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Impact of an educational program on parents' knowledge about chelation therapy & nutrition of their children with beta thalassemia major

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Abstract--The study aimed to determine the effect of an educational program on parents' knowledge about chelation therapy, and nutrition of their children with beta thalassemia major. A quasi experimental study was carried out at Thalassemia Center in Al-Najaf City during the periods 25th February 2021 to 15th March 2022. Non-probability (purposive) sample of (70) parents were selected from thalassemia center (38 mothers and 32 fathers).The result of the study findings indicate that education program about home health care management was highly effective on parents' knowledge in the study group evidenced by high significance associated with "Greenhouse-Geisser" correction at p-value=0.001. Also there is a significant relationship between parents' knowledge with regard to affected father with disease at p-value= .049.

Keywords--Educational Program, Chelation therapy, nutrition, Children, beta Thalassemia.

Introduction

Thalassemia major is still the most serious form of beta-thalassemia. (homozygous state). Because beta globin production is not required during fetal life and the immediate postnatal period, affected infants are healthy at birth. It is commonly detected in second half of infancy with complaints like decreased activity, progressive pallor (Anemia) and abdominal fullness. The infants do not grow and may suffer feeding difficulties, fever, and diarrhea. (Mannoor, 2019)

The major portion of α -thalassemia cases are located in Southeast Asia, Malaysia, and Southern China, with an increase in diagnosis in North America due to immigration. Beta-thalassemia mutations are widespread in the Mediterranean, Southeast Asia, Africa, Italy, India, Spain, North America, and Greece, but are uncommon in Korea, Japan, and Northern Europe, (Piel, 2016). B-thalassemia presents with various clinical features such as anemia, growth retardation, hepatosplenomegaly and changes in bone structure. In countries where diagnosis is made early and typical patients, are not seen severe anemia, very large spleen, low stature, facial and skeletal changes, the designations thalassemia major, intermedia, and minor are not used. (Origa, 2017)

However, the pathophysiology of various features is unclear, and there is no evidence of a genotype-phenotype association. Bone causes deformity and occasional fractures. This leads to swelling of maxillary overgrowth and dental defects. All of this is attributable to an increase in bone marrow volume as a result of increasing erythropoiesis. It is first observed before the age of one year and is most prevalent between the ages of eight and ten. There is no evidence of a growth hormone deficit. It is unclear if late growth impairment occurs in appropriately treated thalassemia. It has been discovered that the adolescent rapid growth rate and the development of sexual organ characteristics are delayed. (Yardumian, et al., 2016).

Clinical features of iron overloading usually appear during ten years old but indicate of iron toxicity has been noticed in much younger children. Hepatic fibrosis usually begins within two years of starting packed red cells infusion. Cirrhosis of the liver can develop before the age of ten in the absence of chelation therapy, particularly in presence of hepatitis B and/or C. Cardiac complications due to iron overloading usually appear after 15 years or more, but have been reported within 10 years of starting transfusion therapy. Iron loading does not spare endocrine organs. It is an important cause of delayed puberty in 50 percent of both male and female thalassemia patients. Twenty five percent of females fail to conceive. It can also damage pancreas resulting in diabetes mellitus. Excess iron can also damage thyroid and parathyroid glands. (Piperno, Pelucchi, & Mariani, 2020).

Caregiver's knowledge regarding thalassemia is one of the vital areas in the prevention of the disease. Thalassemia is a blood disorder for which there is no cure. Only one way to minimize its impact is to prevent it. When compared to providing optimal treatment to thalassemia patients, it is a more cost-effective method. As a result, improving disease knowledge is one of the most important techniques for prevention. Caregivers are people who help individuals who are suffering and ill. In the presence of chronic disorders such as thalassemia, their role is increased. Their awareness of the disease has an impact not only on the quality of life of their patients, but also on their own. A caregiver with good disease knowledge not only provides better care to his or her ward, but also works as a knowledge percolator in the society in which he or she lives. As a result, it greatly aids in improving community awareness of the disease. (Biswas, et al., 2021)

Materials and Methods

The Study Design: A quasi-experiment study designing to improve the parents' knowledge about home health care management to children with Beta-thalassemia major. For two groups of samples, the pre-test and post-test 1&2 technique had been used (study and control),

Administrative arrangements: After granting agreement the College of Nursing Council related to the study, official letters are submitted, with the research proposal, to the following: Permission was obtained by the Ministry of Planning's Central Council of Statistics, which accepted the questionnaire for the study. The Iraqi MOH vital and health statistical department in order to obtain the statistical tables about the thalassemia. Al-Najaf health directorate. Al-Zahra Teaching Hospital.

Ethical Considerations: Ethical approvals for the study were getting from the Scientific Research Ethics Committee at the College of Nursing and Ethics committee of the Al-Najaf health directorate and permission to conduct research to ensure their approval and collaboration for data collection of the parent's. All study participants from Al najaf city sign the consent form.

Study Setting: The research was carried out at Thalassemia Center in Al-Najaf City in order to obtain accurate and comprehensive data. This hospitals provides free healthcare to children with.

Study Samples: A non-probability (purposive) samples of (70) parents was chosen from the thalassemia center (38 mothers and 32 fathers). In this study, the study population was split into two groups: 35 parents for the study who were introduced to the education program, and 35 parents for the control group.

Criteria for Choosing a Sample: Parents who agreed to participate in the study and were willing to do so, Parents of all educational levels, and Fathers and mothers of children with beta thalassemia-major.

Validity of the Questionnaire and the Program: The content validity of the early produced instrument is determined by an expert panel that evaluates into the questionnaire's clarity, relevancy, and suitability in measuring the conception of interest. The questionnaire design is a preliminary version that was submitted to (16) specialists.

Data Collection: The researchers' have come up with the necessary arrangements for getting the study samples at the in Al-Zahra Teaching Hospital in Al-Najaf City before beginning the data collection process. The data were collected during the period from 17th August 2021 to 7th of November 2021.

Results

Table (1)
Distribution of the Sample According to Disease related Variables

No.	Variables	Study group		Control group	
		F	%	F	%
1	Number of 1	22	62.9	15	42.9
	inflicted 2	12	34.3	15	42.9
	children in 3	1	2.9	5	14.3
	family <i>Total</i>	35	100	35	100
2	Duration of 1 – 5 year	7	20	13	37

	illness	6 – 10 year	12	34.3	10	28.6
		11 – 15 year	6	17.1	8	22.9
		16 – 20 year	8	22.9	3	8.6
		21 ≤ year	2	5.7	1	2.9
		<i>Total</i>	35	100	35	100
		<i>M±SD</i>	11.36 ± 7.031		8.66± 5.406	
3	Affected father	Yes	2	5.7	2	5.7
		No	33	94.3	33	94.3
		<i>Total</i>	35	100	35	100
4	Affected mother	Yes	6	17.1	0	0
		No	29	82.9	35	100
		<i>Total</i>	35	100	35	100
5	Carrier father	Yes	33	94.3	33	94.3
		No	2	5.7	2	5.7
		<i>Total</i>	35	100	35	100
6	Carrier mother	Yes	29	82.9	35	100
		No	6	17.1	0	0
		<i>Total</i>	35	100	35	100

No: Number, f: Frequency, %: Percentage, M: Mean, SD: Standard deviation

Table demonstrates those in the study group (62.9 %), the number of inflicted children is "one," but in the control group, the number of inflicted children is "one" and "two," as observed with the same percentage of inflicted children (42.9 %). The duration of illness refers to 6-10 years (11.36±7.031 year) as reported by parents in the study group (34.3%) and refers to 1-5 years (8.66±5.406) in the control group (37%).

The analysis shows that only two (5.7%) of fathers are affected in both group; study and control. Only six (17.1%) of mothers are affected in the study group while no affected mother in the control group. The carrier of disease shows that 94.3% of fathers are carrier in the study group and control group, while 82.9% of mothers are carriers in the study group and 100% of mothers are carriers in the group of control.

Table (2)

Assessment the Level of Parents' Knowledge about Iron Accumulation in a Child with Thalassemia and how to treat it in the Study and Control groups

List	Knowledge about Iron Accumulation in a Child with Thalassemia and how to treat it	Study Group (N=35)						Control Group (N=35)					
		Pre-test M.S	Ass.	Post-test I M.S	Ass.	Post-test II M.S	Ass.	Pre-test M.S	Ass.	Post-test I M.S	Ass.	Post-test II M.S	Ass.
1	Iron accumulation in the body occurs due to the lack of blood transfusions to a child with beta thalassemia major	1.11	Poor	2.71	Good	2.69	Good	1.15	Poor	2.23	Poor	1.20	Poor
2	Complications of iron accumulation in the body cause multiple damages, including damage to the heart, liver, endocrine glands and change in skin color	1.90	Fair	2.94	Good	2.74	Good	1.71	Fair	2.00	Fair	1.98	Fair
3	Capturing excess iron and excreting it out of the body through the urine is a process called chelation	1.31	Poor	2.57	Good	2.77	Good	1.26	Poor	1.31	Poor	1.20	Poor
4	Giving drugs to expel iron from the body such as azithromycin under the skin	1.23	Poor	2.80	Good	2.60	Good	1.54	Poor	1.60	Poor	1.60	Poor
5	Medications to expel iron from the body are given when the ferritin level is less than 1000 mcg / l	1.36	Poor	2.63	Good	2.46	Good	1.31	Poor	1.14	Poor	1.24	Poor
6	Possible side effects of iron-expelling drugs are blurred vision and dizziness	1.51	Poor	2.89	Good	2.77	Good	1.17	Poor	1.14	Poor	1.03	Poor
7	Iron-expelling medication should be continued even if swelling of the face, lips, tongue, or throat occurs	1.54	Poor	2.63	Good	2.60	Good	1.86	Fair	1.80	Fair	1.97	Fair

M.S: Mean of score, Poor= 1 – 1.66, Fair= 1.67– 2.33, Good= 2.34 – 3

This table presents the items related to parents' knowledge about iron accumulation in child and how to treat it; the parents in the study group show all items performed poor level, with the exception of item 2, which did fair on the pre-test, while they show good performance in the first and second post-tests, among all items. Over Pre, post 1, and post 2 test, the parents in the control group demonstrate a poor knowledge on most of the items

Table (3)
Assessment the Level of Parents' Knowledge about the Nutrition of Thalassemia Patient in the Study and Control groups

List	Knowledge about the Nutrition of Thalassemia Patient	Study Group (N=35)						Control Group (N=35)					
		Pre-test		Post-test I		Post-test II		Pre-test		Post-test I		Post-test II	
		M.S	Ass.	M.S	Ass.	M.S	Ass.	M.S	Ass.	M.S	Ass.	M.S	Ass.
1	Iron-rich foods are oranges, strawberries, and kiwis, which should be avoided or reduced	1.03	Poor	2.80	Good	2.63	Good	1.11	Poor	1.14	Poor	1.17	Poor
2	Foods rich in vitamin C should be given to a child with thalassemia to increase the absorption of iron in the intestines	1.46	Poor	2.97	Good	2.89	Good	1.49	Poor	1.57	Poor	1.60	Poor
3	Red, yellow and green peppers and pineapple are the most important vegetables and fruits that do not contain vitamin C, and it is preferable to eat them with iron-rich foods	1.73	Fair	2.91	Good	2.86	Good	1.51	Poor	1.27	Poor	1.06	Poor
4	Dairy, fat, cantaloupe and mushrooms are considered iron-free or low-iron foods	1.31	Poor	2.97	Good	2.94	Good	1.20	Poor	1.46	Poor	1.43	Poor
5	Tea, coffee, milk and its derivatives are given to the child to prevent the breakdown of red blood cells	1.54	Poor	2.97	Good	2.89	Good	1.60	Poor	1.71	Fair	1.60	Poor

M.S: Mean of score, Poor= 1 – 1.66, Fair= 1.67– 2.33, Good= 2.34 – 3

This table presents the items related to parents' knowledge about nutrition; the parents in the study group show poor level in all items except item 3 show fair during the pre-test while they show good performance in the first and second post-tests, among the items. Except for item 5, the parents in the control group have a poor knowledge at all three phases of the test: pre, post 1, and post 2.

Table (4)
Repeated Measure Analysis of Variance (RM-ANOVA) Test for Effectiveness of Education Program on Parents' knowledge about chelation therapy & nutrition to Children with Beta-Thalassemia Major among the Study Group (N=35)

Descriptive Knowledge	Mean (S.D)	Within-Subjects Effect											
		Source	Type Sum Squares	III of	df	Mean Square	F	P-value	Sig.	Partial Eta Squared			
Pre-test	53.71 (13.02)	Time	<u>Sphericity</u> Assumed	22696.705	2	11348.35	102.2	.001	H.S	.750			
Post-test I	127.63 (6.82)					2	11						
Post-test II	125.83 (6.64)					15415.47	102.2	.001	H.S	.750			
			<u>Greenhouse-Geisser</u>	22696.705	1.472	7	11						
			<u>Huynh-Feldt</u>	22696.705	1.523	9	11	14905.03	102.2	.001	H.S	.750	
			Lower-bound	22696.705	1.000	5	11	22696.70	102.2	.001	H.S	.750	
		Error(Time)	<u>Sphericity</u> Assumed	7549.962	68	111.029							
						<u>Greenhouse-Geisser</u>	7549.962	50.059	150.820				
						<u>Huynh-Feldt</u>	7549.962	51.774	145.826				
						Lower-bound	7549.962	34.000	222.058				

S.D: Standard Deviation, df: Degree of Freedom, f: F-statistics, P-value: probability value, Sig: Significance, H.S: High Significant

The results of the RM-ANOVA test show that the education program on home health care management has been highly effective on the knowledge of parents in group of the study, as indicated at (p-value=0.001), the "Greenhouse-Geisser" correction has a high level of significance. The descriptive findings indicate that there has been a significant increase in the mean score Knowledge of parents during pre-test to post-test 1 and a minor drop during post-test 2, indicating the efficacy of the education program.

Table (5)
Repeated Measure Analysis of Variance (RM-ANOVA) Test for Parents' knowledge about chelation therapy & nutrition to Children with Beta-Thalassemia Major among the Control Group (N=35)

Descriptive Knowledge	Mean (S.D)		Within-Subjects Effect								
			Source	Type III Sum of Squares	df	Mean Square	F	P-value	Sig.	Partial Eta Squared	
Pre-test	49.37	(15.59)	Time	<u>Sphericity Assumed</u>	2	12.010	.190	.827	N.S	.006	
Post-test I	51.94	(14.21)		<u>Greenhouse-Geisser</u>	24.019	1.525	15.754	.190	.767	N.S	.006
Post-test II	53.77	(13.97)		<u>Huynh-Feldt</u>	24.019	1.582	15.187	.190	.776	N.S	.006
			Error(Time)	<u>Lower-bound</u>	24.019	1.000	24.019	.190	.666	N.S	.006
				<u>Sphericity Assumed</u>	4298.648	68	63.215				
				<u>Greenhouse-Geisser</u>	4298.648	51.837	82.926				
				<u>Huynh-Feldt</u>	4298.648	53.773	79.941				
				<u>Lower-bound</u>	4298.648	34.000	126.431				

S.D: Standard Deviation, df: Degree of Freedom, f: F-statistics, P-value: probability value, Sig: Significance, N.S: No Significant

The table indicates the "Greenhouse-Geisser" correction has no statistical relevance. The description indicates the scores did not differ significantly of parents' mean of knowledge in the group of control throughout a pre-test, a first-time post-test, and a second-time post-test, indicating that parents' knowledge who are not engaged in an educational program has not changed.

Table (6)
Independent T-test for Parents' Knowledge with regard to Affected Father among Study and Control Group

Knowledge	Affected	Study Group (N=35)						Control Group (N=35)					
		M	SD	T	df	Sig.	p≤0.05	M	SD	t	df	Sig.	p≤0.05
Iron accumulation and how to treat it	No	13.33	1.947	.608	33	.548	N.S	13.52	1.873	.093	33	.927	N.S
	Yes	15.00	4.243					14.50	.707				
Nutrition	No	13.97	2.243	2.135	33	.040	S	14.36	2.044	3.016	33	.005	H.S
	Yes	11.50	2.121					13.50	2.121				
Total	No	8.61	1.853	2.049	33	.049	S	9.64	1.747	-.126	33	.901	N.S
	Yes	109.00	21.213					95.50	9.192				
	No	92.79	10.380					96.42	10.134				

M: Mean, SD: Standard deviation, t: t-test, df: Degree of freedom, Sig: Significance, p: Probability value, N.S: Not significant

These table indicates there are a significant relation among the parents' knowledge in regard to affected father with disease at p-value= .049 "nutrition" (p-value=.040). With (p-value=.005), there is a clear association (high

significant) between of parents' nutrition knowledge and the affected father with disease in the control group.

Table (7)
Independent T-test for Parents' Knowledge with regard to Disease carrier Father among Study and Control Group

Knowledge	Carrier	Study Group (N=35)					Control Group (N=35)						
		M	SD	t	df	Sig.	p≤0.05	M	SD	t	df	Sig.	p≤0.05
Iron accumulation and how to treat it	No	15.50	2.121					15.00	1.414				
	Yes	13.97	2.243	-.608	33	.548	N.S	14.36	2.044	-.093	33	.927	N.S
Nutrition	No	15.00	4.243					14.50	.707				
	Yes	8.61	1.853	-2.135	33	.040	S	9.64	1.747	-3.016	33	.005	H.S
Total	No	11.50	2.121					13.50	2.121				
	Yes	92.79	10.380	-2.049	33	.049	S	96.42	10.134	.126	33	.901	N.S
	No	109.00	21.213					95.50	9.192				

M: Mean, SD: Standard deviation, t: t-test, df: Degree of freedom, Sig: Significance, p: Probability value, N.S: Not significant

The table demonstrates a significant relation among parents' knowledge in the study group with regard to carrier disease father with disease at p-value= .049 and “nutrition” at (p-value=.040). Among parents in the control group, There is a clear association (high significant) between the parents' nutrition knowledge with regard to carrier disease father with disease at (p-value= .005).

Discussion

Number of inflicted children is “one” in the study participants (62.9%), whereas in the control group to “one” and “two” as seen with same percentage of 42.9%. The study findings agree with study done by (Hossain, Hasan, Petrou, Telfer, & Al Mosabbir, 2021) who conducted a study to investigating the parental thalassemia knowledge gaps and perceptions in Bangladesh, Were found (82.7%) of his samples had one child regarding inflicted children in family.

Regarding to the duration of illness refers to 6-10 years (11.36±7.031 year) as reported by parents in the study group (34.3%) and refers to 1-5 years (8.66±5.406) in the control group (37%). This results agree with study by (Abu Samra, Auda, Kamhawy, & Al-Tonbary, 2015) who conducted a study to explore the effectiveness of a chelation therapy educational curriculum on the quality of life of thalassemia youngsters in Egypt, that show (27.7%) of sample have duration of illness between (6-9) years.

The current study shows that only two (5.7%) of fathers are affected in both group; study and control. Only six (17.1%) of mothers are affected in the study group while no affected mother in the control group. While the carrier of disease shows that 94.3% of fathers are carrier in the study group and control group, while 82.9% of mothers are carriers in group of study and 100% of mothers are carriers in group of control. This results agree with (Khan, 2018) who conducted a study to determined clinical and demographic variables of thalassemia patients,

that found the regard family history of thalassemia in their study about (92.1%) have a family history with thalassemia.

Parents' knowledge about iron accumulation in child and how to treat it; the parents in the study group show poor level in most items during the pre-test, while they show good level among items during the post-test 1 and 2, The study findings agree with study done by (Abo Jeesh, Yousif, & Al-Haboub, 2018) who exhibits an improvement in caregivers' knowledge of blood components and functions, hemoglobin level, causes of thalassemia, prevention, therapy, blood transfusion, and nutrition after obtaining the teaching guide The general knowledge of caregivers on thalassemia has improved, with the mean and standard deviation of 34.124.50 before getting the teaching guide and 37.434.61 after receiving the teaching guide.

Parents' knowledge about nutrition; the parents in the study group show poor level in majority of items during the pre-test, while they show good level among items during the post-test 1 and 2. Also the parents in the control group show poor level of knowledge in majority items over the three times of test; pre, post 1, and post 2. This result agree with the study done by (El-Esrigy, Farahat, & Othman, 2021). who wanted to increase parental knowledge and practice by implementing an Egyptian health teaching program. Who reveals that the majority of the study participants (85 percent) had a poor total knowledge score before to health education. In addition, the study found that interventional educational programs were highly helpful in improving knowledge and perceptions of the disease, with (65%) having good understanding.

The results of the RM-ANOVA test imply that education program about chelation therapy and nutrition was extremely effective in increasing parents' knowledge in the study group, This finding is consistent with the findings of the study (Abu Samra, Auda, Kamhawy, & Al-Tonbary, 2015) who aimed to evaluate the impact of a chelation therapy health education program It was discovered that (97.7 %) and (2.3 %) of them had poor and average pre-program scores, respectively. On the other side, it was revealed that (61.8%) and (38.2%) of them had average and good post-health teaching program scores, respectively.

The study shows there is significant relationship between parents' knowledge with regard to affected & carrier father with disease, The study findings agree with study done by (Manzoor & Zakar, 2019) who conducted the study to evaluate the sociodemographic variables that affecting parental knowledge about thalassemia major. That revealed significant association was seen between fathers knowledge and their positive history with thalassemia.

Conclusion

The education program was highly effective on parents' knowledge in the study group, that increasing mean score of parents' knowledge through post-testing 1 and post-testing. There is statistical significant. Relationship between parents' knowledge with regard to their, affected father, father and mother carriers.

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