

Improve Caregivers' Competency Level Regarding Care of Children Suffering from Hemophilia: An Educational Program

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Abstract

Background: Caregivers are an instrumental partner taking active participation in affecting the nature and direction of care process of hemophilic children. Parental competence and success in facing difficult circumstances may increase parental self-efficacy and serve as a protective factor against negative outcomes for children. **Aim:** The aim of this study was to evaluate the effect of an educational program on improving caregiver's competence level regarding care of children suffering from hemophilia. **Design:** A quasi-experimental design was utilized in the current study. **Settings:** The study was conducted at inpatient pediatric hematology units in Benha and Nile Health Insurance Hospitals. **Sample:** A purposive sample of 50 caregivers (mainly mothers) accompanying their children were selected from the above mentioned settings. **Tools of data collection:** Three tools were used: A structured interviewing questionnaire sheet, mothers' reported practices and parenting sense of competence scale. **Results:** There was a significant increase in mothers' competency level after one and three months of program implementation compared to pre-program. **Conclusion:** The educational program was an effective method in improving mothers' knowledge, their reported practices, and their competency level regarding care of children suffering from hemophilia. **Recommendation:** Establish a regularly training program for mothers who have children suffering from hemophilia and were newly diagnosed in order to improve their competency regarding care of their children.

Keywords: Caregivers, children, competency level, educational program, haemophilia.

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Introduction:

Hemophilia is a coagulation disorder arising from a genetic defect of the X chromosome; the defect can either be inherited or result from spontaneous gene mutation. Hemophilia A (factor VIII deficiency) is more common than hemophilia B (factor IX deficiency),

representing 80–85% of the total hemophilia population. The ratio between hemophilia A and hemophilia B is about 4:1 (Srivastava et al., 2013).

Worldwide, the number of hemophiliac children is about 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. All

ances and ethnic groups are affected (Wicklun, 2018). In United States, the prevalence is 20,000 people per year (about 400 babies born with hemophilia annually). In Palestine, the incidence is one hemophilia child every 200 male newborn and in Algeria, the number of hemophiliac children is about 3000 cases (Curry, 2016 & Butler, 2016).

Both hemophilia A and B are characterized by spontaneous internal bleeding and excessive bleeding after injuries or surgery. The most common sites for bleeding are into joints and less commonly in muscles and organs such as the brain or kidneys. Uncontrolled and repeated bleeding into joints causes acute pain and results in severe osteoarthritis and crippling. Untreated bleeding into muscles can result in nerve damage and permanent loss of function and bleeding into organs such as the brain can be fatal. Without treatment most children with severe haemophilia will not survive past adolescence (Mazepa et al., 2016).

Based on the residual activity of the defective factor, hemophilia was divided into three different degrees of severity: severe, moderate, and mild. In severe hemophilia, the plasma content of coagulation factor activity (FVIII:C for hemophilia A and FIX:C for hemophilia B) is less than 1% of normal, compared with 1 to 4% in moderate hemophilia and 5 to 40% in mild cases (Valdez et al., 2012).

The parent competence was defined as a system of knowledge, skills, capabilities, abilities and habits that allow the parent to successfully deal with crisis situations in a manner that contributes to the child's development. The educational environment built by a

competent parent is propitious to the formation of a harmonious personality of the child, which is characterized by originality, spontaneity, autonomy, authority and strong individuality seeking self-affirmation (Glveanu, 2016 & Shapiro, 2017).

Dealing with hemophilia is sometimes difficult. Hemophilia has emotional impacts on each parent, the child, siblings and other family members. However, with help and support from the health care team, the family will find the strength and ability to adapt with their children chronic conditions. Also, the family will discover child's core values in life and a deep loving bond that will guide child through the lifelong journey with hemophilia (Todres et al., 2017).

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 for early signs of complication, teaching caregivers about preventive measures of the disease, diet information, signs of major bleeding and how to deal with accident (Tietze & Gurley, 2014).

Significance of the study:

Hemophilia is a serious lifelong health problem and is an inherited X-linked coagulation disorder caused by deficiencies of the clotting factor VIII or

of factor IX. It can lead to chronic disease and lifelong disabilities, if not properly managed since early infancy. Caregivers are often confronted with a stressful life and are exposed to exaggerated worries associated with the illness of the children, as well as to other related stressors (Widayanti, 2011).

In Egypt, Consanguineous marriage is frequent, therefore recessive characteristic coagulation disorder reach a higher incidence than in many other countries. The incidence rate in Egypt is about 250,000 cases per year approximately 30-40 cases in every each million person (Al-Torbary et al., 2010).

Hemophilic children need special attention and care by caregivers. The inability of the caregivers to successfully play this role may frustrate them & deprive the children from better skills. Caregiver's education is an important component of hemophilic intervention, as it can provide positive outcomes for caregivers and in turn, their children. This study investigated the effect of caregiver's education on their competence level to manage their children with hemophilia.

Aim of the study:

The aim of this study was to evaluate the effect of an educational program on improving caregiver's competence level regarding care of children suffering from hemophilia.

Research hypotheses:

- Caregiver's knowledge regarding care of children suffering from hemophilia will be increased after attending the educational program.
- Caregiver's reported practices regarding care of children suffering from hemophilia will be improved after attending the educational program
- Caregiver's competency level regarding care of children suffering from hemophilia will be improved after attending the educational program.

Subjects and Methods

A. Research design: A quasi-experimental design was utilized in the current study.

B. Setting: The study was conducted at inpatient pediatric hematology units in Benha Health Insurance Hospital in Benha city and Nile Health Insurance in Shubra city which affiliated to the Health Insurance Hospitals. The inpatient pediatric hematology unit in Benha health insurance hospital found in the second floor, composed of three rooms with 20 beds, while the inpatient pediatric hematology unit in Nile Health Insurance in Shubra city found in the first floor, composed of two rooms with 30 beds.

C. Subjects: A purposive sample of 50 caregivers (mainly mothers) accompanying their children were selected from the above mentioned settings after fulfilling the following criteria.

Inclusion criteria:

- Having children suffering from haemophilia.
- Having children free from any other blood diseases and congenital anomalies.

- Responsible for providing direct care for their children.
- Free from any psychiatric or mental diseases.
- Willing to participate in the study.

Tools of data collection:

Data were gathered by using the following tools:

Tool (I) A structured Interview Questionnaire Sheet: It was designed by the researchers based on **Farragia, (2013) & Curry, (2016)** to collect the characteristic data of the studied subjects and to assess mothers' knowledge regarding care of their children suffering from hemophilia. It was written in an Arabic language and composed of two main parts:

Part I: It was comprised the following:

- a. Characteristics of the studied mothers: Age, occupation, educational level, residence, consanguinity and previous attendance of educational sessions about hemophilia.
- b. Characteristics of the studied children: Age, gender, educational level, child's Rank, number of affected children and diagnosis.
- c. Medical data of the disease: Age of child at first bleeding attack, the duration of the first bleeding attack, diagnosed of first bleeding attack, sites of first bleeding and level of severity. The researchers were collected from the children's medical record.

Part II: Mothers' knowledge about hemophilia: It includes (11) multiple choice questions concerning; definition, risk factors, types, levels of severity,

etiology, clinical manifestations, laboratory investigations, complications, treatment, prevention and importance of follow-up.

Scoring system:

The studied mothers' answers were compared with a model key answer, where complete correct answer of mothers' knowledge scored (2), incomplete correct answer scored (1) and unknown or wrong answer scored (0). Total scores were ranged from (0-22). In this aspect, the total level of mothers' knowledge was categorized as the following:

- Unsatisfactory knowledge (< 60%) was ranged from (0 -13) points.
- Satisfactory knowledge (\geq 60%) was ranged from (14 - 22) points.

Tool (II): Mothers' reported practices:

It was adapted from **Mohammed & hattab, (2013)** to assess mothers' reported practices regarding care of their children with hemophilia. It consists of (51) items concerning control of bleeding from different sites (13 items), bruises care (3 items), wound care (3 items), protection from joint deformities (3 items), play activities (4 items), protection against home accident (3 items), child's exercise (3 items), dietary pattern (5 items), preventive measures (10 items) and home care (4 items).

Scoring system: one score was given for done and a zero for not done. Total scores were ranged from (0-51). Accordingly, mothers' reported practices were categorized as the following:

- Incompetent practice (< 85%) which ranged from (0 - 43) items.
- Competent practice (\geq 85%) which ranged from (44 - 51) items.

Tool III: Parenting sense of Competence Scale (PCOS):

It was adopted from **Johnston & Mash, (1989)** to assess mothers' competence level regarding care of their children with hemophilia. It was a 17 items grouped under two main domains namely; Satisfaction domain that contains 9 items (2, 3, 4, 5, 8, 9, 12, 14, and 16) and self-efficacy domain which contains 8 items (1, 6, 7, 10, 11, 13, 15, and 17). Each item is measured on a 5 point Likert scale ranging from (1) strongly disagree to (5) strongly agree.

Scoring system:

The scoring system for **self-efficacy domain** was ranged from (1) strongly disagrees, (2) disagree, (3) neutral, (4) agree, and (5) strongly agree. On the other hand, the scoring system for **satisfaction domain** was reversed (1) strongly agrees, (2) agree, (3) neutral, (4) disagree, and (5) strongly disagree. The total items of mother's competence level were ranged from (1-85).

The mothers' competency level was grouped as the following:

- Low competence (< 60%) was ranged from (17-50) items.
- Moderate competence (60 % to < 75%) was ranged from (51 - 65) items.
- High competence (\geq 75 %) was ranged from (66 - 85) items.

Tool IV: Educational program:

The educational program were developed by the researchers and aimed to improve caregiver's competence level regarding care of children suffering from hemophilia.

Preparatory Phase:

This phase included reviewing the related literatures and theoretical knowledge of various aspects of the study using books, articles, internet, and periodical magazines at the local as well as international level to develop the study tools and to get acquainted with the various study aspects of the research problems.

Content validity:

Tools of data collection were translated into Arabic and investigated for their content validity through distribution to 3 experts (Two experts in the field of pediatric nursing from faculty of nursing, Benha University and one expert of hematology specialty from faculty of medicine, Benha University) to test the content validity of the instruments and to judge its clarity, comprehensiveness, relevance, simplicity and accuracy. All of their remarks were taken into consideration; some items were re-phrased to arrive at the final version of the tools. The tools were regarded as valid from the experts' point of view.

Reliability:

Reliability of the tools was applied by using Cronbach's alpha coefficient test. This turned to be ($\alpha = 0.91$) for a structured interview questionnaire sheet, ($\alpha = 0.85$) for mothers' reported practices and ($\alpha = 0.82$) for Parenting sense of

competence scale. These indicate a high degree of reliability for the study tools.

Ethical considerations & human rights:

The researcher clarified the aim of the study to the mothers included in the study. Informal consent was a prerequisite to recruit all mothers in the study. Mothers were assured that all gathered data was used for research purpose only and the study was harmless. Also, the mothers have right to withdrawn from the study at any time. Confidentiality of the gathered data were secured.

Pilot study:

A pilot study was conducted to test the clearness and applicability of the study tools and to estimate the time needed for each tool. It was done on 10% of the total study subjects, (5) mothers who excluded in the present study to avoid sample bias and contamination. In the light of pilot study analysis, modification was done accordingly and the last form was developed. This phase was conveyed from the earliest starting point of September 2017 to the end of September 2017.

Field of Work:

The educational program was implemented to achieve the aim of the current study by these phases; assessment, planning, implementation and evaluation phase. These phases were conveyed from the earliest starting point of October 2017 to the end of May 2018 covering 8 months.

Assessment phase: This phase involved interviews with caregivers (mainly mothers) to collect baseline data.

The researchers were available three days/week; (Saturday, Monday and Thursday) from 10.00 am to 2 pm by rotation in each study setting over a period of 8 weeks. The average number of interviewed mothers was 2-3 per /day. At the beginning of interview; the researchers welcomed each mother, explained the purpose, duration and activities of the study and took oral consent. Then, mothers' knowledge, their reported practices and their competency level were assessed before implementation of the program (pretest) using study tools I, II and III. The time required for finishing each tool was around 15-25 minutes.

Planning phase: Based on the results of pretest and after reviewing the related literature, the educational program was developed by the researchers in simple Arabic language. The contents of educational program were selected based on identified needs. Teaching methods were used to suit small groups teaching such as modified lecture, brain storming, demonstration, re-demonstration and group discussion. Teaching media were prepared as handouts that covered theoretical and practical information and also, real equipment's to help proper understanding of the contents by mothers.

Implementation phase: Before starting of the program sessions, the mothers were informed about the time and place of sessions which were carried out at a separate room at inpatient pediatric hematology unit. The studied mothers were divided into 10 groups, each group consisted of 5 mothers, the program were implemented in five sessions for each group and delivered by

the researchers, distributed as the following; (3) sessions for theoretical part, each session kept going from (30-45) minutes and (2) session for practical, each session kept going for 60 minutes (30 minutes for demonstration and 30 minutes for re-demonstration), 3 days/week in the morning shift. Each session started with a summary of the previous session and objective of the new one using simplified Arabic language that suits mothers' educational level. Three sessions were given each day and all the sessions were repeated to each group.

The first session of the theoretical part includes; definition, risk factors, etiology, level of severity, types and clinical manifestations of hemophilia, **the second session** includes, laboratory investigations, complications and treatment of haemophilia and **the third session** includes nursing instructions about mouth and teeth care, diet pattern, exercise, play activity, bruise care, measures to protect joint deformities, prevention measures and importance of follow-up.

The first session of practical part concerned with demonstrating steps of wound care and the **second session** includes applying steps of control of bleeding from different sites as mouth, nose and joint.

Evaluation phase:

After program implementation, the post test was carried out to assess mothers' knowledge, reported practices and their competency level regarding care of their children suffering from hemophilia by using the same pretest

Results:

tools after 1 month (post-program) and 3 months of program implementation (during children's follow-up).

Administrative design:

An official approval was obtained from the dean of faculty of nursing Benha University, hospital directors and head of the inpatient pediatric hematology units at Benha Health Insurance Hospital in Benha city and Nile Health Insurance in Shubra city. A clear explanation was given about the nature, importance and expected outcomes of the study to carry out the study with minimal resistance.

Statistical Design:

The collected data were organized, categorized, tabulated and analyzed using SPSS advanced statistics version 20. Numerical data were expressed as mean and stander deviation as appropriate. Qualitative data were expressed as frequency and percentages. For quantitative data, one way analysis of variance test (ANOVA) was used to analyze the difference between three or more continuous variables. Pearson correlation analysis was done for assessment of interrelationship among quantitative variables. Reliability of the study tools was done using Cronbach's Alpha test. Significances were considered at p- Value < 0.05, <0.01 and < 0.001.

Table (1): Distribution of the studied mothers according to their characteristics (n=50).

Mothers' characteristics	No	%
Age		
<40	20	40.0
>40	30	60.0
Mean ±SD	36.5±5.19	
Occupation		
Employee	14	35.0
Housewife	36	65.0
Level of education		
Illiterate	16	65.0
Read and write	10	15.0
Primary education	2	4.0
Preparatory	8	16.0
Residence		
Urban	12	24.0
Rural	38	76.0
Consanguinity		
Yes	30	60.0
No	20	40.0
Attended any educational sessions about hemophilia		
Yes	0	0.0
No	50	100.0

Table (1): Showed that 60% of the studied mothers were >40years, with mean age 36.5±5.19 years. 65% of them were housewife and illiterate. 76% of mothers were living in rural area. 60% of them had positive consanguinity and 100% not attend any educational sessions about hemophilia.

Table (2): Distribution of the studied children regarding their characteristics (n=50).

Children' characteristics	No	%
Age in years		
3-<6 years	18	36.0
7-12 years	17	34.0
≥ 12 years	15	30.0
Mean ±SD	2.92±1.79	
Gender		
Male	50	100.0
Educational level		
Pre nursery school	8	16.0
Nursery school	10	20.0
Primary school	17	34.0
Preparatory school	8	16.0
Secondary school	7	14.0
Number of affected children in the family		
One	34	68.0
Two	16	32.0
Rank of affected child in family		
First	29	58.0
Second	18	36.0
Third	2	4.0
Four	1	2.0
Diagnosis		
Hemophilia A	46	92.0
Hemophilia B	4	8.0

Table (2) clarified that 34% of the studied children were in the age group of 7-12 with mean age 2.92±1.79 years. All of them 100% were males, 34% of them were in primary school. 68% of family had one child affected with hemophilia, 58% ranked as the first child affected in the family and 92% of them diagnosed as hemophilia A.

Table (3): Distribution of studied children according to their medical data (n=50).

Medical data	No	%
Age of child at first diagnosis of hemophilia		
Less than 2 years	35	70.0
More than 2 years	15	30.0
The duration of the first bleeding attack		
15-30 minutes	20	40.0
31-45 minutes	11	22.0
46 minutes to an hour	15	30.0
More than an hour	4	8.0
Diagnosis of first bleeding		
After cutting umbilical cord	6	12.0
Circumcision	15	30.0
by tooth extraction	6	12.0
Falling	8	16.0
Physical trauma	7	14.0
Operation	8	16.0
Sites of first bleeding		
Joint	47	94.0
Muscle	3	6.0
Level of severity		
Low	20	40.0
Moderate	25	50.0
Severe	5	10.0

Table (3): illustrated that 70% of the studied children had first diagnosed with hemophilia at the age of less than 2years. 40% of them mention that the duration of the first bleeding attack was ranged from 15- 30 minutes and 30% of them diagnosed after circumcision. 94% of children were reported that the first bleeding occurs into joint and 50% of children had moderate level of hemophilia.

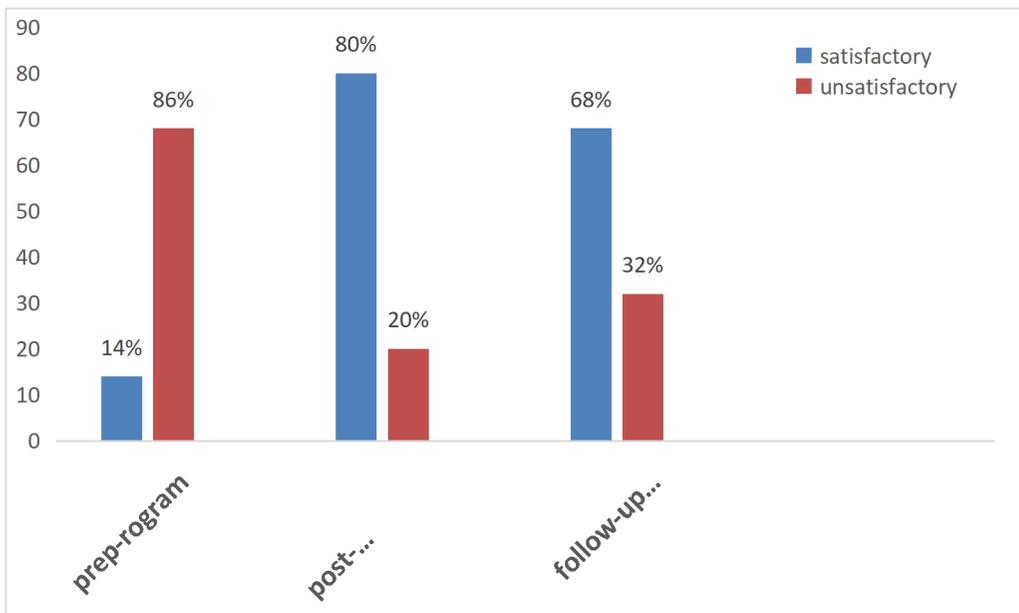


Figure (1): Distribution of total level of mothers' knowledge about hemophilia through phases of program implementation (n=50).

It is clear from figure (1) that 86% of the studied mothers had unsatisfactory knowledge level about hemophilia pre-program implementation. On the other hand, (80% & 68% respectively) of them had satisfactory knowledge level after one month and three months of program implementation.

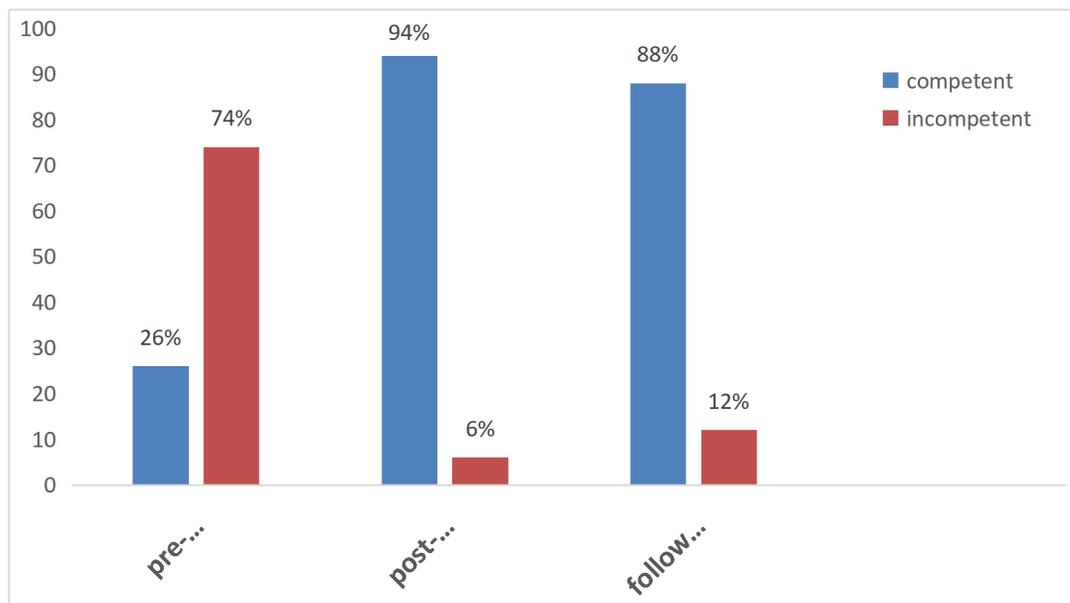


Figure (2): Distribution of total level of mothers' reported practices about hemophilia through phases of program implementation (n=50).

Figure (2) showed that 74% of the studied mothers had incompetent reported practice about hemophilia pre-program implementation. While, (94% & 88% respectively) of them had competent reported practices after one month and three months of program implementation.

Table (4): Total mean scores of mothers' competency level regarding total mean scores of self-efficacy and satisfaction through phases of program implementation (n=50)

Mothers' competency level	Preprogram implementation n=(50)	Post-program implementation After 1 month n=(50)	After 3 month Of program implementation n=(50)	F	P-value
	Mean ± SD	Mean ± SD	Mean ± SD		
Self-efficacy	22.08±2.84	31.96±2.44	29.08±2.03	169.9	0.000**
Satisfaction	26.90±3.07	28.48±3.64	28.08±1.77	21.23	0.000**
Total competency level	49.00±4.17	60.44±4.94	51.44±5.30	77.69	0.000**

**Highly statistically significant at $p < 0.001$

Table (4) presented that there was a highly statistical significant improvement in the total mothers' competency level through the phases of program implementation. Where, the total mean scores increased from 49.00±4.17 pre-program to (60.44±4.94 & 51.44±5.30 respectively) after one month and three months of program implementation ($P < 0.000$). Also, this table showed that the total mean score of self- efficacy increased from (22.08±2.84) preprogram to (31.96±2.44 & 29.08±2.03 respectively) after 1month and three months of program implementation.

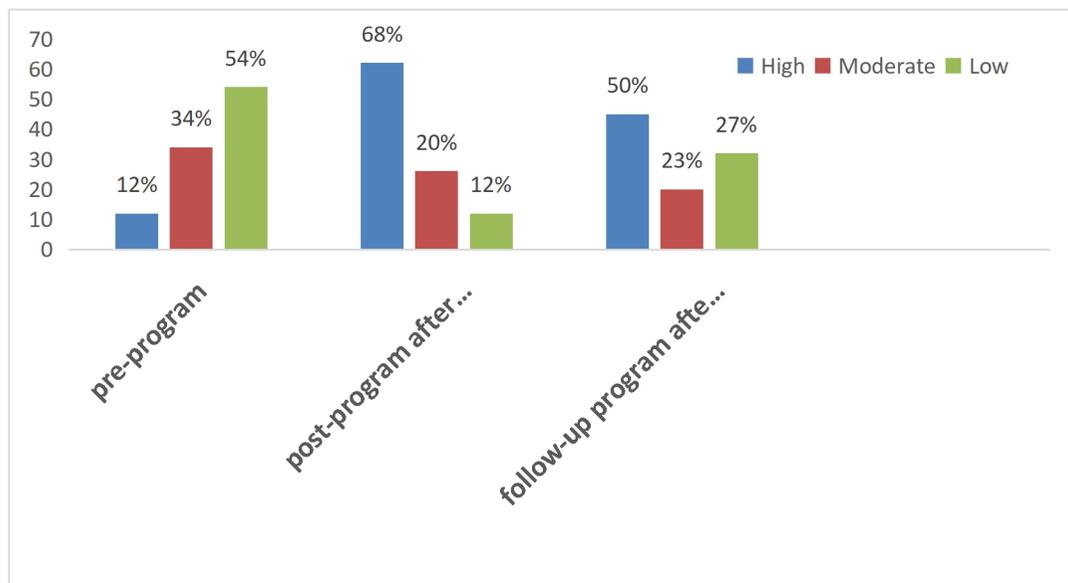


Figure (3): Distribution of total competency level of mothers regarding care of their children with hemophilia through phases of program implementation. (n=50)

Figure (3) revealed that 54% of the studied mothers had low competency level pre-program implementation. While, (68% & 50% respectively) of them had high competency level at one month and three months post-program implementation.

Table (5): Correlation between total mother's knowledge, total reported practices and total competency level regarding hemophilia through phases of program implementation (n=50).

Variables	Total competency level					
	Pre-program implementation		Post-program after 1 month implementation		After 3 month of program implementation	
	R	p-value	R	p-value	R	p-value
Total mother's knowledge	0.24	0.08*	0.80	0.03*	0.91	0.01*
Total reported practices	0.45	0.02*	0.19	0.04*	0.20	0.015*

* Significant at the 0.01 level (-tailed).

It is evident from table (5) that, there was a statistically significant positive correlation between total competency level and total mother's knowledge pre-program, after 1 month and 3 months of program implementation (P-value= 0.08, 0.03 & 0.01 respectively). Additionally, the same table reflected that there was a statistically significant positive correlation between total competency level and total reported practices pre-program, after 1 month and 3 months of program implementation (P-value= 0.02, 0.04 & 0.015 respectively).

Discussion

Caregivers are an instrumental partner taking active participation in affecting the nature and direction of care process of hemophilic children. Parental competence and success in facing difficult circumstances may increase parental self-efficacy and serve as a protective factor against negative outcomes for children. Parental self-efficacies have a direct impact on the behaviors and refer to parent's perceptions of their capability in the role of caring for that positively nurturing the growth and development of their children. (Marrelli et al., 2014).

The current study revealed that, more than half of the studied mothers were older than 40 years, more than two thirds of them were housewife and illiterate. This result was related to the fact that the data were collected from the health insurance hospital where treatment is for free or covered by medical insurance and it serves usually those from low or middle socioeconomic classes. This result was supported with Motaharian et al. (2015) who carried out a study entitled " Investigating the Relationship between Coping Strategies and Quality of Life among the Principal Caregivers of Children with Hemophilia" and found that 55.1% of the caregivers were older than 40, 46.9% were unemployed and 42.9% were illiterate.

The present study result reflected that, more than half of mothers had positive consanguinity. This could be explained by slightly more than three quarters of mothers live in rural areas where consanguineous marriage was more common among families in these

communities and this may lead to hereditary diseases. Bittles & Hammany, (2009) reported that Offspring of consanguineous parents are at two-fold greater risk than the offspring of non-related parents for autosomal recessive disorder. This finding was supported with Bildirici et al. (2016) who conducted a study entitled "An Investigation of Hemophilia, Consanguineous Marriages and Economic Growth" and found that the offspring of consanguineous marriages in Middle East and African countries are greatly exposed to autosomal recessive genetic disorders including hemophilia.

Our study result showed that all children with hemophilia were male and the vast majority of them diagnosed hemophilia A. In this regard, Montgomery & Scott, (2008) mentioned that hemophilia A is inherited as a sex-linked, life-long disorder occurring predominantly in males being transmitted through unaffected females.

The current study illustrated that, More than two thirds of family had one child affected with hemophilia and more than half ranked as the first child affected in the family. This result was matched with Mohammed & hattab, (2013) in a study entitled "Assessment of Mothers Knowledge and Practices with Hemophilic Children Type A At Azadi Teaching Hospital In Kirkuk City" who revealed that the majority (69.1%) of family had one child affected with hemophilia A and highest (40%) had first male child affected.

The finding of this study revealed that, more than two thirds of the studied children had first diagnosed with hemophilia at the age of less than two

years, nearly one third of them diagnosed after circumcision and vast majority of them reported that the first bleeding occurs into joints. This result agree with **Tengborn et al. (2012)** who stated that hemophilia diagnosed within 1 year following childbirth and 90% of all bleeding episodes occur into the joints and muscles. In addition, **Srivastava et al. (2013)** stated that hemophilia should be suspected because of unusual bleeding following invasive procedures such as circumcision. In contrast, **Dekoven et al. (2014)** who conducted a study entitled "Understanding the Experience of Caring for Children with Hemophilia: Cross-Sectional Study of Caregivers in the United States" and found that most children of caregivers (85.81%) had been diagnosed with hemophilia more than 2 years ago.

The current study finding illustrated that majority of studied mothers' had unsatisfactory knowledge level before program implementation. This could be due to the fact that all of the studied mothers did not attend any training courses regarding hemophilia. This result was similar with the study carried out by **Noval et al., (2015)** who reported that most of the studied caregivers had insufficient knowledge regarding hemophilia and its management in the assessment phase. In this regard, **Singleton et al., (2010)** recommended that family members of hemophilia Patients should educate about the disease and its management, which can significantly reduce morbidity and mortality. Also, **Ergun & Sülü, (2011)** concluded that's mothers should be having good knowledge, practice and home management teaching to prevent complication.

After program implementation, the majority and more than two thirds of mothers had respectively satisfactory knowledge level after one month and three months. This difference could be related to the effect of the educational program, its content and the methods of teaching used in applying the educational program, the small number of sessions and short duration of each session. This finding was congruent with **Phadnis & Kar (2017)** who conducted 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, which remained significantly higher than baseline and 1 year after intervention.

The current study showed that nearly three quarters of the studied mothers had incompetent reported practice about hemophilia pre-program implementation. This might be due to lack of awareness program for mothers regarding care of hemophilic children. In contrast, this finding was contradicting with **Mohammed and hattab, (2013)** who showed that 72.7% of Mother's had fair level of practices about hemophilia in the assessment phase.

Following program implementation, the results of the current study revealed that the vast majority and majority of the studied mothers had respectively competent reported practices after one month and three months. This could be attributed to the educational program were sufficient and effective in improving mother's reported practices. In this respect, **Aloks, (2015)** stated that

mothers should participate in educational program to improve their practices towards their hemophilic children because the educational program helps them to transfer the training procedures learned to the home setting and teach their children to continually practice by themselves. Similarly, **Poon and Card, (2012)** concluded that improving hemophilia care can best be met by comprehensive care program which designed to provide education to families had children with hemophilia. This finding was in accordance 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 (107.9714, 109.086, & 99.485 respectively) compared to the control ones (43.2857, 56.086 & 57.102) respectively.

The finding of the current study has highlighted that there was a significant improvement of the total mean score of mothers' competency level and their self- efficacy after 1month and three months of program implementation compared to the preprogram phase. This could be explained by higher mothers' self-efficacy is often associated with greater mothers' competence level in performing skills toward their hemophilic children. In this respect, **Solish and Perry (2008)** stated that parents with higher self-efficacy showed more responsibility, responsiveness, kindness, sympathy, and attempt for developing appropriate behaviors in their children and, as a result, were more competent to take care of their children.

Additionally, **Safe et al. (2012)** reported that parents' self-efficacy and self-confidence were two important predictors of good parenting competence.

On investigating mothers' competency level, the current study revealed that more than half of the studied mothers had low competency level pre-program implementation. This might due to lack of continuous education for mothers regarding care of their hemophilic children. This finding was in harmony with **Mohammadi et al. (2019)** who conducting a study entitled "Parental Competence in Parents of Children with Autism Spectrum Disorder" and found that Competence level among these parents was lower compared to other parents having healthy children. Following implementation of the program, more than two third and half of mothers had high competency level at one month and three months. This could be due to the program made refreshment in mothers' knowledge and reported practices which in turn led to an improvement of their competency level of care regarding hemophilia.

From the researchers' point of view, the drop of knowledge, reported practices and competency scores after 3 months of educational program implementation below those one month after implementation of the educational program should guide us to the importance of regular mothers' education to maintain satisfactory knowledge and competent practices.

The present study finding revealed that there were a statistically significant positive correlation between total competency level with total mother's

knowledge and total reported practices pre-program, after 1 month and 3 months of program implementation. This means that increasing mothers' knowledge would help to improve their competency level and subsequently, improve their practices towards care of their hemophilic children. This finding was supported with **Shams El Deen et al. (2016)** who conducted a study entitled "Effect of an Educational Training on Mothers' Competency Level for Managing the Children with Autism" and found that there were a significant positive correlation between total competency level of care regarding autism with total mother's knowledge, and total practices before, after and 3 months after program implementation.

Conclusion:

In light of the study findings, this study concluded that the research hypotheses was accepted, and the educational program was an effective method in improving mothers' knowledge, their reported practices, and their competency level regarding care of children suffering from hemophilia. Additionally, there was a statistically significant positive correlation between total competency level with total mothers' knowledge and total reported practices pre-program, after 1 month and 3 months of program implementation.

Recommendations:

Based on the study findings, the following recommendations can be suggested:

- 1- Establish a regularly training program for mothers who have children suffering from hemophilia and were

newly diagnosed in order to improve their competency regarding care of their children.

- 2- Mass media should play a significant role to increase public awareness about hemophilia.
- 3- Consanguineous marriage must be an important issue of concern in any hemophilia management plan via raising awareness, education and genetic counseling.

For further studies:

- 1- More researches are needed to identify most common family problems in the community and available resources that meet family needs.
- 2- An educational program regarding the provision of immediate and emergency care for hemophilic children at schools should be conducted and directed to the teachers who dealing with those children.

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