Effectiveness of an educational health programme on mothers' knowledge and practices of thalassaemic children receive desferal therapy in Hawler thalassemia center/Erbil City

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Abstract

Background and objective: Thalassaemia is a heredity blood diseases characterised by decreased synthesis of one of the two types of polypeptide chains (β or α) which form the normal adult human hemoglobin molecule (HbA, α2,β2), resulting in decreased filling of the red cells with haemoglobin, and cause anaemia. The study aimed to improve mothers' knowledge and practices of Thalassaemic children who are using Desferal therapy.
Methods: A quasi-experimental study was carried out at Hawler Thalassemia Center in Erbil City from the 1st of March to the end of May 2010. One hundred mothers were selected and divided into two groups, 50 mothers exposed to the educational programme (study group) and a second group of (50) mothers were served as control. Pre and post test of subject of interest were done during the two occasions.
Results: The results revealed that mothers' knowledge and practices in the study group were improved. There is no significant association between mothers' knowledge and practices with socio-demographic characteristics at pre-test which became significant at post-test .

Conclusion: Yet, most of the mothers in the study group have gained benefit from implementation of this educational programme.

Keywords: Thalassaemia, Mothers' knowledge and practices, Desferal Therapy.

Introduction

Thalassaemia is the most common genetic disorders worldwide. It is a hereditary hemolytic anemia resulting from defects in hemoglobin production [1]. Thalassaemias is classified according to which hemolytic chain 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]. Currently Thalassaemia (Mediterranean anemia) is the most widespread single genetic disease. It isestimated 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 hemoglobinopathies 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 with a round 30000 people are carries of β-thalassaemia [7]. Hawler Thalassaemia center serves about 493 regular registered

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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 Desferal (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].the aim of the study is to improve mothers' knowledge and practices of thalassaemic children using Desferal therapy.

Methods

A quasi-experimental design was carried out throughout the present study with application of pre and post tests approach for the study and control groups, from 1st of march to the end of May 2010 at Hawler Thalassemia Center in Erbil City. The sample consisted of (100) mothers having thalassemic child, they were divided into two groups, the 1st group included 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 were considered as (control group).the sample of present study included Mothers who have children diagnosed with Thalassaemia major and recipients of Desferal Therapy by attending Hawler Thalassaemic Center in Erbil city for blood transfusion and follow-up with their age ranging from 3 to 18 years including both sex, data were collected through the use of a questionnaire tool and direct interview techniques were used as a mean of data collection which was carried out between 28th of March to 27th May 2010 which consisted of three major parts: Socio -demographic information of mothers and their children with Questionnaire concerning mother's knowledge and practices. content validity was determined by panel (15) of experts. Most of them had agreed that the questionnaire and educational health programme were clear, understandable, relevant and adequate. There are certain modifications were employed based on the experts' recommendation and suggestions. reliability; Internal consistency of questionnaire and educational health programme were assessed by person's Coefficients correlation (r-test). The result was (0.878) for mothers knowledge and (0.891) for mothers practices. The results of person's coefficients correlation (r-test) indicated excellent scale reliability. The educational health programme concentrated on several major topics and it was implemented through two sessions in the clinics of Hawler Thalassemia Center. The sessions were designed and scheduled for approximately (1.30 hours/day). The educational methods used for educational programme were lectures, group discussion, film and practical observed applications.

Statistical analysis

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}.

Results

The present study found that most of mothers' age in the study group were (31-39) years old which represents 40%, while in the control group ranged from (40-49) years old which represents 34%. Regarding the mothers' occupation, majority in the both groups were housewives 96%. In respect to residential area most of mothers in the study and control groups were from urban areas 42%, 36% respectively, Table1. Table 2 shows that most of children's ages were between (3-6) years which represented 40% and 36% in the study and control groups respectively. Thalassemic children males made 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.doctors were the Sources of information regarding Desferal Therapy in 40% of

cases including both groups, Table 3.there were no significant differences between the control groups in relation to knowledge and practices at pre and post-test but there they were a highly significant difference between the study and control groups with knowledge and practices relative to post–test, Table 4. Also there were very highly significant difference between the study group with knowledge and practices relative to pre and post-test while there were no significant difference between the control group with knowledge and practices relative to pre and post-test, Table 4.

Table 1: Demographic characteristic Thalassemic children's families

Items	Study group			Control group		
	NO.	%	Mean	NO.	%	Mean
Mothers age:						
<30	12	24		13	26	
31-39	20	40		15	30	
40-49	10	20	37.34	17	34	37.96
>49	8	16		5	10	
Total	**50**	**100**		**50**	**100**	
Mother's education level:						
Illiterate	26	52		33	66	
read and write	3	6		4	8	
primary	16	32	1.04	9	18	0.6
intermediate and secondary	3	6		2	4	
institute and college	2	4		2	4	
Total	**50**	**100**		**50**	**100**	
Father's education level:						
Illiterate	15	30		28	56	
Read and write	9	18		3	6	
Primary	15	30	1.52	13	26	1.0
Intermediate and secondary	7	14		3	6	
Institute and college	4	8		3	6	
Total	**50**	**100**		**50**	**100**	
Mother's occupation:						
Employed	2	4	1.96	2	4	1.96
Housewives	48	96		48	96	
Total	**50**	**100**		**50**	**100**	
Father's occupation:						
Employed	6	12		5	10	
Unemployed	44	88	1.88	45	90	1.9
Total	**50**	**100**		**50**	**100**	
Residential area:						
Urban	21	42		18	36	
Rural	9	18	1.98	16	32	1.96
Suburban	20	40		16	32	
Total	**50**	**100**		**50**	**100**	

Table 2: Characteristics of Thalassemic children (age, gender and Days of absenteeism)

Items	**Study group**			**Control group**		
	No.	**%**	**Mean**	**No.**	**%**	**Mean**
Age / years						
3-6	20	40		18	36	
7-10	18	36	8.926	13	26	8.556
11-14	7	14		16	32	
15-18	5	10		3	6	
Total	**50**	**100**		**50**	**100**	
Gender:						
Male	33	66		28	56	
Female	17	34	1.34	22	44	1.44
Total	**50**	**100**		**50**	**100**	
Days of absenteeism / week:						
Zero (no absent)	2	8.3		7	30.4	
1	8	33.3	0.88	13	56.5	0.38
≥2	14	58.3		3	13	
Total	**24**	**100**		**23**	**100**	

Table 3: Information Sources Regarding Desferal Therapy:

Items	**Study group**			**Control group**		
	N	%	Mean	N	%	Mean
Information sources toward Desferal Therapy:						
Doctors	23	46		20	40	
Nurses	15	30		16	32	
Pharmacy and health worker	2	4	4.66	2	4	4.26
Friends and family	10	20		12	24	
Total	**50**	**100**		**50**	**100**	

Table 4: pre and post test mean score of both groups (study and control)

Groups	**Variables**	**Pre-test X**	**Post-test X**	**p-value**
Control	Knowledge	9.5	9.72	0.06
	Practices	18.9	19.18	0.09
Study	Knowledge	9.06	15.7	0.000
	Practices	18.6	23.3	0.000

Table 4 displays the mean score gained by participants during pre and post test occasions. Study group showed significant difference in the mean score of knowledge and practices (P value = 0.000 and 0.000), while no significant difference was observed in the two domains among the control group.

Discussion

The finding of the present study showed that the majority of mothers' age ranged from (31-39) years old in the study group, while (40-49) years old in the control group. They were illiterate and they were housewives, also fathers' educational levels were classified as illiterate and most of them were unemployed. These results were similar to the study of Al-Mosowi [9] which showed that the majority of the mothers who participated in her study were unable to read and they were housewives. The results of this study provided the evidences that the mothers, who were selected for the study, were considered as appropriate for the educational programme as they had low educational level and were housewives.Dehkordi and Heydarnejad [10] stated that the few studies have been devoted to assess the impact of educational programmes. In addition, little thought was given to the effects of these prgramms on parents of children with Thalassaemia. 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 suffers from this disease. nurses can help to increase knowledge of families about children with this disorder. regarding demographic characteristics among both groups, the result revealed that most of children's aged between (3-6) years old, more than half of them 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 results were supported by Al-Mosowi [9] and Al-attar and Shekha [11] who showed that most of the thalassaemic children in the study and control groups were males and 6 years old. regarding information sources in relation to Desferal Therapy (DT), we observed that the prominent source of information was doctors and nurses; this result agreed with the result of Mahanil [12] who reported that the majority of thalassaemia parents take information about Thalassaemia from doctors and nurses. there were no significant differences in relation to knowledge and practices between the study and control groups on pre-test assessments. The results indicated that the mothers have limited knowledge and practices regarding Desferal Therapy.Dhamcharee [13] documented that the main problems in genetic counseling for Thalassaemia in Thailand were the followings; Thalassaemic problems not visible to the administrators, unorganized teamwork and services, lack of knowledge, inadequate numbers of counselors, lack of Thalassaemia support group, and inadequate researches in Thalassaemia prevention and control. after implementing of educational programme of Desferal Therapy on the study group, highly significant differences were revealed between the study and control groups with regard to knowledge and practices of the mothers. The findings of the present study is consistent with Al-Mosowi [9] who revealed that there were significant differences between the study and control groups regarding knowledge and practices on Thalassaemia on post test assessments. in the present study, the researcher tried to introduce the information and the items of the educational programs in a simple, clear language using visual aids for better understandability targeting all mothers' educational levels. The present study showed that there was high significant differences between knowledge and practices, after the application of the educational programme on post-test assessment with relative comparison to pre -test values in the study group. This finding was supported by Al-Mosowi [9] who indicated that there were significant differences between pre and post tests relative

to the mothers' knowledge and practices in the study group. There were no significant differences between knowledge and practices relative to the control group during pre and post-test.

Conclusion

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

There were no statistical significant differences between study and control groups on pre-test knowledge and practices regarding Desferal Therapy but they were statistical significant differences in post-test knowledge and practices between both groups after implementing the educational program.. Mothers who were not exposed to the educational programme did not show any improvement in their knowledge and practices regarding Desferal Therapy in post-test.

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