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RESEARCH ARTICLE

Impact of Education Program about Knowledge and Practice of Thalassemic Adolescent in Rahma Governmental Hospital, Jordan, Irbid

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Abstract

Background & objective: Teenagers with thalassemia require knowledge about their condition in order to give adequate care, eliminate uncertainty, and create reasonable goals for themselves. The aim of the present study was to assess the knowledge and practices among adolescents with thalassemia at Rahma Governmental Hospital, Jordan, Irbid.

Materials & methods: In this study, a descriptive study was carried out on a sample of 50 teenagers with thalassemia in the pediatric hematology outpatient clinic at Rahma Governmental Hospital, Jordan, in order to ascertain the effect of health instructions on enhancing their knowledge and practices. A structured interview questionnaire, a clinical checklist, and health instructions were the three instruments employed in the current study to inform the adolescents being studied about -thalassemia major and its treatment.

Results: The findings demonstrated that, prior to putting the health recommendations into practice, the examined teenagers lacked sufficient knowledge about their disease and how to manage it. After the health guidelines were put into effect, the teenagers with thalassemia's understanding and behaviors greatly improved. The adolescents with thalassemia had better knowledge and habits as a result of the health recommendations.

Conclusion: Adolescents with thalassemia should get health instructions and ongoing education regarding their condition, its treatment options, and care procedures, according to the current study's recommendations. The effect of health advice on thalassemia children's compliance with their treatment plan requires more investigation.

Keywords

Thalassemia, Adolescents with the disease, Health advice, Patient education

Introduction

Hereditary hemolytic illnesses known as thalassemia's arise when there is an imbalance in the production of globin chains. They are the most prevalent single gene disorders in humans as a whole [1].

Genetically defective production of the -globin chains in hemoglobin results in -thalassemia, an autosomal hematological condition [2]. The excessive -globin chain precipitates and damages the red blood cell membrane in -thalassemia. Anemia, bone marrow growth, extramedullary hematopoiesis, and increased intestinal iron absorption are all effects of inefficient erythropoiesis [3].

Up to 80 million people globally are thought to be -thalassemia carriers, according to the World Health Organization [4]. With an average carrier rate of 1:30, -thalassemia is quite prevalent in the Middle Eastern nations of Iraq, Lebanon, Egypt, and Morocco. Thalassemia, the most prevalent cause of chronic hemolytic anemia in Egyptians, is a serious health issue [2].

People with -thalassemia major typically develop severe anemia within the first two years of life and

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need frequent red blood cell transfusions. Growth retardation, pallor, jaundice, poor muscle tone, hepatosplenomegaly, leg ulcers, the formation of masses from extramedullary hematopoiesis, and skeletal alterations as a result of bone marrow expansion are all symptoms of untreated ness inadequately transfused thalassemia major patients. Regular transfusion therapy increases the risk of consequences from iron overload, such as cirrhosis, dilated myocardiopathy, liver fibrosis, and endocrine problems [5].

Children with thalassemia typically aren't aware of the seriousness of their condition, but as they get older, either on their own or with the help of their healthcare professional, they learn more about the condition's characteristics. We cannot deny children's rights to awareness about their own bodily state, even though this realization can cause some denial and distress [6].

Even while the knowledge is necessary, it could be too much to handle. A pediatric nurse must evaluate the child's and his carers' level of preparation for learning before modifying the pace and volume of information. Nurses should also pay attention to how the child and his caregivers react to the instruction and gauge their comprehension by probing the right questions or having them demonstrate a newly learned ability [7]. The sufferers can then concede the gravity of their condition and its repercussions [6].

Aim of the Study

The aim of the present study was to:

Assess the knowledge and practices among adolescents with thalassemia at Rahma Governmental Hospital, Jordan, Irbid.

Significance of the Study

The patient's survival and quality of life will be significantly impacted by how they deal with having thalassemia and its treatment. The challenges of chelation therapy and lifelong transfusion will not be overcome if the condition is not understood and accepted, which will raise the risk of disease complications and lower survival. Helping children cope with the challenging demands of treatment while retaining a good attitude through appropriate health education and instructions is one of the pediatric nurse's important responsibilities.

Subjects and Methods

Research design

A cross sectional descriptive design was used in carrying out the present study.

Setting

The current study was conducted in the pediatric outpatient hematology clinic at Rahma Governmental Hospital, Jordan, Irbid.

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

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.

Tool III: Health Guidelines: Health Guidelines were developed to educate adolescents about beta thalassemia major and its management, and aim to improve knowledge and practice of adolescents with thalassemia to provide appropriate care for them.

Field work

The researchers created the data collection methods after carefully reviewing the literature. Five professionals conducted a jury to evaluate the instruments (two professors of pediatric nursing, two professors of pediatrics and one professor of community health nursing). The scientists went to the Pediatric.

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.

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.

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.

Table 2 shows how health instructions affected thalassemic adolescents' overall knowledge score [2]. Results showed that only 2% of the thalassemic adolescents who were being studied prior to the implementation of health instructions had satisfactory knowledge scores regarding blood and blood components, chelation therapy, and chelating agents, compared to 98% of them after the implementation of health instructions. The prior percentages for knowledge of blood and blood components and knowledge of chelation therapy and chelating drugs declined to 58%

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
$\overline{x} \pm SD$	14.63 ± 1.96	
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.

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	
Unsatisfactory	48	96.0	0	0.0	3	6.0	92.367**
Knowledge about disease's complications							
Satisfactory	0	0.0	50	100.0	45	90.0	
Unsatisfactory	50	100.0	0	0.0	5	10.0	91.000**
Knowledge about diet and premarital genetic counseling							
Satisfactory	21	42.0	50	100.0	49	98.0	
Unsatisfactory	29	58.0	0	0.0	1	2.0	56.069**
Knowledge about chelation therapy and iron chelating agents							
Satisfactory	1	2.0	49	98.0	17	34.0	
Unsatisfactory	49	98.0	1	2.0	33	66.0	75.796**

Table 3: Effect of health instructions on thalassemic adolescents' total knowledge and knowledge about care practices scores.

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*

and 34%, respectively, during the follow-up period. The variations were statistically quite 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 showed that before receiving health instructions, none of the studied adolescents had a satisfactory knowledge score regarding the complications of disease, but that after receiving those instructions, 100% of them had a satisfactory score, and 90% of them did so during the follow-up phase. Highly statistically significant differences existed. On the other hand, throughout the three phases of putting health recommendations into practice, knowledge about food and premarital genetic counseling had the highest knowledge scores. In the before, after, and follow-up phases, it had changed from 42% to 100% and then to 98%, with a very statistically significant difference.

The impact of health education on teenagers' overall knowledge and understanding of care is explained in Table 3. Only 4% of the thalassemic adolescents who were evaluated had a sufficient total knowledge score prior to receiving health instructions, according to the data. After receiving health advice, this percentage rose to 100% and then slightly fell to 90% during the follow-up phase. Highly statistically significant differences existed.

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.

Table 4 shows how health advice affected how thalassemic adolescents administered deferoxamine subcutaneously with an infusion pump during the preparatory phase (4). Only 6% of the teens who were studied cleaned their workspace with antibacterial soap or alcohol prior to putting health recommendations into practice. Following the application of health recommendations and throughout the follow-up period, this number rose to 100% and 94%, respectively.

Additionally table shows how health advice affected how thalassemic adolescents administered deferoxamine subcutaneously with an infusion pump during the preparatory phase (4). Only 6% of the teens who were studied cleaned their workspace with antibacterial soap or alcohol prior to putting health recommendations into practice. Following the application of health recommendations and throughout the follow-up period, this number rose to 100% and 94%, respectively. Additionally, it was discovered that 48% of

Table 4: Effect of health instructions on thalassemic adolescents' practices in administration of deferoxamine subcutaneously with infusion pump (preparatory phase).

Practices	No.	%	No.	%	No.	%	Z1	Z2	Z3	Test
▪ 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 into 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	26	52.0	47	94.0	47	94.0	4.379*	4.379*	0.000	36.280*

the adolescents in the study washed their hands (before to making food) before receiving health instructions, as opposed to 100% after receiving health instructions and 94% during the follow-up period. Statistics showed that the differences were substantial.

The impact of health advice on thalassemic adolescents' behaviors for administering deferoxamine subcutaneously with an infusion pump during deferral preparation is shown in Table 5. It was discovered that there was a statistically significant improvement over the course of the three phases of putting the health recommendations into practice with relation to all deferral's preparation steps.

Table shows how health advice affected how thalassemic teenagers administered deferoxamine subcutaneously with an infusion pump while receiving deferral [6]. Only 16% of the teens who participated in the study cleansed the injection site with alcohol or betadine (iodine) using friction and then dried it before following health instructions, according to the findings. After receiving health advice, the prior proportion increased to 94%, and then during the follow-up phase, it increased to 96%, with a statistically significant difference.

In the before, after, and follow up phases, 36%, 96%, and 98% of the examined adolescents pinched a small region of skin with fat tissue with their thumb and index finger, respectively. Statistics showed that the difference was significant. In contrast, just 2% of the adolescents in the study pulled back the plunger to check if blood was entering the syringe prior to receiving health instructions; this number increased to 86% after receiving health instructions, and then to 90% during the follow-up period. Statistics showed that the difference was significant.

Discussion

Patient education is a crucial part of nursing care and

Table 5: Effect of health instructions on thalassemic adolescents' practices in administration of deferoxamine subcutaneously with infusion pump (desferal administration).

Practices	No.	%	No.	%	No.	%	Z1	Z2	Z3	Test
☐ 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 plunger to see if blood	18	36.0	48	96.0	49	98.0	5.303*	5.568*	1.000	58.188*
	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 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	37	74.0	49	98.0	50	100.0	3.464	3.606	1.000	24.154*

a requirement for every chronic disease to be effectively treated. There is likely consensus that educating a child with a chronic illness about his or her condition is essential to meeting all of his or her needs and has many immediate advantages, such as better patient care, lower healthcare costs, better patient compliance, fewer emergency room visits, and fewer hospital admissions [8].

According to the findings of the current study, more than one third of the thalassemic adolescents were in the 14-16 age group. This may be because they were more motivated and willing to participate in the study than the other two age groups, which may have contributed to their higher age distribution (12-14 & 16-18). Three fifths (60%) of the sample was made up of men. Other investigations revealed a similar, predominately male population [9-11]. On the other hand, a study conducted in Karachi revealed a modest gender bias, with more than half (57.5%) of the thalassemic patients being female [12].

More than two fifths (44%) of the teenagers evaluated in the current study were the family's firstborn. This outcome is consistent with an Iranian study that found that slightly more than half of the sample (53.3%) was a family's first-born child [13]. According to the findings of a different study carried out in the city of Faisalabad, the incidence of -thalassemia was highest in the first birth order and lowest in the eighth [14]. An increase in the proportion of thalassemic teenagers in the first birth order may be a result of parents' ignorance of the condition and consanguinity.

In this study, teenagers with thalassemia were most commonly seen in rural locations. The incidence of beta-thalassemia was significantly greater (P 0.001) in the urban population (80.66%) than in the rural population (19.33%), according to a study on particular thalassemia units in several hospitals in Faisalabad city [14]. This contrast may demonstrate that, in cases when premarital testing and genetic counseling are disregarded, thalassemia can manifest in both urban and rural regions. Additionally, information was gathered from Al-Bashir Governmental Hospital's pediatric hematology outpatient clinic, the only facility that treats people with thalassemia.

The findings of the current study showed that the majority (82.14%) of the parents of the adolescents were first cousins, and more than half (56%) of the thalassemic adolescents evaluated had positive mother-father consanguinity. This is consistent with research on the relationship between schooling and thalassemia undertaken in Peshawar, Pakistan, where inter-family marriages were found to be one of the primary causes of the illness and where more than half (56.9%) of the patient's 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.

It is useful to understand the normal blood components and their roles in order to better

comprehend what happens to the blood when a person has a hematological disorder [17]. Only 2% of the thalassemic teenagers in this study had sufficient knowledge ratings on blood and blood components prior to receiving health instructions, according to the study's results. After receiving health instructions and throughout the follow-up phase, nearly all thalassemic teenagers (98%) and around three fifths (58%) achieved good knowledge scores regarding the same knowledge item. Other studies that showed a considerable improvement in the investigated patients' knowledge of blood functions and blood components after the adoption of educational programs corroborated these findings [8,18].

The weakest knowledge score was the knowledge of complications, according to a study done in Taiwan on teenagers with significant -thalassemia to investigate the links between sickness awareness, social support, and self-care behavior [19,20]. This is consistent with the current study's findings, which showed that none of the adolescents studied had a satisfactory total knowledge score about the complications of a disease prior to the application of health advice, but that 90% of them had a satisfactory score both immediately and two months later. This poor understanding of disease consequences may be explained by the fact that many patients avoid acquiring information regarding problems because they are anxious about the future.

According to the investigated adolescents' total knowledge score on chelation therapy and chelation medicine, only 2% of the screened adolescents had a suitable total knowledge score for this knowledge item before putting the health recommendations into practice. Another study that revealed a similar knowledge gap regarding chelation therapy discovered that the children with thalassemia being studied lacked the requisite information in this area prior to the implementation of the educational program [20]. Inadequate interpretation by healthcare professionals or (2) the majority of the adolescents believed that decisions regarding medication and treatment fell under the purview of doctors and did not necessitate in-depth knowledge on their part may be to blame for the lack of understanding among adolescents with thalassemia in the current study.

The nurse should evaluate the patient's knowledge of the medication to be administered and how to utilize the medication pump during continuous subcutaneous infusion (CSQI) to ascertain the patient's capacity for problem-solving and pump management [21].

In the current study, the majority of the adolescents were examined had correctly completed most of the processes needed for deferral subcutaneous infusion with the pump before receiving health instructions. This may be because deferoxamine subcutaneous infusion has been a regular part of the adolescents' everyday lives since they were young children, and they have become accustomed to the procedure. Despite this, they have a flaw in carrying out some of the necessary tasks, sanitizing the workspace with antibacterial soap.

One of the practical measures that can help to maximize compliance is correctly teaching the patient to ensure that subcutaneous rather than intradermal infusions are accomplished [22].

In the current investigation, several of the teens were not making sure to obtain subcutaneous rather than intradermal infusions prior to the application of health guidelines. Where, slightly more than one-third of the investigated teens were found to pinch a small patch of skin covered in fat tissue with their thumb and index finger. Only one patient slightly retracted the plunger to check for blood in the syringe. These results may be attributed to the nurses' inadequate instruction of the boy and his parents on how to obtain subcutaneous, as opposed to intradermal.

Another researcher concurred with the study's findings and claimed that once the training program was put in place, thalassemic children's understanding of the illness significantly increased. At the program's conclusion, they did not, however, appear to have maintained their level of knowledge. At the same time, their level of knowledge was significantly higher than it was prior to the educational program after six months [20].

Conclusion

Health instructions had improved thalassemic adolescents' knowledge and practices.

Recommendations

For thalassemic kids of various ages, further health advice and educational initiatives are required. Additionally, more research is required to determine how health advice affects thalassemic children's compliance with their treatment plan.

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