Effectiveness Of An Educational Health Programme On Mothers' Knowledge Of Thalassaemic Children Who Receiving Desferal Therapy In Hawler Thalassemia Center/ Erbil City

تاثير البرنامج الصحي التثقيفي على معارف امهات الاطفال المصابين بالثلاسيميا والذين يعالجون بالديسفرال في مركز هولير للثلاسيميا/مدينة اربيل

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خلفية البحث: الثلاسيميا من اكثر الامراض الوراثية شيوعا في العالم

الأهداف: تهدف الدراسة الى تحسين معلومات امهات الاطفال المصابين بالثالاسيميا والذين يتعاطون علاج الدسفيرال في مركز هولير للثالاسبمبا/مدبنة اربيل

منهجية البحث: اجريت دراسة شبة تجريبية في مركز هولير للثلاسيميا للفترة من 2010-1-1 الى2012-5-30 اختيرت عينة من مئة (١٠٠) ام من الذين اصيب اطفالهن بالثلاسيميا وقسمت العينة الى مجموعتين خمسون للمجموعة التجريبة وخمسون ام بالمجموعة الضابطة طبق الاختبار القبلي لكلا المجموعتين ومن ثم طبق البرنامج التثقيفي الصحي حول كيفية اعطاء علاج الدسفيرال على المجموعة التجريبية وبعدها اجراء الاختبار االبعدي لكلا المجموعتين تم جمع البيانات من خلال استخدام أداة الاستبيان من خلال تقنيات المقابلة المباشرة التي كانت تستخدم كوسيلة لجمع البيانات. وقد تم تحليل البيانات عن طريق برنامج Excel و SPSS الإصدار 17. في ≤ 20.0 ذات دلالة إحصائية عالية جدا

: اظهرت النتائج ان معلومات الامهات في المجموعة التجريبية قد تحسنت بعد تطبيق البرنامج التثقيفي الصحي بدلالة إحصائية عالمة حدا 0.000

: أن أغلب الامهات في المجموعة التجريبية قد استفادوا من البرنامج التثقيفي الصحي الذي طبق عليهم بما يخص علاج الدسفير ال للأطفال المصابين بالثالاسيميا في مركز هولير للثالاسيميا / مدينة اربيل.

Abstract

Background: Thalassaemia is one of the most common genetic blood disorders in the world.

Objectives: The study aimed to improve mothers' knowledge of Thalassaemic children who using Desferal therapy.

Methods: A quasi-experimental study was carried out at Hawler Thalassemia Center in Erbil City from the 1^{st} of March to the end of May 2010. One hundred mothers were selected and divided into two groups, (50) mothers as control group and another (50) mothers as study group. Educational Health Program was concentrated on several major topics and it was implemented through two sessions, a pretest was done for both groups before implementing the health education program and the post-test was done after one month for both groups .Data were collected through the use of a questionnaire tool by direct interview techniques which was used as a mean of data collection. Data were analyzed by Excel and SPSS version 17 program me . At ≤ 0.05 was statistically significant and p-value ≤ 0.01 was statistically highly significant.

Results: The results revealed that the mothers' knowledge in the study group was improved their knowledge after implementation health education program at p –value 0.000 comparing in control group.

Conclusion: Most of the mothers in the study group had got benefit from implementation of educational programmer about their knowledge concerning who using Desferal therapy.

Recommendation: Health education programmes apply in mass media (TV, radio journal....). As well as screening should be apply for the risk groups(Carrier population screening detection at population level, Pre-marital, Prenatal and suspected family and their children). Also booklet and pamphlet of education programme should be distributed for all mothers who are attending Thalassemia Center. And Specialized nurse or thalassemia nurse should be knowledgeable about Desferal Therapy **Key words: Thalassaemia, Mothers' knowledge, Desferal Therapy.**

INTRODUCTION

Thalassaemia is a hereditary hemolytic anemia resulting from defects in hemoglobin production ¹. Thalassemias are classified according to which chain hemolytic of the hemoglobin molecule is affected. In α - thalassemias, production of α globin chain is affected, while in β- thalassaemia production of the β globin chain is affected ². World Health Organization (WHO) has calculated that about 7 percent of the world's populations carry a haemoglobinopathy gene ³. Thalassaemia (Mediterranean anemia) is the most widespread single genetic disease in the world today. It is estimated to affect up to 270 million people worldwide. In the Mediterranean area, there are 15 to 25 million of healthy carriers ⁴. It is estimated that 300,000 infants are born with major hemoglobino pathies worldwide, each year 60,000 to 70,000 are born with β-thalassaemia major cases especially in the Mediterranean area, Middle East, Far East, and East Asia. Severe β-thalassaemia accounts for 50,000 to 100,000 deaths per year or 0.5% to 0.9% of all deaths of children under 5 years in low or middle income countries ⁵. Iraq is one of the countries in which 6-10% of the populations have hemoglobinopathy of which thalassaemia is a major part ⁶. There are over 2,000 cases of thalassemia in the Kurdistan Region and Kirkuk (Table 1) 7. In Kurdistan region around 30000 people are carrier of β-Thalassaemia. Hawler Thalassaemia center serves about 493 regular registered patients on a daily attendance to follow up and to have blood transfusion of about 20-25 patients per day ⁷. Iron chelation therapy is, therefore, necessary to prevent or decrease the iron burden. Iron chelating agent DFO has dramatically reduced the mortality and improved the quality of life in regularly transfused patients ⁸, and it is largely responsible for doubling the life expectancy of patients with Thalassaemia major ¹.

AIM OF THE STUDY:

The aim of the study is to improve mothers' knowledge of thalassaemic children using Desferal therapy through implementation educational programmer in Hawler Thalassemia center /Ebril city.

SUBJECTS AND METHODS:

A quasi-experimental design was carried out throughout the present study with application of pre-post tests approach for the study and control groups, during the period from 1st of March.2010to the end of May 2011 at Hawler Thalassemia Center in Erbil City. The purposive non-probability sample was selected which consisted of (100) mothers having Thalassemic child, they were divided into two groups, one group of (50) mothers exposed to the educational health programme (study group) and another group of (50) mothers were not exposed to the educational health programme and considered as (control group). The criteria of the sample selection were mothers who have children diagnosed as Thalassaemia major and receive Desferal Therapy, both gender, child age from 3-18 years old. Mothers who are willing to participate in the programme and attend regularly in the Hawler Thalassaemic Center in Erbil city. Ethical Consideration Data collection is done by the researcher, who kept the confidentiality and anonymity of the data. The form for data collection was applied without mentioning the name of patients, their address, or any other information. The purpose of the study was explained to all participants; explaining ethical aspects of the study, and taking a verbal agreement were obtained from participants in the study. Construction of the Educational Health Program was concentrated on several major topics and it was implemented through two sessions in the clinic classroom of Hawler Thalassemia Center that aimed to promote mothers' knowledge toward Desferal Therapy which applicator for the study group. The sessions were designed and scheduled for approximately (1.30 hours/day) from period of 28th of March to 8th of April 2010., a pre-test was done for both groups before implementing the health education program and the post-test was done after one month for both groups.

Data were collected through the use of a questionnaire tool by direct interview techniques which was used as a mean of data collection during the period of 28th of March to 27th May 2010 and it was comprised of three major parts: Sociodemographic information about mothers with their children and second part including questionnaire concerning mother's knowledge of Desferal therapy which comprised of (18) questions each question comprised of two options. The items were rated according to 2 points type rating scale as (know and don't know) and levels of scale were scored as (1 for know, and 0 for don't know). Questionnaire and health educational programme was validity by panel (15) of experts in different specialty and the Internal consistency of questionnaire was assessed by person's Coefficients correlation (r-test). The result was (0.878) for mother's knowledge The results indicated excellent scale reliability. Data were analyzed by Excel and SPSS version 17 programme through the application descriptive statistical data analysis (Frequencies, percentage, mean of score) and inferential statistical data analysis {Chi - Square and Correlated (paired) t-test At p-value > 0.05 was considered as statistically no significant, p-value ≤ 0.05 was statistically significant and p-value ≤ 0.01 was statistically highly significant.

RESULT:

Table (1): Demographic characteristic of parents of Thalassemic children

	Items		ol group = 50	Study group N=50		
		F	%	F	%	
Mothers age(years)	<30	13	36	12	24	
5 4	31-39	15	34	20	40	
	40-49	17	30	10	20	
	>49	5	10	8	16	
Mother's education level	Illiterate	33	66	26	52	
	Read and write	4	8	3	6	
	Graduated from: primary	9	18	16	32	
	intermediate and secondary	2	4	3	6	
	institute and college	2	4	2	4	
Father's education level	Illiterate	28	56	15	30	
	read and write	3	6	9	18	
	Graduated from: primary	13	26	15	30	
	intermediate and secondary	3	6	7	14	
	institute and college	3	6	4	8	
Mother's occupation	Employed	2	4	2	4	
•	Housewives	48	96	48	96	
Father's occupation	Unemployed	45	90	44	88	
•	Employed	5	10	6	12	
Residential area	Urban	42	36	21	42	
	Rural	18	32	9	18	
	Suburban	40	32	20	40	
Socio-economic status of	Low	27	54	25	50	
the family	Medium	21	42	23	46	
•	High	2	4	2	4	

N = Number F = Frequently % = percentage

Table (1) found that most of mothers' age in the study group were (31-39) years old which present (40%), while in the control group ranged from (40-49) years old

which present (34%) majority of them were illiterate in both parents(66%,52%) for mothers and (56%,30%) in both groups respectively. Regarding the mothers' occupation, the majority in the both groups were housewives which present (96%) respectively, most of them in the study and control groups were from urban areas (42%, 36%) respectively and most of the families in the study group were from low socio-economic status which presents (50%), while in the control group were (54%) from low socio-economic status.

Table (2): Demographic characteristics of Thalassemic children

Items		trol group N = 50	Study group N =50		
	F	%	F	%	
Age / years	3-6	20	40	20	40
	7-10	13	26	18	36
	11-14	16	32	7	14
	15-18	3	6	5	10
Gender	Male	28	65	33	66
	Female	22	44	17	34
school attendance	6-9	13	26	17	48
Age / year	10-13	20	40	13	37
	14-18	5	10	5	14
	Not	12	34.3	14	38
Days of absenteeism / week	Zero	7	30.4	2	8.3
-	1	13	56.5	8	33.3
	2	3	13	14	85.3

N = Number F = Frequently % = percentage

Table (2) shows that most of children's age were between (3-6) years which presents (40%), most of Thalassaemic children were male were present (66%, 56%) in the study and control groups respectively. In the study group the highest percentage of absenteeism were (58.3%) for ≥ 2 days, while in the control group were (56.5%) for 1 day.

Table (3): Information sources toward Desferal Therapy

Items	Stud	y group	Control group		
	N	N=50]	N=50	
	F	%	F	%	
Information sources toward Desferal Therapy:					
Doctors	23	46	20	40	
Nurses	15	30	16	32	
Pharmacy and health workers	2	4	2	4	
Friends and family members	10	20	12	24	

N = Number F = Frequently % = percentage

The table 3 shows that the highest percentages of information sources toward Desferal Therapy in the study and control groups were (46%, 40%) for doctors and nurses respectively.

Table (4): Medical treatment used for Thalassaemic child in both groups

Items		Control group N= 50		Study group N=50		
		F	%)	F	%)	
Serum ferritin level	<2500ng/ml	14	28	15	30	
	2500 ng/ml	36	72	35	70	
Age of initial Desferal Therapy	3-5	34	68	32	64	
/years	6-8	16	32	18	36	
Receiving Desferal Therapy days	3-4	12	24	8	16	
/week.	5-6	38	76	42	84	
Receiving tab. vitamin C	Yes	43	86	46	92	
-	No	7	14	4	8	
Getting practice of using Desferal	Yes	22	44	25	50	
Therapy at Center	No	28	56	25	50	
Who was giving Desferal Therapy	Mother	30	60	27	54	
at home?	Father	11	22	15	30	
	Self	5	10	5	10	
	Sister and	4	8	3	6	
	brother					

N = Number F = Frequently % = percentage

Table (4) shows that most of the serum ferritin level of Thalassaemic children were ≥ 2500 ng/ml which presented (72%, 70%), highest percentage (68%) and (64%) were initiated Desferal Therapy at age 3-5 years old, while the days of receiving Desferal Therapy/week showes 5-6 days / week, which presented (76%, 84%), high percentage (86%, 92%) of children receiving tablet of vitamin C were respectively, (60%, 54%) of children were receiving Desferal Therapy at home by their mothers and most of the them (56%, 50%) were did not get training of how using DT to their children in Hawler Thalassemia Center, in the control and study groups respectively.

Table (5): The association between mothers' knowledge with thir ages at pre and post tests of the study and control groups

			St	udy gro	ир		Control group							
Mothers			K	nowledg	ge		Knowledge							
age/years	Pre-test				Post-te	st		Pre-te	st		Po	st-test		
	kn ow	don't know	Tota l	know	don't know	Total	know	don't know	Total	know	don't know	Total		
30	11 6	112	228	204	24	228	107	140	247	110	137	247		
31-39	20 6	147	380	335	45	380	140	146	286	150	136	285		
40-49	11 2	78	190	153	153	190	150	172	322	156	166	323		
>49	90	62	152	130	130	152	36	59	95	36	59	95		
Total	52 4	426	950	822	128	950	4461	504	950	462	488	950		
	P	= 0.268	NS	P = (0.035 S		P = ().239 N	IS	P = 0	.062 NS	-		

P = P value NS = Not Significant S = Not

Significant

This table shows that there is no significant association between mothers' knowledge with their ages at pre-test in study and control groups but there is significant association between mothers' knowledge with their ages at post-test of the study group at p=0.035.

Table (6): The association between mothers' knowledge with their educational

level at pre and post tests of the study and control groups.

-		-	Study	group			Control study						
Mother's			Know	ledge			Knowledge						
education		Pre-test	t	Post-test				Pro	e-test		Post-test		
	know	don't know	Total	kno w	don't know	Total	know	don't know	Total	know	don't know	Total	
Illiterate	272	222	494	400	94	494	300	270	570	295	275	570	
Read and write	31	26	57	51	6	57	55	40	95	56	39	95	
Primary	156	148	304	275	29	304	91	80	171	91	80	171	
Intermedi ate and secondary	24	33	57	56	1	57	49	27	76	50	26	76	
Institute and ollege	13	25	38	37	1	38	25	13	38	26	12	38	
Total	496	454	950	826	124	950	496	520	520	520	520	520	
	P =0.0	6 NS	•	P =0.	P=0.00002 HS			P =0.175 NS			P =0.0501 NS		

P = P value

Hs = Highly Significant

NS = Not Significant

This table indicates that there is no significant association between mothers' knowledge with their educational level at pre-test in both groups respectively but there is very highly significant association between mothers' knowledge and practices with their educational level at post-test of the study group.

Table (7): The association between mothers' knowledge with their residential

area at pre and post tests of the study and control groups.

			Study	group			Control group						
Mothers	Knowledge							Knowledge					
occupation	Pre-te	st		Post-test			Pre-test			Post-test			
	know don' Total		kno	don't	Total	know	don't	Total	know	don't	Total		
		t		w	know			know			know		
		kno											
		W											
Employed	221	178	399	367	32	399	173	168	341	175	166	341	
Housewives	102	69	171	139	32	171	131	173	304	133	171	304	
Total	198	182	380	324	56	380	157	148	305	160	145	305	
	P =0.2	41 N	S	P =0.0006 HS			P =0.07	NS NS		P =0.063	3 NS		

P = P value

NS = Not Significant

H S = **Highly Significant**

This table demonstrates that there is no significant association between mothers' knowledge with their residential area at pre-test in both groups but there is very highly significant association between mothers' knowledge and their residential area at post-test of the study group.

Table (8): The association between mothers' knowledge with their occupation at

pre and post tests of the control and study groups

pre ana p	ost u	SIS OI	the c	Onu	n anu	Stuu	, 8	Toups						
	Study group							Control study						
Mothers	Knowledge							Knowledge						
occupatio	Pre-test Post-test						P	re-test			Post-test			
n	kno w	don't kno	Tota l	kno w	don' t	Tota 1		know	don't know	Total	know	don't know	Total	
		W			kno w									
Employed	11	27	38	35	3	38		20	18	38	22	16	38	
Housewiv es	402	510	912	673	239	912			428	484	912	462	450	
Total	413	537	950	708	242	950			448	502	950	484	466	
	P = 0.065 NS P = 0.011 s					P	=0.49	NS		P =0.38	31 N	S		

P – P valu

NS = Not Significant

S = Significant

This table indicates that there is no significant association between mothers' knowledge with their occupation at pre-test in both groups but there is significant

association between mothers' knowledge with their occupation at post-test of the study group.

Table (9): Comparative difference between knowledge, scores of the pre and post-test, after the application of the educational program of the study group and Comparative difference between, knowledge, scores of the pre and post-test, of the control group

Groups	Variables	Pre-test X	Post-test X	р	C.S
Control	Knowledge	9.5	9.72	0.06	NS
Study	Knowledge	9.06	15.7	0.000	HS

 $X = chi \ square$ $P = P \ value$ C.S = correlation Significant NS = Not Significant Hs = Highly Significant

Table 9 shows that there were no significant difference between the study and control groups with knowledge relative to pre-test but there were very highly significant difference between the study and control groups with knowledge relative to post-test.

DISCUSSION:

The finding of the present study showed that the majority of mothers' age ranged years old in the study group and from (31-39) and(40-49) respectively. They were illiterate and housewives, also fathers' education were illiterate and most of them were unemployed (Table 1). These results similar to the study which showed that the majority of the mothers who participated in her study were unable to read and write and they were housewives⁹. The results of the study provided the evidences that the mothers, who selected for the study, were considered as appropriate as possible candidates for the educational programmer because they had low educational level and were housewives. Many studies added that the educational programmer were given to the effects of education on parents of children with Thalassaemia on reduction of this disease. Advances in the management of this disease may result in longer life expectancy and improved quality of life. Parents' education can have a significant role in supporting patients who suffer from the disease. Nurses can help to increase knowledge of families having children with Thalassaemia disorder 10. Regarding demographic characteristics of Thalassemic children in the study and control groups (Table 2),

The result revealed that most of children's ages were between (3-6) years old, more than half of them they were males in both groups and the highest percentage of abscentism were ≥ 2 days in the study group, and 1 day in the control group. These result supported by a study which showed that the most of the thalassaemic children in the study and control groups were males and ages in 6 years old ⁹, also consistent with the finding with other study exhibited that the majority of the thalassaemic child in Hawler City were males¹¹. Regarding to information sources toward Desferal Therapy (DT) the best sources information toward DT were obtained from doctors and nurses (Table 3); this result agreement with the result of a study which reported that the majority of thalassaemia parents take information about Thalassaemia from doctors and nurses¹³. In (**Table 4**) which shows that most of the serum ferritin level of Thalassaemic children in the study and control groups were ≥2500 ng/ml, most of them were initiated Desferal Therapy at age 3-5 years old, and the days of receiving Desferal Therapy/week shows 5-6 days / week, , high percentage receiving tablet of vitamin C were receiving Desferal Therapy at home by their mothers and most of them their mothers did not get training of how using DT in Hawler Thalassemia

Center, in the control and study groups respectively. The results was agreed with a study ,which found that the majority of Thalassaemia patients with serum ferritin level were > 2500 mg/mL¹⁴. And other study added that Thalassaemia patients should with Desferal which depending on the degree of iron overload. Thalassaemia patient should take vitamin C every day, ideally at the same time as DFO is administered. However, it is generally recommended that patients only begin taking vitamin C supplements after they have been receiving DFO for a few weeks 15 also the result was agree with a study report that safety and effectiveness of DFO in pediatric patients under the age of 3 years have not been established ¹⁶. The analysis of the study results has indicated that the mothers' knowledge to their age had significant association only at post test in the study group while there was no significant association among mothers' knowledge and their ages at pre and post tests in the control groups (Table 5). This result was agreement with the results of a study stated that there was no significant differences were found between the three groups (control group and two groups of cases, two methods of education; lecture and booklet were used for groups of cases) tested in terms of the age, gender, level of education, job, number of affected children, and age of the child. However young parents were better educated as regards knowledge about thalassaemia disorders 17. The improvement of the study group mothers' knowledge was obviously associated to their exposure to the education programme which reflected its impact or effectiveness.

High significant association was observed between mothers' knowledge at post occasions in all educational levels in the study groups while in the control group there was no significant association was noticed at pre and post tests in all educational levels (**Table 6**). This showed that the mothers in all educational levels improved their knowledge about Desferal Therapy after implementation of the educational programme in the study group ,this result which demonstrated that the mothers' knowledge who had an educational level behind intermediate school had been greatly improved as they were exposed to educational programme ¹⁸. The finding of the present study indicated that there was significant association between mothers' knowledge at post test with their occupation in the study group but there was no significant association at pre and post tests occasions with their occupation in control group (Table7). This means that the housewives mothers try to improve their knowledge after implementation of educational programme in the study grouped provide good caring to their children. High Significant association was noticed regarding mothers' knowledge at post test with their residential area in the study group but In contrast there was no significant association between mothers' knowledge at pre and post tests with their residential area in the control groups (Table 8). That is mean urban, suburban and rural mothers in the study group improved their knowledge after implementation of the educational programme. But, in the control group did not improve due to unexposed to the educational programme. The present study showed that there was high significant differences between knowledge at P≤ 0.01, after the application of the educational programme in post-test conducts with relative comparison to pre-test occasion in the study group (Table 9). This finding supported by study who indicated that there were significant differences between pre and post tests at $P \le 0.05$ relative to the mothers' knowledge of the study group ⁹. This means that they did not expose to the educational programme and did not get information from anyone about Desferal Therapy during this period so their knowledge did not change. The result presented that the mothers have limited knowledge regarding Desferal Therapy which agree with a study documented that the main problems in genetic counseling for Thalassaemia in Thailand are Thalassaemia problems not visible to the administrators, unorganized teamwork and services, lack of knowledge and inadequate numbers of counselors, lack of Thalassaemia support group, and inadequate researches in Thalassaemia prevention and control 17 . After implementing of educational programme of Desferal Therapy on the study group, high significant different was revealed between the study and control groups at $P\!\!\leq\!\!0.01$, with regard to knowledge of the mothers in post-test .

This result is an agreement with a study who revealed that there were significant differences between the study and control groups at $P \le 0.05$ about knowledge on Thalassaemia in post tes⁹. In the present study, the researcher tried to introduce the information and items of the educational programme in a simple and clear language. So that to be more appropriate and acceptable for all educational level of mothers for better understanding.

CONCLUSIONS:

Based on the results of this study, it has been found that:

- 1. There are no statistical significant differences between study and control groups of pre-test mother's knowledge regarding Desferal Therapy using.
- 2. All mothers at study group improved their knowledge about Desferal Therapy after implementation of the educational programme with their socio-demographic characteristics (mother's age, level of education, occupation, residential area).
- 3. There are statistical significant differences in post-test mother's knowledge between study and control groups after implementation of the educational programme of Thalassaemic children.
- 4. Mothers who were not exposed to the educational programme did not show any improvement in their knowledge about Desferal Therapy in post-test.

RECOMMENDATIONS

- 1. Health education programmes apply in mass media (TV ,radio journal ...).
- 2-Screening should be apply for the following groups(Carrier population screening detection at population level,Pre-marital,Prenatal and suspected family and their children).
- 3-Booklet and pamphlet of education programme should be distributed for all mothers who are attending Thalassemia Center.
- 4-Specialized nurse or thalassemia nurse should be knowledgeable about Desferal Therapy and implemented routinely for all caregivers visiting center and their children treated by DFO.

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