Assessment of Mothers Knowledge and Practices with Hemophilic Children type A at Azadi Teaching Hospital in Kirkuk City

تقييم معارف وممارسات أمهات الأطفال الناعور الوراثي نوع- أ - في مستشفى أزادي التعليمي بمدينة كركوك

Aram O. Mohammed, MsC* Khatam M. hattab, PhD**

* Academic Nurse, Dakuk General Hospital, Ministry of Health

**Instructor, Pediatric Nursing Department, College of Nursing, University of Baghdad

المستخلص:

الهدف: تهدف الدراسة لتقييم معارف وممارسات الأمهات تجاه أطفالهن المصابين بمرض الناعور نوع-أ- وتقييم حالتهم الاجتماعية ولاقتصادية و إيجاد العلاقة بين المعلومات الديموغرافية ، معارف وممارسات الأمهات اتجاه أطفالهن المصابين بمرض الناعور بمستشفى أز ادي التعليمي بمحافظة كركوك. المنهجية: دراسة وصفية تم اختيار عينة غير عشوائية (غرضية) مكونة من خمس وخمسون أم أطفالهن مصابين بمرض الناعور نوع تشرين الثاني ٢٠١٢ إلى أيار ٢٠١٣.وتم إجراء الدراسة في مستشفى أز ادي العام التعليمي بمحافظة كركوك. تتفرين الثانور أجزاء تشمل الخصائص الديموغرافية لكل من الأم والطفل والحالة الاجتماعية الاقتصادية للعائلة ومعارف مصابين بمرض الناعور نوع أ-بدأت من أجزاء تشمل الخصائص الديموغرافية لكل من الأم والطفل والحالة الاجتماعية الاقتصادية للعائلة ومعارف وممارسات الأم من المباشرة مع الأمهات في المستشفى.وتم تحديد صدق المحتوى وثبات الأستمارة الأستبيانية من خلال دراسة أولية والستخدام التحليل الإصرين المباشرة مع الأمهات في المستشفى.وتم تحديد صدق المحتوى وثبات الأستمارة الأستبيانية من خلال دراسة أولية والتراب ال

النتائج: تشير نتائج الدراسة إن (٣٠,٩%)من الأمهات كانت أعمارهم من (٤٠ ٤٤)و(٤٣,٩%) كانوا من خريجي الابتدائية. و أطفالهن كلهم ذكورا وأن(٢,٩٤%) من الأطفال كانت أعمارهم بين (٥-٩)سنوات وأن(٣٠,٩%) ليسوا في المدرسة وأن (٦٩,١%)من العائلة لديهم طفل واحد مصابا بالمرض و(٢٧,٦%) كانت إصابتهم بالمفصل، بالنسبة إلى مستوى شدة المرض (٥-٥٣%)كانت متوسطة و(٣٩,٢%) من العائلة يعتمدون على المستشفى لإعطاء العامل الثامن للطفل عند حدوث النزف <u>و</u>إن(٦١,٨%) حالتهم الاجتماعية-الاقتصادية ضعيفة و إن (٨٣,٦%)من العائلة يعتمدون على متأكدين من معلوماتهم وإن ممارساتهم كانوا(٢٢,٧%)أحيانا.وإن (٢٦,٦%) أبدا اتجاه أطفالهن المصابين.

ا**لتوصيات:** تطوير برنامج وكتيب خاص للأمهات باللغات المحلية(كردية والتركمانية...) واستحداث برامج ودورات التوعية نظرية وعملية للأمهات وتحسين واقعهم الاقتصادي لتقليل معاناة العائلة وتجهيز عامل التخثر الثامن للمستشفيات والمراكز الصحية بأطراف المدينة لمناطق تواجد المرضى.

Abstract:

Objective: The study aims to assess the knowledge and practices of mothers with hemophilia children type - A - , socio-economic status and association between mother demographic information with their knowledge and practices toward their children in Azadi Teaching Hospital in Kirkuk.

Methodology: Descriptive study no probability (purposive) sample. Selected Fifty-five of mothers having hemophilia children, started from November 2012 to May 2013. Study was carried out in the Azadi teaching hospital in Kirkuk. By using questionnaire which consists from five parts include demographic characteristics for mother and children, socio-economic, Knowledge and practices data gathered, by direct interview with the mothers in the hospital. Reliability and content validity of questioner were identified form of the pilot study. Descriptive and inferential statistical used to analysis of data.

Results: The results of the study (30.9%) of the mothers were aged (40 - 44) and (43.6%) were graduates from primary school. And their hemophilia children in all sample sex male, (41.8%) of hemophilia children were aged between (5-9) years though (30.9%) are not in school and that (69.1%) of the families have one child hemophilia infected and (27.6%) were diagnosis bleeding in joint , level of severity of the disease (65.5%) was moderate ,(98.2%) of family depended on hospital to provide factor eight and other treatment to hemophilia child when bleeding. socio – economic status of family show (61.8%) low status. (83.6%) of mothers uncertain of their information about hemophilia, mother practices were (72.7%) sometimes and (23.6%) never done good practice to their hemophilia children.

Recommendations: Develop special booklet for mothers local languages (Kurdish , Turkish) develop programs and awareness courses (theoretical and practical) for mothers and support family financial improve and provide factor eighth for hospitals and health center where patients found.

Key words: hemophilia, mothers with hemophilia children type A, knowledge, practice

Introduction:

Today's children are the citizens of tomorrow, and they are the treasures of nation. Healthy children are the greatest resources and pride of any nation. There is no task more important, so investment in the children development is an investment in the future of the nation. Thus their health and development must be monitored at every step of their life ⁽¹⁾.

Hemophilia is a genetic disorder where blood does not clot normally. The term hemophilia has Greek roots; the two parts are hemo, meaning blood and philia, meaning a tendency towards bleeding .people with hemophilia have a tendency to bleeding ,hemophilia blood disorder manifests three type Hemophilia A, Hemophilia B, and Hemophilia C⁽²⁾.

Hemophilia is the blood clotting disorder caused by mutation of the factor VIII and IX genes respectively, which lead to defective synthesis or synthesis of dysfunctional factor VIII or IX. Hemophilia A is more common than hemophilia B. Inheritance is Xlinked recessive; hence, males are affected while females are carriers. A hemophilic pseudo tumor is an encapsulated, chronic, slowly expanding hematoma, due to recurrent hemorrhage; and is seen in 1-2% patients with severe coagulate disorder (less than 1% of normal factor VIII activity). It usually occurs in soft tissues, muscles and tendons. The tumor enlarges slowly, develops a fibrous capsule, and can destroy underlying tissues by progressive necrosis ⁽³⁾.

Hemophilia has been indirectly known about since the second century AD. During those times families did not have to get their baby boys circumcised if they already had two sons die after the procedure. A Philadelphia doctor, Dr. John Otto, wrote about a "hemorrhagic disposition in certain families."Dr. Otto saw that the bleeding disorder was genetic and that males were significantly more likely to have the condition. In England hemophilia plagued the royal family because Queen Victoria (1837-1901) was a carrier of the disorder. She passed hemophilia to one of her sons, and two of her daughters became carriers. When her daughters married royalty from other countries, hemophilia was then passed into the ruling families of Russia, Spain and Germany⁽⁴⁾.

A child who has hemophilia is lacking a sufficient amount of a certain protein, also known as clotting factor. In order for proper blood coagulation to occur, the body's clotting factors work to form a blood clot. When a blood vessel is injured a blood clot is needed to stop the vessel from bleeding. Blood platelets form the clot and the clotting factors help the platelets clump and stick together to cover the injury and stop the bleeding. When the clotting protein is not present, clotting occurs at a much slower rate and sometimes will not happen at all. A seemingly minor or small injury to a person with hemophilia can take much more time to heal because of the slower rate of coagulation. Fortunately, there are injections that people with hemophilia can take to normalize the clotting process ⁽²⁾.

Though Hemophilia is a hereditary disorder without proper treatment it will leads to serious damage to limb and joints function within the first one to two decades of life, this is due to joint mobility contractures muscle atrophy and chronic pain. Certain serious complications can further complicate the management of hemophilia, between (10-20%) of people with Hemophilia A and (2-3%) of those with Hemophilia B develop inhibitors deficient factor such patients do not respond to usual replacement therapy ⁽⁵⁾

Ergun mention that's in result of study mother with hemophilic children that low knowledge by not received well education about (disease and first aid) that effect negatively on management and care of child, poor practice by afraid dealing when the child injury or accident, mother with hemophilia child feel needed health care personnel and become sad when their child was ill. They mention also mothers should be having good knowledge, practice, and home management teaching to prevent complication ⁽⁶⁾.

In one study mention in abstract that children with severe hemophilia in the United Kingdom have very different experiences of their condition compared with many adults' early experiences of haemophilia. However, haemophilia can still have physical and social effects which can impact on the quality of life, not only for a child who has the condition, but also for their parents. Parents are deeply affected by their child's condition and their lives are transformed by the experiences of living with a child with haemophilia. Parents' responses are influenced by how well the child manages the disorder and the difficulties they experience ⁽⁷⁾.

As the mothers are in close interaction with their children and they are in better position to identify the health problems of the children. As a part of this, mothers have to be given adequate orientation in early diagnosis of common health problems of children. Thus they will be a dynamic force, instrumental and indispensable to health team for promoting health and preventing diseases. This can play a major role in the early detection and treatment of disease.

Methodology:

A descriptive study (Cross-sectional design) was carried out the direct interview of mothers to assess knowledge and practice. Non probability (purposive) sample consist of (55) mothers with hemophilic children type A were visited Azadi teaching hospital.

The questioner form is consisted of five parts which included mother demographic (6) items, child demographic (9) items, sostatus (SES), cio-economic mothers knowledge (37) items the response scored (1) don't know (2) uncertain (3) know and practice (53) items the response scored (1) never (2) some time (3) always, evaluate the validity of the questioner form the researchers presented it to fourteen experts in specialist field. reliability of the questioner was determined that mothers knowledge(r=0.912)and mothers practice(r=0.896) at level (p<0.05),the correlation coefficient above 0.70 is accepted, A pilot study included the 6 mothers with hemophilic children type A from azadi teaching hospital to determine the reliability of the study, average time required for the data collection. the statistical procedure include descriptive statistic (frequency, mean, percentage) and inferential statistic approach have been used.

Results:

Table 1. Demographic characteristics of mothers with hemophilic children type A

Variables		
1-Mother age (years)	F	%
2024	6	10.9
2529	11	20.0
3034	12	21.8
3539	9	16.4
40-44	17	30.9

Table 1. Continues

2-Education status	F	%
Not read& No Write	15	27.3
Read & Write	6	10.9
Primary	24	43.6
Intermediate	5	9.1
Secondary	3	5.5
Institute	2	3.6
3-Mother occupation	F	%
Housewife	51	92.7
Employee	4	7.3
4-Residential area	F	%
Rural	32	58.2
Urban	23	41.8
5-History of bleeding Disorder from relative	F	%
Yes	23	41.8
No	32	58.2
6-Mother relationship with husband	F	%
Relative	30	54.5
Not relative	25	45.5
Total	55	100

F=frequency %=percentage

This table shows that the third of the mothers (30.9%) in the age (40-45),(43.6%)of mothers graduated from primary school and (27.3%) are not read write and(92.7%)were house wife,(58,2%) living in rural area and (58.2%) of mothers relation have no history of bleeding disorder from relative,(54.5%) of mothers relative relationship with husband.

Table 2. Demographic characteristics of hemophilic children type A

Variable		
1-child age(years)	F	%
1-4	8	14.5
5-9	23	41.8
10-14	10	18.2
15-18	14	25.5
2-child school level	F	%
Kindergarten	6	10.9
Primary	21	38.2
Intermediate	7	12.7
Secondary	1	1.8
Not in school	17	30.9
3-Child received complete vaccine	F	%
Yes	39	70.9
No	6	10.9
Not complete	10	18.2
4-Number of affected children in one family	F	%
One	38	69.1

Table 2. Continues

Тwo	14	25.5
Three	2	3.6
Four	1	1.8
5-Order affected child in family	F	%
First	22	40.0
Second	26	47.3
Three	5	9.1
Four	2	3.6
6-first diagnosis Bleeding	F	%
After birth (umbilical cord)	7	12.7
Circumcision	2	3.6
By nose or mouth	10	18.2
Fall	8	14.5
Joint	15	27.3
Bruise	13	23.6
7-Level of disease severity	F	%
Severe	12	21.8
Moderate	36	65.5
Mild	7	12.7
Total	55	100

F = frequency %= percentage

This table show (41.8%) of age group between(5-9), school age group (30,9%) was not in school, (70,9%) receive all vaccine, (69,9%) of family have one male child effected with hemophilia A, (40.0%) first series son was affected in families , (27.3%) bleeding on joint most time and (65.5%) was moderate on level of severity in hemophilia A.

Table 3. Socio-economic status of the family with hemophilic children according to (SES) scales

Level	F	%
1-Low	34	61.8
2-Moderate	21	38.2
Total	55	100

F = frequency %=percentage

This table show that (61.8%) of family with hemophilic children is low socio-economic status.

Table 4. Hemophilia children Treatment Source

Treatment source of children	F	%
1-From hospital	54	98.2
2-From both family and hospital	1	1.8
Total	55	100

F = frequency %=percentage

This table shows that (98.2%) of family depend on hospital to get factor VIII and other child's treatment.

Table 5. Mothers' knowledge within two levels by frequency and percentage

ITEMS	Kr	now	unc	ertain	Don	Don't know		
	F	%	F	%	F	%		
1.4.Hemophilia type A from heredity disease thatis								
Males affected	50	90.9	4	7.3	1	1.8		
Female disease carrier	15	27.3	28	50.9	12	21.8		
Disease characterized by the length of bleeding	32	58.2	12	21.8	11	20.0		
2.4.Severity of Hemophilia A divided to (sever-	15	27.3	8	14.5	32	58.2		
moderate-mild)according to factor level in blood								
3.4. Signs and symptoms of Severe hemophilia are								
Bleeding inter joint or muscle	37	67.3	6	10.9	12	21.8		
Bleeding without injury or accident (spontaneous)	20	36.4	18	32.7	17	30.9		
4.4. Signs and symptoms of moderate hemophilia								
Bleeding when surgery	43	78.2	5	9.1	7	12.7		
Bleeding when accident or mild injury	28	52.7	13	21.8	14	25.5		
5.4. Signs and symptoms of mild hemophilia are:								
Not bleeding except when become hemophilia	35	63.6	12	21.8	8	14.5		
Bleeding in major surgery or sever injury	26	47.3	12	34.5	10	14.5		
6.4. Signs and symptoms of bleeding Joints :	20	47.5	19	54.5	10	10.2		
Swelling and pain	52	94.6	2	3.6	1	1.8		
Inability to movement	11	20.0	34	61.8	10	18.2		
High temperature	19	34.5	34 17	30.6	19	34.5		
7.4. Signs and symptoms of Muscle hemorrhage	15	54.5	1/	50.0	15	54.5		
Swelling	49	89.1	4	7.3	2	3.6		
Redness	28	50.9	22	40.0	5	9.1		
Pain	31	56.4	13	23.6	11	20.0		
8.4.Hemophilia child diet should								
Balance diet to easy chewing and digestion	7	12.7	6	10.9	42	76.4		
Rich nutrition substance diet like protein and iron	11	20.0	7	12.7	37	67.3		
9.4. Joint pain care through								
Analgesic	51	92.7	1	1.8	3	5.5		
Put ice bag on bleeding area	38	69.1	13	23.6	4	7.3		
Pressure on bleeding area	43	78.2	7	9.1	5	12.7		
10.4. The quality games for hemophilia children								
Dangerous plays to child is bicycle and football	32	58.2	9	16.4	14	25.5		
Safety plays to child is drawing, swimming and sing	27	49.1	15	27.3	13	23.6		
	2/	45.1	15	27.5	15	23.0		
11.4. Mother knowledge at child care and treat are								
Regular and continue child receive factor will help to	40	72.7	3	5.5	12	21.8		
decrease bleeding								
Not use suppositories to treat high temperature	7	12.7	7	12.8	41	74.5		
Not inject muscle	11	20.0	6	10.9	38	69.1		
Not use aspirin to treat pain or heat	10	18.2	6	10.9	39	70.9		
Continue to immunization by injection in subcutane-	10	20.4	6	10.0	22			
ous not in muscle	16	29.1	6	10.9	33	60.0		
12.4. Symptoms and signs of an allergic reaction								
High temperature	40	72.7	5	9.1	10	18.2		
Skin rash	17	30.9	19	34.5	19	34.5		
		00.0		04.0		0.1.0		

13.4. Recurrent Joint bleeding in hemophilic child						
lead to						
Restrict joint motion that bleed many time	22	40.0	9	16.4	24	43.6
Deformity of affected joint	9	16.4	16	29.1	30	54.5
Muscle atrophy surround joint	12	21.8	10	18.2	33	60.0
14.4. Complication Hemophilia is Intra-cranial bleed-						
ing the signs include						
Sever head ache	11	20.0	3	5.5	41	74.5
Nausea and vomiting	3	5.5	10	18.2	42	76.4
Vision confusion	4	7.3	7	12.7	44	80.0

Table 5. Continues

F=frequency, %= percentage

This table show in severity type of hemophilia (58.2%)of mothers don't know there is three level of hemophilia according to factor VIII in blood ,(61.8%)of mothers uncertain that joint bleeding can lead to inability to movement (76.4%),(67.3%)of mothers don't know about balance diet and rich nutrition diet can help hemophilia children type A ,Mother information when treat children show (74.5%)don't know that Suppository to treat high temperature should be prevented ,(69.1%)don't know muscle injection should be prevention ,(70.9)don't know aspirin should be prevented, Continue immunization by injection in subcutaneous not in muscle show (60.0%)don't know ,Joint injury complication in hemophilia items show (43.6%),(54.5%) and (60%) of mothers don't know about restrict joint motion ,deformity and muscle atrophy Hemophilia A complication is intra-cranial bleeding the sign is show (74.5%),(76.4%) and (80%) of mothers don't know about sever headache , nausea and vomiting and vision confusion

Table 6. Distribution of mother's knowledge to hemophilia children type a score with three levels(knows, uncertain and don't know)

Mother knowledge(37)	Score level of knowledge	Frequency	Percentage
Know	Good (=>93)	6	10.9%
Uncertain	Fair (75-92)	46	83.6%
Don't know	Poor (=<74)	3	5.5%

In this table show (83.6%) of mother's uncertain knowledge about hemophilia children type A in all items.

Table 7. Mother practice with two level frequency and percentage

Items	Always		Some times		Never	
	F	%	F	%	F	%
1- Transfer the child to hospital when						
Continue bleed	54	98.2	1	1.8	-	-
Impairment health status	10	18.2	42	76.4	3	5.5
Elevation of body temperature	5	9.1	15	27.3	35	63.6
2- The child carry ID card when out home	5	9.1	9	16.4	41	74.5
3- Mouth and teeth care of children through:						
Regular examination by dentist	-	-	14	25.5	41	74.5
Mouth & teeth care using smooth brush & slowly teeth washing	4	7.3	30	54.5	21	38.2

Table	7.	Continues
		00110110000

					-	
Daily follow and care by mother	18	32.7	29	52.7	8	14.5
4- Wound care in hemophilic child's						
Bind bleeding area by clean and dry bandage	49	89.1	4	7.3	2	3.6
Elevate affected area	31	56.4	23	40.0	1	3.6
Apply poultice cold	47	85.5	7	12.7	1	1.8
5- Care Joint bleeding through						
No movement the bleeding area	45	81.8	5	9.1	5	9.1
Apply ice bag cold	36	65.5	18	32.7	1	1.8
Elevate affected area	36	65.5	19	34.5	-	-
Relax not confuse child	13	23.6	37	67.3	5	9.1
Keep children calm	17	30.9	32	58.2	6	10.9
6- Care bleed nose through						
Few minute pressure on nose thumb and finger	24	43.6	20	36.4	11	20.0
Down head on downward	11	20.0	33	60.0	11	20.0
Open mouth child to breath	30	54.5	20	36.4	5	9.1
7- Avoidance hemophilic child exposure to bleeding by						
Prevent hits child special in head	43	78.2	10	18.2	2	3.6
Observe the child during daily activity	9	16.4	44	80.0	2	3.6
give the factor VIII before any operation or hard activity	36	65.5	17	30.9	2	3.6
8- Hemophilic child care when bruise through						
Apply poultice cold	51	92.7	4	7.3	-	-
Decrease children move ment in injure area	20	38.2	35	61.8	-	-
Observe any skin color change to injure area	23	41.8	29	52.7	3	5.5
9- Mother role in child's play activities:		1210		52.7		0.0
Keep away from group player like football	19	34.5	26	47.3	10	18.2
Prevent from violent friction with other children	11	20.0	35	63.6	9	16.4
Choose toys made by plastic to protect him	10	18.2	23	41.8	22	40.0
Continue Choose appropriate toys to child age and dis-	10	10.2	23	41.0	22	40.0
order	9	16.4	6	10.9	30	72.7
10- Mothers role in protection management against						
home accident through						
Cover house ground, floor and ladder carpet	35	63.6	17	30.9	3	5.5
Provide support rubber to child joint	16	29.1	35	63.6	4	7.3
Cover sharp (head, apex) furniture and house apparatus	10	25.5	32	58.2	9	16.4
11- Dietary care for Hemophilic child through	14	25.5	52	56.2	9	10.4
Give easily digestion nutrition substance	10	18.2	5	9.1	40	72.7
					-	
Slowly chewing	4	7.3	15	27.3	36	65.5
Prevent the hard fiber nutritionlike(apple,carrot)	11	20.0	9	16.4	35	63.6
12- Protection hemophilic child's from joint deformities						
by	20	50.7		44.0	2	
Placing bolster on children joint to decrease prevention	29	52.7	23	41.8	3	5.5
Prevent child from accident and fall	13	23.6	36	65.5	6	10.9
Care sport strengthens to joint and muscle	18	32.7	24	43.6	13	23.6
13- Hemophilic child's exercise should be			4=			
should be under mother observation	35	63.6	17	30.9	3	5.5
children protect from injury by wearing preventive and	16	29.1	36	65.5	3	5.5
appropriate clothes						
practice exercise single play, swimming walking	27	49.1	22	40.0	6	10.9
14- Help and encourage hemophilic child						
increase the children attention and awareness	26	47.3	23	41.8	6	10.9
protect himself from injury	19	34.5	33	60.0	3	5.5
carefully and attention children from injury when out home	27	49.1	19	34.5	9	16.4
15-Home treatment practice and mother role						

Table 7. Continues

Put the factor VIII in cold and dry place	34	61.8	9	16.4	12	21.8
Give any medicine before, when the patient have cannula.	2	5.5	7	12.7	46	81.8
Distinguish the factor that child needed.	21	38.2	7	12.7	27	49.1
Did you try to give the factor , when the child have can- nula	9	16.4	4	7.3	42	76.4
Home care and management according to physician or nurse recommendation	25	45.5	27	49.1	3	5.5
When home care unsuccessful to protect child ,did ask advice and instruction to care the child	30	54.5	18	32.7	7	12.7
16- Keep bleeds record						
date and time of bleed events		10.9	8	14.5	41	74.5
Record the any adverse effects	2	3.6	7	12.7	46	83.6
Record name of product that give to children	4	7.3	7	12.7	44	80.0

F=frequency, %=percentage

This table show that (63.6%) of mothers never move the children to hospital when high temperature (74.5)never put or have identify card to child pocket when out home (40%),(72.7%)never choose plastic toys and appropriate toys according to child status and age (67.2%)not nutrition care to hemophilia children type A (81.8%)of mothers never have any practice treatment given especially I.V, (49,1%)never knowing the type factor that given to children and (76.4%)never done any practice factor given by I.V. in home. (79.3%) show never done any record or storage data that related to child bleeding status.

Table 8. Distribution of mothers practice to hemophilia children type A score with three level (al-
ways, some time and never) by frequency and percentage

Mother practice (52)	Score level of practice	Frequency	Percentage
Always	Good (=>132)	2	3.6
Sometime	Fair (105-131)	40	72.7
Never	Poor (=<104)	13	23.6

This table show that (72.7%) of mothers sometime practice done not all time, and (23.6%) never done practice at best toward hemophilic children type A

Table 9. Association between demographic mother items and each knoweldge and practice ofMothers with Hemophilia children type A

Score of	Mother knoweldge			Mother practice		
knoweldge	Don't know	Un certain	Know	never	Some times	Always
Practic	Poor(=<74	Fair (75-92)	Good=>93	Poor=<106	Fair (107-133	Good=>134
Items of	%	%		%	%	%
demographic						
1-Mother age						
20—24	-	100.0%	-	-	100.0%	-
25—29	-	63.6%	36.4%	27.3%	72.7%	-
30—34	-	100.0%	-	25.0%	66.7%	8.3%
35—39	-	77.8%	22.2%	11.1%	77.8%	11.1%
40-44	17.6%	82.4%	-	35.3%	64.7%	-
	Chi-square=19	0.256 sig=.014		Chi-square=7.2	267 sig.=.508	·

Table 9	9. Continues	
---------	--------------	--

2-Mother edu-						
cation						
Not read&Write	13.3%	86.7%	-	40.0%	60.0%	-
Read&Write	-	100.0%	-	50.0%	50.0%	-
Primary	-	83.3%	16.7%	16.7%	75.0%	8.3%
Intermediate	-	60.0%	40.0%	-	100.0%	-
Secondary	-	100.0%	-	-	100.0%	-
Institute	50.0%	50.0%	-	-	100.0%	-
	Chi-square=19.256 sig=.014			Chi-square=10.704 sig=.381		
3-Mother						
occupation						
Housewife	5.9%	82.4%	11.8%	23.5%	72.5%	3.9%
Employee	-	100.0%	-	25.0%	75.0%	-
	Chi-square=.844 sig=.656			Ch-square=.163 sig=.922		
4- Residential						
area						
Rural	6.2%	87.5%	6.2%	21.9%	75.0%	3.1%
Urban	4.3%	78.3%	17.4%	26.1%	69.6%	4.3%
	Chi-square=1.748 df=2 sig=.417			Chi-square=.210 sig=.900		
5-History of						
bleeding disor-						
der relative						
yes	4.3%	87.0%	8.7%	30.4%	69.6%	-
No	6.2%	81.2%	12.5%	18.8%	75.0%	6.2%
6- Mother with						
husband						
Relative	3.3%	93.3%	3.3%	23.3%	73.3%	3.3%
Not relative	8.0%	72.0%	20.0%	24.0%	72.0%	4.0%
	Chi-square=4.759 sig=.093			Chi-square=0.23 sig=.989		

*the chi-square statistic is signifigant at the .05 level sig.=level of signifigance

This table showes the high signifigant relationship between mother age and education level with mother knoweldge only another item there is no significant.

Discussion:

Sample of the study consisted of (55) mothers with hemophilia children type A who visited hospital when child bleeding or treatment needed for child.

The study result show high percentage (30%) of mothers were included in the study their age group (40-44) years and high significant with mothers knowledge (x^2 =19.256 sig=.014). while the low percentage (10.9%) of them were the age group of (20-24) years. this result agree with Wiedebusch who mention that a total of (55) parents the age about (39.6) years Parents reported

a pronounced need for further information on the comprehensive management about hemophilia children and psychosocial care of families with a child suffering from –hemophilia , reducing psychosocial strains and strengthening adaptive coping strategies may be a preventive intervention for improving parents' quality of life⁽⁸⁾.

Regarding education level of mothers it was found that highest percentage (43.6%) graduated from primary school there is high significant with mother knowledge (x^2 =19.256 sig=.014) while the lowest percentage(3.6%) graduated from institute, and majority of mothers occupation (92.7%) house wife and (7.3%) employee , residential area of family majority (58.2%) rural while lowest percentage (41%) in urban. Chuansumrit A. mention in Home care treatment is essential and can be adopted even by parents with low literacy ⁽²⁰⁾.

Bleeding disorder history from mother relatives show high (58.2%) has no history of bleeding. This result disagree with Karema mention that's in result of study the majority of sample have history of bleeding disease ⁽²⁵⁾.

Mother's relationship with husband show majority (54.5%) relative This agree with Jelvehgari Mitra they show in study result of demographic hemophilia mothers relationship with husband show majority (54.5%) relative and minority (45.5%) while not relative ⁽¹¹⁾.

Demographic data of hemophilia children show that all sample gender is male Female become carrier of disorder without sign of bleeding. This result agree with Montgomery mention that's hemophilia A and B are X-linked hereditary bleeding disorders affecting males which are caused by a deficiency or lack of coagulation factor VIII or IX in the blood, female become carrier of disorder without sign in most cases ⁽²⁷⁾.

Regarding to child age group high age between (5-9) (41.8%) This result agree with Kulkarni mention that's usual Age of Diagnosis Severe Age \leq 2 years, Moderately Age <5-6 years and Mild Often later in life, depending on haemostatic challenges ⁽¹²⁾.

Regarding school age group show the majority (38.2%) in primary school (30.9%) not in school while the minority (1.8%) in secondary school ,Aubrey mention is very important to continue to encourage the child be expected to perform at school according to his abilities. Normal relationships with other children consider the following: All school staff members should know hemophilia, the child wear a Medic Alert bracelet, meet the teacher and establish a good relationship. Discuss how will pick up homework for child and help, most parents find this is a positive step ⁽²⁴⁾.

Child who receive vaccine show highest (70.9%) receive all vaccine and (18.2%) part of vaccine not all, child receive vaccine very important especially hepatitis virus that common in hemophilia children according to many study.

The number of affected children in onefamily show majority (69.1%) of one child affected and series children affected in one family show highest (40%) first male child affected

Regarding to result the first diagnosis bleeding show (27.3%) highest in joint bleeding, Lozier mention clinically, hemophilia manifests through a wide and varied pattern of bleeding events. Most bleeding events in severe and moderate hemophilia occur in the joints and muscles (13).Perrin in study to examine the relationship of stress and incidence of bleeding in boys with hemophilia. Show in result of Fifty-eight percent of study participants had severe hemophilia. The sample population shows the bleeding high incidents occurred into joints 44% after injury and in conclusion Short- and long-term parental stress may lead to increased bleeding incidence in hemophilia, although factor level much more strongly predicts bleeding ⁽¹⁴⁾. A cording to level of severity highest (65%) moderate type of hemophilia A, Al Tonbary distribution of hemophilia cases(72 period children) during from 2000 to 2008.summaries the severity of bleeding disorder among patients. The moderate presentation represents the majority in 17.2% followed by sever presentation in $(4.7\%)^{(15)}$.

Mother's knowledge of the hemophilic children shows in general uncertain information about hemophilia A (83.6%) in all items. Singleton mention in hemophilia Patients and family members should well educated about the disease and its management, which can significantly reduce morbidity and mortality ⁽¹⁶⁾. In severity type of hemophilia (58.2%) of mothers don't know there is three level of hemophilia according to factor VIII in blood ,(61.8%)of mothers uncertain that recurrent joint bleeding can lead to inability to movement, Singleton mention to facilitate appropriate management in emergency situations like joint bleeding, all patients and parents should carry easily accessible identification, indicating the diagnosis, severity of the bleeding disorder, inhibitor status, type of treatment product used, initial dosage for treatment of severe, moderate, and mild bleeding, and contact information of the treating physician/clinic ⁽¹⁷⁾.

Regarding to mother nutrition diet to hemophilia children show (76.4%) of mothers doesn't know about balance diet can help the child and (67.3%) of mothers don't know rich nutrition diet can help hemophilia children. DGFA (diet guideline for America,2010) published guideline that recommends eating a diet rich in whole grains, fruits, and vegetables, sugars, and salt (sodium) and low in solid fats. Balancing food intake with physical activity helps in the maintenance of healthy specially in bleeding disorder patient ⁽¹⁸⁾.

Mother information when treat children show (74.5%) don't know that suppository to treat high temperature should be prevented, (69.1%) don't know muscle injection should be prevention, (70.9%) don't know aspirin should be prevented. Continue immunization by injection in subcutaneous not in muscle show (60.0%) don't know Shrivastava mention in Precautions in Hemophilia: 1. Aspirin is strictly contraindicated in any one with bleeding disorders. Aspirin has a side adverse effect on platelet function, and an inflammatory effect on gastric mucosa, which may result in he-2. Non- steroid anti- inflammatory matemesis. drugs (as used in arthritic conditions) should be prescribed with caution in hemophilia 3.Intramuscular injections are contraindicated because they may provoke severe intramuscular bleeding with subsequent cyst formation or fibrotic scarring. Oral, rectal, subcutaneous or intravenous medications are alternatives. it is probably safer to give all immunizations subcutaneously. 5 Activities and sports are positively encouraged in hemophilia because it is recognized that a healthy musculoskeletal system helps prevent bleeding. Only those sports likely to result in head injury (boxing and rugby football are the main examples) should be actively discouraged ⁽¹⁹⁾.

Joint injury complication in hemophilia items show (43.6%),(54.5%) and (60%) of mothers

don't know about restrict joint motion , deformity and muscle atrophy ,AI Tonbary reported in study Distribution of cases(72 children) during period from 2000 to 2008. The bleeding complications as hematoma or hemarthrosis were the common complications54.6%. Nevertheless, the common presenting symptom was bleeding following male circumcision. Hepatitis C infection and arthropathy represented the main complications ⁽¹⁵⁾. Regarding to mother knowledge about hemophilia A complication like intra-cranial bleeding sign show (74.5%), (76.4%) and (80%) of mothers don't know about sever head ache, nausea and vomiting and vision confusion. Abtahi1 mention in study hemophilia child became irritable, vomiting and difficult to feed. Diagnosed The Intracranial hemorrhage (ICH) in the newborn is common complication in hemophilia, occurring with an incidence of (1–4%) (21)

Mothers practice with hemophilia children the result show (72.7%) of mothers sometime practice done I not all time in all items .(23.6%) of mothers never done practice toward hemophilic children type A , Sibel mention in descriptive study of mother with hemophilic children that low knowledge by not received education about (disease and first aid)effect negatively on management and care of child, poor practice by afraid dealing with child in accident and attitude affected by she felt needed health care personnel , she become sad when their child was ill along medical administration. They mention also mothers should be have good knowledge, practice, home management teaching to prevent complication by pediatric hematology nurses or developed program⁽²⁵⁾.

Regarding to child care (74.5%) of mothers never put identify card to child pocket when out home, there should be have and take identify card to any were to be safe.

Play type of hemophilia children and mother role show (40%),(72.7%) never choose plastic toys and appropriate toys according to child status and age. Markova mention that's in study to mother with hemophilic children recommended that counseling should emphasize the deliberate preparation and training of the mothers with haemophilic child in when use or play of tools and toys by child which are potentially dangerous should be prevented⁽²²⁾.

Home management practice of mothers show (81.8%) of mothers never have any practice treatment given especially I.V,(49,1%) of mothers never knowing the type factor that given to children and (76.4%) mothers never done any practice factor given by I.V. in home. Schrijvers mention that's all hemophilia patients and parent help in the Netherlands practice self infusion at home. Learning intravenous administration of clotting factor requires time and effort. In 77% of cases, the mother was the first who started learning to infuse the child. Patients started with self infusion at a median age of 12.9 years, the majority of patients and parents were able to learn intravenous infusion, with 50% of all parents and patients succeeding within eight visits during 7 weeks ⁽²³⁾.

Mothers role to home record an storage information relate to child bleeding show (79.3%) of mothers never done any record or storage data that related to child bleeding status ,Ergün mention experienced by mothers of children with hemophilia in maintaining their care at home and establishing appropriate interventions. mothers were observed to have not received education about accidents and first aid and were afraid that their child would have an accident (55%); they experienced difficulty finding medications (75%); and they were sad that their child was ill (80%). Pediatric hematology nurses should educate mothers with hemophiliac children about the disease and how to deal with accidents, keep any information that need to inform the physician, and medication administration ⁽²⁴⁾.

Recommendations:

Develop special booklet for mothers local languages (Kurdish, Turkish) develop programs and awareness courses (theoretical and practical) for mothers and support family financial improve and provide factor eighth for hospitals and health center where patients found.

References:

- 1. Availablefrom:http//www.wrongdi agnosis.com /hemophilia-a/intro.htm
- Available from: http://www.med prorx.com / about-hemo.html
- 3. Karunanithi, **introduction to hemophilia**, Oman Journal of Ophthalmology.2009:86-88.
- 4.World Federation of Hemophilia India ; 2006:13. From <u>http://www.wfh.org HistoryHemophilia.htm</u>.
- Alok Srivastava. A book on management of Hemophilia. India: Hemophilia federation;2003:5-6.
- 6.SibelErgün,EsmaSülü Supporting the need for home care by mothers of children with hemophilia,(online) www.lib.bioinfo.pl/ pmid/jourinal/J. Home Healthc Nurse. 2011 Oct ;29 (9):530-8 21956007.html.
- Beeton K, Neal D, Watson T, Lee CA.,Source,School of Health and Emergency Professions, University of Hertfordshire, UK ,.,Parents of children with haemophilia--a transforming experience. Haemophilia. 2007 Sep;13(5):570-
- Wiedebusch S, Pollmann H, Siegmund B, Muthny FA ..Quality of life, psychosocial strains and coping in parents of childrenwithhaemophilia <u>www.ncbi.nl</u>.nih.gov/pubmed/18624702.. Haemophilia.2008
- Jelvehgari M. and Mashayekhi S.O. Demographic and Clinical Aspects In Thalassemic or Hemophilic Patients Referred to Pediatric Hospital in Tabriz City, 2004, Journal of Biological Sciences 2 (5): 543-545, 2007
- 10.Allain JP, A boarding school for hemophiliacs: a model for the comprehensive care of hemophilic children. Ann N YAcadPMID: 1053868, www.ncbi. nih.pubmed.htm, 19/4/2013
- Jelvehgari Mitra,S.O. Mashayekhi :Iran Demographic and Clinical Aspects In Hemophilic Patients : Iran, Research Journal of Biological Sciences 2 (5): 543-545, 2007
- 12. Kulkarni R, Soucie JM, Lusher J, Presley R, Shapiro A, Gill J.; Sites of initial bleeding episodes, mode of delivery and age of diagnosis in babies with haemophilia diagnosed before

the age of 2 years: a report from The Centers for Disease Control and Prevention's (CDC). Haemophilia.j. 2009;15:1281–90. (PubMed)

- 13.Lozier JN, Kessler CM. Clinical aspects and therapy of hemophilia. Benz-Jr EJ, Shattil SJ, Furie B, Cohen HJHJ, Silberstein LE editor(s). Hematology Basic Principles and Practice. 4th Edition. Elsevier, 2004:2047-69.
- 14.Perrin JM, MacLean WE Jr, Janco RL, Gortmaker SL Stress and incidence of bleeding in children and adolescents with hemophilia.. Source Children's Service, Massachusetts General Hospital, Boston 02114, USA. Abstract,www.the jourenal of pediatric.com review at 18/4/2013.
- 15.Al Tonbary Y., Rasha ElAshry, 'Descriptive Epidemiology of Hemophilia and Other Coagulation Disorders in Mansoura, Egypt: Mediterr J Hematol Infect Published online 2010 August 13.
- 16.Tammuella S., Rebecca K. Cindy L. Emergency department care of patients with hemophilia disease, The Journal of Emergency Medicine, Vol. 39, No. 2, pp. 158–165, 2010.
- 17.Singleton T , Kruse-Jarres R , Leissinger C . Emergency department care for patients with haemophilia and von Willebrand disease. J Emerg Med 2010; 39: 158–65,CrossRef,Web of Science®
- 18.DGFA(Dietary Guidelines for Americans) 2010. United States Department of Health & Human Services website. <u>http://www.health</u>. Gov / dietaryguidelines/dga2010/DietaryGuidelines 2010.pdf.
- 19.Shrivastava M., Orthopaedic Surgeon ,**NEPAL HEMOPHILIA SOCIETY**,Kathmandu,Nepal.15 April 1999,update in 1/4/2004,
- 20.Chuansumrit A. **Treatment of haemophilia in the developing countries**. Haemophilia.J. 2003 Jul;9(4):387-90.www.pubmed.org/ PMID:12828673.
- 21.Abtahi S., Khalili M.,Intracranial Hemorrhage In A Newborn with Hemophilia.2006 November; 165: 1–389. PMC2799065,www.dx.doi.org
- 22.Markova I, Phillips JS.**The use of tools by children with haemophilia**. (online) www.ncbi.

Pubmed.htm. PMID: 6707112(PubMed - indexed for MEDLINE) review at 2012/4/18.

- Schrijvers LH, Beijlevelt-van der Zande M, Peters M, Schuurmans MJ, Learning intravenous infusion in haemophilia: experience from the Netherlands. Haemophilia. J.2012 Jul; 18(4) :516-20. doi: 10.1111/j.1365 2516. Epub 2012 Feb 1 http://www.ncbi.nlm.nih .gov / pubmed/22292416
- 24.Ergün S, Sülü E, Başbakkal Z. Supporting the need for home care by mothers of children with hemophilia. Abstract, J.Home Healthc Nurse. 2011 ,www.ncbi.nlm. nih.gov/pubmed
- 25. Hussein K. A.: impact of educational program on knowledge and practice of mothers having hemophilic type A children: thesis submitted, college of nursing Baghdad university.2002.
- 26.Aubrey M.,The Hospital for Sick Children, Toronto,ch9-p20- All About Hemophilia ,Guide for Families,2009.
- 27.Montgomery R. and Scott JP. , (2008)
 :Hemorrhagic and thrombotic diseases; hemostasis. IN : Colman R , Hirsh J,MarderV ,et al. ,editors. Nelson Text book of pediatrics. 18 th ed.. philaelphiaWBV;206