highly statistically Significant at < 0.01

Table (3): Effect of Health Instructions on Thalassemic Adolescents' Total Knowledge and Knowledge about Care Practices Scores

Total Score	Before		After		Follow Up		Cochran Test
	No.	%	No.	%	No.	%	
Total Knowledge Score							
Satisfactory	2	4.0	50	100.0	45	90.0	87.042**
Unsatisfactory	48	96.0	0	0.0	5	10.0	
Total Knowledge about Care Practices Score							
Satisfactory	21	42.0	50	100.0	48	96.0	54.276**
Unsatisfactory	29	58.0	0	0.0	2	4.0	

(**)P value is highly statistically Significant at < 0.01

Table (4): Effect of Health Instructions on Thalassemic Adolescents' Practices in Administration of Deferoxamine Subcutaneously with Infusion Pump (Preparatory Phase)

Practices	Before		After		Follow Up		Wilcoxon Rank Test			Cochran Test
	No.	%	No.	%	No.	%	Z1	Z2	Z3	
▪ Never refrigerate Desferal	31	62.0	50	100.0	48	96.0	4.355*	4.123*	1.414	34.421*
▪ Clean work area with antibacterial soap or Alcohol	3	6.0	50	100.0	47	94.0	6.856*	6.633*	1.732	88.383*
Gathering supplies										
▪ Subcutaneous or butterfly needle with IV tubing	41	82.0	50	100.0	50	100.0	3.000*	3.000*	0.000	18.000*
▪ Alcohol wipes	4	8.0	48	96.0	46	92.0	6.633*	6.481*	1.414	81.182*
▪ Betadine (Iodine) swabs	0	0.0	16	32.0	6	12.0	4.000*	2.449*	2.887*	23.059*
▪ Antibacterial soap	6	12.0	15	30.0	15	30.0	2.714*	2.714*	0.000	10.000*
▪ Infusion pump	26	52.0	49	98.0	48	96.0	4.796*	4.690*	1.000	44.087*
▪ Transparent dressing	7	14.0	34	68.0	17	34.0	5.196*	2.673*	4.123*	38.552*
▪ Sharps container	2	4.0	12	24.0	8	16.0	2.887*	2.449*	1.633	12.667*
▪ Desferal and sterile water	40	80.0	50	100.0	50	100.0	3.162*	3.162*	0.000	20.000*
▪ 10 cc syringe with needle	40	80.0	50	100.0	50	100.0	3.162*	3.162*	0.000	20.000*
▪ Wash hands	24	48.0	50	100.0	47	94.0	5.099*	4.796*	1.732	46.692*

(*) P value is statistically significant at < 0.05

Table (5): Effect of Health Instructions on Thalassemic Adolescents' Practices in Administration of Deferoxamine Subcutaneously with Infusion Pump (Desferal Preparation)

Practices	Before		After		Follow Up		Wilcoxon Rank Test			Cochran Test
	No.	%	No.	%	No.	%	Z1	Z2	Z3	
▪ Remove the caps of desferal vial	43	86.0	50	100.0	50	100.0	2.646*	2.646*	0.000	14.000*
▪ Clean the exposed rubber cap with alcohol swab	1	2.0	47	94.0	44	88.0	6.782*	6.557*	1.134	82.792*
▪ Let alcohol dry	1	2.0	47	94.0	44	88.0	6.782*	6.557*	1.134	82.792*
▪ Take up the syringe, attach the needle to it and then remove the needle cover	37	74.0	50	100.0	50	100.0	3.606*	3.606*	0.000	26.000*
▪ Do not touch the uncovered needle or set it on any surface	15	30.0	46	92.0	48	96.0	5.396*	5.745*	1.000	58.686*
▪ Insert the needle into the sterile water ampule	36	72.0	50	100.0	50	100.0	3.742*	3.742*	0.000	28.000*
▪ Take the prescribed amount of water	44	88.0	50	100.0	50	100.0	2.449*	2.449*	0.000	12.000*
▪ Inject the sterile water in to the desferal vial	44	88.0	50	100.0	50	100.0	2.449*	2.449*	0.000	12.000*
▪ Shake it well	44	88.0	50	100.0	50	100.0	2.449*	2.449*	0.000	12.000*
▪ Turn the bottle upside down; pull back slowly on the plunger. Fill the syringe with the amount of medicine needed	41	82.0	50	100.0	50	100.0	3.000*	3.000*	0.000	18.000*
▪ If air bubbles are present, tap the side of the syringe, so that the air goes to the top. Push the air out	20	40.0	48	96.0	45	90.0	5.292*	4.811*	1.342	47.267*
▪ Check for correct dose	29	58.0	50	100.0	49	98.0	4.583*	4.472*	1.000	40.095*
▪ Remove the needle from the syringe, and then attach the syringe to the subcutaneous or butterfly needle	44	88.0	50	100.0	50	100.0	2.449*	2.449*	0.000	12.000*
▪ Push the medicine through the tubing until you see the drops come out of the needle to get rid of air bubbles	26	52.0	47	94.0	47	94.0	4.379*	4.379*	0.000	36.280*

(*) P value is statistically significant at < 0.05

Table (6): Effect of Health Instructions on Thalassemic Adolescents' Practices in Administration of Deferoxamine Subcutaneously with Infusion Pump (Desferal Administration)

Practices	Before		After		Follow Up		Wilcoxon Rank Test			Cochran Test
	No.	%	No.	%	No.	%	Z1	Z2	Z3	
▪ Choose a subcutaneous site - usually on the abdomen or thigh	30	60.0	50	100.0	50	100.0	4.472*	4.472*	0.000	40.000*
▪ Clean the injection site with alcohol or betadine (Iodine) using friction	8	16.0	47	94.0	48	96.0	6.091*	6.325*	0.577	74.333*
▪ Let the alcohol or betadine dry	8	16.0	47	94.0	48	96.0	6.091*	6.325*	0.577	74.333*
▪ With your thumb and index finger, pinch a small area of skin with fat tissue	18	36.0	48	96.0	49	98.0	5.303*	5.568*	1.000	58.188*
▪ Insert the needle through the skin into the fat tissue at a 45 degree angle if you use a long needle. Insert the needle through the skin into the fat tissue at a 90 degree angle if you use a short needle	37	74.0	50	100.0	50	100.0	3.606*	3.606*	0.000	26.000*
▪ Pull back slightly on the plunger to see if blood comes into the syringe	1	2.0	43	86.0	45	90.0	6.481*	6.633*	0.816	80.522*
▪ Secure the needle at place by transparent tape	35	70.0	48	96.0	49	98.0	3.606*	3.742*	0.577	24.400*
▪ Place syringe into the infusion pump and attach the syringe's cylinder safely with the "Velcro" attaching strap	35	70.0	49	98.0	49	98.0	3.742*	3.742*	0.000	26.133*
▪ Insert a new battery if needed	37	74.0	49	98.0	50	100.0	3.464*	3.606*	1.000	24.154*
▪ Switch the infusion pump (on) and make sure you hearing the sound and saw the flashing light	37	74.0	49	98.0	50	100.0	3.464*	3.606*	1.000	24.154*

(*) P value is statistically significant at < 0.05

Table (7): Effect of Health Instructions on Thalassemic Adolescents' Practices in Administration of Deferoxamine Subcutaneously with Infusion Pump (After Procedure)

Practices	Before		After		Follow Up		Wilcoxon Rank Test			Cochran Test
	No.	%	No.	%	No.	%	Z1	Z2	Z3	
▪ Stopping the infusion by turning off the infusion pump	39	78.0	49	98.0	50	100.0	3.162*	3.317*	1.000	20.182*
▪ Remove the adhesive tape and the needle	41	82.0	49	98.0	50	100.0	2.828*	3.000*	1.000	16.122*
▪ Apply dressing at the site of injection	41	82.0	49	98.0	50	100.0	2.828*	3.000*	1.000	16.122*
▪ Wash your hands as previously instructed	31	62.0	49	98.0	50	100.0	4.243*	4.359*	1.000	36.105*
▪ Carefully remove the needle and discard into the sharps container	31	62.0	49	98.0	50	100.0	4.243*	4.359*	1.000	36.105*

(*) P value is statistically significant at < 0.05

Table (8): Effect of Health Instructions on Thalassemic Adolescents' Total Practices Score

Total Score	Before		After		Follow Up		Cochran Test
	No.	%	No.	%	No.	%	
Total Practice Score							
Satisfactory	37	74.0	50	100.0	43	86.0	15.875**
Unsatisfactory	13	26.0	0	0.0	7	14.0	

(**)P value is highly statistically Significant at < 0.01

References:

1. Harvey RA, Ferrier DR. Globular Proteins. In: *Biochemistry*. 5th ed. Baltimore, Lippincott Williams and Wilkins| a Walters Kluwer business; 2011: 27, 33-4, 38-9.
2. Lahiry P, Al-Attar SA, Hegele RA. Understanding Beta-Thalassemia with Focus on the Indian Subcontinent and the Middle East. *The Open Hematology Journal* 2008; 2(1): 5-13.
3. Rivers AE, Srivastava A. Gene Therapy of Hemoglobinopathies. In: Herzog Rw, Zolotukhin S, Eds. *A Guide to Human Gene Therapy*. Singapore, World Scientific Publishing; 2010: 197-199.
4. Patrinos GP, Antonarakis SE. Human Hemoglobin. In: Speicher MR, Antonarakis SE, Motulsky AG, Eds. *Vogel and Motulsky's Human Genetics Problems and Approaches*. 4th ed. New York, Springer; 2010: 380.
5. Galanello R, Origa R. Beta-Thalassemia Review. *Orphanet Journal of Rare Diseases* 2010; 5(11): 1-15.

6. Musallam K, Cappellini MD, Taher A. Challenges Associated With Prolonged Survival of Patients With Thalassemia: Transitioning From Childhood to Adulthood. *Pediatrics* 2008; 121(5): 1426-1429.
7. Potts NL, Mandleco BL, Eds. Chronic Conditions. In: *Pediatric Nursing: Caring for Children and Their Families*. 3rd ed. Canada, Delmar Cengage Learning; 2012: 571-572.
8. Husssein HA. The Impact of Health Education Program about Bone Marrow Transplantation on Improving Quality of Life of Thalassemic Children. Unpublished doctoral dissertation, Faculty of nursing, Cairo University. Cairo, 2007.
9. Ishaq F, Abid H, Kokab F, Akhtar A , Mahmood S. Awareness Among Parents of β-Thalassemia Major Patients, Regarding Prenatal Diagnosis and Premarital Screening. *Journal of the College of Physicians and Surgeons Pakistan* 2012; 22(4): 218-221.
10. Singhal S, Shama N, Mathur R. Iron Overload and Growth of Thalassemic Patients in Marwar Region. *International Journal of Pharmaceutical Sciences and Research* 2012; 3(7): 2043-2049.
11. Tabatabaei SV, Alavian SM, Keshvari M, Behnava B, Miri M, Elizee PK, et al. Low Dose Ribavirin for Treatment of Hepatitis C Virus Infected Thalassemia Major Patients; new Indications for Combination Therapy. *Hepatitis Monthly* 2012; 12(6): 372-381.
12. Arif F, Fayyaz J, Hamid A. Awareness among Parents of Children with Thalassemia Major. *J Pak Med Assoc* 2008; 58(1): 621-624.
13. Dehkordi AH, Heydarnejad MS. Effect of Booklet and Combined Method on Parents' Awareness of Children with β-thalassemia Major Disorder. *J Pak Med Assoc* 2008; 58(9): 485-487.
14. Ain QU, Ahmed L, Hassan M, Rana SM, Jabeen F. Prevalence of β-thalassemic Patients Associated with Consanguinity and Anti-HCV – Antibody Positivity – A Cross Sectional Study. *Pakistan J Zool* 2011; 43(1): 29-36.
15. Zaman Q, Salahuddin. Association between the Education and Thalassemia: A Statistical Study. *Pak J Stat Oper Res* 2006; 11(2): 103-110.
16. El Dakhakhny AM, Hesham MA, Mohamed SE, Mohammad FN. Quality of Life of School Age Thalassemic Children at Zagazig City. *Journal of American Science* 2011;7(1): 186-197.
17. Frempong KO, Rapport EB, Schwartz ZW. *Comprehensive Pediatric Nursing*. 3rd ed. New York, McGraw Hill; 2006.
18. Hassan EA. Impact of Educational Program on Adherence of Thalassemic Children with Iron Chelation Therapy in Hematology Clinics. Unpublished doctoral dissertation, Faculty of nursing, Cairo University. Cairo, 2009.
19. Lee YL, Lin DT, Tsai SF. Disease Knowledge and Treatment Adherence among Patients with Thalassemia Major and Their Mothers in Taiwan. *Journal of Clinical Nursing* 2008; 18(1): 529-538.
20. Yang HC, Chen YC, Mao HC, Lin KH. Illness Knowledge, Social Support and Self-care Behavior in Adolescents with Beta-Thalassemia Major. *Metabolism* 2005; 54(1): 15-23.
21. Hashem SF. Thalassemic Children and Their Mothers' Understanding: Effect on Compliance to Thalassemia Management Plan. Unpublished doctoral dissertation, Faculty of nursing, Ain Shams University. Cairo, 2006.
22. Ibrahim NK, Al-Bar H, Al-Fakeeh A, AL-Ahmadi J, Qadi M, Al-Bar A, Milaat W. An Educational Program about Premarital Screening for Unmarried Female Students in King Abdul-Aziz University, Jeddah. *Journal of Infection and Public Health* 2011; 4(1): 30-40.
23. El-Awany TA. Nutritional Program for Children with Beta-Thalassemia Major and Their Mothers. Unpublished doctoral dissertation,

Faculty of Nursing, Ain Shams University. Cairo, 2002.
24. Elkin MK, Perry AG, Potter PA. Continuous Subcutaneous Medications. In: *Nursing interventions & clinical skills*. 3rd ed. Philadelphia, Mosby; 2004: 485-489.
25. Porter JB, Evangeli M, El-Beshlawy A. The Challenges of Adherence and Persistence with Iron Chelation Therapy. *International Journal of Hematology* 2011; 94(5): 45

أثر الارشادات الصحية على تحسين معلومات وممارسات المراهقين المصابين بالثلاسيميا فى مستشفى جامعة الزقازيق

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مقدمة:
المراهقون المصابون بأنيميا البحر المتوسط بحاجة إلى معلومات عن مرضهم حتى يستطيعوا توفير رعاية مناسبة ويعقدوا توقعات واقعية لأنفسهم وأيضا لتقليل عدم اليقين والخوف من المرض.

الهدف من الدراسة:
هدفت الدراسة إلى التعرف على أثر الارشادات الصحية على تحسين معلومات وممارسات المراهقين المصابين بالثلاسيميا فى مستشفى جامعة الزقازيق.

عينة و مكان البحث:
أجريت دراسة شبه تجريبية على عينة من ٥٠ مراهق مصابين بأنيميا البحر المتوسط بالعيادة الخارجية لأمراض الدم (عيادات الأطفال) ، في مستشفى جامعة الزقازيق بمحافظة الشرقية ، مصر.

أدوات جمع البيانات:
تم استخدام ثلاث أدوات لجمع البيانات الخاصة بالدراسة كما يلى:

- استمارة استبيان (مقابلة شخصية)
- قائمة تدقيق عملية وارشادات صحية لتثقيف المراهقين عن مرض أنيميا البحر المتوسط (بيتا ثلاسيميا الكبرى) وخطة علاجها.

النتائج:
كشفت نتائج هذه الدراسة أن المراهقين موضوع الدراسة لم يكن لديهم معلومات مرضية عن مرضهم وخطة علاجه قبل تنفيذ الارشادات الصحية. وقد تحسنت معلومات وممارسات المراهقين المصابين بأنيميا البحر المتوسط بشكل ملحوظ بعد تنفيذ الارشادات الصحية سواء بعد تنفيذها مباشرة أو بعد مرور شهرين لاحقين .

الخلاصة:
الإرشادات الصحية حسنت معلومات وممارسات المراهقين المصابين بأنيميا البحر المتوسط.

التوصيات:
بناءا على نتائج الدراسة الحالية فإنه يجب إعطاء ارشادات صحية وبرامج تثقيفية مستمرة للمراهقين المصابين بأنيميا البحر المتوسط لتزويدهم بالمعلومات الأساسية حول المرض ، وعلاجه وممارسات الرعاية الخاصة به. كما أن هناك حاجة إلى مزيد من الأبحاث لدراسة أثر الارشادات الصحية على مدى التزام الأطفال المصابين بالثلاسيميا بخطة علاجهم.