

## Assessment of Caregiver's Knowledge and Practices Regarding Care of their Children with Hemophilia

Sabrein Elsayed Mahmoud Abdel Maqsood, Prof Dr.Salma Elsayed Hassan \*\* Assist Prof Dr.Fathia Elsayed El-Ghadban \*\*\* Prof Dr.Safaa Salah Ismail \*\*\*\*

Assistance Lecturer of pediatric nursing, \*Professor at pediatric nursing, \*\* Assist Professor at pediatric Nursing, \*\*\* Professor at pediatric Nursing.

Faculty of nursing- Fayoum University\*, Ain-Shams University\*\*, Fayoum University\*\*\* & Helwan University.\*\*\*\*

### ABSTRACT

**Back ground:** Hemophilia is one of the most common serious congenital coagulation factor deficiency diseases characterized by decreased function or absence of factor VIII or factor IX that is associated with significant morbidity and mortality. **Aim:** the current study aimed to assess caregivers' knowledge and practices regarding care of their children with hemophilia. **Design:** a descriptive research design was used. **Setting:** the study was conducted at inpatient department and outpatient clinic department in Badr University Hospitals affiliated to Helwan University Hospitals and Mustafa Hassan Pediatric Hospital affiliated to Fayoum University Hospitals. **Sample:** A purposive sample consisted of 60 children and their accompanying caregivers suffering from hemophilia. **Tools:** consisted of two tools: **I:** A structured interviewing questionnaire sheet to assess caregivers' knowledge regarding hemophilia, **II:** Observational checklists to assess caregivers' reported practices regarding care of their children suffering from hemophilia. **Results:** All of the studied children were males. The most of the studied children were suffering from hemophilia A. More than half of the studied caregivers had unsatisfactory knowledge regarding hemophilia. Less than two thirds of the studied caregivers had inadequate practices regarding care of their children with hemophilia. **Conclusion:** the present study concluded that the studied caregivers had deficit total level of knowledge and poor of total level of reported practices, and also there were a statistical significant positive correlation between the studied caregivers' knowledge and their total level of reported practices regarding care of children with hemophilia. **Recommendation:** A periodical educational program for caregivers to improve knowledge and practices regarding care of their children suffering from hemophilia.

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**Key words:** Children, Caregivers, Care, Knowledge, Practice, Hemophilia.

### Introduction:

Hemophilia is a group of inherited blood disorders in which there is life-long defect in the clotting mechanism. It is inherited as an x-linked recessive; therefore, males are affected and females are carriers. In rare cases females can be affected. In 30% of cases, no family history is obtainable when spontaneous new mutation occurs (*Bertamino et al., 2017*). Factor deficiencies cause bleeding in joints, muscles, brain, and other internal organs, with recurrent muscular skeletal bleeds leading to severe destruction of cartilage and bones, resulting in arthropathy, disability and impairment in quality of life (*Rambod et al., 2018*).

Hemophilia is one of the most common serious congenital coagulation factor deficiency diseases (*Alrashidi et al., 2019*) and considered the third most common disease associated with the X chromosome due to a deficiency or lack of coagulation factors VIII and IX which the body's ability to form blood clots and coagulate to prevent bleeding is disrupted if the artery injury (*Rostami et al., 2020*). Hemophilia is a bleeding disorder due to coagulation pathway factor deficiency that is associated with significant morbidity and mortality (*Alblaihed et al., 2022*).

The deficiency of clotting factor in the blood (factor VIII in type A, and factor IX in type B) causes hemorrhages, particularly in joints and muscles. Bleeding occurs spontaneously in severe hemophilia, and mildly affected children

Vol. 2, Issue 2, Month: December 2023, Available at: <https://hijnrp.journals.ekb.eg/>

experience hemorrhages after trauma, dental procedures, or surgery. Factor concentrates are administered in a hospital or at home by the children himself or parents to treat or prevent bleeding (Fischer et al., 2016; El Hawary et al., 2019).

According to World Federation of Hemophilia (WFH), 2018, the incidence of hemophilia in Egypt of 6028 distributed as 4885 hemophilia A and 1143 hemophilia B (Elsakka et al., 2022). In Egypt, consanguineous marriage is frequent, therefore recessive characteristic coagulation disorder reach a higher incidence than in many other countries. The incidence of hemophilia in Egypt is about 250,000 cases per years and also about 30-40 cases in each million people (Damad & Muttaleb, 2022).

The most common types of hemophilia are hemophilia A (factor VIII deficiency) and Hemophilia B (factor IX deficiency). Hemophilia A representing 80- 85 % of the total number of diagnosed cases of hemophilia, hemophilia B representing 15%-20% of the total diagnosed cases of hemophilia (Gaber et al., 2019). According to World Health Organization (WHO), 2018, Hemophilia estimated to be 1 in every 5,000 live male births annullay worldwide. Hemophilia A affects about 1 in 5000-10000 while hemophilia B affects about 1 in 40000 males at birth, but Hemophilia C generally occurs in 1 of every 100000. Hemophilia affects mostly male, about 1 in every 5,000-10,000 is born with it, but females are more rarely affected (Hazendonk et al., 2018). Hemophilia is classified as mild, moderate or severe, depending on the amount of factor VIII or factor IX present in the blood. The normal range of factor VIII and IX is 50-150% (Bacci et al., 2021).

Early recognition of joint and muscle bleeds is emphasized because immediate adequate treatment with clotting factor is possible using home infusion therapy (Bolick et al., 2020). Early treatment has significantly reduced the morbidity formerly associated with hemophilia. The availability of comprehensive hemophilia treatment centers offers the child with hemophilia and the family a coordinated multidisciplinary approach to meet their needs and improving the child's health and wellbeing (Speedie et al., 2021).

Nurses play an important role in the nursing care of children with hemophilia. Nurses have a positive role includes: providing individualized education and support, promote joint therapies, minimize disability in children with severe hemophilia, encourage family members to verbalize problem areas and develop solutions on their own and also encourage them to express their feelings such as how they deal with the chronic needs of a family and coping patterns that help or hinder adjustment to the problems (Silbert-Flagg & Pillitteri, 2018).

### **Aim of the Study:**

The study aimed to assess caregivers' knowledge and practices regarding care of their children with hemophilia.

### **Research Questions:**

1. What is caregiver's knowledge and practices regarding care of their children with hemophilia?
2. Is there correlation between caregivers' knowledge and reported practices regarding care of their children with hemophilia?

### **Subjects and Methods:**

#### **1) The technical design:**

##### **A) Research design:**

A descriptive design was used to conduct this study.

##### **B) Setting:**

The study was conducted at inpatient department and outpatient clinic department in Badr University Hospitals affiliated to Helwan University Hospitals and Mustafa Hassan pediatric Hospital affiliated to Fayoum University Hospitals.

### C) Subject:

A purposive sample was consisted of all available children suffering from hemophilia and their accompanying caregivers (60) who attained in the previously mentioned settings under the following inclusion criteria:

- 1-Both gender.
- 2-Children confirmed diagnosis with hemophilia.
- 3- Children free from any other physical or mental disease.

### D) Tools for data Collection:

#### Tool I: structured interviewing questionnaire sheet: It consisted of three parts:

**Part 1: a-** It concerned with characteristics of the caregivers included age, gender, level of education, occupation, residence and marital status.

**b-** It concerned with characteristics of the children included age, gender, educational level, and diagnosis of hemophilia.

**Part 2:** Child's medical history that included family history of hemophilia, age of hemophilic children at the first diagnosed and sites of the first bleeding .

**Part 3:** Caregivers' knowledge about hemophilia that consisted of the following; It concerned with caregivers' knowledge:

- Regarding hemophilia disease which consisted of 8 multiple choice questions about definition, causes, types, signs and symptoms, most sites of bleeding, complications, diagnostic tests and treatment about hemophilia.

- Regarding nutrition which consisted of 2 open ended and one multiple choice questions that included foods should be given to a child, foods not recommended to a child and characterized of foods recommended to a child with hemophilia.

- Regarding protection of teeth, joint deformities and sports to child which consisted of 4 multiple choice questions that included teeth and mouth care, the ways to protect the child from joint deformities, types of sports and unfavorable types of sports for child with hemophilia.

- Regarding protection the child from infection, skin inflammation or constipation which consisted of 3 multiple choice questions that included preventive measures to avoid infection, skin inflammation and constipation for child with hemophilia.

#### Scoring system:

The caregivers' complete correct answers were scored "two" & those incomplete correct answers were scored "one" and unknown was scored "zero". Total score was 36. The total caregivers' knowledge was categorized into unsatisfactory → less than 60% and satisfactory → 60% and more.

#### Tool II: Observational checklists:

The observational checklists were adapted from **Bowden and Greenberger (2013)**, to assess caregivers' reported practices regarding care of their children with hemophilia. It was modified and translated into Arabic form by researcher to suit the nature of study. It included six procedures divided into; care of nosebleeding (6 steps), joint bleeding (4 steps), hand washing (11 steps), oral & dental care (10 steps), exercises for flexibility of the child's body (14 steps) and cough & deep breathing exercises (5 steps).

#### Scoring system:

Each practice item done correctly was scored "one" and not done was scored "zero". The total numbers of steps in the observational checklist were 50 steps. Total score was 50. The total caregiver' reported practice was categorized into inadequately → less than 60% and adequately → 60% and more.

#### Validity:

The content validity of the tools reviewed by 3 experts in the field of pediatric nursing to test the content validity. The tools were examined for content coverage, clarity, relevance and applicability. Minor modifications of the tools were done according to the experts' comments on clarity of sentences, appropriateness of content and sequence of items.

**Reliability:**

Reliability of the tools were tested by using Cronbach's Alpha for testing internal consistency of the tools was performed. The results were 0.825 for structured interview questionnaire, 0.804 for observational checklists.

**II. Operational design:**

This phase includes a preparatory phase and a pilot study.

**Preparatory phase:**

Review of the available past, current, national and international related literature and theoretical knowledge of various aspects of the study was done using books, articles, Websites, periodicals and magazines to get acquainted with various aspects of the research problem and develop the tools for data collection.

**Pilot study:**

Pilot study was conducted on 10% of the study subjects which constitute 6 caregivers based on sample criteria. It was conducted to evaluate the clarity and applicability of the study tools. According to the obtained results from the pilot study, some modifications were done in the form of rephrasing and rearrangements of some items. The involved caregivers were excluded later from the main study sample.

**Field work:**

The actual field work was carried out for data collection over 9 months started from October 2021 till end of June 2022 through interviewing every child and their accompanying caregivers at the inpatient and outpatient clinics.

**Ethical Consideration**

Prior study conduction, ethical approval was obtained from the Scientific Research Ethical Committee of the Faculty of Nursing Helwan University. The purpose of the study was simply explained to the caregivers who agree to participate in the study prior to data collection. The researcher was assured maintaining anonymity confidentiality of the subject data. Caregivers were informed that they will be allowed choosing to participate or not in the study and they have the right to withdraw from the study at any time without giving any reasons.

**III- Administrative design**

After explanation of the study aim and objectives, an official permission was obtained from the Dean of faculty of nursing and the directors of children's hospital as well as outpatient clinic and inpatient pediatric departments in pediatric hospital affiliated to El fayoum University Hospital and Helwan University Hospitals to conduct the study.

**IV- Statistical design**

Data were organized, arranged, coded, entered, and analyzed by using statistical package of social science (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp). The quantitative data were presented as mean and standard deviation. The qualitative data were presented as number and percentage. The P-value to detect the relations between the variables of the study.

**Results:-**

**Table (1):** showed that more than two thirds (71.7 %) of the studied caregivers aged 25 <35 years old with a mean age  $34.26 \pm 4.78$  years. The same table clarified that 45 % & 78.3 % of the studied caregivers were in preparatory school and were not working respectively, while the majority (88.3% & 93.3%) of them were from rural residence and married respectively. The same table illustrated that 63.3% of the studied caregivers had consanguinity with their husbands.

**Table (2):** clarified that more than half (51.7%) of the studied children aged 5 <10 years with a mean age  $8.34 \pm 4.74$  years, mean while the all of them were males. The same table illustrated that more than half (51.7%) of the studied children were in primary school, while 95% of them were diagnosed as hemophilia A.

Vol. 2, Issue 2, Month: December 2023, Available at: <https://hijnrp.journals.ekb.eg/>

**Table (3):** showed that more than half (55%) of the studied children had family history, while less than three quarter (71.7 %) of them were diagnosed of hemophilia when aged less than 2 years. The same table clarified that the majority (91.7% & 86.7%) of the studied children had the first joint bleeding and disease affected their daily activity respectively, while 75% & 60 % of them were followed treatment regularly and had regular follow up respectively.

**Figure (1):** revealed that 55% of the studied caregivers had unsatisfactory total level of knowledge regarding hemophilia

**Figure (2):** illustrated that 63.3% of the studied caregivers had inadequate total level of reported practices regarding care of their children with hemophilia.

**Table (4):** indicated that there were a highly statistical significant difference between caregivers' characteristics namely; age, occupation and educational level and their total level of knowledge respectively, while there were no statistical significant difference between caregivers' knowledge and their residence and marital status.

**Table (5):** clarified that there were statistical significant difference between caregivers' characteristics namely; age, residence and educational level and their total level of reported practices respectively, while there were no statistical significant difference between caregivers' practices and their occupation and marital status.

**Table (6):** showed that there were statistical significant positive correlation between their total level of knowledge, reported practices regarding care of their children with hemophilia.

**Table (1):** Distribution of the studied caregivers according to their characteristics (n=60)

Caregiver's Characteristics	N	%
<b>Caregivers</b>		
Mother	52	86.7
Father	8	13.3
<b>Age (years)</b>		
25 < 35	43	71.7
35 < 45	13	21.7
≥ 45	4	6.6
<b>Mean±SD</b>	<b>34.26±4.78</b>	
<b>Education level</b>		
Illiterate	8	13.3
Primary	12	20
Preparatory	27	45
Secondary	10	16.7
University	3	5
<b>Occupation</b>		
Working	13	21.7
Not working	47	78.3
<b>Residence</b>		
Rural	53	88.3
Urban	7	11.7
<b>Marital status</b>		
Married	56	93.3
Divorced	4	6.7
<b>The consanguinity</b>		
Yes	38	63.3
No	22	36.7

Vol. 2, Issue 2, Month: December 2023, Available at: <https://hijnrp.journals.ekb.eg/>

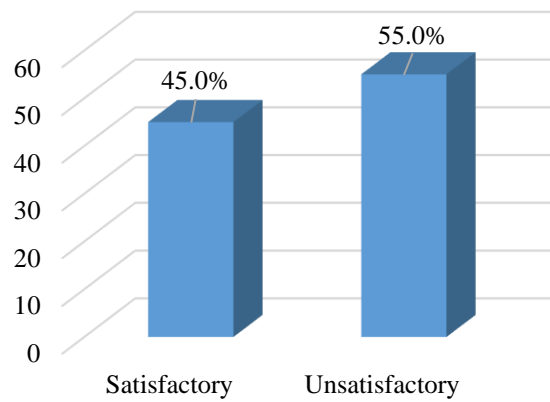
**Table (2):** Distribution of the studied children according to their characteristics (n=60)

Children's Characteristics	N	%
<b>Age in years</b>		
1 < 5	15	25.0
5 < 10	<b>31</b>	<b>51.7</b>
10 < 15	9	15.0
≥ 15	5	8.3
<b>Mean±SD</b>	<b>8.34±4.74</b>	
<b>Education level</b>		
Pre nursery school	7	11.7
nursery school	8	13.3
primary school	<b>31</b>	<b>51.7</b>
Preparatory school	10	16.7
secondary school	4	6.6
<b>Diagnosis</b>		
Hemophilia A	<b>57</b>	<b>95</b>
Hemophilia B	3	5

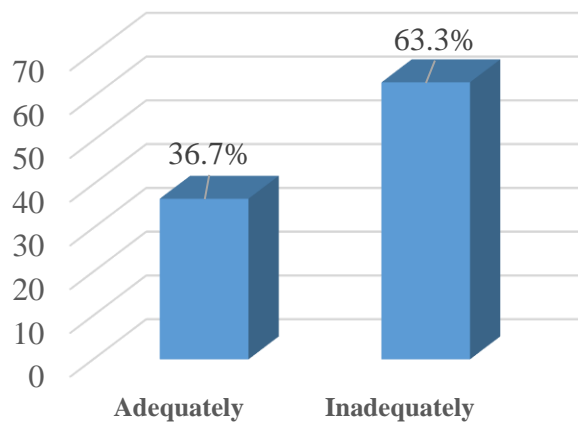
**Table (3):** Distribution of the studied children according to their past history (n=60)

Items	N	%
<b>Family history of hemophilia:</b>		
+ve	<b>33</b>	<b>55</b>
-ve	27	45
<b>Age of child at first diagnosis of hemophilia/ years</b>		
< 2	<b>43</b>	<b>71.7</b>
>2	17	28.3
<b>Sites of the first bleeding</b>		
Joint	<b>55</b>	<b>91.7</b>
Muscle	5	8.3
<b>The disease affect the daily activity of the child</b>		
Yes	<b>52</b>	<b>86.7</b>
No	8	13.3
<b>Types of effect</b>	<b>N=52</b>	<b>%</b>
Decreased usual daily living activities	<b>19</b>	<b>31.7</b>
sleep disturbance	7	11.7
Difficulty concentrating while studying	11	18.3
Absence from school	8	13.3
Refuse to play with children	7	11.7
<b>Following the treatment regularly</b>		
Yes	<b>45</b>	<b>75</b>
No	15	25
<b>Follow up</b>		
Regular	<b>36</b>	<b>60</b>
Irregular	24	40

**Figure (1):** Percentage distribution of the studied caregivers' according to their total level of knowledge regarding hemophilia



**Figure (2):** Percentage distribution of the studied caregivers' according to their total level of reported practice regarding care of their children with hemophilia



**Table (4):** Relation between the studied caregivers' characteristics and their total level of knowledge regarding hemophilia n=60

Items	Total level of knowledge					
	Satisfactory (27)		Unsatisfactory (33)		Chi-square	
	N	%	N	%	X <sup>2</sup>	P-value
<b>Caregivers</b>						
Mother	22	42.3	30	57.7	1.142	0.285
Father	5	62.5	3	37.5		
<b>Age (years)</b>						
25 < 35	12	27.9	31	72.1	18.208	<0.001*
35 < 45	11	84.6	2	15.4		
≥ 45	4	100.0	0	0.0		
<b>Residence</b>						
Rural	22	41.5	31	58.5	2.236	0.135



Urban	5	71.4	2	28.6		
<b>Occupation</b>						
Working	11	84.6	2	15.4	10.523	<0.001*
Not working	16	34.0	31	66.0		
<b>Education level</b>						
Illiterate	0	0.0	8	100.0	25.425	<0.001*
Primary	1	8.3	11	91.7		
Preparatory	14	51.9	13	48.1		
Secondary	9	90.0	1	10.0		
University	3	100.0	0	0.0		
<b>Marital status</b>						
Married	24	42.9	32	57.1	1.558	0.212
Divorced	3	75.0	1	25.0		

**Table (5):** Relation between the studied caregivers' characteristics and their total level of reported practices related to care of their children with hemophilia n=60

Items	Total level of reported practices					
	Adequately (22)		Inadequately (38)		Chi-square	
	N	%	N	%	X <sup>2</sup>	P-value
<b>Caregivers</b>						
Mother	18	34.6	34	65.4	0.707	0.401
Father	4	50.0	4	50.0		
<b>Age (years)</b>						
25 < 35	12	27.9	31	72.1	7.592	0.022*
35 < 45	9	69.2	4	30.8		
≥ 45	1	25.0	3	75.0		
<b>Residence</b>						
Rural	17	32.1	36	67.9	4.124	0.042*
Urban	5	71.4	2	28.6		
<b>Occupation</b>						
Working	7	53.8	6	46.2	2.109	0.146
Not working	15	31.9	32	68.1		
<b>Education level</b>						
Illiterate	0	0.0	8	100.0	17.982	<0.001*
Primary	1	8.3	11	91.7		
Preparatory	14	51.9	13	48.1		
Secondary	7	70.0	3	30.0		
University	0	0.0	3	100.0		
<b>Marital status</b>						
Married	19	33.9	37	66.1	2.712	0.100
Divorced	3	75.0	1	25.0		



**Table (6):** Correlation between the studied caregivers' total level of knowledge and reported practices regarding care of their children with hemophilia n=60

Total level of reported practice	Total level of knowledge			
	Satisfactory (27)		Unsatisfactory (33)	
	N	%	N	%
Adequate (22)	18	30	4	6.6
Inadequate (38)	9	15	29	31.6
	<b>r=</b>	r=0.731		
	<b>P-value</b>	p=<0.001*		

**Discussion:**

Regarding to characteristics of caregivers, the findings of the present study showed that more than two thirds of the studied caregivers were aged 25 < 35 years with a mean age 34.26±4.78 years. This finding was supported with **Damad & Muttaleb (2022)**, who carried out a study entitled “Effectiveness of Hemophilia Educational Program on Parents' Knowledge of Children with Hemophilia” and reported that the majority of the sample were between 25 -37 years old.

As regards educational level of caregivers, the results of the current study revealed that less than half of the studied caregivers were in preparatory school. This finding was inconsistent with that of **D’souza et al (2018)** , who found in a study about Knowledge among Mothers’ of Children and Youth with Hemophilia–A Cross Sectional Survey at a Hemophilia Center, and found that the majority of the studied sample were in primary school.

Concerning the occupation of caregivers, the present study revealed that more than three quarters of the studied caregivers were housewives. This finding is in agreement with that of **Damad & Muttaleb (2022)**, who reported that the majority of them were not working. From researcher point of view this may be due to that most of the Egyptian mothers preferred to stay at home to provide care for their husbands and children especially if they had chronic ill child.

Considering the place of residence, the present study clarified that the majority of the studied caregivers were from rural residence. This finding is supported by that of **Ahmed et al, (2022)** who carried out a study entitled “Evaluation of The Quality of Life in Children with Haemophilia and Their Caregivers.” and illustrated that the majority of the studied sample were from rural residence. On the same line with **Sebaq & Deraz, (2021)** in a study entitled " Improve Caregivers' Competency level regarding care of children suffering from hemophilia: an educational program" who showed that the most of them were from rural residence.

As regard to characteristic of the studied children, the findings of the present study showed that more than half of the studied children aged 5 <10 years with a mean age 8.34±4.74 years. This finding is contrasting with that of **D’souza et al (2018)**, who demonstrated that less than half of them were between 6-12 years.

Regarding to gender of the studied children, the findings of the present study showed that the all of them were males. This finding is supported with that of **Hassab et al (2022)** , who found in a study entitled “Quality of life and clinical assessment of joint health in children with hemophilic arthropathy, Alexandria University, Alexandria, Egypt.” and reported that the all of them were males.

Concerning the children’s diagnosis, the findings of the present study demonstrated that the majority of the studied children were diagnosed as hemophilia A. This finding is in agreement with finding of **D’souza et al (2018)**, who revealed that the most of them were diagnosed as hemophilia A.

In relation to family history of the disease, the result of the current study revealed that, more than half of the studied children had relative family history of hemophilia. This result was in accordance with that of **EL-Ghadban & Mustafa (2020)**, who found that less than three quarter of them were had family history. In the same context, **Paul et al (2018)**, who stated in the study conducted about A practical guide to the management of the fetus and newborn with hemophilia, denoted that hemophilia is inherited disorder, often occur with a family history or in children born to mothers who are known carriers.

As regards the diagnosed disease, the findings of the present study clarified that more than two third of the studied children were diagnosed of hemophilia when aged less than 2 years. This finding was in agreement with finding of **Ahmed et al (2022)**, who found that the majority of them were detected at the first year of age.

Vol. 2, Issue 2, Month: December 2023, Available at: <https://hijnrp.journals.ekb.eg/>

Regarding to caregivers' total level of knowledge regarding hemophilia. The present study revealed that more than half of the studied caregivers had unsatisfactory knowledge regarding hemophilia. These were consistent with that of **Sebaq & Deraz (2021)**, who showed that more than half of the studied sample had poor knowledge about hemophilia.

Regarding to caregivers' total level of reported practices towards the care of their children with hemophilia. The present study revealed that less than two thirds of the studied caregivers had inadequate reported practices towards care for their children with hemophilia. This finding is consistent with that of **Header et al (2016)**, who showed that less than two thirds of the studied sample had inadequate reported practices towards the care of their children with hemophilia.

The findings of the current study illustrated that, there were statistical significant relation between caregivers' characteristics namely; age, occupation and educational level and their total level of knowledge respectively. The result of the present study was in agreement with that of **Damad & Muttaleb (2022)**, who revealed that there were statistical significant relation between between caregivers' characteristics namely; age, occupation and educational level and their total level of knowledge.

The findings of the current study illustrated that, there were statistical significant relation between caregivers' characteristics namely; age, residence and educational level and their total level of reported practices respectively. This result was consistent with that of **Mohammed (2022)**, who studied Assessment of Knowledge, Attitude and Practice Among Parents of Children with Hemophilia at the National Hemophilia Center-Khartoum and revealed that there were statistical significant relation between between caregivers' characteristics namely; age, residence and educational level and their total level of reported practices.

As regard correlation between caregivers' total level of knowledge and their total level of reported practices, the current study demonstrated that there were highly statistical significant positive correlation between their total level of knowledge, reported practice regarding care of their children with hemophilia. This result was supported with that of **Hussein et al. (2013)** who carried out a study entitled "Impact of Education Program upon Mother's Knowledge and Practices of Haemophilic Children Type A." Khartoum and revealed that there were statistical significant positive correlation between their total level of knowledge, reported practice regarding care of their children with hemophilia.

### Conclusion:

Based upon the results of the present study concluded that the studied caregivers had deficit total level of knowledge and poor of total level of reported practices, and also there were a statistical significant positive correlation between the studied caregivers' knowledge and their total reported practices regarding care of children with hemophilia.

### Recommendations:

A periodical educational program for caregivers to improve knowledge and practices regarding care of their children suffering from hemophilia.

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Vol. 2, Issue 2, Month: December 2023, Available at: <https://hijnrp.journals.ekb.eg/>

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