Impact of Education Program upon Mother's Knowledge and Practices of Haemophilic Children Type A

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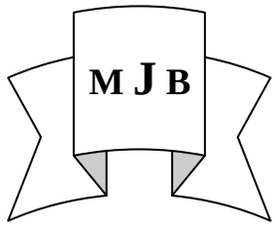

Abstract

Background and objectives: World Health Organization and Haemophilia Foundation Australia 2000 [1] reported that the identification of patients with haemophilia remains a major problem, even in countries which have made a great efforts to establish haemophilia care facilities. Only 10-60% of expected number of patients have those facilities and 50% of problems seen in people with haemophilia could be avoided simply by education [2].

Subjects and methods: Quasi experimental study was carried out at Hereditary Bleeding Diseases center in AL-Mansur Pediatric Teaching Hospital in Baghdad, to identify the impact of education program upon knowledge and practices of Haemophilic children type A **,**Seventy mothers having haemophilia A children were included in this study and divided into study and control groups..

Results: The results revealed that mothers of the study group had benefit from the implementation of educational program, their knowledge and practices were adequately improved and developed.

.**Conclusion:** The study concluded that the educational program could be considered as a need for all mothers having haemophilic child.

Keywords: educational program. , haemophilia , mothers , knowledge and practices.

الخلاصة

الخلفية والأهداف: اكدت منظمة الصحة العالمية ان الأطفالهن المصابين بالهيموفيليا مازالوا يشكلون مشكلة كبيرة حتى في البلدان التى تبذل جهودا كبيرة في توفير مستلزمات الرعاية لهم فحوالي ١٠-٦٠ % من عدد المرض تتوفر لهم هذه المستلزمات و٥٠% من المشاكل التي لديهم يمكن تجنبها من خلال البرنامج التثقيفي البسيط

منهجية البحث : أجريت دراسة شبة تجريبه في مركز الأمراض النزفية لمستشفى المنصور الأطفال لمعرفة مدى تاثير البرنامج لتثقيفي على امهات الاطفال المصابين بالهيموفيليا لغرض تحسين معلوماتهن وممارساتهن تجاه الأطفالهن المصابين بالهيموفيليا تم اختيار سبعون ام قسمت الى مجموعتين (ضابطة وتجريبية).

الاستنتاج والتوصية: أظهرت النتائج بان أمهات المجموعة التجريبية تحسين معلوماتهن وممارساتهن من خلال تطبيق البرنامج التثقيفي. استنتجت الدراسة أن البرنامج التثقيفي يمكن اعتباره حاجة لجميع أمهات الأطفال المصابين بالهيموفيليا لذا أوصت الدراسة أن البرنامج التثقيفي يمكن تطبيقه لجميع الأمهات لتحسين معلوماتهن وللعناية بأطفالهن المصابين بالهيموفيليا.

Introduction

The term haemophilia refers to a group of bleeding disorders in which there is a deficiency in one of the factors necessary for coagulation of the blood such as factor VIII , IX or XI[3] and the most common type of haemophilia is factor VIII deficiency or haemophilia A [4].

Haemophilia A is inherited as a sex-linked, life-long disorder occurring predominantly in males which affects approximately 1 in 10,000 male births. All races and socioeconomic groups are affected [5] the incidence of haemophilia A has been calculated that, worldwide there are approximately 350,000 people with severe or modrate haemophilia A, as mentioned by H FA [6].

Haemophilia Foundation Australia reported that within the end of this century the number of patients suffering severe haemophilia A and B will be 450,000 patients, about 80% of them would be in the developing countries [4].

The people with severe haemophilia usually experience frequent bleeding episodes (as often as once monthly) that required treatment with clotting factor concentrate, and there are many competing health needs from few resources usually as cryoprecipitate made from locally supplied blood [3] and the majority of bleeding episodes in haemophilic patients occur within the joints; haemarthrosis of the knees, elbows and ankles account for almost 80% of the bleeding episodes [7] and the bleeding is the most frequent cause of death in children with congenital coagulation disorder and intracranial hemorrhage (ICH) as accounts for the majority of mortality in all age groups. Immediate diagnosis and rapid medical management are mandatory [8].

It is clear from what has been mentioned above that mothers greatly need a health care program to help their haemophilic children to reduce the complications and bleeding episodes as much as possible so that their children can live near normal life.

Objective of the study

To assess the knowledge and practices of mothers towards their haemophilia A children and to determine the effectiveness of educational program upon the mothers knowledge and practices through post-test and a follow-up approach for four months after program implementation.

Methodology

This study was carried in Hereditary Bleeding Disease Center in Al-Mansur Pediatric Teaching Hospital, on mothers having haemophilia A children, which were admitted to the hospital.

I .Assessment of needs: The researcher use primary and secondary assessment format was constructed and designed depending on open format information and after reviewing the related literatures to assess the mother's need for the educational program through assessing the knowledge and practice of mothers about haemophilia A as well as problems experienced by children with haemophilia A, and how mothers can manage them.The application was conducted on a sample consisting of (100) mothers having haemophilic children type A who were selected randomly from Hereditary Bleeding Disease Center in Al-Mansur Pediatric Teaching Hospital in Baghdad city.

II- The educational program

1.Program construction

The educational program for mothers having haemophilia type(A) children was developed depending on the results were obtained from the assessment of the mothers knowledge and practices, and from reviewing the literature Its also comprised components that aimed to achieve the following objectives:

a. Promote mothers knowledge towards their haemophilia (A) children.

b. To improve mothers practices to achieve better care for their sick children.

2.The Implementation of the educational program me

The education program concentrated on six major topics and it was implemented through six classroom sessions, Each session was designed and scheduled for approximately (60) minutes and was presented in Hereditary Bleeding Diseases center in AL-Mansur Pediatric Teaching Hospital in Baghdad city. This was carried out from the 2nd of February to 10th of March 2001.

2.Validity and reliability

Validity of the educational program and questionnaire format was determined by a panel of 14 experts of different specialization. Pearson's coefficient of correlation was used, the result was (r = 0.85) for the mothers knowledge and (r = 0.87) for the mother's practices and it was significant at $p < 0.01$ level. This means that the format was adequately reliable.

III- The research methods

1- Design and setting of the study.

A quasi-experimental design was carried throughout the present study with the application of pre-post tests approach for the study group & control group. It was carried out at Hereditary Bleeding Diseases Center in AL-Mansur Pediatric Teaching Hospital in Baghdad city.

2.The sample of the study

The purpose (judgmental sample) was selected at the Hereditary Bleeding Disease Center in Al-Mansur Pediatric Teaching Hospital in Baghdad city, which was the source of the study and control groups.The study sample consisted of (70) mothers having haemophilia type (A) children, they were divided into two groups, one group of (35) mothers who were exposed to the educational program (study group) and another group of (35) mothers were not exposed to the program and considered as (control group).

Criteria of the sample Selection

Mothers of children who were diagnosed as haemophilia type (A) patients, admitted to Hereditary Bleeding Disease Center in Al-Mansur Pediatric Teaching Hospital in Baghdad city, their children age ranged from birth to 18 years, all are males mothers who give care to haemophilic type (A) children and the mothers who were willing to participate in the study and attended regularly in the Heredity Bleeding Diseases Center follow up.

3. The study instruments

The program comprised of many aspects , it includes the following :1. Demographic data of mothers & families concerning their characteristics and their children ,*2.* Questionnaire concerning mothers knowledge .It was comprised of (11) questions. Each question comprised of 3 items, regarding the nature of disease, definition, genetic, type of bleeding, signs and symptoms of bleeding, site of bleeding, information about diet, hygiene and complications. The items were rated according to 3 points

type rating scale as (know, uncertain and don't know) and levels of the scale were scored as (3 for know, 2 for uncertain, and 1 don't know)

3. Questionnaire concerning mothers practice .It was comprised (13) questions. Each question consisted of 3 items regarding the management of different types of bleeding (wound, joint, nose, mouth, teeth bleeding) safe environment,

when to seek medical advice, schooling, rehabilitation, play and playing. The items were rated according to (3) point type rating scale as (always, sometimes, never), the levels of the scale were scored as (3 for always, 2 for sometimes, and 1 for never).

4- Data collection

This was carried out during the period of 2nd February to 10th of March 2001.

The data were collected by the following technique: -

a. All the participants mothers (control and study groups) were interviewed for explaining the purpose of the study. All the participants mothers of the study group were exposed to the educational program at the same time.

b. All the participants were exposed to pre and post-test in order to detect the mother's knowledge and practices regarding their care provided to their haemophilic children.

c. All mother's (control and study groups) were exposed to the post-test approximately two weeks after the implementation of program.All mothers (control and study groups) were exposed to the follow-up after 2 and 4 months.

5- Data Analysis Data were analyzed through the application: Pearson's coefficient correlation (r-test): for determining the reliability of the pilot study) , Basic pooled t-test and One way analysis of variance.

Results

Table 1 Demographic characteristics of the sample

Variables	Study group N=35		Control group N=35	
	F	%	F	%
(a) Mother age				
≤ 20	**5**	**14.3**	**4**	**11.4**
21 – 25	**1**	**2.8**	**6**	**17.1**
26 – 30	**7**	**20.0**	**10**	**28.6**
31 – 35	**7**	**20.0**	**5**	**14.3**
36 – 40	**10**	**28.6**	**8**	**22.9**
41 - < 45	**5**	**14.3**	**2**	**5.7**
(b) Educational level				
Unable to read and write.	**5**	**14.3**	**4**	**11.4**
Able to read and write.	**4**	**11.4**	**6**	**17.1**
Primary school graduate.	**10**	**28.6**	**11**	**31.5**
Secondary school graduate.	**7**	**20.0**	**5**	**14.3**
High institute/college graduate	**9**	**25.7**	**9**	**25.7**
(c) occupational status:-				
Employed	**12**	**34.3**	**10**	**28.4**
unemployed	**23**	**65.7**	**25**	**71.6**
(d) Residential area				
Urban	**17**	**48.6**	**13**	**37.4**
Rural	**18**	**51.4**	**22**	**62.6**

Concerning to the study group the highest percentage mothers age range from (36-40) years old which present (28.6%) while the control group range from (26-30) years old which presents (28.6%).Most of the mothers in the study and control groups, are primary school graduate which represents (28.6%, 35.2%) respectively, were unemployed (65.7% , 71.6%) respectively and majority of them come from rural areas (51.4% , 62.6%) respectively.

Table 2 Distribution of child's age according to school attendance in the study group.

School attendance / Age of child	Yes		No	Total
	Regular	Irregular		
Birth - < 6 years	-	-	10	10
6 years - < 10 years	3	8	6	17
10 years - < 14 years	2	3	1	6
14 years – 18 years	-	1	1	2
Total	5 (14,3%)	12 (34,3%)	18 (51,4%)	35 (100%)
X^2 obs = 15.045 df = 3 X^2 crit = 7.815 p < 0.05				

This table shows that the majority of children age range between (6- < 10) years old. The majority of children are attending school regular {5,(14,3%)}, and irregularly {12,(34,4%)}, while { 18,(51,4%)} where not attending school at all due to their illness about 8children, and 10 children were excluded because they were preschool age (Birth - <6 years).

Table 3 Distribution of children affected in one family according to family history of haemophilia A.

Number of Children affected / Family history of hemophilia A	Study group				Control group			
	1	%	> 1	%	1	%	1	%
Yes	17	48.6	9	25.7	21	60	8	22.9
No	7	20	2	5.7	6	17.1	-	-
Total	24	68.6	11	31.4	27	77.1	8	22.9

This table shows that the highest percent (48.6% , 60%) in study and control groups respectively are in families having one child effected with hemophilia.

Table 4 The comparative difference between control group's knowledge and practices, scores of the pre and post-test.

Variables	Control group		t- observed	p-value	C.S
	Pre-test $\overline{X}$	Post-test $\overline{X}$			
Knowledge	36.8857	37.4286	1.461	p>0.01	N.S
Practices	43.9143	43.2857	1.0681	p>0.01	N.S
t critical = 1.6896 df = 34					

This table shows that there are no significant difference between, knowledge and practices relative to the pre and post-test in the control group.

Table 5 The comparative differences between study group's knowledge and practices scores of the pre and post-test.

Variables	Study group		t- observed	p-value	C.S
	Pre-test $\overline{X}$	Post-test $\overline{X}$			
Knowledge	36.6714	94.3143	134.086	P<0.01	H.S
Practices	43.3429	107.9714	78.230	P<0.01	H.S
t critical = 1.6896 df = 34					

This table reveals that there are significant differences between, knowledge and practices relative to the pre and post-test in the study group.

Table 6 Analysis of variance for the differences between the pre test post-test, and follow up 1 and 2, relative to the mothers practices in the study group.

Source of variation	Sum of square	df	Mean square	F
Between Groups	19.371	2	9.686	8.167
Within Groups	37.952	32	1.186	
Total	57.323	34		
F critical = 5.432 P≤ 0.01				

The table shows that there are a significant differences between the pre, post test and follow-up 1 and 2, and within groups, as well as relative to mothers practices in the study group.

Table 7 Analysis of variance for the differences between the pre test post test, and follow up 1 and 2, relative to the mothers practices in the control group.

Source of variation	Sum of square	df	Mean square	F
Between Groups	30.448	2	5.077	3.408
Within Groups	41.695	32	1.489	
Total	81.143	34		

F critical = 5.432	P > 0.01

This table shows that there are no significant differences between pre, the post test and follow up 1 and 2 groups, and within groups as well as relative to mother's practices in the control group.

Table 8 Comparison between the study and control groups with knowledge during 2 and 4 months of follow up.

Groups	df	2 months				4 months			
		$\overline{X}$	S.D.	t-test	P.	$\overline{X}$	S.D.	t-test	P.
Study Group	34	94.371	2.045	17.388	< 0.01	89.028	5.327	13.276	< 0.01
Control Group	34	53.942	8.57	0.375	> 0.01	54.321	9.623	1.07	> 0.01
t critic = 2.750									

This table indicates significant differences at P < 0.01 between the study and control groups concerning the improvement of the mothers knowledge during the period of 2 and 4 months after implementing the educational program.

Table 9 Comparison between the study and control groups with practices during 2 and 4 months of follow up.

Groups	df	2 months				4 months			
		$\overline{X}$	S.D.	t-test	P.	$\overline{X}$	S.D.	t-test	P.
Study Group	34	109.086	3.760	280.193	< 0.01	99.485	6.635	22.173	< 0.01
Control Group	34	56.086	7.2858	0.566	> 0.01	57.102	9.324	1.29	> 0.01
t critic = 2.750									

This table shows significant differences at P < 0.01 between the study and control groups concerning the improvement of practices of mothers during 2 and 4 months after implementing the educational program.

Discussion

Part I: Demographic characteristics of mothers and their hemophilia type A A children.

The results of the present study revealed that the highest percentage of the mothers were selected for implementation of the educational program, had low educational level they were primary school graduate both in the study and control groups (Table 1), indicating that mothers had low level of education. These results are consistent with the findings of HFA [10], which indicated that mothers in developing countries need an educational program about haemophilia type A, and how to manage their children during episodes of bleeding.

Regarding the demographic characteristics of the haemophilic children in the study and the control groups, the results showed that the high percentage of children are (6 - <10) years of age, and most of children irregularly attend school (48% , 63.64%) respectively or do not attend school (32% , 31.81%) respectively in study and control groups (Table 2) , because schools for haemophilic children only are rare , but in some countries the haemophilic children share their special schooling with children suffering different physical impairments, and children miss 25% of their schooling because of their bleeding [11]. Family history of the disease in the present study found to be (48.6%) in families having one child affected in the study group. While in the control group was (60%) of families having one child affected (Table 3).

Haemophilia type A is herediatory disorder of blood clotting mechanism primarily affecting males, being transmitted through unaffected females [11], while the HFA [12] stated that one quarter to one third of all occurrences appear in families with no previous history of the disorder. This is in agreement with the present results were (25.7%) of the study group and (17.1%) of the control group are new cases without family history.

Part II: The comparative difference between the mothers knowledge and practices in the study and control groups.

There were no differences relative to mothers knowledge and practices between the control and study groups in pre-test at $p \leq 0.01$ occasion (Table 4). The result presented that mothers have limited knowledge and practices about how to manage their haemophilia child, in agreement with study who indicated that most mothers have no adequate knowledge and practices concerning haemophilia type A [13]. Therefore, educational program give them the chance to improve their knowledge and practices toward their haemophilia type A children and give mothers a chance to meet with others to exchange ideas and experience.

The result is also consisted with that of the finding of the WHO/WFH which indicated that most mothers in developing countries need educational program concerning haemophilia definition, incidences, genetic, signs and symptoms of bleeding, type of bleeding, investigation prevention & treatment to reduce the episodes of bleeding and to let the child live normal life [14].

After implementing the educational program of haemophilia on the study group, significant different was found between the study and control groups at ($P \leq 0.01$) regard to knowledge and practices of mothers in post-test (Table 5).This finding is supported by study who stated that the increased education about haemophilia management was effective for the mothers knowledge and practices[15]. The results of the present study are in agreement with finding of study who indicated that attendance of educational program did improve mothers haemophilia knowledge and practices to reduce episodes of bleeding in their children[16].

Part III : Determination of haemophilia A educational program effectiveness for mothers knowledge and practices during follow up at 2 and 4 months

Significant difference between the study group concerning mothers practices after a period of 2 and 4 months of program implementation (Table 6). While there was no significant difference between the control group concerning mothers practices after a period of 2 and 4 months of program implementation (Table 7).In this study it was found that its useful when a follow up is applied in two and four months after educational program implementation. This indicate that the amount of information acquired by these mothers were sufficient and effective after the educational program so they have

greater benefit more than of those in the control group. So that the present study shows significant difference between the pre, post-test and follow up 1 and 2 of the study group when haemophilia educational program was applied, while there were no significant difference found in pre, post-test and follow up 1 and 2 of the control group (Table 8 and 9). Is supported researchers who reported that the education about haemophilia is a primary requirements for affected families and their doctors[17]. Morbidity and mortality are reduced by retraining rom necessary intervention, as well as by treating bleeds appropriately.

Conclusions

a. There are no statistical significant differences between study and control groups of pre-test knowledge and practices regarding haemophilia type A.

b. There are statistical significant differences in post-test knowledge and practices between study and control groups after implementation of educational program to mothers of haemophilia type A children.

c. The follow – up approach showed clearly that mothers haemophilia knowledge and practices were consistently improved after 2, and 4 months, in the study group.

d. Mothers who were not exposed to the educational program did not show any improvement in their haemophilia knowledge and practices in the follow up period of 2 and 4 months.

Recommendations

a. Booklet of educational program should be developed and implemented for all mothers having children with haemophilia A, in order to increase their knowledge and practices toward the disease.

b. Specialized nurse should be master the educational program implemented routinely for all registered mothers having haemophilia A children.

c. Family members should be involved in the educational program activity to acquire important information that may contribute to the improvement of the patient recovery.

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