

Effectiveness of an Educational Program on Parents' Knowledge about Home Health Care Management to Children with Beta Thalassemia-Major at Thalassemia Center in Al-Zahra Teaching Hospital for Maternity and Children in Al-Najaf City

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ABSTRACT

Background Thalassemia is a hereditary condition that affects the formation of globin chains. Children with beta-thalassemia major have a complete absence of globin production. beta thalassemia- major is a severe type of disease that require life-long blood transfusions for survival.

Objectives: To evaluate the effectiveness of an educational program on parents' knowledge regarding home health care management related to children with Beta Thalassemia-Major

Methodology: A quasi experimental study was carried out at Thalassemia Center in Al-Najaf City during the periods 25 February 2021 to 20 March 2022. Non-probability (purposive) sample of (70) parents were selected from thalassemia center (38 mothers and 32 fathers).

Results: The study findings show that there are high significant difference in overall main domains relating parents' knowledge of beta-thalassemia major between pre and post-tests 1&2 in the study group. In addition there is a statistical relationship between parental knowledge with regard to their age. Also there is high statistical significant relationship during parents' knowledge with regard to their educational level

Conclusion: The study finds that the efficacy of an educational program to improving parents' knowledge of home health care management for children with β -Thalassemia Major is high

Keyword: Educational Program, Beta thalassemia, Children, AL-Najaf City

INTRODUCTION

Thalassemia is condition of inherited hemoglobin characterized by decreased or missing globin formation, an unbalanced buildup of globin chains, and inefficient erythropoiesis with hemolysis. Iron chelation therapy and regular red blood cell transfusions for transfusion-related iron excess, as well as supportive care to manage the consequences of iron overload, are the hallmarks of treatment. The absence of treatment, prior to the age of five years, the majority of children with -thalassemia major is diagnosed¹. Beta Thalassemia it is caused by complete suppression of beta globin chains (B 0) or partial suppression of beta globin chains (b+). A compensatory increase in Hb A2 and Hb F occurs in all due The number of alpha globin chain excess in homozygotes (Beta Thalassemia major) determines the severity of the following clinical manifestations, whereas heterozygotes (Beta Thalassemia minor) have little or no anemia and no symptoms².

The treatment of thalassemia requires the collaboration of a comprehensive therapeutic team. To ensure continuity of specialized care and to build a supportive connection with each patient, the treating doctor should remain the same. It's also critical to have committed nurses and to have continuous monitoring by experts including a hematologist, endocrinologist, cardiologist, orthopedic surgeon, nutritionist, ophthalmologist, neurologist, and psychologist, as well as health education for caregivers at home¹.

The main responsibility of the nurse is to plan an effective educational intervention. Children and their care givers must know about the disease process; what it means, how it is transmitted from parents to children. Also, importance of compliance; how to give desferal at home using the subcutaneous pump; and possible side effects; and how to manage them. In addition to knowledge related to anemia, signs and symptoms, effects, management; the importance of blood transfusion and managing side effects, also the educational intervention about diet is very important. B-thalassemia causes increased gastrointestinal iron absorption that leads to iron overload. Therefore, Patients should avoid foods heavy with iron, such as liver, green leafy vegetables, cereals, spleen, molasses legumes, and nuts³.

METHODOLOGY

Design of the Study: A quasi-experimental study design to improve the parents' knowledge about home health care management to children with Beta thalassemia-major. Had been applied with the use of pre-test and post-test 1& 2 approach for two groups of samples (study and control)

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.

Setting of the Study: In order to get valid and comprehensive data, the study has been done at Thalassemia Center in Al-Zahra Teaching Hospital for Maternity and Children in Al-Najaf City. This hospitals provides free healthcare to children with thalassemia

Sample of the Study: Non-probability (purposive) sample of (70) parents were selected from thalassemia center in Al-Zahra teaching hospital for maternity and children (38 mothers and 32 fathers). The study sample in this research was divided into two groups; (35) parents for the study, which was exposed to the health education program, and (35) parents for control group.

Data Collection: The researcher has made the necessary preparations for getting the study samples at the Thalassemia Center in Al-Zahra Teaching Hospital for Maternity and Children 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.

The analysis of data in in table 4-1 shows that parents are with age 39.83±10.110 year in the study group and 37.60±9.114 year in the control group in which the highest percentage of age group refer to 40-49 year among both groups: study (42.9%) and control group (34.3%).

The gender variable refers that 62.9% of participants in the study group were mothers of children while 54.35% of participants in the control group were fathers.

Regarding level of education, the highest percentage in the study group refers to 34.3% for parents who graduated from primary school and the same percentage for those who graduated

from secondary school; the highest percentage in the control group refers that parents are graduated from secondary school (37.1%).

RESULTS

Table 1: Distribution of the Sample According to their Socio-demographic Characteristics

No.	Characteristics	Study group		Control group		
		f	%	f	%	
1	Age (year)	20 – 29	6	17.1	8	22.9
		30 – 39	11	31.4	11	31.4
		40 – 49	15	42.9	12	34.3
		50 – 59	2	5.7	4	11.4
		60 ≤	1	2.9	0	0
		Total	35	100	35	100
		M±SD	39.83 ± 10.110		37.60± 9.114	
2	Gender	Male	13	37.1	19	54.3
		Female	22	62.9	16	45.7
		Total	35	100	35	100
		Level of education	Doesn't read & write	0	0	1
3	Level of education	Read & write	5	14.3	5	14.3
		Primary school	12	34.3	11	31.4
		Secondary school	12	34.3	13	37.1
		Institute/Diploma	2	5.7	2	5.7
		Bachelor +	4	11.4	3	8.6
		Total	35	100	35	100

Table 2: Overall Assessment of Parents' Knowledge about Home Health Care Management to Children with Beta-Thalassemia Major in the Study and Control Group:

Levels of Knowledge	Study Group (N= 35)								Control Group (N=35)															
	Pre-test		Post-test I				Post-test II				Pre-test		Post-test I				Post-test II							
	f	%	M	S.D	f	%	M	S.D	f	%	M	S.D	f	%	M	S.D	f	%	M	S.D				
Poor	30	85.7	53.71	13.02	0	0	127.63	6.82	0	0	125.83	6.64	32	91.4	49.37	15.59	28	80	51.94	14.21	30	85.7	53.77	13.97
Fair	4	11.1			1	2.6			3	8.6			2	5.7			6	17.1			4	11.4		
Good	1	3.2			34	97.4			32	91.4			1	2.9			1	2.9			1	2.9		
Total	35	100			35	100			35	100			35	100			35	100			35	100		

f: Frequency, %: Percentage, M: Mean of total score, SD Standard deviation of total score
 Poor= 46 – 76, Fair= 77 – 107, Good= 108 – 138

Table 3: Analysis of variance for Parents' Knowledge with regard to their Age among Study and Control Group

Age Knowledge	Sources	Study Group (N=35)					Control Group (N=35)				
		Sum of squares	df	Mean Square	F	Sig.	Sum of squares	df	Mean Square	F	Sig.
General	Between Groups	108.976	21	5.189	1.600	.193	80.571	23	3.503	1.752	.168
	Within Groups	42.167	13	3.244			22.000	11	2.000		
	Total	151.143	34				102.571	34			
Definition, causes, and types of disease	Between Groups	170.976	21	8.142	4.380	.004	148.886	23	6.473	1.295	.337
	Within Groups	24.167	13	1.859			55.000	11	5.000		
	Total	195.143	34				203.886	34			
Signs & symptoms and methods of diagnosis	Between Groups	61.352	21	2.922	.919	.582	71.100	23	3.091	1.388	.292
	Within Groups	41.333	13	3.179			24.500	11	2.227		
	Total	102.686	34				95.600	34			
Treatment and prevention	Between Groups	293.410	21	13.972	1.603	.192	210.576	23	9.155	1.142	.425
	Within Groups	113.333	13	8.718			88.167	11	8.015		
	Total	406.743	34				298.743	34			
Blood transfusion	Between Groups	107.019	21	5.096	2.395	.054	78.900	23	3.430	.955	.559
	Within Groups	27.667	13	2.128			39.500	11	3.591		
	Total	134.686	34				118.400	34			
Iron accumulation and how to treat it	Between Groups	152.971	21	7.284	3.382	.004	89.505	23	3.892	.958	.557
	Within Groups	28.000	13	2.154			44.667	11	4.061		
	Total	180.971	34				134.171	34			
Nutrition	Between Groups	103.005	21	4.905	2.347	.058	100.119	23	4.353	1.587	.215
	Within Groups	27.167	13	2.090			30.167	11	2.742		
	Total	130.171	34				130.286	34			
Total	Between Groups	3954.310	21	188.300	5.578	.001	2213.005	23	96.218	.913	.593

	Within Groups	438.833	13	33.756			1159.167	11	105.379		
	Total	4393.143	34				3372.171	34			

df: Degree of freedom, F: F-Statistic, P: Probability value

Table 4: Analysis of Variance for Parents' Knowledge with regard to their Educational level among Study and Control Group

Education Knowledge	Sources	Study Group (N=35)					Control Group (N=35)				
		Sum of squares	df	Mean Square	F	Sig.	Sum of squares	df	Mean Square	F	Sig.
General	Between Groups	61.276	4	15.319	5.114	.003	34.568	5	6.914	2.948	.029
	Within Groups	89.867	30	2.996			68.003	29	2.345		
	Total	151.143	34				102.571	34			
Definition, causes, and types of disease	Between Groups	48.010	4	12.002	2.447	.068	81.068	5	16.214	3.828	.009
	Within Groups	147.133	30	4.904			122.818	29	4.235		
	Total	195.143	34				203.886	34			
Signs & symptoms and methods of diagnosis	Between Groups	24.152	4	6.038	2.307	.081	31.056	5	6.211	2.791	.035
	Within Groups	78.533	30	2.618			64.544	29	2.226		
	Total	102.686	34				95.600	34			
Treatment and prevention	Between Groups	122.276	4	30.569	3.224	.026	84.275	5	16.855	2.279	.073
	Within Groups	284.467	30	9.482			214.468	29	7.395		
	Total	406.743	34				298.743	34			
Blood transfusion	Between Groups	26.652	4	6.663	1.850	.145	31.231	5	6.246	2.078	.097
	Within Groups	108.033	30	3.601			87.169	29	3.006		
	Total	134.686	34				118.400	34			
Iron accumulation and how to treat it	Between Groups	40.338	4	10.085	2.151	.099	16.473	5	3.295	.812	.551
	Within Groups	140.633	30	4.688			117.699	29	4.059		
	Total	180.971	34				134.171	34			
Nutrition	Between Groups	12.388	4	3.097	.789	.542	20.851	5	4.170	1.105	.379
	Within Groups	117.783	30	3.926			109.435	29	3.774		
	Total	130.171	34				130.286	34			
Total	Between Groups	1775.360	4	443.840	5.086	.003	1552.018	5	310.404	4.946	.002
	Within Groups	2617.783	30	87.259			1820.153	29	62.764		
	Total	4393.143	34				3372.171	34			

df: Degree of freedom, F: F-Statistic, P: Probability value

This table displays that parents in the study group are showing poor level of knowledge about home health care of child with thalassemia during the pre-test time and prior application of educational program (85.7%), the parents' knowledge is increasing to good level of knowledge after application of educational program during the post-test time 1 (97.4%) and post-test 2 (91.4%).

The parents in the control group are showing poor level of knowledge that is still the same during the three time of test: pre (91.4%), post1 (80%), and post 2 (85.7%).

This table reveals that among those in the study group, there is high significant relationship between parents' knowledge with regard to their age at p-value= .001 particularly the domains of "definition, causes, and types of disease" (p-value= .004) and "iron accumulation and how treat it" (p-value=.004).

Among parents in the control group, there is no significant relationship has been seen between their knowledge with regard to their age.

This table shows that among parents in the study group, there is high significant relationship between parents' knowledge with regard to their educational level at p-value= .003 particularly the domains of "general knowledge" (p-value= .003) and "treatment prevention" (p-value=.026).

Among parents in the control group, there is high significant relationship between parents' knowledge with regard to their educational level at p-value= .002 particularly the domains of "general knowledge" (p-value= .029), "definition, causes, and types of disease" (p-value=.009) and "signs and symptoms and methods of diagnosis" (p-value=.035).

DISCUSSION

The analysis of data shows that parents are with mean age 39.83 ± 10.110 year in the study group and 37.60 ± 9.114 year in the control group in which the highest percentage of age group refer to 40-49 year among both groups: study (42.9%) and control group (34.3%). The result agree with study which found that the most of his samples were between the ages of 39 and 49⁴. The present results is supported by study, which reporting that majority of the samples were between the ages of 37 and 46 years⁵.

The gender variable refers that 62.9% of participants in the study

Group was mothers. These results agree with findings, which discovered that mothers made up a large portion of his study group (75%)⁴. These findings support by study, which found that mothers made up a large portion of his study group (66.6%)⁶. Additional support is found by stud that discovered the most of his samples were collected from mothers⁷. Extra support can be found at study, which discovered that the great majority of his samples were taken from mothers (n=25; 68%), while the majority of his samples in control group were father (n=24 69%). According to the researcher, caring for a chronically unwell child is one of the most stressful and hardest duties a parent may face⁸. Beyond dealing with the needs of the children and the impact that a prolonged illness may have on the entire family, in addition to dealing with physical difficulties and medical issues. The mother is always who takes care of the ill child because the mothers more efficient during dealing with children.

Based on the study results in regarding level of education, the highest percentage in the study group refers to 34.3% for parents who graduated from primary school and the same percentage for those who graduated from secondary school; the highest percentage in the control group refers that parents are graduated from secondary school (37.1%). These findings are consistent with study which show that most of the parents were graduated from the secondary school in both groups (64% study group; 75% control group)⁸. Supportive evidence has been found by study which reported that (83.3%) percent had completed secondary school⁹.

parents in study group are showing poor knowledge level about home health care of child with thalassemia during the pre-test time and prior application of educational program (85.7%), Following the implementation of an educational program, the parents' knowledge increased to a good level of knowledge during post-test times 1 (97.4 %) and post-test times 2 (91.4 %) . The parents in the control group had a poor knowledge that has remained constant during the three testing sessions: pre (91.4%), post1 (80%), and post 2 (85.7%).

These results agree with study done in Egypt which carried out a research to determine the impact of an educational program about iron chelation therapy in Egypt¹⁰. Demonstrates that the area of lowest percentage of satisfactory knowledge between the studied parents prior to the program was that of management (12.0%). Statistically significant improvements were revealed at the post-intervention phase in all knowledge domains ($p < 0.001$). In the follow-up, there was slight decrease, especially into the area of management (54.0%). However, the percentages of satisfactory knowledge remained significantly higher compared to pretest.

Parents' knowledge with regard to their age, the study findings agree with study which aimed to increase parent's knowledge and practice related febrile convulsions by establishing a health education program in Egyptian. Who shows the level of parental knowledge and their age group had a statistically significant relationship ($p\text{-value} < 0.05$)¹¹.

Parents in group of study, there is high statistical significant relationship between parents' knowledge with regard to their educational level, the study findings agree with study done by who designed to determine the level of knowledge of carers of thalassemia children and its socio-demographic determinants. Demonstrates that high significant relationship between parents' knowledge with regard to their educational level¹².

CONCLUSION

The parents in the study group are demonstrating poor of knowledge about home health care of child with thalassemia during the pre-test time and prior application of educational program. 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 2.

Recommendations: Providing educational guidelines, posters, pamphlets and manuals about thalassemia and should be available at each parents in wards and encourage parents to get use from them. Encourage the parents to participate in training courses and congresses held by specialists about thalassemia to update their knowledge.

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