Assessment of Mothers' Practices Regarding their Children with Hemophilia in Blood Disease Center at Maternity and Pediatric Babylon Hospital/Al-Hilla City

تقييم ممارسات الامهات مع اطفالهم المصابين بمرض الناعور الوراثي المراجعات لمركز أمراض الدم في مستشفى بابل للنسائية والاطفال مدينة الحلة

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لخلاصة:

الهدف: لتقييم الحالة الاجتماعية للأم والطفل المصاب بمرض الناعور الوراثي وتقييم ممارسات الأمهات اتجاه أطفالهم المصابين بالناعور. المنهجية: تماختيار عينة (غرضية)غير عشوائية تتكون من100 اممن الامهات الذين لديهم أطفال مصابين بمرض الناعور الوراثي اللاتي يراجعن مركز امراض الدم في مستشفى بابل للنسائية والاطفال في مدينة الحلة، بين الفترة من 242 انون الثاني لمغاية الاول من اذار لسنة 2015 وتمجمع العينة بطريقة المقابلة مع الامهات وجُمِعَت البيانات بواسطة استبيان خاص يتضمناً منالة. عن الحالة الاجتماعية للأمهات (العمر،مستوى التعليم، المهنة) والحالة الاجتماعية لأطفالهن المصابين بالناعور واسئلة اخرى عن ممارسات الامهات للعناية بأطفالهن واستخدام طريقة ليكاردحيث قسمت إلى ثلاثة درجات (دائما، احيانا وابدا)، تم تحليل البيانات عن طريق الإحصاء الوصفي والإحصاء التحليلي.

النتائج: أُظّهرت نتائج الدراسة من خلال خصائص الأمهات الاجتماعية ان (20%) من الأمهات اعمار هن تتراوح بين (20 – 30) عاما، بينما الغالبية منهن (79%) ربة منزل، و (43%) هن خريجات الدراسة الابتدائية ويسكن مناطق حضرية، وعلاوة على ذلك أظهرت الدراسة من خلال الخصائص الديموغرافية للأطفال المصابين بمرض الناعور ان (32%) أعمار هم تتراوح بين (7 – 9) سنوات. و (41%) منهم كان تسلسلهم الثاني في أطفال وظهرت نتائج ممارسات الأمهات المتعلقة برعاية وتغدية ومتابعة الأطفال المصابين بمرض الناعور الوراثي أظهرت الدراسة ان المتوسط الحسابي للممارسات كان (1.64) والذي هو اقل من المتوسط الحسابي المرجح وهو (2) وهذه النتيجة تشير الى ضعف ممارسات الأمهات في رعايتهم لأطفالهن المصابين بالناعور الوراثي.

الاستنتاج: ان ممارسات الأمهات المقدمة للأطفال المصابين بمرض الناعور الوراثي المتعلقة بالرعاية والتغذية والمتابعة دون المستوى المطلوب. التوصيات: والتوصيات المقترحة من خلال هذه الدراسة، وضع برنامج تدريب منتظم في مراكز امراض الدم للأمهات الجدد اللاتي تم تشخيصهن اطفالهن حديثا بمرض الناعور الوراثي للتحسين من ممارساتهن.

مفردات البحث الرئيسية: تقييم ، مرض الناعور ، الأمهات مع أطفالهم المصابين بالناعور ، الممارسات.

Abstract:

Objectives: To assess the demographic data to the mothers and their hemophilic children and to assess practices of mothers with hemophilic children

Methodology: Non- probability (purposive) sample of 100mothers with hemophilic children revision to blood disease center in Babylon for maternity and pediatric hospital in AL. Hilla city. The data collected from January 24th until March 1st 2015. A structured interviewing constructed with mothers who were attended blood disease center by questionnaire. The questionnaire form is consisted of five parts which included mother demographic data and child demographic data, and mother's practice questionnaire. The response scored as Likert rating scale (never, sometime and always), The data analyzed by using descriptive statistical measures and inferential statistical measures.

Results: Concerning mothers practices related to care, follow up and nutrition the arithmetic mean was (1.64) which was less than the mean premise (2) this finding indicate poor practices of mothers in care in their care of hemophilic children.

Conclusion: The practices of mothers provided to hemophilic children regarding care, nutrition and follow up was below the required level.

Recommendations: The suggested recommendation. Establish a regularly training program in blood disease centers to new mothers with hemophilic children who were newly diagnosis was essential to improve their practices regarding the care of their children with hemophilia.

Key words: assessment, hemophilia, mothers with hemophilia children, practices.

INTRODUCTION

The term of bleeding disorder is a general refers to wide range of blood problems lead to deficiency in blood factors, poor clotting and continuous bleeding, which result from abnormality in blood or blood vessels. If the abnormality in factors of blood clotting or platelets the blood disorder diagnosed at different forms, Hemophilia and Willebrand disease ⁽¹⁾.

The most common genetic blood disorder is a Hemophilia that refers to lack of clotting factors in the blood where blood don't clotting normally, this blood disorder have three forms Hemophilia A, Hemophilia B, Hemophilia C depending on the factor deficiency in blood (f VIII, f IX and f XI)⁽²⁾.

Hemorrhage differs from patient to another according to severity of hemophilia. At now a day there is no cure to hemophilia patient, they can lead to a relatively normal life by taking preventive measures in daily life to obviate hemorrhage⁽³⁾.

Mothersmust be in close interaction with their children and know the health problem that face hemophilic children have to give adequateattention in early diagnosis of common health problem in children this to improve the health and avoid complications this play a major role in early detection and management ofhemophilia⁽⁴⁾.

Hemophilia is lifelong condition and it is important to the mothers and their children learn about the condition in order to live a positive manner with the situation. Education about practices of disease make mothers in good deal with their hemophilic children to live a healthy and normal life⁽⁵⁾.

OBJECTIVES

- 1. To assess the demographic data of mothers with hemophilia children.
- 2. To assess the demographic data of children with hemophilia.
- **3.** To assess mother practices regarding their hemophilic children.

METHODOLOGY

Non- probability (purposive) sample of 100 mothers with hemophilic children revision to blood disease center in Babylon for maternity and pediatric hospital in AL. Hilla city. The data collected from January 24th until March 1st 2015. Itwas carried out the direct interview of mothers to assess practices regarding their hemophilic children. Non probability (purposive) sample consist of (100) mothers with hemophilic children were visited blood disease center at Babylon to maternity and pediatric hospital.

The questionnaire form is consisted of five parts which included mother demographic data (7) items, child demographic data (10) items, practice consist of three part practice related to (care (18) items, nutrition (5) items and follow up (10) items) the response scored as Likert rating scale (never, sometime and always), evaluate the validity of the questionnaire form the researcher presented it to (17) experts in specialist field. Reliability of the questioner was determined that mothers practice(r=0.87) at level (p<0.05).

A pilot study included the (15) mothers with hemophilic children from Babylon to maternity and pediatric hospital teaching 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 (ANOVA).

RESULTS

Table. (1) Distribution of sociodemographical characteristics of the mothers.

Varia	Number	Percentage	
Mother's age	20 yrs and less	12	12%
	21 – 25 yrs	10	10%
	26 – 30 yrs	20	20%
	31 – 35 yrs	16	16%
	36 – 40 yrs	18	18%
	41 – 45 yrs	9	9%
	46 yrs and more	15	15%
	Total	100	100%
Mother's educational level	Neither read nor write	7	7%
	Read and write	6	6%
1,10,1101 % 0401044101141 10 / 01	Primary Graduated	43	43%
	Secondary Graduated	29	29%
	Institute or University Graduated	15	15%
	Total	100	100%
Mother's occupation	Employed	21	21%
	Unemployed (housewife)	79	79%
	Total	100	100%
	Urban	43	43%
Resident	Rural	32	32%
	Parties	25	25%
	Total	100	100%
Kinshipbetween mother and	Relatives	67	67%
father	Not relative	33	33%
	Total	100	100%
There is a genetic history of	Yes	53	53%
the family with hemophilia	No	47	47%
me many with nemophina	Total	100	100%
Number f hemophilic	One child	60	60%
children in the family	More than one child	40	40%
	Total	100	100%

Table (1) showed the highest percentage of mothers age (26-30) yrs accounted for (20%), Primary Graduated mothers has achieved (43%), unemployed (housewife) class achieved (79%), Urban (43%).Relativekinship between mother and father (67%). There is a genetic history of the family with hemophilia (53%).Number of hemophilic children in the family (60%).

Table. (2) Distribution of sociodemographical characteristics of the hemophilic children

Variables		Number	Percentage	
Child's age	1 – 3 yrs	17	17%	
	4 – 6 yrs	20	20%	
	7 – 9 yrs	32	32%	
	10 – 12 yrs	31	31%	
	Total	100	100%	
Birth order of the affected	First	21	21%	
child in family	d in family Sconed			
	25	25%		
Third Fourth and above		13	13%	
	Total	100	100%	
Child's age at diagnosis for	Less than 6 month	30	30%	
the first time	More than 6 month	70	70%	
	Total	100	100%	
Site of first bleeding	Bleeding during birth (umbilical cord)	8	8%	
	Circumcision	13	13%	
	Bruising	32	32%	
	Injury (mouth and nose bleeding)	27	27%	
	Joint bleeding	19	19%	
	Others	1	1%	
	Total	100	100%	
child vaccinated on regular	Yes	62	62%	
basis	Sometimes	26	26%	
	No	12	12%	
	Total	100	100%	
If the answer is sometimes,	Fear of mother on her child	18	47.3%	
or no, what is the reason?	Distance of the health center from home	9	23.7%	
,	Receiving faulty information from	11	28.9%	
	relatives about the			
	effects of vaccination			
	Total	38	100%	
child attendance the school	Yes	63	63%	
	No	37	37%	
	Total	100	100%	
If yes, is the attendance	Regular	36	57.1%	
• /	Irregular	27	42.8%	
	Total	63	100%	
If the answer irregular,			40.7%	
what is the reason?	Child's remain in hospital	10	37%	
	Fear of mother from hemorrhage in school	6	22.2%	
	Total	27	100%	

Table (2) showed the highest percentage of Child's age (7-9) yrs accounted (32%), The second birth order was (41%), children diagnosis age of more than 6 months achieved (70%),bruises (32%),Child vaccinated on regular basis(62%),children attended the school (63%).

Table. (3) Distribution, of mothers practices of mother regarding hemophilic children

Dimension	Items	Score of answer					Relative	
Difficusion					Mean	SD	efficiency	
		Always	Sometimes	Never	Wican	SD	cificiency	
Items about	Cover the floor and the stairs	15	71	14	2.1	0.8	70%	
assessment	Avoid hitting the child	17	75	8	2.9	1.2	96%	
of mother's			21	73	2.2	1.2	74%	
practices	Avoid harmful play	6 18	66	16	2.0	0.8	67%	
related to	Perform continuous personal care.	19	74	7	2.1	1.0	70%	
care can	Brush the teeth	10	32	58	1.2	1.0	50%	
give to the	Of bleed nose	11	61	28	1.8	0.9	60%	
child	Dressing of the hemorrhagic wound	21	78	1	2.2	1.1	66%	
	Having complete bed rest	9	60	31	1.7	1.0	58%	
	Revision hospital in hemoptesis, hematuria	6	55	39	1.3	0.8	43%	
	Revision hospital in constant bleeding.	23	76	1	2.2	0.9	74%	
	Applying cold compressor on joints	4	21	75	1.2	0.7	43%	
	apply poultice cold on bruise	5	27	68	1.5	1.1	52%	
	Having viral hepatitis B vaccine	27	51	22	2.3	1.5	78%	
	Assist child's if develops AIDS	10	56	34	1.6	1.2	54%	
	Notice any sign to Intracranial bleeding	5	34	61	1.4	1.3	48%	
	Factor replacement when child has surgery or	12	84	4	2.0	1.1	69%	
	circumcision.							
	Keep the factors in cold dry place.	17	69	14	2.0	1.0	67%	
	The rate	_	1		1.62		54%	
Items about	Using the straw to drink fluid after surgery	6	27	67	1.4	1.8	46%	
mother's	Give easily digestion nutrient	16	50	34	1.8	0.9	61%	
practice	Provide to child the nutrition's performed	13	75	8	1.9	1.7	65%	
related to	Avoid hard fiber nutrient.	17	53	30	1.8	1.9	62%	
nutrition	Drinking cold fluids during oral bleeding.	5	41	54	1.5	1.7	50%	
	The rate	1.0	1 22		1.71	1.0	57%	
Items about	Visiting the dentist on continuous bases	10	23	67	1.4	1.2	47.8%	
the	Visiting the heredity bleeding disease center	17	81	2	2.1	1.1	71.6%	
mother's practices	regularly.	12	66	22	1.0	1.2	620/	
related to	Visiting the heredity bleeding disease center as needed.	12	66	22	1.9	1.2	63%	
the visiting		14	61	22	1.0	0.8	64%	
the clinic	Visit the health center in the case of emergency Monitoring physiotherapy exercises regularly	5	64 18	77	1.9 1.3	1.0	42.6%	
and follow	and continuously	3	10	//	1.3	1.0	42.0%	
up	Keep bleeding record	14	16	70	1.4	1.3	48%	
	The child goes and comes of the school with	10	28	25	1.1	1.4	37%	
	parents	10	20	2.5	1.1	1.4	31/0	
	The child carry hemophilic center ID card when	10	12	78	1.3	1.1	44%	
	out home.		12	, 0	1.5	1.1	11/0	
	The mother visits the child's school	9	49	5	1.3	1.1	43%	
	The care at home according to physician or	13	85	2	2.1	0.9	70%	
	nurse recommendation			_				
	The rate				1.59		53.2%	
General rate					1.64		54.6	
Cutoff point Total weight ratios \div Ranks number= $1 + 2 + 3 \div 3 =$						-3 = 2	•	

Table (3) indicated that The practices related to care which can be provided by the mother of the child has achieved at all clauses mean which was (1.62) which is less than Cutoff point(2) this indicates the care and practices provided by the mothers was below the required level. While mothers practices, related to child nutrition in all its clauses the mean was (1.71) which is less than Cutoff point which indicated the presence of a shortening of the

mothers related to feed their children. The mothers practices regarding visit clinics and followup of the child in all its clauses the mean practices reached (1.59) which is less than Cutoff point(2) this showed there were shortened by mothers in their visiting the medical clinics and followed up the cases of their children.

DISCUSSION

Table (1) explaining the socio demographic characteristics of the mother's under study, the results showed that the first category of mother's age is(26-30) years accounted for (20%) this result agreed with Markova $(2010)^{(6)}$. and disagree with Wiedebusch (2008) mentioned in their study titled assessment parents with hemophilic child, parents of the study sample age were between (40-44) years⁽⁷⁾.

Regarding to mother's education level the majority of mothers (43%)they were Primary Graduated and regarding the Mother's occupation high percentage of mothers (79%)were Unemployed (housewife) however, the Environment of residential area majority of them who was (43%) live in urban areas. This result agreed with harpreet, (2012) mentioned in his study (Titled assessment the knowledge regarding home care management of children with hemophilia) that (72%) were primary graduates, mother's occupation showed (75%) that housewife. However, mentioned that's the people in rural had poor information about disease and how to management of child with this disorder (8).

Regarding bleeding disorder from hemophilia history in the family the high percentage of the sample had hemophilic relative(53%) and (67%) of mother's sample had kinship with their husband. This result agreed with Markova (2010) mentioned majority of his study sample have history of bleeding. Although that the majority of sample had relative with hemophilia and had kinship between mother and father of sample ⁽⁶⁾.

Concerning to the hemophilic children in the family the majority of sample (60%) had one child with hemophilia. This result inconsistent with harpreet, (2012) that she mentioned in his study that the majority of family sample (53%) have one child that make the family give greater attention to the child and his management⁽⁸⁾.

Table (2) showed that's the majority of the sample (32%) their ages between (7-9) years old this finding supported by Ergun (2009) who mentioned that's most of participants of his study of hemophilic children aged(7-10) years old⁽⁹⁾.

The same table indicated that the Birth order of the affected child in family, the majority was second birth order (41%) these results agreed with Wiedebusch (2008) who declared that the highest percentage of child's order affected was the second child $(35\%)^{(7)}$.

According to the Child's age at diagnosis for the first time the majority (70%) was diagnosed after the six month and the highest percentage of the Site of first bleeding (32%) was bruises. This result agreed with harpreet, (2012) she showed that's most of the participants in his study was having bruising after 6 month of age at the first time of diagnosis. This finding declared that the activities of nearly infancy when crawling and walking are first attempted, these produce the inevitable knocks and twists and could result bruises⁽⁸⁾.

Regarding the child vaccination status the majority of the mother's answer (62%) in the current study result indicated that the children had regular vaccination and those who answer sometimes or not vaccinated were because fear of mother's on their children (47.3%) from vaccination and side effect this result agree with Markova (2010) mention (64%) of study sample take all vaccination (61).

Relative to child attendance the school, the highest percentage of hemophilic children in the sample were (63%) attending school,(57.14%) have regular attendance and the majority of mothers who answer of irregular attendance of their children was (40.74%) due to Permanent child's illness. This result agreed with Ergun (2009) in that his study showed

the largest part of study sample attending school (56%).increase school truancy in hemophilic children due to barriers in physical function among children with reported frequency episodes. Study this identified an important correlation between the number of bleeding episodes experienced and academic qualification in a school age children with hemophilia⁽⁹⁾.

The results of table (3) showed (70%) of mothers were sometimes cover the floor and the stairs with carpet all year, (96%) of mothers were sometimes avoid hitting the child especially on the head. Moreover, (67%) of mothers were sometimes avoid harmful play to hemophilic child. Markova (2011) reported that's mothers with hemophilic children emphasizes to prepare and have good information when use of tools and choose toys and save Playing environment to hemophilic child and potentially dangerous games should be prevented to hemophilic child.

Regarding the care with joint (74%) of mothers, never tie rubber pillow on the child's knee and other joints when needed.(43%) of mothers never applying cold compressors on the hemorrhagic joint. (52%) of them never apply poultice cold and decreased movement When bruise. Figgie (2005) indicated in his study that there should be an emphasize on the joints of Children with hemophilia care by putting compresses on the affected area and reduce the movement with ties put on the place of pain⁽¹⁰⁾.

Concerning the personal care that the mother should be performed to her child (70%) of mothers sometimes, perform continuous skin and personal care. (50%) showed of them never brush the teeth gently with soft brush. Alok (2005) mention that's the caregiver showed provide good personal hygiene, good oral hygiene is essential to prevent gum and periodontal disease. Teeth brushes help reduce plaque⁽¹¹⁾.

Relative to the care with bleeding episodes (66%) of mothers responses were sometimes dressing the Bleeding wound with clean and dry dressing.(58%)stated sometimes but their children were in complete bed rest during hemorrhagic episodes.(60%) of mothers said sometimes stop bleeding nose by pressure and dawn word head and keep the child claim. (74%) sometimes of them carry their hemophilic children to the hospital when continuous bleeding. In addition (43%) of them sometimes carry them to hospital when hemoptysis and hematuria. Berntorp (2011) stated that the family with hemophilic children should had a good practice to deal with hemorrhage from minor injury and nose and should be shift the child to the hospital especially when there is continuous bleeding⁽¹²⁾.

As regards the complications that may the hemophilic child developed.(78%) of mothers said sometimes having hepatitis B vaccine. (54%) of them answered sometimes can deal with their children if they develop AIDS. Moreover, (48%) never notice the signs of intracranial bleeding. Abtahil (2006) reported that the hepatitis B, AIDS, intracranial bleeding are common complications to hemophilic children and should notice the signs of the complications and take complete vaccination to avoid any complication (13).

Regards the factors the child takes on the mother's practices. (69%) of mothers sometimes give factor replacement to their children when he has surgery or circumcision. In addition (67%) of them sometimes identify the factor the child needed and the way to store it. That miller (2008) mention that's mother need to practice about the factor the child take and stores and necessary to give it to him when needed⁽¹⁴⁾.

Regarding the hemophilic children nutrition, (46%) the mothers never using the straw to drink fluid and soluble nutrients after having oral surgery. (61%) of them sometimes give to their children easily digested nutrients with slowly chewing.(65%) of sample sometimes gives to child nutrition items that performed by him.(62%) sometimes avoid hard fiber nutrient. However (50%) never drinking cold fluids during oral bleeding. No single food can provide all the essential nutrients to the body needs. Thus, it is important to consume a wide variety of foods to provide adequate intakes of nutrients, including vitamins, minerals and dietary fiber, which are important for health. However, mothers of hemophilic children

should keep in mind to get away from the hard foods and drinking cold water through bleeding from the mouth $^{(15)}$.

Regarding visiting the clinic and follow up.(47.8%) of mothers never visiting the dentist on continuous bases.(71.6%) of them sometimes visiting the heredity bleeding disease center regularly. (63%) were sometimes visiting the center as needed.(64%) of mothers sometimes visit the health center in the case of emergency of any signs of cranial bleeding & take the prescribed medicine. (42.6%) of them never Monitoring physiotherapy exercises regularly and continuously and (70%) treatment and care at home according to physician or nurse recommendation. Alok (2005) mentioned that's hemophilic children needs to close collaboration between the physician, health care team and the caregiver to receive safe comprehensive care and coordination with mothers by following the guidance specialists and follow-up treatment at home⁽¹¹⁾.

Relative to the follow up of schoolchildren.(37%) of children were sometimes goes and comes of the school with parents, family members and relatives. (43%) of mothers were sometimes visits the child's school to explain progress on the child health status to the class teacher & adviser. HFA (2012) stated that many mothers were willing to talk to daycare and school personnel. This can help to rest assured teachers and daycare workers for easily childcare and management. It is important that daycare or school personnel can meet the parents at all times and in case of emergency. In addition, it is helpful to provide the telephone number of the child home and nearest Hemophilia/Bleeding Disorder Treatment Centre⁽¹⁶⁾.

Regarding recording and carry ID card, (44%) of child were never carry hemophilic center ID card when out home.(48%) of mothers never keep bleeding record to record the date and time of bleeding, any adverse effect appears on the child. Ergun (2011) mentioned that mothers with hemophilic child should maintain home management and should keep a card to write the important information in case of bleeding that need to inform the physician and medication administration to avoid any adverse effect⁽⁹⁾.

CONCLUSIONS

Concerning mothers practices related to care, finding indicate poor practices of mothers in their care of hemophilic children.

RECOMMENDATIONS:

- 1. Establish a regularly training programin blood disease center to new mothers with hemophilic childrenwho were newly diagnosis was essential to improve their practices regarding the care of their children with hemophilia.
- 2. Encourage the mothers and their children to carry the ID card of blood disease center when they were out of their home and when they went to school to identify their situation if they had any accident or bleeding episode away from home.

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