



## The Effect of Family Centered Care Model on Caregivers of Children with Hemophilia

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Article History	Abstract
<p>Received: 06 June 2023 Revised: 05 Sept. 2023 Accepted: 13 Sept. 2023</p>	<p><i>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. <b>Aim:</b> the current study aimed to evaluate the effect of family centered care model on caregivers of children with hemophilia. <b>Design:</b> A quasi-experimental research design (one group pre-posttest) was used. <b>Setting:</b> the study was conducted at inpatient department and outpatient clinic in Badr University Hospitals affiliated to Helwan University Hospitals and Mustafa Hassan pediatric Hospital affiliated to Fayoum University Hospitals. <b>Sample:</b> the study involved 60 children and their accompanying caregivers suffering from hemophilia disease. <b>Tool:</b> consists of four tools to assess: <b>I:</b> A structured interviewing questionnaire sheet to assess caregivers' knowledge regarding hemophilia disease (one group pre/posttest). <b>II:</b> Observational checklist to assess caregivers' reported practice regarding care of their children with hemophilia. <b>III:</b> caregiver's coping patterns, <b>IV:</b> The Family-Centered Care (FCC) scale for caregivers. <b>Results:</b> the current results referred that there was statistically significant difference between family centered care scale and their total knowledge and their total practices regarding hemophilia pre and post intervention. Also, there were statistically significant a positive correlation between their total knowledge, their total practices, their total coping and family centered care scale. <b>Conclusion:</b> the present study concluded that there was a positive effect of implementation of model on improving knowledge, practices and coping pattern of the studied caregivers. <b>Recommendations:</b> encourage family centered care programs periodically for caregivers having children with hemophilia to help them improve care for their children and reduce complications of the disease.</i></p>
<p><b>CC License</b> CC-BY-NC-SA 4.0</p>	<p><b>Keywords:</b> Caregivers, Family-Centered Care Model, Hemophilia.</p>

### 1. Introduction

Hemophilia is a bleeding disorder due to coagulation pathway factor deficiency that is associated with significant morbidity and mortality (Alblaihed et al., 2022). Hemophilia is the most common hematopoietic, inherited bleeding disorder characterized by decreased function or absence of factor VIII (classic hemophilia or hemophilia A) or factor IX (Christmas disease or hemophilia B). Hemophilia is a male disorder, yet females with hemophilia are rarely seen in communities but they are carriers (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)

Worldwide, the number of hemophiliac children is approximately 400,000 cases and the incidence is estimated to as 1 in every 7,500 live male births and 1 in every 25,000,000 live female births (Sebaq & Deraz, 2021). In United States, the prevalence is 20,000 people per year (about 400 babies born with hemophilia annually (Ali, 2020). Hemophilia is affecting all ethnic and racial groups (Abdul-Qader, 2021).

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 (El Hawary et al., 2019). Bleeding occurs spontaneously in severe hemophilia, and mildly affected children 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).

Hemophilia affects all ethnic and racial groups. About one-third of children who diagnosed with hemophilia have no family history of the disease and hemophilia occurs as a result of a new mutation of the gene (Lewandowski et al., 2018). In most cases of hemophilia is inherited and manifests clinically in males but female carrier the gene that causes hemophilia (Rojas et al., 2022). When a female who a carrier the gene, she has a 50% chance that her sons will have hemophilia and a 50% chance that her daughters will be carriers. Although sons of male with hemophilia will not inherit the disease, all daughters born to fathers with hemophilia will be carriers (Laino et al., 2019).

Children with hemophilia need others, especially the family, due to the illness and special care needs. Family as a fundamental support system is essential and its role could not be ignored. A family member's disease can affect all family members which cause bad psychological effects on families and impaired quality of life (Von Mackensen et al., 2019). So that families play an important role meeting the care needs of children who require assistance due to illness or disability (Deyhoul, et al., 2020).

Family-centered care (FCC) is a care model based on collaboration and communication between healthcare professionals, family members, and the children. Communication between the family and the healthcare staff at the FCC should be continuous, comprehensive, open and encouraging (Franck et al., 2022). The philosophy of FCC requires nurses to meet not only clinical, but also emotional, affective and social needs to develop a relationship with the families based on respect and dignity (Fonseca et al., 2020).

Family centered care can improve child and family outcomes, develop a sense of confidence before discharge for family and child, decrease the frequency of visits to the emergency room, increase child and family satisfaction (Rasoolpur et al., 2022), increase the awareness of the families about the necessary care, decrease the emotional distress of children and family, increase the children's coping capacity during the procedures and positively affects children's adaptation to life after discharge and while in hospital (Avçin et al., 2021).

### **Aim of the Study**

This study aimed to evaluate the effect of family centered care model on caregivers of children with hemophilia. This aim achieved through:

1. Assessing caregivers' knowledge and practices regarding care for their children with hemophilia.
2. Developing and implementing family centered care model for caregivers regarding care of their children with hemophilia.
3. Evaluate the effect of the family centered care model on caregivers' knowledge and practices regarding care for their children with hemophilia.

### **Research hypothesis**

The family centered care model had a positive effect on caregivers' knowledge and practices about care of children with hemophilia.

## 2. Materials And Methods

### The technical design

#### Research design

A quasi-experimental research design (one group pre-posttest was used in the current study) to achieve the aim of the study.

#### Setting

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

#### Subject

A convenient 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 genders.
- 2-Children confirmed diagnosis with hemophilia.
- 3-Children free from any other physical or mental disease.

#### D) Tools for data Collection:

**Tool I: structural interviewing questionnaire sheet (one group pre/posttest): It consisted of three parts:**

**Part 1:** It concerned with characteristics of the caregivers included age, gender, level of education, occupation, residence and marital status. 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 first diagnosed and sites of first bleeding .

**Part 3:** Caregivers' knowledge about hemophilia that consisted of the following (pre & posttest): It concerned with caregivers' knowledge regarding hemophilia disease which consisted of 8 multiple choice questions about definition, causes, types, sign and symptoms, most sites to bleeding, complication, diagnostic test and treatment about hemophilia. It concerned with caregivers' knowledge 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.

It concerned with caregivers' knowledge 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.

It concerned with caregivers' knowledge regarding protecting the child from infection, skin infections or constipation which consisted of 3 multiple choice questions that included prevention methods to avoid infection, prevention methods to avoid skin infections and prevention methods to avoid constipation for child with hemophilia.

#### Scoring system

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

#### Tool II: Observational checklist

The observational checklist was adapted from Bowden and Greenberger (2013), to assess caregivers' reported practice 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; nose

bleeding (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 then converted into percentage. Total score was 50. The total caregiver’ reported practice was categorized into inadequately → less than 60% and adequately → 60% and more.

### **Tool III: Caregiver's coping patterns**

It was adapted from **McCubbin et al. (2003)**, to measure caregivers' response to management of family life when they have child with hemophilia. It was modified and translated into Arabic form by researcher to suit the nature of study. This scale was consisted of 25 items divided into: Maintaining family integration, cooperation and an optimistic definition of the situation (9 items), Maintaining social support, self-esteem and psychological stability (9 items) and understanding the medical situation through communication with other parents and consultation with medical staff (7 items).

### **Scoring system**

Caregivers were asked to rate their coping on 4 points rating scale ranging from "0 – 3" where, then converted into percentage.

0 = Not helpful.

1= Minimally helpful.

2= Moderately helpful.

3 = extremely helpful.

Total Coping Health Inventory for caregivers were divided into 3 levels: Poor coping (0-<40), Average coping (40-< 80) and good coping ( $\geq 80$ )

### **Tool IV: The Family-Centered Care (FCC) scale for caregivers**

It was tool adapted from **Arslan, Geckil (2019) and Gill, et al., (2014)**. It was used to assess caregivers' perception (knowledges) regarding core concept of family centered care. This scale was modified and translated into Arabic form by researcher. The FCCS consists of 17 items. This scale was composed of three sub-dimensions which are: Support (6 items), Collaboration (7 items) and Respect (4 items).

### **Scoring system**

The caregivers' responses of the FCCS items were scored using a five-point Likert type rating scale ranging from (1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = always). Total score varies between 17 and 85 then converted into precentage. Higher score indicates relatively more positive effects in each respective area (good knowledge for core concept of FCC).

### **Family centered care model**

The researcher designed and implemented a family centered care model after reviewing the related literature based on actual need assessment of the studied sample (caregivers). It covered the theoretical knowledge and practical procedures. Each caregiver was assessed twice pre/post implementation of family centered care model using the same previously mentioned tools. Family centered care model was prepared by the researcher in form of handout to suit reference for caregivers, which includes colorful pictures and simple statement in Arabic form.

### **Validity**

The content validity of the tools reviewed by 3 experts in the fields 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 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 check list and 0.793 for coping pattern and 0.856 for family centered care scale.

### **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, internet, 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 children and their accompanying 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. Data collected two days per week (one day in Mustafa Hassan and one day in Badr University hospital) during the morning shift from 9 a.m. to 12 p.m. The researcher directed FCC model for caregivers and their children.

#### **The actual field work was divided into four phases**

##### **Assessment phase**

In this phase, the researcher was used constructed tools in collecting the data about caregivers' knowledges and practices as well as coping patterns for caregivers regarding to care of their children suffering from hemophilia (pretest). The purpose of the study and its expectations were explained by the researcher to the studied caregivers before starting interviewing and data collection. The time spent to fill the questionnaire ranged between 10 to 15 minutes. The time needed to filling in the checklist depended on caregivers' own practices ranged between 5-10 minutes and the average time needed to fill in the two scales were 10- 15 minutes.

##### **Planning phase**

According to the actual need assessment of the caregivers and their children, the content of the family centered care model was designed by the researcher. In addition, the relevant literature regarding to caregivers' needs and care for their children with hemophilia. The aim of model was to enhance caregivers' knowledge and practices regarding care of their children suffering from hemophilia as well as improve coping patterns for caregivers. The content of model included knowledges about definition, causes, signs and symptoms, sites of bleeding, diagnostic tests, complications and treatments, nutrition's and sports recommended for children with hemophilia. As well as model included practices related to hand washing, care of nose bleeding, care of joint bleeding, mouth care, exercises of child's range of motion and coughing breathing exercises. An illustrated booklet was designed by the researcher in an Arabic language to meet caregivers' needs, knowledges and care for their children with hemophilia. Selecting suitable teaching methods and appropriate media for teaching this content.

##### **Implementation phase**

The implementation of family centered care model aimed to improve knowledge and practice of caregivers having children with hemophilia as well as coping pattern of caregivers.

At the beginning of the first session; an orientation and explanation of the program were done; the aim and objective of the study were explained for caregivers to gain their cooperation. Four sessions were done to provide caregivers with knowledge related to the disease. Furthermore, four sessions were held by the researcher to cover the practical skills. Simple words and Arabic language were used to suit the caregivers' level of understanding.

##### **Evaluation phase**

The researcher evaluated the caregivers' knowledge at the beginning of each session through asking questions verbally about the content from the previous session. The caregivers' practice was evaluated

using the same observational sheet immediately after sessions. Also, role of the caregivers and their coping pattern were evaluated through posttests using the same coping pattern and family centered care scales.

### 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.

### 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 department in pediatric hospital affiliated to El fayoum University Hospital and Helwan University Hospital to conduct the study.

### Statistical design

Upon completion of data collection, data was organized, categorized, tabulated, entered, computed and analyzed using Statistical Package for the Social Science (SPSS), version 20.0 for analysis. Descriptive statistics tests as numbers, percentage, mean  $\pm$  standard deviation ( $\pm$  SD), was used to describe the results. Appropriate inferential statistics such as “F” test or “t” test was used as well. The P-value to detect the relations between the variables of the study.

## 3. Results and Discussion

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

Caregiver's Characteristics	N	%
<b>Caregivers</b>		
Mother	<b>52</b>	<b>86.7</b>
Father	8	13.3
<b>Age (years)</b>		
25 < 35	<b>43</b>	<b>71.7</b>
35 <45	13	21.7
45 and more	4	6.6
<b>Mean<math>\pm</math>SD</b>	<b>34.26<math>\pm</math>4.78</b>	
<b>Education level</b>		
Illiterate	8	13.3
Primary	12	20
Preparatory	<b>27</b>	<b>45</b>
Secondary	10	16.7
University	3	5
<b>Occupation</b>		
Working	13	21.7
House working	<b>47</b>	<b>78.3</b>
<b>Residence</b>		
Rural	<b>53</b>	<b>88.3</b>
Urban	7	11.7
<b>Material status</b>		
Married	<b>56</b>	<b>93.3</b>
Divorced	4	6.7

**Table (1)** showed that more than two thirds (71.7 %) of 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 studied caregivers were

in preparatory school and were house wives respectively, while the majority (88.3% & 93.3%) of them were from rural area and married respectively.

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

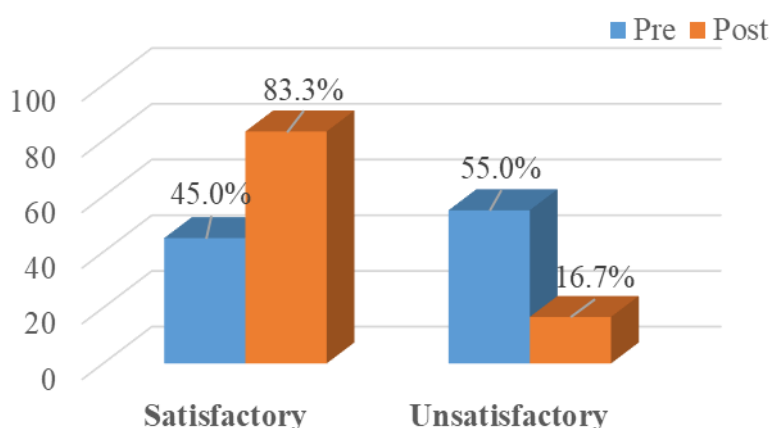
Children's Characteristics	N	%
<b>Age in years</b>		
1 < 5	15	25
5 < 10	31	51.7
10 < 15	9	15
≥ 15	5	8.3
<b>Mean±SD</b>	<b>8.34±4.74</b>	
<b>Educational level</b>		
Pre nursery school	7	11.7
nursery school	8	13.3
primary school	31	51.7
Preparatory school	10	16.7
secondary school	4	6.6
<b>Children's diagnosis</b>		
Hemophilia A	57	95
Hemophilia B	3	5

**Table (2)** clarified that more than half (51.7%) of studied children aged 5 <10 years with a mean age 8.34±4.74 years, meanwhile the all (100%) of them were male. The same table illustrated that more than half (51.7%) of studied children were in primary school, while 95% of them were diagnosed as hemophilia A.

**Table (3):** Distribution of the studied caregivers' according to their total level of knowledge about hemophilia (pre and post implementation model) n=60

Total knowledge	Pre		Post		Chi-square	
	N	%	N	%	X <sup>2</sup>	P-value
<b>Satisfactory</b>	27	45	50	83.3		
<b>Unsatisfactory</b>	33	55	10	16.7	19.172	<0.001*
<b>Mean±SD</b>	15.78±2.64		31.54±4.7			

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

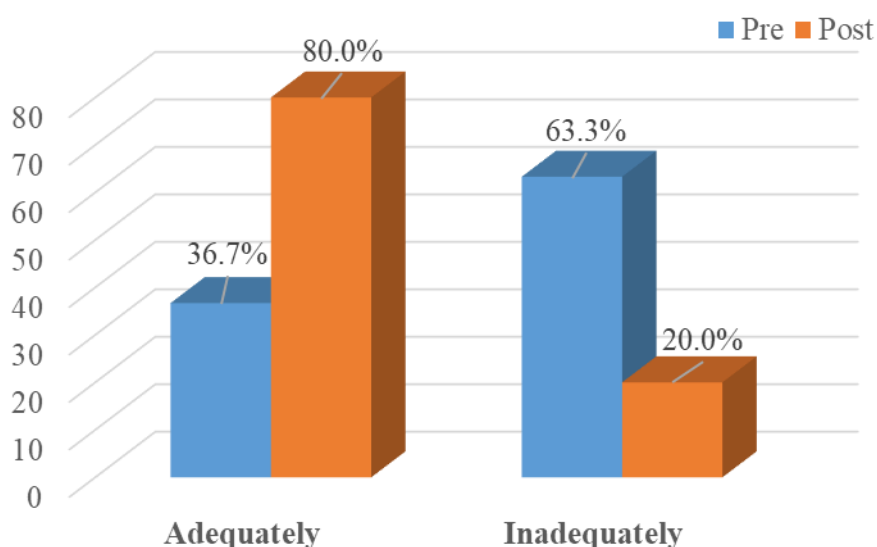


**Table (3), fig (1)** revealed that 45% of studied caregivers had satisfactory total level of knowledge regarding hemophilia pre implementation model, compared to the majority 83.3% of them had satisfactory total level of knowledge regarding hemophilia post implementation model with statistically significant difference pre/post implementation model regarding to total caregivers' knowledge about hemophilia.

**Table (4):** Distribution of the studied caregivers' according to their total level of reported practice related to care of their children with hemophilia (pre and post implementation model) n=60

Total practice	Pre		Post		Chi-square	
	N	%	N	%	X <sup>2</sup>	P-value
Adequately	22	36.7	48	80	23.177	<0.001*
Inadequately	38	63.3	12	20		
Mean±SD	18.35±2.07		41.5±3.8			

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



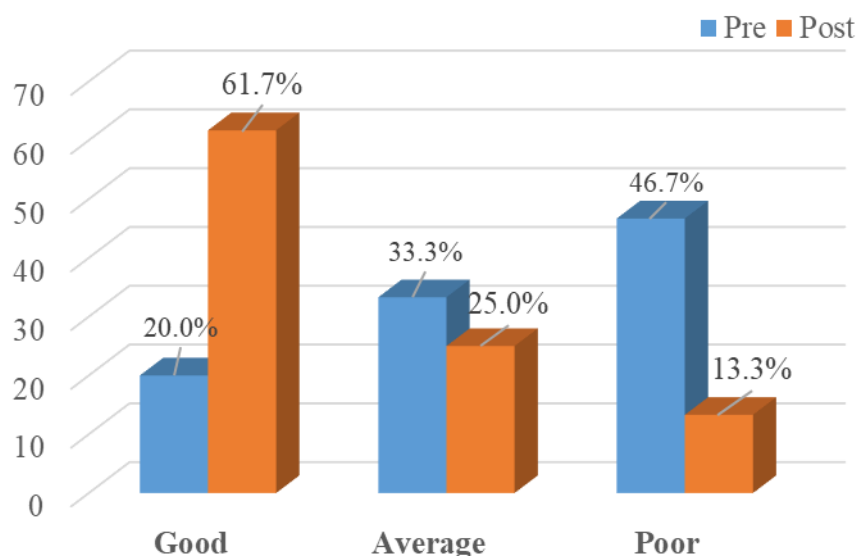
**Table (4), fig (2)** illustrated that 36.7% of studied caregivers had adequate total level of practice regarding care of their children with hemophilia pre implementation model, compared to the majority 80% of them had adequate total level of practice regarding care of their children with hemophilia post implementation model with statistically significant difference pre/post implementation model.

**Table (5):** Distribution of the studied caregivers regarding total level of coping pattern (pre and post implementation model) n=60

Total Coping scale	Pre		Post		Chi-square	
	N	%	N	%	X <sup>2</sup>	P-value
Good	12	20	37	61.7	24.580	<0.001*
Average	20	33.3	15	25		
Poor	28	46.7	8	13.3		
Mean±SD	32.41±3.25		76.4±5.7			



**Figure (3):** Percentage distribution of studied caregivers regarding to total level of coping pattern

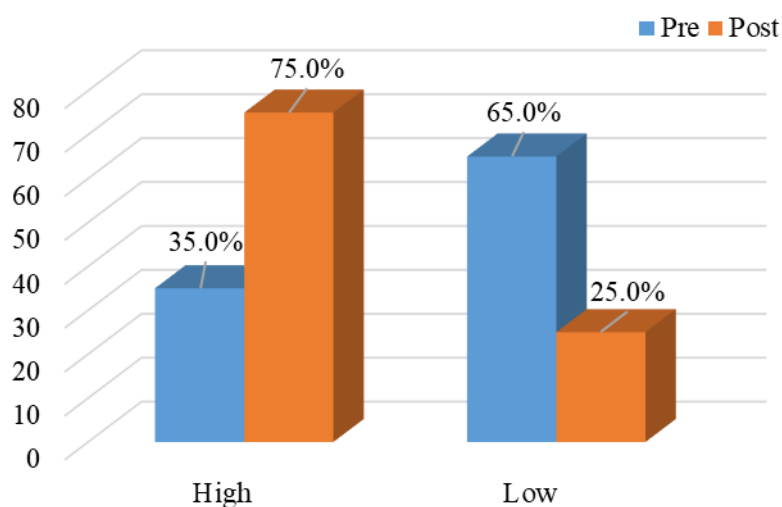


**Table (5), fig (3)** illustrated that 20 % & 46.7% of studied caregivers had good and poor coping respectively pre implementation, while 61.7% of them had good coping and 13.3% had poor coping post implementation model with significant difference pre/post implementation model, where  $p=0.001$ .

**Table (6):** Distribution of the studied caregivers regarding total level of family centered care (pre and post implementation model)  $n=60$

The Family Centered Care Scale	Pre		Post		Chi-square	
	N	%	N	%	X <sup>2</sup>	P-value
High	21	35	45	75	19.394	<0.001*
Low	39	65	15	25		
Mean±SD	38.85±4.53		82.41±5.97			

**Figure (4):** Percentage distribution of studied caregivers regarding to total level of family centered care scale.



**Table (6), fig (4)** illustrated that 35% of studied caregivers had high perception about core concept of FFCS pre implementation model, while 75% of them had high perception about core concept of FFCS post implementation model with statistically significant difference pre/post implementation model, where  $p=0.001$ .

**Table (7):** Correlation matrix between total level of knowledge, reported practice, coping pattern and family centered care scale (pre and post implementation model) n=60

Items	Total knowledge		Total reported practices		Total coping	
	Pre-implementation	Post-implementation	Pre-implementation	Post-implementation	Pre-implementation	Post-implementation
<b>Total reported practices</b>	r=0.731 p=<0.001*	r=0.875 p=<0.001*				
<b>Total coping</b>	r=0.832 p=<0.001*	r=0.917 p=<0.001*	r=0.644 p=<0.001*	r=0.797 p=<0.001*		
<b>Total Family-Centered Care Scale</b>	r= 0.822 p=0.001*	r=0.894 p=<0.001*	r=0.694 p=<0.001*	r= 0.808 p=<0.001*	r=0.713 p=<0.001*	r=0.796 p=<0.001*

**Table (7)** demonstrated that there was statistically significant positive correlation between their total knowledge, their total reported practices, their total coping and family centered care scale  $p<0.001$  respectively pre and post implementation model. Also, there was statistically significance positive correlation between total practices, their total coping and family centered care with  $p<0.001$  respectively pre and post implementation model. Another statistically significance positive correlation between their total coping and family centered care  $p<0.001$  pre and post implementation model.

Regarding to characteristics of caregivers, the findings of the present study showed that more than two thirds of studied caregivers were aged  $25 < 35$  years with a mean age  $34.26\pm 4.78$  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 studied sample were between 25 -37 years old. In the same context, this finding is supported by that of **EL-Ghadban & Mustafa (2020)**, who found in a study about Effect of Self Learning Module on Caregivers of Children Suffering from Common Blood Disorders, and found that less than half of studied sample were between 25- 35 years.

As regarding to educational level of caregivers, the results of the current study revealed that more than two fifths of studied caregivers were in preparatory school. This finding is supported by 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 studied sample were in primary school.

Concerning the occupation of caregivers, the present study revealed that more than three quarters of studied caregivers were not working. This finding is contrasting with that of **Damad & Muttaleb (2022)**, who reported that the majority of them were house wives. 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 studied caregivers were from rural area. 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 studied sample were from rural areas. 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 area.

As regard to characteristic of the studied children, the findings of the present study showed that more than half of studied children aged  $5 < 10$  years with a mean age  $8.34\pm 4.74$  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 male. This finding is contrasting 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 male.

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

In relation to the studied caregivers's knowledge about hemophilia, the results of the present study revealed that, there was statistically significant difference between pre/post implementation model regarding to total caregivers' knowledge about hemophilia, it was found that less than half of the studied mothers had satisfactory total knowledge pre implementation model, compared to majority post implementation model. From the research point of view this difference may be attributed to the knowledge that acquired through the program, which interested for caregivers and motivate them to be active participant with their children health condition. This finding in agreement with **Phadnis&Kar (2017)**, in a study entitled "The Impact of Haemophilia Education Intervention on the Knowledge and Health related Quality of Life of Parents of Indian Children with Haemophilia" and reported that there was improvement in knowledge scores immediately after intervention. In addition, this result was in congruent with **Sebaq & Deraz (2021)**, who suggested that, there is an improvement in the overall caregivers' knowledge regarding hemophilia, after receiving the program than before.

In relation to total reported practice of the studied caregivers regarding to care of their children with hemophilia. The result of current study clarified that the highest adequate level about caregivers practice was found after implementation model compared by before implementation model with statistically significant difference. From the researcher point of view this improvement in caregiver's practice could be due to the caregivers' severe need to health education and their anxiety about their children which lead to need learning to improve their health of children and give caregivers a chance to meet with others to exchange ideas and experience. This result is in congruent with **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" and found that the mean scores of mothers' practices were higher in the study group at the post-test, after 2 and 4 months of program implementation. Also, this result goes in the same line with **Sebaq & Deraz (2021)**, who found that the majority of the studied caregivers had competent reported practices after program than of the preprogram.

In relation to total coping pattern of the studied caregivers, the results of the present study clarified that, there was statistical significant difference between pre/post implementation model regarding to coping pattern of caregivers, it was found that less than half of them had good coping pre implementation model, compared to majority of them had good coping post implementation model. From the research point of view this difference may be attributed to coping pattern that improved through implementation model that increase information about disease which reduce stress, increase satisfaction and improve outcomes. This result was in congruent with **Yuan et al (2021)**, in a study entitled "Coping patterns among primary informal dementia caregivers in Singapore and its impact on caregivers—Implications of a latent class analysis." who reported that, there was statistical significant difference between pre/post interventions regarding to coping pattern of caregivers.

Regarding too total of family centered care of studied caregivers, this finding of the present study, revealed that there was statistically significant difference regarding to caregiver's service levels post implementation model. From the researcher point of view, this indicates success of intervention in improving caregivers' awareness of their children disease and how to cope with the disease and its problems appropriately. This result was in congruent with **Albayrak & Büyükgönenç (2022)**, in a study entitled "The impact of family-centered care interventions on neonatal and parental outcomes in a Turkish hospital." who demonstrated that there was statistical significant difference between pre/post interventions which implement evidence-based FCC interventions that lead to achieve

positive outcomes related to preterm infants, parents, and the institution, positive effect on the quality of life of children, coping pattern for caregivers, and increase satisfaction and self-esteem of caregivers.

The findings of the current study illustrated that, there was statistical significance difference between family centered care and their total knowledge regarding hemophilia pre and post implementation model. This result in agreement with **Sadeghi et al (2019)**, who conducted a study entitled "The impact of family-centered care and meeting the need to learn how much of global anxiety in parents of children with urinary tract infection: arandomized clinical trial", who found that, the FCC was effective at range of meet information needs of hospitalized children parent's and increase their satisfaction. This result in agreement with **Hussein et al (2022)**, who conducted a study entitled " Effect of Family-Centered Care on Mothers' Information Needs, Anxiety and Depression Level Regarding Care for their Children Undergoing Heart Surgery." who revealed that statistically significant difference was found as regards mothers' needs for information, trust and support & guidance before and after FCC intervention.

The findings of the current study illustrated that, there was statistical significance difference between family centered care and their total practice regarding hemophilia pre and post implementation model. This result in agreement with **Boshagh et al (2022)**, who conducted a study entitled " Effect of Family-Centered Empowerment Model on Knowledge and Caring Performance of Mothers of Children with Leukemia: A Randomized Clinical Trial." who clarified that there was statistical significance difference between family centered care and their total practice pre and post intervention which family-centered empowerment provides an opportunity for families to acquire the knowledge and skills needed to better manage their children's problems.

#### 4. Conclusion

Based upon the results of the current study, it can be concluded that there was a positive effect of implementation family centered care model on caregivers of children with hemophilia.

In the light of the finding of this study, the following recommendations are suggested; Continuous health education to caregivers regarding hemophilia diseases, complications and management plan. Encourage family centered care programs periodically for caregivers having children with hemophilia to help them improve care of their children and reduce complications of the disease. The importance of regular follow up for periodic assessment of children with hemophilia for early detection of complications and management for them.

#### References:

- Abdul-Qader, W. (2021): Inhibitors of Hemophilia A in Children Less Than 15 Years Attending Children Welfare Hospital in Baghdad. *Kirkuk Journal of Medical Sciences*; 4(1): 7-12.
- Ahmed, Y., EL-Moazen, A. & Abu-Rehab, R. (2022): Evaluation of The Quality of Life in Children with Haemophilia and Their Caregivers. *The Egyptian Journal of Hospital Medicine*; 89(2): 7643-7649.
- Albayrak, S. & Büyükgönenç, L. (2022): The impact of family-centered care interventions on neonatal and parental outcomes in a Turkish hospital. *Collegian*; 29(5): 738-747.
- Alblaihed, L., Dubbs, S., Koyfman, A. & Long, B. (2022): High risk and low prevalence diseases: Hemophilia emergencies. *The American Journal of Emergency Medicine*; 56(1): 21-27.
- Ali, Sh. (2020): Needs of patients with hemophilia: Suggested clinical pathway at Cairo University, Egypt. *Clinical Practice*; 17(6): 1552-1562.
- Avçin, E., Can, Ş. & Yeşil, F. (2021): Parents' Family-Centered Care Perception and Investigating Factors Affecting Such Perception. *The Anatolian Journal of Family Medicine*; 4(2):128-133.
- Boshagh, F., Hakim, A., Alghasi, A. & Haghhighzadeh, M. (2022): Effect of Family-Centered Empowerment Model on Knowledge and Caring Performance of Mothers of Children with Leukemia: A Randomized Clinical Trial. *Jundishapur Journal of Chronic Disease Care*; 11(3):1-6.
- D'Souza, A., Nayak, D., Kurien, A., Shah, H., George, A., Nayak, B. & Pai, M. (2018): Knowledge among Mothers' of Children and Youth with Hemophilia–A Cross Sectional Survey at a Hemophilia Center. *Indian Journal of Public Health Research & Development*; 9(3): 27-32.
- Damad, H. & Muttaleb, W. (2022): Assessment Knowledge of Parents Regarding Health Preventive Measures and Self-Care of Hemophilia Children, Baghdad, Iraq. *Pakistan Journal of Medical & Health Sciences*; 16(6): 425-427.

- Damad, H., & Muttaleb, W. (2022): Effectiveness of Hemophilia Educational Program on Parents' Knowledge of Children with Hemophilia. *Mosul Journal of Nursing*; 10(2): 260-265.
- Deyhoul, N., Vasli, P., Rohani, C., Shakeri, N. & Hosseini, M. (2020): The effect of family-centered empowerment program on the family caregiver burden and the activities of daily living of Iranian patients with stroke: a randomized controlled trial study Iran. *Aging clinical and experimental research*; 32(7): 1343-1352.
- El Hawary, M., EL Dash, H., Foad, N. & Mohamed, M. (2019): Effect of joint range of motion on health-related quality of life in children with hemophilia. *Egyptian Rheumatology & Rehabilitation*; 46 (4):237-243.
- EL-Ghadban, F. & Mustafa, M. (2020): Effect of Self Learning Module on Caregivers of Children Suffering from Common Blood Disorders *International Journal of Novel Research in Healthcare and Nursing*;7(1): 545-559.
- Elsakka, E., Azouz, H., Hassab, H., Abdelfattah, M. & Abdel Ghany, H. (2022): Screening of behavioral disorders in children with hemophilia. *International Journal of Rheumatic Diseases*:1-8.doi: 10.1111/1756-185X.14352.
- Fischer, K., Nijdam, A., Holmström, M., Petrini, P., Ljung, R., van der Schouw, Y. & Berntorp, E. (2016): Evaluating outcome of prophylaxis in haemophilia: objective and self-reported instruments should be combined. *Haemophilia*; 22(2): 80-86.
- Fonseca, S., Silveira, A., Franzoi, M. & Motta, E. (2020): Family centered-care at the neonatal intensive care unit (NICU): nurses' experiences. *Enfermería: Cuidados Humanizados*; 9(2):170-190.
- Franck, L., Bisgaard, R., Cormier, D., Hutchison, J., Moore, D., Gay, C. & Parker, L. (2022): Improving family-centered care for infants in neonatal intensive care units: Recommendations from frontline healthcare professionals. *Advances in Neonatal Care*; 22(1):79-86.
- Hassab, H., Saad, H. & Abdel Ghany, H. (2022): Quality of life and clinical assessment of joint health in children with hemophilic arthropathy, Alexandria University, Alexandria, Egypt. *Egyptian Rheumatology and Rehabilitation*; 49:22:1-10.
- Hussein, K., Al-Azzawi, S. & Al-Khateeb, E. (2013): Impact of Education Program upon Mother's Knowledge and Practices of Haemophilic Children Type A. *Medical Journal of Babylon*; 10(1): 100-109.
- Hussein, A., Ouda, W. & Adly, R. (2022): Effect of Family-Centered Care on Mothers' Information Needs, Anxiety and Depression Level Regarding Care for their Children Undergoing Heart Surgery *Egyptian Journal of Health Care*; 13 (2): 158-172.
- Laino, L., Cicciù, M., Fiorillo, L., Crimi, S., Bianchi, A., Amoroso, G. & Cervino, G. (2019): Surgical risk on patients with coagulopathies: guidelines on hemophiliac patients for oro-maxillofacial surgery. *International journal of environmental research and public health*;16(8): 1386.
- Lewandowski, B., Wojnar, J., Brodowski, R., Mucha, M., Czenczek-Lewandowska, E. & Brzęcka, D. (2018): Dental extractions in patients with mild hemophilia A and hemophilia B and von Willebrand disease without clotting factor supplementation. *Pol Arch Intern Med*; 128(7-8): 488-490.
- Phadnis, S. & Kar, A. (2017): The impact of a haemophilia education intervention on the knowledge and health related quality of life of parents of Indian children with haemophilia. *Haemophilia*; 23(1): 82-88.
- Rasoolpur, P., Rahkar Farshi, M. & Jabraeili, M. (2022): Perceptions of Preterm Infant Mothers from Receiving Family-Centered Care in Neonatal Intensive Care Unit: A Cross-Sectional Study. *Journal of Health and Care*; 24(1): 76-85.
- Rojas, M., Garza, H., Santoy, A., Lozano, R., Quintana, G., Najera, R. & Soto, S. (2022): Hemophilia and its considerations in the dental practice. *International Journal of Applied Dental Sciences*; 8(1): 65-69.
- Sadeghi, H., Mehrabi, F., Darabiyan, P., Shabani, Y. & Bahrami, M. (2019): The impact of family-centered care and meeting the need to learn how much of global anxiety in parents of children with urinary tract infection: a randomized clinical trial. *International Journal of Ayurvedic Medicine*; 10(1): 68-74.
- Sebaq, A. & Deraz, F. (2021): Improve Caregivers' Competency level regarding care of children suffering from hemophilia: an educational program. *Egyptian Journal of Health Care*; 12(1): 193-212.
- Von Mackensen, S., Myrin Westesson, L., Kavakli, K., Klukowska, A., Escuriola, C., Uitslager, N. & Khair, K. (2019): The impact of psychosocial determinants on caregivers' burden of children with haemophilia (results of the BBC study) Sweden. *Haemophilia*; 25(3): 424-432.
- World Federation of Hemophilia (WFH) (2018): *World Federation of Hemophilia report on the annual global survey*. WFH; 2018. [Google Scholar](https://scholar.google.com/)
- Yuan, Q., Wang, P., Tan, T., Devi, F., Poremski, D., Magadi, H. & Subramaniam, M. (2021): Coping patterns among primary informal dementia caregivers in Singapore and its impact on caregivers—Implications of a latent class analysis in Singapore. *The Gerontologist*; 61(5): 680-692.