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***Caregivers Burden of Care among
Children with Hemophilia in AL-
Hilla City***

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﴿بِسْمِ اللّٰهِ الرَّحْمٰنِ الرَّحِیْمِ﴾

یَرْفَعُ اللّٰهُ الَّذِیْنَ اٰمَنُوا مِنْكُمْ وَالَّذِیْنَ اٰتَوْا الْعِلْمَ دَرَجَاتٍ وَاللّٰهُ

بِمَا تَعْمَلُونَ خَبِیْرًا .

صدق الله العلي العظيم

[سورة المجادلة، آية: ١١]

شكر وتقدير

قال الرسول الله صلى الله عليه وسلم :

«مَنْ لَمْ يَشْكُرِ النَّاسَ لَمْ يَشْكُرِ اللَّهَ مِنْ صَنَعَ إِلَيْكُمْ مَعْرُوفًا فَكَافَتْهُ، فَإِنْ لَمْ تَجِدُوا مَا تُكَافِتُونَهُ

فادعوا له»

تتقدم بالشكر الجزيل والامتنان والتقدير العميق الى

الأستاذة المشرفة (م . م مها احمد كاظم) التي رافقتنا طيلة هذا البحث وامتدتنا بالمعلومات

والنصائح القيمة راجين من الله عز وجل ان يسدد خطاها ويحقق مناها فجزاها الله عنا كل

خير وأنعم عليها بالصحة والعافية.

وكذلك تتقدم بالشكر الجزيل لكل اعضاء الهيئة التدريسية

والانسى الطلبة الذين ساهموا في انجاح هذا المشروع متمنين لهم التوفيق والنجاح الدائم.

الإهداء

إلى...

من أنزل النور على قلبه وجعله للعالمين سراجاً منيراً أنينا رسول الله محمد (صلى الله عليه
واله وسلم) جزاه الله خير

ما جرى رسولا عن أمله ونبياً عن قومه.

اعز الناس... أمي الغالية التي علمتني محبة الخير للناس

والابن سامة والامل... حباً وبراء.

صاحب القلب الكبير... الذي قدس العلم دائماً... أبي تحية إكبار وإعجاب.

وأخيراً أهدي نخث النخرج مع بالغ النحيات والنواضع الى اطفال من كتر امراض الدم الذين لولا

تعاونهم معنا وجهودهم لما تقدمنا وحققتنا نجاحاً.

سائلين المولى عز وعجل ان يلبسهم ثوب الصحة والعافية.

Supervisor Certification

I certify that the dissertation entitled “*Caregivers Burden of Care among Children with Hemophilia in AL-Hilla City*” was prepared under my supervision at the Department of Maternal and Child health/ College of Nursing /University of Babylon, by the students:

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شهادة المشرف

أشهد أن الأطروحة التي بعنوان " عبء مقدمي الرعاية حول العناية بأطفالهم المصابين بتلف الدم الوراثي في مدينة الحلة" في عمس السنة لحد سن ١٩ سنة في مدينة الحلة" تم إعدادها تحت إشرافي في قسم صحة الأمر والطفل /كلية التمريض / جامعة بابل ، من

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list of content

No	Content Object	Page NO	
1	Abstract English	I	
2	Chapter One: Introduction	2_ 4	
3	Chapter Two: Methodology	6	
4	Chapter Three: Result	8 -11	
5	Chapter four: Discussion	13-15	
6	Conclusions	17	
7	Recommendations	17	
8	Reference	19- 20	
9	List of Appendices	A (Questionnaires)	22-27
		B (Formal agreements)	28
		C (list of experts)	29
10	Abstract Arabic		
	Abbreviations	17	

Table

No	Content Object	Page NO
1	Sociodemographic data of caregivers and their children.	8-9
2	Relationship between caregivers- burden and some variables	11

figures

No	Content Object	Page NO
1	Assessment of caregiver_ Burden	10
2	Assessment caregivers knowledge	10

Abstract:

Background: Caring for a child with hemophilia is burdensome and impacting on caregivers' emotional and financial status. Hemophilia is sex-linked hereditary bleeding disorder that impacts mostly men. It is caused by clotting factor gene mutation on X chromosome, which results in lack of factor VIII or -IX in hemophilia A or B. The most common symptom of hemophilia is bleeding, which occurs after trauma or surgery, with severity correlated with degree of clotting factor deficiency. Aim of the study: Assessment of the burden of mothers on the care of children with hemophilia and determine the relationship between the burden of mothers and demographic factors.

Design of the study: A quantitative study include (100) samples during through the period of 11th November to 2nd march 2023.

Results: the majority of the sample were mothers who care for their children (64.3), and their ages ranged between (32.00 - 41.00) (35.7%), most of them had a high level of education (23.0%), who had a relatively sufficient income and their knowledge was average mild-moderate (56.3%) to this disease.. There is a positive relationship between (caregivers- burden) and caregiver (age, time working, chronic disease, severity of hemophilia, prophylaxis) at level (p value 0.05) , and inversely with (level of education , income) at level p value(0.01, \geq 0.05) respectively.

Conclusions: The analysis of study revealed that the greatest burden impact on the child and caregiver . The research indicated that there was an economic impact on the parents of children with hemophilia.

Key words: Hemophilia, Burden, Caregiver, child.

Chapter one
Introduction



Introduction:-

The child's diagnosis of a chronic genetic disease such as hemophilia is life-changing and impacts not only the child, but also the parents (Halimeh & Siebert, 2019). Caring for a child with hemophilia is burdensome and impacting on caregivers' emotional and financial status (Khair, 2017). Hemophilia is sex-linked hereditary bleeding disorder that impacts mostly men. It is caused by clotting factor gene mutation on X chromosome, which results in lack of factor VIII or -IX in hemophilia A or B. The most common symptom of hemophilia is bleeding, which occurs after trauma or surgery, with severity correlated with degree of clotting factor deficiency. Bleeding can happen in muscles, joints, or soft tissue, as well as in neck, throat, chest, gastrointestinal system, or intracranially in life-threatening case. Repeated joint bleeding results in severe joint damage and pain, resulting in disability (Ahmed, El-moazen, & Abu-rehab, 2022), (Shapiro, 2022).

Hemophilia is an umbrella term for several different diseases. The most well-known are hemophilia A and hemophilia B. Each form is caused by the lack of a particular protein in the blood that helps it to clot: People with hemophilia A don't have clotting factor VIII (eight), while people who have hemophilia B lack clotting factor IX (nine) (Fijnvandraat & Cnossen, 2012). Hemophilia A is more common, the estimated incidence of haemophilia A is between 1:5,000 and 1:10,000 in live male births and rarely in females who mostly act as carriers which inherit the defective gene from either their mother or father, or it may be a new mutation (Hassan, Jabber, & Zoology, 2016), (Abdul, Kadhim, Al-lami, & Baldawi, 2019).

Even though hemophilia runs in families, some families have no prior history of family members with hemophilia. Sometimes, there are carrier females in the family, but no affected boys, just by chance. However, about one-third of the time, the baby with hemophilia is the first one in the family to be affected with a mutation in the gene for the clotting factor (Schwartz & Eldar-lissai, 2017).

Family members are initiated into a caregiving role as soon as the family becomes aware of the diagnosis (Klassen et al., 2012). Hemophilia differs from many other chronic conditions in its abrupt character. The bleedings are mostly unexpected and require immediate treatment; they may be life-threatening. The risk of bleedings places the parents of young patients in a dilemma. They want to protect the child as much as possible against falls and other accidents, but they do not want to limit the child at play or hinder the child in the development of its personality (Varekamp & Rosendaal, 1990).

Chapter one Introduction

However , Management of pediatric persons with hemophilia and factor VIII (FVIII) inhibitors is challenging; acute bleeding episodes are difficult to treat and prophylaxis has limited efficacy, leaving individuals at higher risk of severe bleed-related complications compared with persons with hemophilia without FVIII inhibitors receiving FVIII prophylaxis. Inadequately managed repeated bleeding episodes result in joint and muscle deterioration, significant physical disability, impaired function, and chronic pain, often within the first one to two decades of life. (Oldenburg et al., 2020). Additionally, the burden of caring for a child with hemophilia and FVIII inhibitors dramatically impacts the caregiver, more than caring for a child with hemophilia without FVIII inhibitors. (Giangrande et al., 2018), (Van et al., 2017).

Caregiving can impact one's employment, career path, finances, social connections, and physical health (Eckhardt et al., 2013). It can impact family functioning, as the focus on the sick family member takes precedence over others' needs and wishes (Mancuso et al., 2012).

In addition to its clinical burden on the patient, the condition also places a significant economic burden on healthcare payers, patients/caregivers, and society. Hemophilia is associated with staggering direct costs from hospitalizations, outpatient visits, and drug treatments, as well as high indirect costs from diminished work productivity and absenteeism from work and school. Additionally, hemophilia incurs tremendous intangible costs, including reduced quality of life, pain and suffering, and the emotional and physical toll on the patient and caregivers (Chen, 2016).

Understanding and tracking caregiver burden in hemophilia can be a useful metric for understanding the disadvantages and benefits of treatments for hemophilia. If a treatment affects the management of hemophilia, it will likely not only improve the patient's clinical profile (e.g., annual bleeding rate) but will also reduce the caregiver's perceived burden. Such a measure could be integrated into standard hemophilia supportive-team care for targeting interventions to prevent further problems (Khair, 2017).

However ,caregivers need a great deal of support, so pediatric hematology nurses play a crucial role in encouraging caregivers to verbalize their feelings because some of them may feel guilty for being disease carriers, assist their coping efforts by providing information about the disease and its management, fostering the child's self-esteem and encouraging to promote a positive self- image, providing assistance during lifestyle adjustments, monitoring

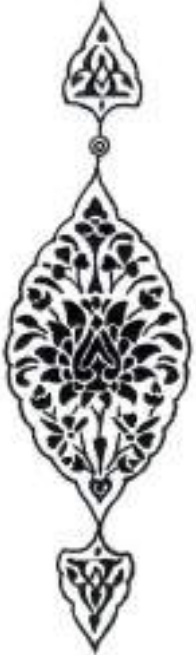
Chapter one Introduction

for early signs of complication, teaching. (Sebaq, & Deraz, 2021). The purpose of this study is to evaluation of caregiver's burden in parents caring for children with hemophilia.

1.2.Objectives :

- 1) Assessment of the burden of mothers on the care of children with hemophilia.
- 2) to determine the relationship between the burden of caregivers and demographic factors.
- 3) To Assess the caregiver knowledge about hemophilia.

Chapter two
Methodology



Methodology:-

Methodology: This chapter presents the (research design)

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2.1. Study design: Descriptive study of cross sectional design was conducted to Assessment of Caregiver burdens of caring for children with hemophilia in AL-Hilla city through the period of 11th November to 2nd march 2023.

2.2 Administrative arrangements: Agreements were obtained from director in ministry of education/ Education directorate of Babylon/ College of Nursing (Appendix B).

2.3. Setting of study: This study conducted at Babylon maternity and Children's Hospital/ Hematology Unit.

2.4. Sample of study: The sample was chosen as a non-probability convenience type and included (100) samples. The sample included all participants who had children under the age of 19 years with hemophilia who came to the hematology unit. Excluded; all patients age more than 20 years, children with other blood diseases.

2.5. Instrument of study: The questionnaire was constructed after extensive literature review and exposed to panel of experts (Appendix B) to be clear and applicable for data collection composed of three parts:

Part one : Socio-demographic characteristic of caregiver and child; which includes 20 items (Appendix A) .

Part two : Caregiver burden scale; describes caregiver health, psychological well- being, relationship between caregiver and the patient, social life, finances, which includes (22) items; are assessed in 5 –point Likert scale ranging from (0 = Never, 1=Rarely, 2= Sometime, 3= Frequently, 4= Nearly Always) . Higher score indicated greater burden.

Part Three : The caregiver's knowledge about hemophilia, which included Knowledge of genes, type and risk, first aid, bleeding care, and transfusion related infections which includes (10) items, rating as 0= No, 1= Yes, 3=Un-known.

2.6.Data collection: After obtaining informed consent from each participant; data were collected by researchers' direct interviews with the Caregivers who have Children with Hemophilia required by spending approximately 15 – 20 minutes.

2.7. Statistical Analysis: The data which are collected for the purpose of the study are analyzed electronically through using statistical Package of Social Science (SPSS) version 24 by application of frequencies, percentages, mean as descriptive and inferential as correlational statistics .

Chapter three
Results



Results :

Table (1): Sociodemographic data of caregivers and their children.

		Frequency	Percent
Who is the child's caregiver?	Father	35	27.8
	Mother	81	64.3
	Sister	5	4.0
	Other	5	4.0
	Total	126	100.0
Caregiver's age	<= 21.00	1	.8
	22.00 - 31.00	30	23.8
	32.00 - 41.00	45	35.7
	42.00 - 51.00	38	30.2
	52.00 - 61.00	8	6.3
	62.00+	4	3.2
Caregiver's Gender	Male	41	32.5
	Female	85	67.5
	Total	126	100.0
Level of Education	Illiterate	11	8.7
	Read and write	22	17.5
	Primary	22	17.5
	Intermediate	24	19.0
	Secondary	18	14.3
	High education	29	23.0
	Total	126	100.0
Income	Insufficient	34	27.0
	Barely sufficient	74	58.7
	Sufficient	18	14.3
	Total	126	100.0
Residency Area	Urban	84	66.7
	Rural	42	33.3
	Total	126	100.0
Participation in Trainings about Hemophilia	No	103	81.7
	Yes	23	18.3
	Total	126	100.0
Chronic illness of caregiver?	No	74	58.7
	Yes	52	41.3
	Total	126	100.0
Time working	Full-time	36	28.6
	Part-time	38	30.2
	Not working	52	41.3
	Total	126	100.0
Hemophilia causes economic impact on family	No	37	29.4
	Yes	89	70.6
	Total	126	100.0
Number of children (under age 18) with hemophilia?	<= 1.00	92	73.0
	2.00 - 2.00	31	24.6

	3.00+	3	2.4
	Total	126	100.0
Number of years caring for patient (year)	<= 1.00	10	7.9
	2.00 - 6.00	18	14.3
	7.00 - 11.00	39	31.0
	12.00 - 16.00	44	34.9
	17.00+	15	11.9
	Total	126	100.0
Child age (year)	<= 1.00	4	3.2
	2.00 - 6.00	12	9.5
	7.00 - 11.00	37	29.4
	12.00 - 16.00	45	35.7
	17.00+	28	22.2
	Total	126	100.0
Severity of hemophilia	Mild	15	11.9
	Moderate	61	48.4
	Sever	50	39.7
	Total	126	100.0
Type of hemophilia	Type A	99	78.6
	Type B	27	21.4
	Total	126	100.0
On prophylaxis regimen?	No	23	18.3
	Yes	103	81.7
	Total	126	100.0
If yes, frequency?	Daily	26	20.6
	5 time/week	7	5.6
	3 time/week	24	19.0
	twice/week	69	54.8
	Total	126	100.0
Treatment administered	Self-administer	9	7.1
	Family	15	11.9
	Hospital staff	70	55.6
	Both	32	25.4
	Total	126	100.0

Table (1.1) The study included; the majority of the sample were mothers who care for their children (64.3), and their ages ranged between (32.00 - 41.00) (35.7%), most of them had a high level of education (23.0%), who had a relatively sufficient income (58.7%), the results showed that; most of them live in an urban community (66.7%), Higher percent (81.7%) of those mothers were not participating in hemophilia training courses. Most of these mothers (58.7%) do not have chronic diseases , and do not work (41.3%). As a result, the percentage indicates that there is a burden or impact on the family's economic position (70.6%).

Children with hemophilia vary in age from 12 to 16 (35.7%), while the percentage of children under 18 is 73.0%, and the average number of years they have been under care is 12 to 16 (34.9%). Our research revealed that 48.4% of children with hemophilia have a moderate level, majority sample were from a type A (78.6%), due to factor VIII absence. Eighty-one percent or more of adolescents with hemophilia are receiving prophylaxis, which (54.8%) they consume every two weeks, The research also revealed that the majority of effected children (55.6%) were being treated by hospital staff. Figure (1); Where it was found that the level of burden of mothers who provide proper health care (Mild-moderate) (45.2 %).

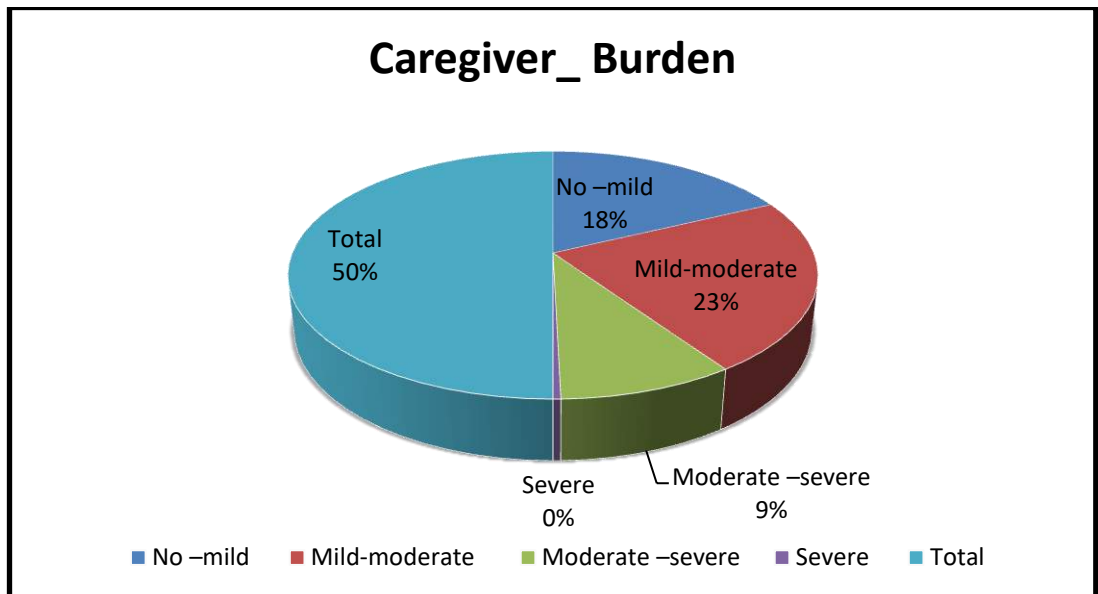


Figure (1): Assessment of caregiver_Burden

Figure (2): It was found that their knowledge was average moderate (56.3%) to this disease.

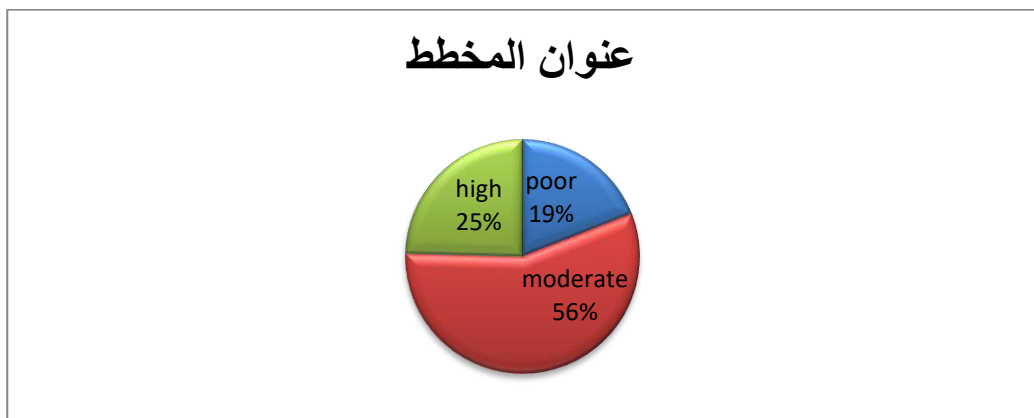


Figure (2): Assessment caregivers knowledge about genetic, type, severity, first aid , managing bleeding, transfusion related infection.

Table (2): Relationship between caregivers- burden and some variables.

Items		Caregiver-Burden
Caregiver age	Pearson Correlation	-.170*
	Sig. (1-tailed)	.029
	N	126
Caregiver gender	Pearson Correlation	.013
	Sig. (1-tailed)	.442
	N	126
Level of education	Pearson Correlation	-.299**
	Sig. (1-tailed)	.000
	N	126
Income	Pearson Correlation	-.182*
	Sig. (1-tailed)	.020
	N	126
Residency area	Pearson Correlation	.034
	Sig. (1-tailed)	.351
	N	126
Training	Pearson Correlation	.058
	Sig. (1-tailed)	.259
	N	126
Chronic illness	Pearson Correlation	.169*
	Sig. (1-tailed)	.029
	N	126
Time working	Pearson Correlation	.168*
	Sig. (1-tailed)	.030
	N	126
Severity of hemophilia	Pearson Correlation	.191*
	Sig. (1-tailed)	.016
	N	126
On prophylaxis	Pearson Correlation	.178*
	Sig. (1-tailed)	.023
	N	126

Correlation is significant at the 0.01 level (2-tailed).

Correlation is significant at the 0.05 level (2-tailed).

Table (3) presented the Relationship between (caregivers- burden) and some demographic variables; The table show that there is a positive relationship between (caregivers- burden) and caregiver age, time working, chronic disease, severity of hemophilia, prophylaxis) at level (p value 0.05), there is a negative relationship between (level of education , income) and caregiver- burden at level p value(0.01, \geq 0.05) respectively.



Chapter four
Discussion

Discussion :

Living with a child with a long-term condition can result in challenges above usual parenting because of illness specific demands(Smith, Rscn, Cheater, & Hons, 2013).

Parents of children with hemophilia face a multitude of demands. The child needs frequent intravenous injections, hospital visits, extra supervision and care. The child's illness and related management might have psychosocial effects on the parents(Li et al., 2019).

Hemophilia is associated with a high financial burden on individuals, healthcare systems, and society. In the current study About (64.3%) of those bearing the burden are mother of child and 35.7% with average age 32-41 years. obviously, the highest percentage of the caregiver for a child with hemophilia is the mother, as she is the main supporter of the child and the person who is most present with him. Hemophilia constitutes a great burden on the family , especially on the mothers, because most patients need periodic and frequent follow-ups to follow up the severity of the disease, and in each follow-up they need to do some tests , also patients need treatment for long time, whether prophylactic or therapeutic and this in itself needs money and this also a burden on the family and impact the family economic .And because the mother most of the time accompanies the patient and observed her child with hemophilia and in some cases is responsible for giving him treatment this will lead a great burden on her and this will lead to her being tired and may even lead to psychological problems (Khair, 2017), (Rayment et al., 2020).

The highest percentage (35.7%) of the sample were (32 - 41) Caregiver's age, this finding is similarity with study of done in London found that (mean age of 39.80 ± 6.2 years) of Caregiver's age. The gender of the study (67.5%) of the sample were female, this finding is in the same line with study found that (88.0 %) of the sample were female , X chromosome disorders in women (Schwartz & Eldar-lissai, 2017).

According to the results of our study, the highest percentage (23.0%) of the sample were High education, this finding is similarity with study found that (47.6%) of the sample were a high school education, This means that the learner has information about caregiver Burden's hemophilia (Halimeh & Siebert, 2019)

Hemophilia causes economic impact on family about (70.6%) and (41.3%) of child's caregiver not work. It is difficult for mothers to seek or return to employment due to the demands of hemophilia care .(Shahly et al, 2014) reported that caring for those with chronic illness increasingly falls on family caregivers who are vulnerable to the burden of financial

strain, with uncompensated family care-giving being an important societal asset that offsets rising formal healthcare costs.

The supported study (Khair, 2017) show (55%) that hemophilia had an economic impact on their family and (50%) worked part-time. Hemophilia is associated with staggering direct costs from hospitalizations, outpatient visits, and drug treatments, as well as high indirect costs from diminished work productivity and absenteeism from work and school.

The highest percentage (81.7%) of the sample were no- training course, This finding is agree with study found that it is necessary to participate in trainings to increases awareness about Hemophilia (Halimeh & Siebert, 2019), (Smith et al., 2013).

There is supported study in UK (Santana et al., 2022),showing that 80% of mothers are bearing the burden of her children with hemophilia. Most patients with hemophilia is hemophilia type A about 78.6 and about 48.4 are moderate hemophilia. The severity of hemophilia it mild ,moderate ,sever. It is determined by the amount of factor in the blood. The lower the amount of the factor, the more likely it is that bleeding will occur which can lead to serious health problems.

Also depend on developing inhibitors or not if develop the patient more likely for sever disease. If the patient on regular prophylactic therapy will reduce severity of disease and have normal quality of life (Rayment et al., 2020).

In another supported study in Europe (Santana et al., 2022) most patients have hemophilia A (about 79%) and 58% of them have severe hemophilia. This finding is reliable because hemophilia A is the most common form of hemophilia, About 9 out of 10 people with hemophilia have type A disease.

About 35.7 the age of child hemophilia with average between12-16 years and most of them resident in urban area (66.7%). (73%) there is on child suffer from hemophilia and the supported study (Schwartz & Eldar-lissai, 2017) show 85% of study sample had at least one child with hemophilia.

The study found that the parents have poor-moderate knowledge about caring in child with hemophilia, this linear with (Damad & Muttaleb, 2022);The study which found that the participants have a low knowledge level about health preventive measures and self-care and health preventive measures of hemophilia children. Little information is usually given to parents to help them adequately address illness-related issues with their children, such as how to decrease the burden of injections or how to discuss risky sports involvements.

Chapter fourDiscussion

The results showed that (57%) of caregiver_ Burden were have a Mild-moderate assessment for children with hemophilia, this study was similar to the results found that 42% were satisfied (mild burden), 36% were neither satisfied nor upset (mild-moderate burden) (Khair, 2017), (Yasser *et al.*2022).

Myrin *et al.*, 2019 state that physical and emotional health was negatively impacted by the demands of care-giving, with caregivers describing chronic physical and emotional ailments directly attributable to care-giving. These were most evident amongst mothers, who were most often primary caregivers.

In certain study reported that all participants described certain symptoms they feel as a consequence of their child's ill health, and it negatively impacts their social and psychological well-being. Respondents feel depression, anxiety, frustration and health issues too. Moreover, their social life is also disturbed due to their hemophilic child (Cutter *et al.*, 2019).

However, Most of the participant reported that their child's condition affects their health adversely as they remain awake the whole night when their child go through pain full treatment (blood transfusion) or have bleed episodes. This nevertheless had a negative impact on the mother caregiver quality of sleep but also impacted badly her health (Smith *et al.*, 2013).

Chapter Five
Conclusion &
Recommendation



Conclusion:-

The analysis of study revealed that the greatest burden impact on the child and caregiver . The research indicated that there was an economic impact on the parents of children with hemophilia. The study showed that most of the sample are mothers with age between (32-41) who not participated in hemophilia training courses. The research indicated that there was an economic impact on the parents of children with hemophilia. There is a positive relationship between (caregivers- burden) and caregiver (age, time working, chronic disease, severity of hemophilia, prophylaxis) at level (p value 0.05) , and a negative relationship with (level of education , income) at level p value(0.01, ≥ 0.05) respectively.

Recommendation

- 1) The researchers recommend the necessity of regular examination and follow up of relatives particularly and to ensure the safety of the couple before entering into marriage.
- 2) The need for training courses for parents and the patients to increase their knowledge about the disease and its prevention.
- 3) The researchers also recommend conducting more studies to explore, reduce and prevent the disease and increase centers to taking Prophylactic treatment.
- 4) The researchers recommend increasing health education about hemophilia by get an annual comprehensive checkup at a hemophilia treatment center. And Get vaccinated (hepatitis A and B)are preventable.

Abbreviations:

VIII = 8

IX = 9

X = 10

Fvili = Factor VIII

SPSS = Statistic Package of Social Science.

Sig= Significant

HIV = Human Immunodeficiency Virus.

AIDS = Acquired Immunodeficiency Syndrome.

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Appendices



List of Appendices

Appendix A

Questionnaire

بحري مقدمي الرعاية حول العناية باطفالهم المصابين بنزف الدم الوراثي

القسم الاول : الصفات الاجتماعية والديموغرافية لمقدم الرعاية والطفل

الاب	(١) من هو الشخص الذي يقدم العناية للطفل ؟	
الام		
الاخت		
اقارب اخرين		
	(٢) كم عمر الشخص مقدم الرعاية ؟	
ذكر	(٣) جنس مقدم الرعاية	
انثى		
لا يقرأ ولا يكتب		
متعلم القراءة والكتابة	المستوى التعليمي	
خريج مدرسة ابتدائية		
خريج مدرسة متوسطة		
خريج مدرسة ثانوية		
خريج التعليم العالي (معهد / جامعة)		
منخفض		
متوسط	(٥) مستوى الوضع الاقتصادي والاجتماعي	
عالي		
متزوج/ة		
مُطلق/ة	(٦) الحالة الاجتماعية	
أرمل/ة		
منفصل/ة		
اعزب		
غير كافٍ	(٧) هل لديك دخل شهري كافٍ لاحتياجات الأسرة ؟	
نوعا ما كافٍ		
كافٍ		
مدينة	(٨) السكن	
ريف		
نعم		
لا	(٩) مشارك في دورات تعليميه حول الهيموفيليا؟	
نعم		
لا	(١٠) هل يعاني مقدم الرعاية من مرض مزمن ؟	
دوام كامل		
دوام جزئي	(١١) وقت العمل	

عاطل عن العمل		
نعم	الهيموفيليا لها تأثير اقتصادي على العائلة ؟	(١٢)
لا		(١٣)
	عمر الطفل	(١٤)
	عدد الاطفال المصابين بالهيموفيليا	(١٥)
	عدد الأطفال (تحت سن ١٨) المصابين بالهيموفيليا	(١٦)
	عدد سنوات رعاية المريض	(١٧)
طفيف	شدة الهيموفيليا	(١٨)
متوسط		
شديد		
نوع A	نوع الهيموفيليا	(١٩)
نوع B		
نعم	على نظام الوقاية ؟	(٢٠)
لا		
يومية	إذا كانت الإجابة بنعم ، كم عدد المرات ؟	
خمس مرات / أسبوع (ما قبل الرياضة)		
ثلاث مرات / أسبوع		
مرتين في الاسبوع		
يأخذ العلاج بنفسه		(٢١)
يعطى له من قبل فرد من العائلة	العلاج المعطى	
يعطى له من قبل كادر المستشفى المختص		

عبء مقدم الرعاية : القسم الثاني

تقريباً دائماً	في كثير من الاحيان	بعض الاحيان	نادراً	ابدأ	المتغيرات
					(١) هل تشعر بالتوتر بين رعاية طفلك ومحاولة تحمل مسؤوليات أخرى تجاه أسرته أو عملك ؟
					(٢) هل تشعر بالأحراج من سلوك طفلك ؟
					(٣) هل تشعر بالغضب عندما تكون بالقرب من طفلك ؟
					(٤) هل تشعر أن طفلك يؤثر حالياً على علاقتك بأفراد الأسرة أو الأصدقاء الآخرين بطريقة سلبية ؟
					(٥) هل تخشى ما يخشاه المستقبل لطفلك ؟
					(٦) هل تشعر بالتوتر عندما تكون حول طفلك ؟
					(٧) هل تشعر أنك لا تمتلك القدر الذي تريده من الخصوصية كما يجب ان تتمتع به بسبب طفلك ؟
					(٨) هل تشعر أنك تعاني في حياتك الاجتماعية بسبب أنك تهتم بطفلك ؟

				٩) هل تشعر بعدم الارتياح حيال صداقاتك وعلاقاتك بسبب طفلك ؟
				١٠) هل تشعر أنك فقدت السيطرة على حياتك منذ ان مرض طفلك ؟
				١١) هل تتمنى أنك فقط لو تترك امر رعاية طفلك لشخص آخر ؟
				١٢) هل تشعر بأنك غير متأكد بشأن ما يجب القيام به بشأن طفلك ؟
				١٣) هل تشعر أنك يجب أن تفعل أكثر مما تفعله وتقدمه لطفلك ؟
				١٤) هل تشعر أنه يمكنك القيام بعمل أفضل مما تفعله في رعاية طفلك ؟
				١٥) ما مدى شعورك بالعبء عند رعاية طفلك ؟
				١٦) هل تشعر ان طفلك يطلب المساعدة أكثر مما هو يحتاج اليه ؟
				١٧) هل تشعر أنه بسبب الوقت الذي تقضيه مع طفلك بأنه ليس لديك الوقت الكافي لنفسك ؟
				١٨) هل تشعر ان طفلك معتمد عليك ؟
				١٩) هل تشعر ان صحتك قد تراجعت بسبب انك متورط مع طفلك ؟
				٢١) هل تشعر انك لن تكون قادر على رعاية طفلك لمدته اطول ؟
				٢٢) هل تشعر بأنه ليس لديك المال الكافي لرعاية طفلك وتحمل التكاليف ؟

الجزء الثالث : معرفة مقدم الرعاية حول مرض الهيموفيليا

غير متأكد	لا	نعم	العناصر
			معرفة الجينات والنوع والخطورة
			الهيموفيليا مرض وراثي. كروموسوم X-Lind
			هل منتقلة الهيموفيليا من الاب الى الابناء
			الوعي حول فرصة الابن للإصابة بالهيموفيليا إذا تزوج الذكر المصاب من أنثى عادية
			الهيموفيليا (A) تعني نقص العامل ٨
			الهيموفيليا المعتدلة تعني مستوى العامل ١-٥٪
			المعرفة حول الإسعافات الأولية ، والعناية بالتنظيف ، والعدوى المتعلقة بنقل الدم.
			وضع الثلج هو الإسعافات الأولية لتنظيف المفاصل
			يجب تجنب الأسبرين في الأشخاص المصابين بالهيموفيليا
			هل ممارسة الرياضة تحافظ على صحة الشخص المصاب بالهيموفيليا
			الوعي حول ان الهيموفيليا معرضة لخطر الإصابة بفيروس نقص المناعة البشرية / الإيدز
			ينتقل التهاب الكبد B من إبرة وحقنة مصابة

Caregiver Burdens of Care among Children with Hemophilia.

Table 1: Socio-demographic characteristic of caregiver and child.

1	Who is the child's caregiver?	Father
		Mother
		Sister
		Other Relatives
2.	Caregiver's Age	
3	Caregiver's Gender	Male
		Female
4	Level of Education	Illiterate
		Literate (read and write)
		Graduate of Primary School
		Graduate of Intermediate School
		Graduate of Secondary School
		Graduate of High Education (Institute/University)
5.	Family history of hemophilia ?	Yes
		No
6.	Marital Status	Married
		Divorced
		Widow
		Separated
		Single
7.	Do you enough monthly income for family needs	Insufficient
		Barely sufficient
		Sufficient
8.	Residency Area (Housing)	Urban
		Rural
9.	Participation in Trainings about Hemophilia	Yes
		No
10	Chronic illness of caregiver	Yes
		No
11	Time working	Full- time
		Part- time
		Not working
12	Hemophilia causes economic impact on family	Yes
		No
13	Child age	
14	Number of children (under age 18) with hemophilia	
15	Number of years caring for patient	
16	Severity of hemophilia	Mild
		Moderate
		Sever

17	Type of hemophilia	hemophilia A
		hemophilia B
18	On prophylaxis regimen?	Yes
		No
19	If yes, frequency?	Daily
		Five times/week (pre-sport)
		Three times/week
		Twice/week
20	Treatment administered	Self
		Family member
		Hospital staff
		Overweight / obese

Table (2) Caregiver burden:

Items	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?					
2) Do you feel embarrassed you're your child's behavior?					
3) Do you feel angry when you are around your child?					
4) Do you feel that your child currently affects your relationship with other family members or friends in a negative way?					
5) Are you afraid what the future holds for your child?					
6) Do you feel strained when you are around your child?					
7) Do you feel that you do not have as much privacy as you would like because of your child?					
8) Do you feel that your social life has suffered because you are caring for your relative?					
9) Do you feel uncomfortable about having friends over because of your relative?					
10) Do you feel that you have lost control of your life since your child illness?					
11) Do you wish you could just leave the care of your child to someone else?					
12) Do you feel uncertain about what to					

do about your child?					
13) Do you feel that you should be doing more for your child?					
14) Do you feel you could do a better job in caring for your child?					
15) Overall, how burdened do you feel in caring for your child?					
16) Do you feel that your child asks for more help than (s)he needs?					
17) Do you feel that because of the time you spend with your child that you do not have enough time for yourself?					
18) Do you feel your child is dependent upon you?					
19) Do you feel your health has suffered because of your involvement with your child?					
19) Do you feel your health has suffered because of your Involvement with your child?					
20) Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
21) Do you feel that you will be unable to take care of your relative much longer?					
22) Do you feel that you do not have enough money to care for your child in addition to the rest of your expenses?					

Table (3): Caregiver knowledge about hemophilia

Items	Yes	No	Un-known
Knowledge about genetic, type, severity			
Haemophilia is a genetic disease . X-link chromosome			
Haemophilia gen are transmitted from father to daughter			
Awareness about chance of son to getting Haemophilia if affected male marries a normal female			
Haemophilia(A) mean factor 8 deficiency			
Moderate haemophilia means factor level 1-5%			
Knowledge about first aid , managing bleeding, transfusion related infection.			
Ice application is the first aid for joint bleeding			
Aspirin should be avoided in person with haemophilia			
Doing exercise keeps a person with haemophilia healthy			
Aware that Haemophilia are at risk for HIV/ AIDS			
Hepatitis B transmitted from infected needle and syringe			

Appendix B

Ministry of Higher Education and Scientific Research
 وزارة التعليم العالي والبحث العلمي
 University of Babylon
 كلية التمريض
 جامعة بابل
 كلية التمريض
 وحدة شؤون الطلبة

Ref. No: ٤٤٥٤
 Date: ١١/٤٢/٢٠٢٢ الى استشاري اهل النسائية والاطفال / وحدة امراض الدم / م / تسجيل همه

(استشار الفائة الطلبة طريفا نحو الفية المسفامة)
 (caregiver burden among children with hemophilja)
 (عنج الامحلت حول الرعاية بالاطفال المصابين بالحموفيليا)

١- زهراء اكرم هادي
 ٢- روية عادل مهدي
 ٣- زركيا مهدي ابراهيم
 ٤- زهراء خالد محسن

غية طبية ..
 طيب لنا حسن التواصل معكم ورحب بتفضلكم بالموافقة على تسجيل همه طلبة كايقتا المدرجة اسمائهم
 شاكرين لتعاونكم معنا ... مع الاحترام ...

ادارة
 مديرها
 سليم السيد المستبد
 ١٤٢٢

ادعاهم لدراسة
 اتمامهم ١١/٤٢/٢٠٢٢

اد. نهاد محمد قاسم
 معاون العميد للشؤون العلمية والدراسات العليا
 ٢٠٢٢/١١/٤٤

السيد هير المحسن المحترم
 الامانة لمتنا من تسجيل همه
 ١١/٢٤
 المودع اليهم فخير البحث المذكور
 اعلاه مع التقدير ..

نسخة منه الى //
 - مكتب السيد العميد المتفرع لتفصل بالاطلاع مع الاحترام
 - شعبة الشؤون العلمية مع الاوليات
 - الملف

E-mail: nursing@uobabylon.edu.iq
 STARS
 07711632208
 009647711632208
 وطني
 المكتب

Appendix C

Panel of Experts

مكان العمل	الاختصاص	الشهادة	اسم الخبير	ت
جامعة بابل / كلية التمريض	تمريض الاطفال	استاذ	أ.د.نهاد الدوري	1
جامعة بابل / كلية التمريض	تمريض صحة الأم و الوليد	استاذ مساعد	أ.م.د. وفاء احمد	2
جامعة بابل / كلية التمريض	تمريض صحة الأم و الوليد	مدرس	أ.م.د. مريم عبد الكريم	3
جامعة بابل / كلية التمريض	تمريض اطفال	مدرس	م .د. محمد طالب عبد	٤
جامعة بابل / كلية التمريض	تمريض الصحة نفسية	مدرس	م.د. امير صلاح الدين	5
جامعة بابل / كلية التمريض	تمريض الاطفال	مدرس مساعد	م.م. علي فاضل	6
جامعة بابل / كلية التمريض	تمريض الصحة نفسية	مدرس مساعد	م .م. زمن احمد حريشيف	7

الخلاصة

المخلص: تعتبر رعاية الطفل المصاب بنزف الدم الوراثي مرهقة وتؤثر على الحالة العاطفية والمالية لمقدمي الرعاية. الهيموفيليا هو اضطراب نزيف وراثي مرتبط بالجنس ويؤثر في الغالب على الرجال. يحدث بسبب طفرة جينية لعامل التخثر على كروموسوم X ، مما يؤدي إلى نقص العامل الثامن أو التاسع في الهيموفيليا A أو B. أكثر أعراض الهيموفيليا شيوعاً هو النزيف ، الذي يحدث بعد الصدمة أو الجراحة ، مع ارتباط شدته بدرجة نقص عامل التخثر. **هدف الدراسة:** لتقييم عبء الأمهات على رعاية الأطفال المصابين بالهيموفيليا وتحديد العلاقة بين عبء الأمهات والعوامل الديموغرافية. ان الدراسة كانت دراسة وصفية شملت (100) عينة خلال شهري نوفمبر و مارس 2023. **النتائج:** ان رعاية الطفل المصاب بالهيموفيليا كانت سائدة في الأمهات اللاتي يقدمن رعاية ل اطفالهن وكانت نسبتهم (64.3) ، وتراوحت أعمارهم بين (32.00 - 41.00) وبنسبة (35.7%)، كان مستوى تعليم الام هو المستوى التعليمي العالي (23.0%) ، الوضع الاجتماعي والاقتصادي كان كافيا ، وكانت معرفة الامهات حول رعاية الاطفال بالهيموفيليا متوسطة (56.3%). بالإضافة الى وجود علاقة إيجابية بين عبء مقدمي الرعاية مع عمر مقدم الرعاية ، وقت العمل ، الامراض المزمن ، شدة الهيموفيليا ، والمرضى الذين يتلقون العلاج الوقائي و ذلك عند المستوى الدلالة ذات قيمة ($\geq 0,05$) ، وبحسب الدراسة هناك علاقة عكسية مع (المستوى التعليمي ، الوضع الاجتماعي والاقتصادي عند المستوى الدلالة ذات القيمة ($\geq 0,01$ ، $\geq 0,05$) الخلاصة : أظهرت نتائج هذه الدراسة ارتباطا أن هناك عبء كبير يؤثر على الطفل ومقدم الرعاية. و أشارت إلى وجود تأثير اقتصادي على آباء الأطفال المصابين بالهيموفيليا.



جمهورية العراق

وزارة التعليم العالي والبحث العلمي

جامعة بابل

كلية التمريض

"عبء مقدمي الرعاية حول العناية بأطفالهم المصابين بنزف الدم الوراثي في مدينة الحلة"

كمشروع بحث مقدم الى

مجلس كلية التمريض في جامعة بابل

جزء من متطلبات نيل درجة البكالوريوس علوم في التمريض

تقدم بها الطلاب:

رقية عادل مهدي

زهراء اكرم هادي

زهراء خالد محسن

زكريا مهدي ابراهيم

ياشرف:

م.م : مها احمد الغانمي

كمشروع تخرج للحصول على درجة بكالوريوس في كلية التمريض للعام الدراسي

٢٠٢٢-٢٠٢٣.

