

The Perspective of the Pediatric Nurses toward Hemophilia in the Teaching Hospitals of Kirkuk city.

وجهة نظر ممرضي الأطفال نحو مرض الهيموفيليا في المستشفيات التعليمية لمدينة كركوك

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الخلاصة.

خلفية البحث : الهيموفيليا هو اضطرابات التخثر الناجمة عن الخلل الجيني للكرموسوم X، ويمكن أن تكون مورثة أو خلل ينتج عن طفرة جينية عفوية. في كل نوع من أنواع الهيموفيليا A,B,C يكون بروتين التخثر مفقود، مما تحدث النزف عند المصابين لفترات طويلة قبل حدوث التخثر.

الهدف :- تهدف الدراسة إلى تقييم معلومات ممرضى ردهات الأطفال حول نزف الدم الوراثي (مرض الهيموفيليا). ومعرفة العوامل المؤثرة على معارفهم.

المنهجية :- دراسة وصفية أجريت على مجموعة من ممرضى ردهات الأطفال والذين يتعاملون مع الأطفال الذين يعانون من مرض نزف الدم الوراثي للفترة من حزيران 2012 ولغاية أيلول 2013. وتم اختيار (50) ممرض وممرضة بالطريقة العشوائية (الغير الاحتمالية). واشتملت ادوات قياس المعرفة لدى الممرضين على جزئين والذي ثبت بالإعتماد على مراجعة الادبيات والدراسات والبحوث السابقة في العراق والعالم والذي تتعلق بمرض الهيموفيليا.

يتضمن الجزء الأول المعلومات الديمغرافية للعينة والمتضمنة العمر، الجنس، المستوى التعليمي وعدد سنوات الخدمة في التمريض وعدد سنوات الخدمة في ردهات أمراض الدم والمشاركة في الدورات التعليمية إن وجد، أما الجزء الثاني فهو مكون من استمارة استبائية مصممة ومكونة من (13) فقرة وقد صممت لأملها بطريقة المقابلة والتي تتضمن المعلومات المتعلقة بمعارف الممرض تجاه الهيموفيليا والتي تشمل المعلومات العامة، علامات وأعراض وطرق العلاج والعناية المستخدمة ومعلومات أخرى.

تم تحليل البيانات من خلال استخدام الاحصاء الوصفي والذي تتضمن التكرارات والنسب المئوية واستخدام الوسط الحسابي.

النتائج:- أظهرت النتائج أن معظم أفراد العينة من الذكور (78%) وضمن الفئة العمرية $31 \leq$ وأن نسبة (60%) من العينة ضمن المستوى الدراسي دبلوم في التمريض ومما يقارب (38%) من العينة لديهم من (1-5) سنوات من الخبرة في مجال التمريض في حيث أن (42%) من العينة لديهم خبرة في مجال امراض الدم، وأن (68%) من العينة لم يسبق لهم الفرصة للمشاركة في الدورات التعليمية.

الاستنتاجات:- أظهرت الدراسة أن العينة لديها مستوى مقبول من المعرفة فقط في مايتعلق بتعريف المرض ودور الوراثة في انتقال المرض وأنواع الهيموفيليا وطرق العلاج المستخدمة وأظهرت نتائج البحث أن العينة لديها مستوى غير مقبول من المعرفة في مايتعلق بخطورة النزف الداخلي أو الخارجي فيمرضى الهيموفيليا وأكثر الأعضاء الداخلية التي يحدث فيها النزف الداخلي وحدث المرض في العوائل التي ليس لها تاريخ مرضي والتسميات الأخرى للمرض هيموفيليا (A) و(B) والتغيير الجيني للإصابة بالهيموفيليا عند النساء والرجال والية تخثر الدم مع توضيح دور العاملين رقم (IX) (VIII). وأظهرت النتائج أن العينة لها مستوى متوسط من المعرفة حول تأثيرات النزف عند مرضى الهيموفيليا على نمط الحياة والمضاعفات الناتجة عن الأجسام المضادة في العلاجات التعويضية مع مرض الهيموفيليا.

التوصيات:- يوصي الباحث بدورات تدريبية خاصة عن مرض الهيموفيليا ومضاعفاته وتأثيراته على الفرد المجتمع والذي بدوره يساعد على زيادة معارف وممارسات الممرضين. والتركيز على برنامج التعليم المستمر في مستشفيات الاطفال. توفير مجلدات وكتب خاصة عن المرض والتركيز أكثر على المرض وأمراض الدم في المناهج الدراسية التمريضية.

Abstract

Background: Hemophilia is a coagulation disorder arising from a genetic defect of the X chromosome; the defect can either be inherited or result from spontaneous gene mutation. In each type of hemophilia (A, B, and C), a critical coagulation protein is missing, causing individuals to bleed for long periods of time before clotting occurs.

Objectives: 1-Assess the pediatric nurses' knowledge toward hemophilia in children. 2-Find out the factors that affecting the knowledge of the sample.

Subjects and methods A descriptive study was conducted on pediatric nurses who were dealing with the children who have hemophilia, carried out in Kirkuk Governorate / teaching hospitals starting from July / 2012 to september 2013 .

Results Based on the results the researcher found that Most of study sample (78%) is males and (42%) at age between (31 and more) years old. Most of the nurses (60%) graduated from nursing institute and around (38%) of them have (1-5) years of experiences in their job as a nurse while (42%) of them have (1-5) years of experiences in blood diseases wards. The (68%) of the sample had no opportunity to be involved in training courses.

Conclusion: the study indicated that the nurses have high rates of acceptable level in knowledge related to definition, type of hemophilia, the hereditary role in the transmission of hemophilia and treatment process of the disease the finding showed that the nurses have a unacceptable level in the knowledge, regarding the type of bleeding in hemophilia is internal and external, place of internal bleeding, the incidence of hemophilia in the families don't have history of the disease, types, other names of hemophilia B, the samples information about genetic roles for males and females to be incidence with hemophilia and the clotting process with the role of factors VIII , IX And these results have a bad effect on quality of care which provided for the pediatric patient. The result of the study found that most of the sample have uncertain information regarding the effect of hemophilia through bleeding on the life style of the carriers and the main complication to replacement therapy is the antibodies respectively.

Recommendations Special training courses should be designed and constructed for nurses in relation to hemophilia. Nurse in hematological units must take their opportunity for continuing education. Increasing the number of professional nurses

assigned to work in the pediatric and blood disease wards. Motivate the nurses to improve their knowledge and practices which help improve their performance with the patients. Providing scientific booklet, publication and journal about hemophilia in nursing educational program.

Keywords: perspective, pediatric nurses, hemophilia, Kirkuk city.

Introduction

Hemophilia usually occurs in males (with rare exceptions) and about 1 in 5,000 males are born with hemophilia each year (Bolton . PH, Pasi KJ.2003) .Hemophilia B, also known as factor IX deficiency or Christmas disease, is an X-linked bleeding disorder caused by defects in the vitamin K-dependent enzyme factor IX of the clotting cascade (Franchini .M,2006). Factor IX is also known as the Christmas factor, hence the association of hemophilia B with the term Christmas disease (Giangrande. P,2005). Activated Factor IX (factor IXa) is the enzyme responsible for the activation of factor X to Xa in a reaction referred to as the "tenase" complex. A cofactor in this reaction is factor VIII, deficiencies in which result in hemophilia A (Roosendaal. G & Lefeber. F, 2007). Multiple mutations have been identified leading to hemophilia (B). A complete compilation of all of the mutations can be found at the hemophilia B database. Hemophilia B results in a bleeding disorder that is clinically indistinguishable from the more common hemophilia A (Graw .J, et al 2005). Hemophilia B occurs in approximately 1 in 30,000 male births (Oldenburg. J, El-Maarri. O, 2006). The other type of hemophilia is Hemophilia C, which is a mild form of hemophilia affecting both sexes. However, it predominantly occurs in Jews. It is the fourth most common coagulation disorder after von Willebrand's disease and hemophilia A and B. In the USA it is thought to affect 1 in 100,000 of the adult population, making it 10% as common as hemophilia (Johnson. M, et al 2007). Person with Hemophilia C has low levels of or is missing completely factor 11 (Also called FXI or factor XI deficiency) Hemophilia C is 10 times more rare than type A or B. Factor XI deficiency in Hemophilia C is different from the other types of Hemophilia, because it can show up in both males and females.

In hemophilia while all acute bleeding episodes are considered serious and emergent, there are five major sites of serious bleeding in hemophilia that threaten life, limb, or function. They are intracranial or spinal cord bleeds, throat bleeds, intra-abdominal bleeds, limb compartment syndromes (e.g. thigh, calf, forearm, upper arm) and ocular bleeds. All of these areas are characterized by bleeding into an enclosed space, compression of vital tissue, and potential loss of life, limb, or function. Since bleeding episodes also cause anxiety and fear in patients and families, the nursing interventions of communication, reassurance, education, and support will help them through these crises (Leticia, et al. 2012).

Objectives of the study:

- 1-Assess the pediatric nurses' knowledge toward hemophilia in children.
- 2-Find out the factors that affecting the knowledge of the sample.

Subjects and methods

Non –probability (purposive) sample of 50 pediatric nurses who deal with children from the pediatric hospitals and wards in Kirkuk city which they are dealing with hemophilic patients. For data collection The instrument was designed and constructed by the investigators to measure the variable underlying the present study, after review of literature. Data were obtained by the investigator who interviewed the nurses and filling the structural questionnaire format for the demographic items, knowledge items. The questionnaire consists of two parts: Part I This part of the questionnaire included demographic data related to the respondents characteristics such as age ,gender, level of education, years of experience in general wards and experience in oncology wards and whether they have continuing education or not. Part II This part of the consists of (13) items includes the structural items concerning knowledge of the sample toward hemophilia. This includes the general information, definition, sign and symptoms and the treatment, which is constructed from review of related literatures

and previous studies. Interviewing techniques are used. In order to measure the previous items accurately and statistically, liker scale are used and scores to find out the knowledge of the pediatric nurse and cut off points were used to identify the level of knowledge which it's determined as a following: 3 – 2.34 High knowledge (H.K), 2.34–1.68, medium knowledge (M.K) and >1.68 Poor Low knowledge (L.K) (Polit & Hungler, 1999).

The data of present study were analyzed through the application of two statistical approaches, which may assist for the determination of the study results. These approaches include Frequencies, Percentage, Mean of scores and one way ANOVA with t-test to find the significance different between the variables (L.K) (Polit, D. & Hungler, B.1999).

Results

Table (1) Distribution Of the study sample regarding Demographic Data

Items	F	%
Age		
20 and less	1	2.0
21 -25	12	24
26-30	16	32
31 and more	21	42
Total	50	100
Sex		
Male	39	78
Female	11	22
Total	50	100
Level of education		
nursing college	2	4
nursing institute	30	60
nursing secondary	13	26
nursing school	3	6
Other	2	4
Total	50	100
Years of employment		
1-5 years	19	38
6-10	16	32
11-15	2	4
16 and more	13	26
Total	50	100
Years of employment in blood diseases ward		
None	15	30
1-5 years	21	42
6-10	10	20
11-15	3	6
16 and more	1	2
Total	50	100
Participating in training courses related to blood diseases		
Yes	16	32
No	34	68
Total	50	100

Table (1) Indicated that (42.0%) of the nurses at age 31 and more years old, 2/3 of the sample were males (78.0%), the findings reveal that (60.0%) of nurses were graduated from medical institutes, (38.0%) of the nurses have (1-5) years of employment (42.0%) have (1-5) years of experience in blood disease wards and (68.0 %) have no opportunity to be involved in nursing training courses.

Table (2) Nurses Response toward knowledge regarding hemophilia

Items		F	%	M.S	Comparative level
Definition of hemophilia					
	I know	42	84	2.82	GK
	not sure	7	14		
	I don't know	1	2		
	Total	50	100		
Hereditary role in the transmission of hemophilia					
	I know	35	70	2.62	GK
	not sure	11	22		
	I don't know	4	8		
	Total	50	100		
The most common type of hemophilia is hemophilia A and hemophilia B.					
	I know	28	56	2.48	GK
	not sure	18	36		
	I don't know	4	8		
	Total	50	100		
The treatment of the hemophilia called replacement therapy by infusions of clotting factor (factor VIII and factor IX)					
	I know	35	70	2.56	GK
	not sure	8	16		
	I don't know	7	14		
	Total	50	100		

Table 2 shows that the nurses have high rates of acceptable level in knowledge related to definition, type of hemophilia and the hereditary role in the transmission of hemophilia and treatment process of the disease (84%), (56%), (70%), (70%) respectively.

Table (3) Nurses Responses toward knowledge regarding Hemophilia Complication

Items		F	%	M.S	Comparative level
The effect of hemophilia through bleeding on the life style of the carriers to the disease.	I know	22	44	2.33	MK
	not sure	23	46		
	I don't know	5	10		
	Total	50	100		
The main complication to replacement therapy is the antibodies (inhibitors) against the clotting factors.	I know	17	34	2.22	MK
	not sure	27	54		
	I don't know	6	12		
	Total	50	100		

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Table 3 presented that that (46%), (54%) of the sample have uncertain information regarding, the effect of hemophilia through bleeding on the life style of the carriers and the main complication to replacement therapy is the antibodies respectively.

Table (4) Nurses Responses toward knowledge regarding bleeding in hemophilia

Items		F	%	M.S	Comparative level
Nurse's information about the clotting process in the body and the two important clotting factors VIII (8) AND IX (9).	I know	13	26	2.18	LK
	not sure	33	66		
	I don't know	4	8		
	Total	50	100		
The nurse's information about the bleeding in hemophilia and which one is most risky internal or external bleeding.	I know	8	16	1.62	LK
	not sure	15	30		
	I don't know	27	54		
	Total	50	100		
Nurses information about the place of internal bleeding in the knee and other joints, muscles, tissues and brain	I know	9	18	1.44	LK
	not sure	4	8		
	I don't know	37	74		
	Total	50	100		
Nurses information about incidence of hemophilia in the families don't have history of the disease	I know	4	8	1.42	LK
	not sure	13	26		
	I don't know	33	66		
	Total	50	100%		
Other names of hemophilia A	I know	9	18%	1.68	LK
	not sure	16	32%		
	I don't know	25	50		
	Total	50	100		
Other names of hemophilia B	I know	9	18	1.56	LK
	not sure	10	20		
	I don't know	31	62		
	Total	50	100		
The male incidence with hemophilia when the gene will be on X chromosome while in female the gene must be in both XX chromosomes and this is rare.	I know	8	16	1.56	LK
	not sure	12	24		
	I don't know	30	60		
	Total	50	100		

Table 4 showed that the nurses have a high rate of unacceptable level in the knowledge regarding the clotting process with the role of factors VIII , IX(66%), type of bleeding in hemophilia is internal and external 54%, place of internal bleeding 74%, the incidence of hemophilia in the families don't have history of the disease(66%), other names of hemophilia A (50%) other names of hemophilia B

(62%), the samples information about genetic roles for male and females to be incidence hemophilia (60%).

Table (5) one –way analysis of variance for the difference between nurse's knowledge, educational level, years of experience in nursing and years of experiences in blood disease wards and their age.

Age					
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1872.471	3	624.157	29.104	.000
Within Groups	986.509	46	21.446		
Total	2858.980	49			
Educational level					
Between Groups	2653.024	4	663.256	144.917	.000
Within Groups	205.956	45	4.577		
Total	2858.980	49			
Years of experience in nursing					
Between Groups	2300.235	3	766.745	63.124	.000
Within Groups	558.745	46	12.147		
Total	2858.980	49			
Years of experience in blood disease ward					
Between Groups	2591.761	4	647.940	109.114	.000
Within Groups	267.219	45	5.938		
Total	2858.980	49			

F critical =2.37

Df= 49

This table shows that there were significant differences between nurses knowledge toward hemophilia regarding educational level, years of experience in nursing and years of experiences in blood disease wards and their age at P value ≤ 0.05 .

Table (6) T-test for comparison for the difference between nurse's knowledge and their gender and their participating in training courses related to blood diseases

sex				
	N	Mean	Std. Deviation	t
male	39	20.6667	7.87178	3.206
female	11	13.0000	.00000	
participating in training courses related to blood diseases				
yes	16	13.0000	.00000	4.474
no	34	21.7941	7.81909	

T critical =2

Df=48

This table shows that there were significant differences between nurse's knowledge and their participating in training courses at P value ≤ 0.05 .

Discussion of the results

Knowledge is to constant change adequate knowledge and practice has been recognized as a necessary ingredient in the nurses' ability to lead normal and productive life to their patients (Al-Botany,1996). She found out that nurse's knowledge and practice in the patients care is considered one of the essential tools in raising the standard of patient care giving by nurse. The nurses must have sound understanding of scientific principles underlying each step of any procedure in order to prevent

possible risk factor, so they become able to apply their knowledge into effective care (Al-Barody, 1990).

The nurses shows that (42%) of them are in age (30 and more) years old, more than the half of the study sample (78%) are males and this are supported by study done by (Al-sa'idi, 2006) which have a study on pediatric nurses and in his result he mentioned that more than the half of the sample are males, around (60%) of them are graduated from nursing institute while just (4%) are graduated from nursing college,

Around (38%) of them have (1-5) years experiences of job as a nurse, while (42%) of them have (1-5) years experience in blood diseases wards and this is have agreement with the result of (Al-sa'idi, 2006) study in which he indicated that (43.3%) of the nurses have (1-5) years of experiences in pediatric units, and also the researcher finds that (68%) of the nurses have no opportunity to be involved in training courses and continuing education and this come with the result of study carried by (Najeeb & Al- Daragy, 1984) in the medical city hospitals in Baghdad, revealed that (75.5%) of the nurses didn't receive training courses and continuing education.

The analysis was conducted on 13 items to assess the pediatric nurses knowledge toward hemophilia regarding to definition, general information, sign and symptoms, types and treatment. Concerning the nurses knowledge the study indicated that the nurses have high rates of acceptable level in knowledge related to definition, type of hemophilia and the hereditary role in the transmission of hemophilia (84%), (56%), (70%) that mean the nurses who work in the pediatric wards and blood diseases ward possess satisfied knowledge which is important for giving care to the patient with hemophilia while regarding the incidence of hemophilia A, the treatment of the hemophilia the result (56%), (70%) indicated that the nurses have acceptable level in knowledge in order to give high quality of patients care, nurses should have high level of knowledge as well as practice While the nurses have a high rate of unacceptable level in the knowledge regarding the type of bleeding of hemophilia 54% , place of internal bleeding 74%, the incidence of hemophilia in the families don't have history of the disease 66% ,other names of hemophilia A 50% other names of hemophilia B 62%, the incidence of hemophilia in male and female 60% And these results have a bad effect on quality of care which provided for the pediatric patient. While the result of the study found that (66%), (46%), (54%) of the sample have uncertain information regarding clotting process, the effect of hemophilia through bleeding on the life style of the carriers and the main complication to replacement therapy is the antibodies. the results shows that there were significant differences between nurses knowledge toward hemophilia regarding educational level, years of experience in nursing and years of experiences in blood disease wards and their age at $P \text{ value} \leq 0.05$. also the result shows that there were significant differences between nurses knowledge And their sex and participating in training courses at $P \text{ value} \leq 0.05$.

As a general nursing school ,secondary nursing school, nursing institute and college of nursing have a course for their students concerning hemophilia, but when the investigator saw the score of the samples knowledge after checking their information by the structural instrument, it was found that there were inadequate score in nursing knowledge and this agreed with the recommendations of the first nursing conference which was held in Baghdad 1985 the participant confirmed that the nurses have less knowledge and practice in giving care to their patients. Therefore, there must be more emphasis regarding information in giving care to patients with hemophilia in the study courses of the nursing students, to perform nursing effectively and satisfactory for themselves and for their patients then there must be more emphasis from the hospital policy for the nurses working in blood diseases wards having an educational program.

CONCLUSION:

The study indicated that the nurses have high rates of acceptable level in knowledge related to definition, type of hemophilia and the hereditary role in the transmission of hemophilia and treatment process of the disease. The finding showed that the nurses have a high rate of unacceptable level in the knowledge regarding the type of bleeding in hemophilia is internal and external, place of internal bleeding, the incidence of hemophilia in the families don't have history of the disease, other names of hemophilia A other names of hemophilia B, the samples information about genetic roles for male and females to be incidence hemophilia and the clotting process with the role of factors VIII, IX. The results found that most of the sample has uncertain information regarding, the effect of hemophilia through bleeding on the life style of the carriers and the main complication to replacement therapy is the antibodies.

RECOMMENDATIONS

Based on the result of the findings of the study, the investigator recommends the following:

1. Special training courses should be designed and constructed for nurses in relation to hemophilia and its complications may be helpful to reinforce their knowledge and practices and promote their experience.
2. Nurse in hematological units must take their opportunity for continuing education to maintain knowledge and practices as well as updating in blood disease nursing.
3. Increasing the number of professional nurses assigned to work in the pediatric and blood disease wards.
4. Providing scientific booklet, publication and journal about hemophilia, is highly recommended.
5. Elevate the scientific level of the nurses regarding the inherited and non inherited blood disorders in the educational program.

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