

Effect of Self Learning Module on Caregivers of Children Suffering from Common Blood Disorders

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Abstract: Self learning module is an essential step to assist caregivers and their children to cope effectively with blood disorders and its complications as well as, reach adulthood safely. Nurse act as a teacher role in learning process, she becomes a resource person, facilitator, manager and consultant in the total learning process. This study aimed to evaluate the effect of self learning module on caregivers of children suffering from common blood disorders. **Research design:** A quasi experimental design was done, **Sample:** A purposive sample that included 40 children having blood disorders from both gender and their caregivers. **Setting:** The study was conducted at outpatient clinic at Fayoum University Children' Hospital, Fayoum governorate. **Tools of data Collection:** include questionnaire sheet, observation check lists and liker type rating scale to assess the caregivers' knowledge, practice, and attitude regarding common blood disorders additionally; self-learning module was used based on actual need assessment of the studied sample. The results of this study revealed statistical significance differences pre, post and follow up of self learning module regarding caregivers' knowledge, practices and attitude towards their children suffering from blood disorders. **Conclusion:** There was a positive effect of self learning module on improving caregivers' knowledge, practices and attitude towards their children suffering from blood disorders. **The study recommendation:** self learning module should be revised and updated for newly caregivers of children suffering from blood disorders.

Keywords: Empowerment module, caregivers, children, blood disorders and nurse.

1. INTRODUCTION

Blood disorders are life-long crippling genetic disorders; need frequent blood or blood product transfusions. These disorders lead to deaths due to complications of disease and transfusion. Thalassemia is an inherited blood disorder, which is characterized by decreased synthesis or absence of globin. This synthetic defect leads to the formation of fragile abnormal red blood cells (RBC), which can be easily hemolyzed, leading to chronic anemia (Ashrafizadeh et al., 2016).

Beta thalassemia, a major type of thalassemia, is commonly caused by a defect of beta globin protein production. Beta thalassemia is divided into three categories: thalassemia trait, thalassemia intermediate and thalassemia major (TM). In the first two categories, one of the beta globin genes is failed and also the amount of beta globin protein in the cell is reduced by the half. In TM, the transfusion-dependent clinical phenotype of thalassemia, both genes is failed and no beta globin protein is produced. This disorder is highly prevalent among children in the Middle East, Mediterranean region, and South Asia (Surapolchai et al., 2010).

Hemophilia is considered the most common of the severe bleeding disorders and it enjoys the most efficacious and had safe treatment among the most prevalent monogenic disorders; however, if not properly managed since early infancy, it

lead to chronic disease and lifelong disabilities. Optimal treatment involves a combination of replacement therapy, with conservative measures (rest, ice compression, elevation) which may be an inexpensive and efficient treatment option to diminish the unfavorable effects of joint bleedings and to increase the functional independence. Performing regular physiotherapy sessions may improve musculoskeletal health by regulating joint mobilization and preventing vicious attitudes and muscle atrophy (**El-Beshlawy et al., 2009**).

Self learning module is a process in which caregivers take the initiation with or without the help of others in identifying human and material resources, implementing learning strategies and evaluating learning expected outcome. Its benefits refer to encourage a degree of self-help within any one group of learner, facilitate decision making and facilitate self learning and evaluation (**Susan, 2008**).

Nurse as an educator considers a facilitator for education process. So, caregivers can return to the teacher (nurse as educator) to ask about what are not understandable in self learning module. Also, she acts as a resource person, facilitator, manager and consultant in the total learning process. Self learning module is a specific type of learning technique which may or may not be a part of an individualized learning perception. It means that learners are in control of their rate of progress through the material. If they are familiar with the ideas they can skip sections or move quickly through suggested activities. If they are uncertain, they spend more time on reading or practicing skills (**Sharma, 2013**).

Learning through self learning module can widely improve care given to children with blood disorder and increase caregivers' confidence. So, current study will be constructed as a trial to promote children health status through helping caregivers to acquire accurate knowledge and to apply pitfalls practice related to children with blood disorders.

Significance of the study:

B thalassemia major is a common health problem in Egypt; it has been estimated that every 1.5 million live birth, there are 1000 children were born with B thalassemia annually. The carrier's rate of B thalassemia in Egypt was reported to be 9–10%. Additionally, it was found that, the incidence of Hemophilia is the most frequent inherited bleeding disorders. The congenital bleeding disorders (hemophilia A and B) are estimated to be one in 5000 live male births annually worldwide (**WHO, 2018 and National hemophilia foundation, 2018**). On the other hand, statistical records derived from Fayoum University Children Hospital at 2017-2018, clarified that mean cases that diagnosed and hospitalized with blood disorders (thalassemia and hemophilia) are 1030 child.

Caregivers of children with blood disorders had reported a lower quality of life, difficulties in managing the child's care and higher levels of anxiety in addition to, other psychological stressors which lead to disruption of life. Sufficient support for caregivers may prevent or ameliorate these problems and indirectly achieve better outcomes for children (**Javed and Muazzam, 2013**). Self learning module is affordable source to guide caregivers' of children suffering from blood disorders in urgent situation especially if there is high distance between caregivers' place of residence and hospital. Therefore, implementing self learning module for caregivers is a helpful aspect in acquisition of knowledge and practices regarding the disease. Also, it is an essential step to assist caregivers and their children to cope effectively with disease and its management in order to reach adulthood safely.

Aim of the study:

This study aimed to evaluate the effect of self learning module on caregivers of children with common blood disorders through 1) assessing knowledge, practices and attitude of caregivers about common blood disorders. 2) Designing and implementing self learning module about common blood disorders. 3) Evaluating the effect of self learning module on caregivers of children with common blood disorders post and follow up self learning module.

Research Hypothesis:

Implementation of self learning module will result in improvement of caregivers' knowledge, practices and attitude regarding their children suffering from common blood disorders.

Subjects and methods of the current study were discussed under the following four designs:

- i. **Technical design:** The technical design of the study included: study design, settings, subjects and tools of data collection.

Design:

A quasi experimental research design was used.

Settings:

The study was conducted at out-patient clinic at Fayoum University children' Hospital.

Subjects:

A convenient sample of 40 caregivers (parents, any of family members or relatives) of children suffering from common blood disorders received care at the previous mentioned settings and can read and write regardless their age

Inclusion criteria:

1. Children's age : <10 to 16 years regardless of their gender, residence and educational level.
2. Confirmed diagnosis of B-thalassemia major and hemophilia.
3. Regular follow up visits.

Exclusion criteria:

Children with other chronic diseases were excluded from the study.

Tools of data collection:

Data collected through using the following tools:

1. A structured interview questionnaire sheet:

It was developed by the researcher in the light of relevant studies and researches. It was written in an Arabic language and composed of:

First part:

It includes characteristics of the studied caregivers such as; age, residence, occupation, and educational level.

Second part:

Caregivers' knowledge about thalassemia such as: definition, risk factors, clinical manifestations, complications of disease, causes which leading to sever complications, importance of blood transfusion, importance of iron chelator therapy, nutrition should be encouraged and nutrition should be avoided.

Third part:

Caregivers' knowledge about hemophilia such as ; definition, clinical manifestations, causes, most common site exposed to bleeding, clinical manifestations of external bleeding, complications of bleeding among hamophilic children, characteristics of food should be introduced to child with heamophilia, nursing care should be given to child to promote mouth and teeth healthy, measures should be considered to protect child from joint deformity, patterns of recommended sports to be practiced by child with heamophillia and patterns of sports not preferable to be practiced by child with heamophillia

Scoring system: Total score of knowledge was 60 marks and graded as the following:

- Good level of knowledge to be more than 75%,
- Average level of knowledge graded from 65% to less than 75% and
- Poor level of knowledge less than 65%.

2. Observation check lists:

i. Observation check lists related thalasemic children:

It was modified by the researcher from **Saxena et al., 2017** to assess caregivers' practices regarding care of children with thalassemia such as taking axillary temperature, desferral injection and dental care.

ii. Observation check lists related hemophilic children:

It was adopted from **Bowden and Greenberger, 2013** to assess caregivers' practices regarding care of children with hemophilia such as caring child with oral teeth bleeding, caring child with epistaxis, caring child with joint bleeding and range of motion exercise.

Scoring system: Total score of practice was 47 marks and graded as the following:

- Satisfactory level of practice: $\geq 65\%$
- Unsatisfactory level of practice: $< 65\%$.

3. Likert type rating scale:

It was developed by the researcher after reviewing **Votroubek & Tabacco (2010)**, to assess caregivers' attitude regarding care of their children with common blood disorders.

Scoring system: Total score of attitude was 48 marks and graded as the following:

- Positive attitude: $\geq 65\%$
- Negative attitude: $< 65\%$.

4. Child medical history sheet:

It was designed by the researcher to collect data in relation to:

First part: children characteristics such as; age, educational level, age at the onset of disease, birth order, school attendance and compliance in treatment.

Second part: includes medical history such as; frequency of blood transfusion, bleeding episodes and frequency of hospitalization.

Third part: Family history such as; consanguinity, relation with child and number of affected sibling in the family.

ii. The operational design:

A) Preparatory designs:

During this phase, the researcher reviewed current, local and international related literature which helped to be more acquainted with the topic and with the process of tools' construction.

Designing self learning module:

The researcher had designed self learning module in Arabic language after reviewing the related literature based on actual need assessment of the studied sample (caregivers). It covered the theoretical knowledge and practical procedures. Theoretic part included caregivers knowledge regarding most common blood disorders among hospitalized children at Fayoum university children' hospital e.g. thalassemia and hemophilia. On the hand, the practical part included practices regarding caring child with thalassemia e.g. taking axillary temperature, desferral injection subcutaneous, caring child with epistaxis and hand hygiene additionally practices regarding care child with hemophilia e.g. care child with joint bleeding, as well as range of motion exercise for body joint (knee, elbow and ankle).

2- Tools validity and reliability:

Validation was done by 3 experts (pediatric nursing and community health nursing) as regards tools of data collections and necessary modifications of the tools were done according to the expert's agreement on the content and sequence of items. Regarding reliability, the reliability coefficients' alpha includes the following:

1. Pre- posttest regarding knowledge was 0.75.
2. Pre- posttest regarding practice was 0.76.

3-Field work

Data collection started from first of January 2018 till the end of June 2018 to take 6 months, researcher was available three days per week from 8 a.m. to 2 p.m. The researcher started by introducing herself to the studied caregivers and their children suffering from hemophilia and thalassemia and giving them a brief idea about the aim of the study, its components and expected outcomes.

The researcher had collected data related to children suffering from thalassemia and hemophilia including their characteristic; age, educational level, age at the onset of disease, birth order, school attendance and compliance in treatment in addition to medical history including; frequency of blood transfusion, bleeding episodes and frequency of hospitalization. Also, gathering data towards family history such as; consanguinity, relation with child and number of affected sibling in the family.

The researcher had assessed caregiver's knowledge, practice and attitude regarding care of their children suffering from thalassemia or hemophilia using pretest tools. Time consuming to fulfill the questionnaire sheet take 20- 30 minute depend on caregivers' own knowledge while observation checklists and attitude tools were filled by researcher taking about 10 to 15 minute.

Implementation of self learning module:

Self learning modules were distributed by the researcher to each caregiver clarified the purpose of the study, the researcher explained to the caregivers how to use the module throughout setting directions including; the caregiver should answer the questions proceeded each chapter then read each chapter carefully, they can return to the researcher to clarify what is vague or difficult for more clarifications, caregiver shouldn't move to the another chapter unless understand and digest the content of current chapter, the studied caregivers should answer the questions which followed each chapter and achieve the desired score .Also, they can review the model key answer of each chapter to check they answer.

B) Evaluation phase:

After finishing of self-learning module implementation, the researcher applied posttest to evaluate caregivers' knowledge, practice and attitude regarding children suffering from common blood disorders also; follow- up test was applied after 3 months of implementation, using the same tools.

iii. Administrative design:

An official permission was obtained through an issued letter from Dean of nursing faculty, Fayoum University to director of Fayoum University children's Hospital to conduct the study.

Ethical considerations:

Each study subject was secured that the study is harmless either physically or psychologically. All gathered data was treated confidentially and was used for research purpose only. Also, the researcher took an oral consent from the caregivers of children before their participation in the study

iv. Statistical design:

All data were organized, categorized, tabulated and analyzed by using SPSS, (statistical Package for Social Sciences) program version 20. Statistical significance and associations were assessed using chi- square and P- value to detect the relation between the variables of the study. Statistical significance difference was achieved when $p < 0.05$, highly statistical difference was achieved when $p < 0.001$ meanwhile, there was statistical insignificance difference when $p > 0.05$.

3. RESULTS

Table (1): Distribution of the studied caregivers according to socio-demographic characteristics no=40

| Socio-demographic characteristics of caregivers | No. | % |
|---|------------|------|
| Age in years: | | |
| 25<35 | 17 | 42.5 |
| 35<45 | 16 | 40 |
| ≥45 | 7 | 17.5 |
| <i>Mean± SD</i> | 35.60±10.2 | |
| Residence: | | |
| Rural | 33 | 82.5 |
| Urban | 7 | 17.5 |
| Occupation: | | |
| Employed | 7 | 17.5 |
| Unemployed (housewife) | 33 | 82.5 |
| Educational level: | | |
| Read & write | 7 | 17.5 |
| Primary education | 12 | 30 |
| Diploma | 13 | 32.5 |
| University education | 8 | 20 |

This table demonstrates distribution of the studied caregivers according to demographic characteristics. It shows that, 42.5% of studied caregivers their age ranged between 25<35 years old with mean age 35.60±10.2. Additionally, it was found that, 82.5% of them were lived in rural area. Most of studied caregivers (82.5%) were housewife and about one third of them (32.5%) had diploma.

Table (2): Distribution of the studied children according to their socio-demographic characteristics (n=40)

| Socio-demographic characteristics of children | Thalassemia=26 | | Hemophilia=14 | |
|---|----------------|------|---------------|------|
| | No. | % | No. | % |
| Age in years: | | | | |
| <10 | 16 | 61.5 | 8 | 57.1 |
| 10<13 | 14 | 35 | 6 | 42.9 |
| 13:16 | 6 | 15 | 0 | 0 |
| <i>Mean± SD</i> | 10.75±3.31 | | | |
| Educational level: | | | | |
| Primary school | 20 | 77 | 10 | 71.4 |
| Preparatory school | 6 | 23 | 4 | 28.6 |
| Age of child at onset of disease: | | | | |
| < 1 year | 20 | 77 | 12 | 85.7 |
| 1:≤3 year | 6 | 23 | 2 | 14.3 |
| Birth order: | | | | |
| The First | 10 | 38 | 4 | 28.5 |
| The Second | 14 | 54 | 10 | 71 |
| The Third | 2 | 7.7 | 0 | 0 |
| School attendance: | | | | |
| Regular | 12 | 46.2 | 3 | 21.4 |
| Irregular | 14 | 53.8 | 11 | 78.6 |
| Compliance in treatment | | | | |
| Regular | 8 | 30.8 | 3 | 21.4 |
| Irregular | 18 | 69.2 | 11 | 78.6 |

This table illustrates that, 61.5% & 57.1% of thalasemic and hamophillic children respectively, their age were less than 10 years old with mean age 10.75±3.31 years. Also, this table shows that, 77% & 71.4% thalasemic and hamophillic children respectively at primary school. As well as, the current table clarified that, most of thalasemic and hamophillic children

(77% & 85.7%) respectively, their age at onset of disease, less than one year old. On the other hand, 54% & 71 % of thalassemic and hamophillic children were the second birth order respectively. It is clear that, 53.8% & 78.6% of thalassemic and hamophillic children respectively were irregular in school attendance. Also, this table demonstrates that 69.2% & 78.6% of thalassemic and hamophillic children respectively are irregular in compliance to their treatment.

Table (3): Distribution of the studied children according to history of consanguinity, family history, relation with child and number of affected children in family (n=40)

| Items | Thalassemia=26 | | Heamophilia=14 | |
|---|----------------|------|----------------|------|
| | No. | % | No. | % |
| Consanguinity | | | | |
| Positive | 18 | 69.2 | 12 | 85.7 |
| Negative | 8 | 30.8 | 2 | 14.3 |
| Family history | | | | |
| Yes | 20 | 76.9 | 10 | 71.4 |
| No | 6 | 23.1 | 4 | 28.6 |
| Relation with child | n=20 | | n=10 | |
| Sibling | 10 | 50 | 7 | 70 |
| Cousin | 7 | 35 | 1 | 10 |
| Others | 3 | 15 | 2 | 20 |
| Number of affected sibling in the family | 10 | | 7 | |
| One | 3 | 20 | 2 | 28.6 |
| Two | 7 | 80 | 5 | 71.4 |

This table illustrates that, there are positive history of consanguinity among 69.2% & 85.7 % of hemophillic and thalassemic children respectively. On the other hand, it is clear that 76.9% & 71.4% of thalassemic and hemophillic children respectively have positive family history. Additionally, this table clarifies that, 50% & 70 % of thalassemia and hemophillic children their siblings had positive family history. It was found that 80 % of thalassemic children had two affected children in their families compared to 71.4 % of hemophillic children.

Table (4): Distribution of the studied children according to frequency of blood transfusion, bleeding episodes and frequency of hospitalization (n=40)

| Items | No. | % |
|--|------|------|
| Frequency of blood or plasma transfusion : | n=40 | |
| Once per month | 12 | 30 |
| Twice per month | 28 | 70 |
| Bleeding episodes among hamophillic children : | n=14 | |
| One- two episodes per month | 5 | 35.7 |
| Three- four episodes per month | 5 | 35.7 |
| More than four episodes per month | 4 | 28.6 |
| Frequency of hospitalization (thalassemic and hamophillic children) | n=40 | |
| One- two time per month | 4 | 10 |
| Three- four times per month | 12 | 30 |
| More than four times per month | 24 | 60 |

This table illustrates that 70% of the studied children received blood or plasma transfusion twice per month. On the other hand, it is clear that, 35.7% of hemophillic children had bleeding episodes three - four episodes per month. More than half (60 %) of thalassemic and hemophillic children were hospitalized more than four times per month.

Table (5): Distributions of the studied caregivers according to their total knowledge regarding common blood disorders pre post and follow up self learning module implementation (n=40)

| Level of knowledge | Pre | | Post | | Follow up | | Significant test | |
|--------------------|-----|----|------|----|-----------|------|------------------|---------|
| | N0. | % | N0. | % | N0. | % | X ² | P |
| Good | 12 | 30 | 20 | 50 | 21 | 52.5 | 52.34 | <0.001* |
| Average | 8 | 20 | 8 | 20 | 8 | 20 | | |
| Poor | 20 | 50 | 12 | 30 | 11 | 27.5 | | |

***A highly statistical significance difference**

This table and figure reveal that one third of caregivers (30%) achieves good knowledge level pre self learning module. Meanwhile, in follow up of self learning module, more than half (52.5%) of them have a good knowledge level.

Also, there is a highly statistical significance difference towards level of caregivers' knowledge pre, post and follow- up of self learning module regarding common blood disorders (X², 52.34 & P value <0.001).

Figure (1): Distributions of the studied caregivers according to their total knowledge regarding common blood disorders pre post and follow up self learning module implementation. (n=40)

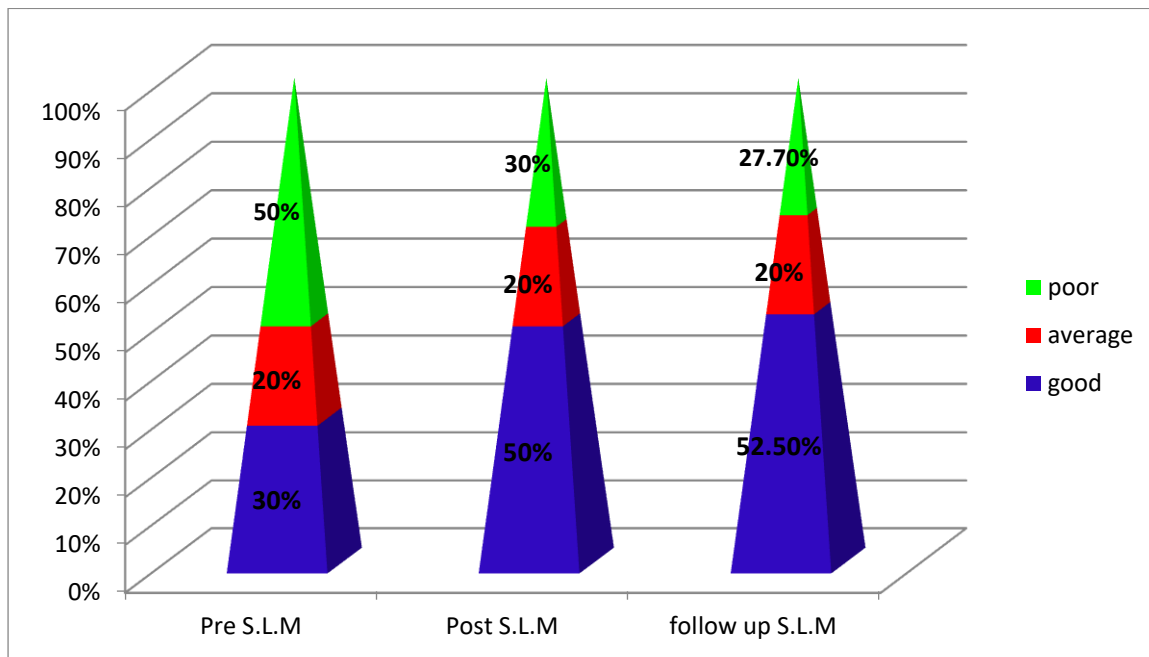


Table (6): Distributions of the studied caregivers regarding total reported practice about care given to children with common blood disorders. (n=40).

| Level of reported practice | Pre | | Post | | Follow up | | Significant test | |
|----------------------------|-----|----|------|----|-----------|----|------------------|----------|
| | N0. | % | N0. | % | N0. | % | X ² | P- value |
| Satisfied practice | 8 | 20 | 24 | 60 | 26 | 65 | 42.57 | <0.001* |
| Unsatisfied practice | 32 | 80 | 16 | 40 | 14 | 35 | | |

***A highly statistical significance difference**

This table and figure reveal that, pre self learning module implementation, low percentage of the studied caregivers (20%) has satisfied reported practice towards caring child common blood disorders however, in follow up of self learning module, (65%) of them has satisfied reported practice.

There is a highly statistical significance difference towards level of caregivers' reported practice pre, post and follow- up of self learning module regarding common blood disorders (X², 42.57 & P value <0.001).

Figure (2): Distributions of the studied caregivers regarding total reported practice about care given to children with common blood disorders. (n=40).

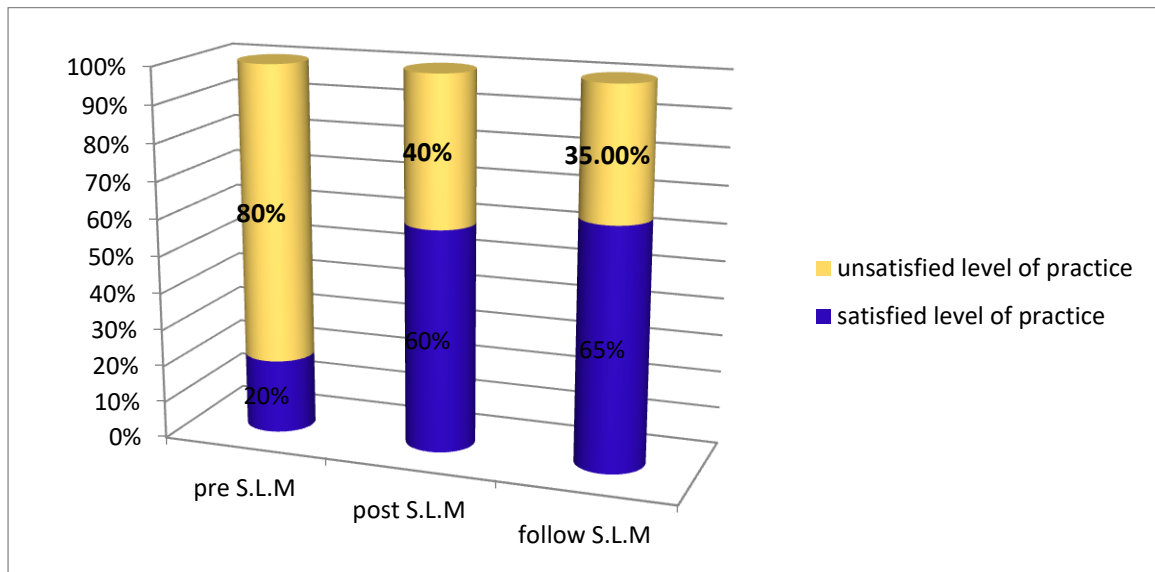


Table (7): Distributions of the studied caregivers according to their attitude regarding the disease and its management pre, post and follow up of self learning module (n=40)

| Attitude | Pre | | Post | | Follow up | | Significant test | |
|----------|-----|----|------|----|-----------|------|------------------|---------|
| | N0. | % | N0. | % | N0. | % | X ² | P |
| Positive | 12 | 30 | 18 | 45 | 23 | 57.5 | 29.27 | <0.001* |
| Negative | 28 | 70 | 22 | 55 | 17 | 42.5 | | |

***A highly statistical significance difference**

Current table and figure illustrate that, only 30% of the studied caregivers have positive attitude pre self learning module implementation. Meanwhile, in follow up self learning module, more than half of caregivers (57.5%) have a positive attitude towards caring of their children with common blood disorders.

That there was a highly statistical significance difference towards level of caregivers' attitude pre, post and follow- up of self learning module implementation regarding common blood disorders (X²,29.27& P value <0.001)

Figure (3): Distributions of the studied caregivers according to their attitude regarding the disease and its management pre post and follow up of self learning module (n=40)

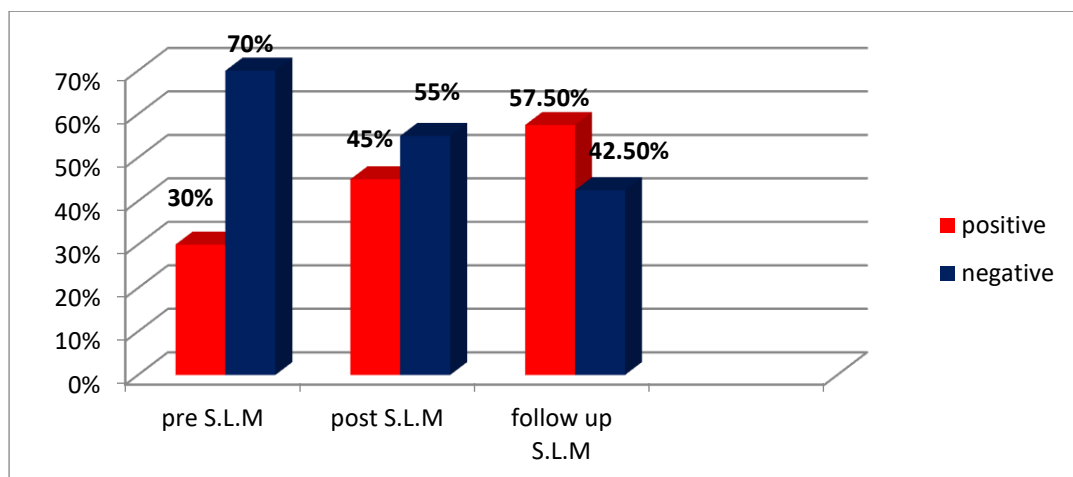


Table (8): Distributions of the studied caregivers according to indicators of self learning module effectiveness pre, post and follow up. (n=40)

| Variables | Pre | | | | Post | | | | Follow- up | | | | Significant test | |
|--|-------------|------|------------|------|-------------|------|------------|------|-------------|------|------------|------|------------------|----------|
| | Thalassemia | | Hemophilia | | Thalassemia | | Hemophilia | | Thalassemia | | Hemophilia | | X ² | P |
| | n=26 | % | n=14 | % | n=26 | % | n=14 | % | n=26 | % | n=14 | % | | |
| Need to monthly blood OR plasma transfusion per month | | | | | | | | | | | | | | |
| Once | 10 | 38.5 | 2 | 14.3 | 14 | 53.8 | 5 | 35.7 | 18 | 69.2 | 7 | 50 | 5.33 | <0.05* |
| Twice | 16 | 61.5 | 12 | 85.7 | 12 | 46.2 | 9 | 64.3 | 8 | 30.8 | 7 | 50 | | |
| Bleeding episodes per month | | | | | | | | | | | | | 40.00 | <0.001** |
| One- two episodes per month | | | 5 | 35.7 | | | 7 | 50 | | | 9 | 64.3 | | |
| Three- four episodes per month | | | 5 | 35.7 | | | 4 | 28.6 | | | 5 | 35.7 | | |
| More than four episodes per month | | | 4 | 28.6 | | | 3 | 21.4 | | | 0 | 0 | | |
| School attendance | | | | | | | | | | | | | 52.28 | <0.001** |
| Regular | 12 | 46.2 | 3 | 21.4 | 14 | 53.8 | 8 | 57.1 | 14 | 53.9 | 10 | 71.4 | | |
| Irregular | 14 | 53.8 | 11 | 78.6 | 12 | 46.2 | 6 | 42.8 | 12 | 64.1 | 4 | 28.6 | | |
| Compliance in treatment | | | | | | | | | | | | | 26.17 | <0.001** |
| Regular | 8 | 30.8 | 3 | 21.4 | 15 | 57.7 | 6 | 42.9 | 17 | 65.4 | 8 | 57.1 | | |
| Irregular | 18 | 69.2 | 11 | 78.6 | 11 | 42.3 | 8 | 57.1 | 9 | 43.6 | 6 | 42.9 | | |

* Statistical significance difference

**A highly statistical significance difference

This table clarifies that there is a statistical significance difference pre, post and follow- up of self learning module towards indicators of its effectiveness namely: blood and plasma transfusion (X²= 5.33 & P value <0.05).). Meanwhile, there were highly statistical significance differences towards bleeding episodes, school attendance and compliance in treatment (X²= 40.00, 52.28, 26.17& P value <0.001) respectively.

Figure (4): Distribution of the studied children according to their frequency of hospitalization pre, post and follow up self learning module implementation. (n=40)

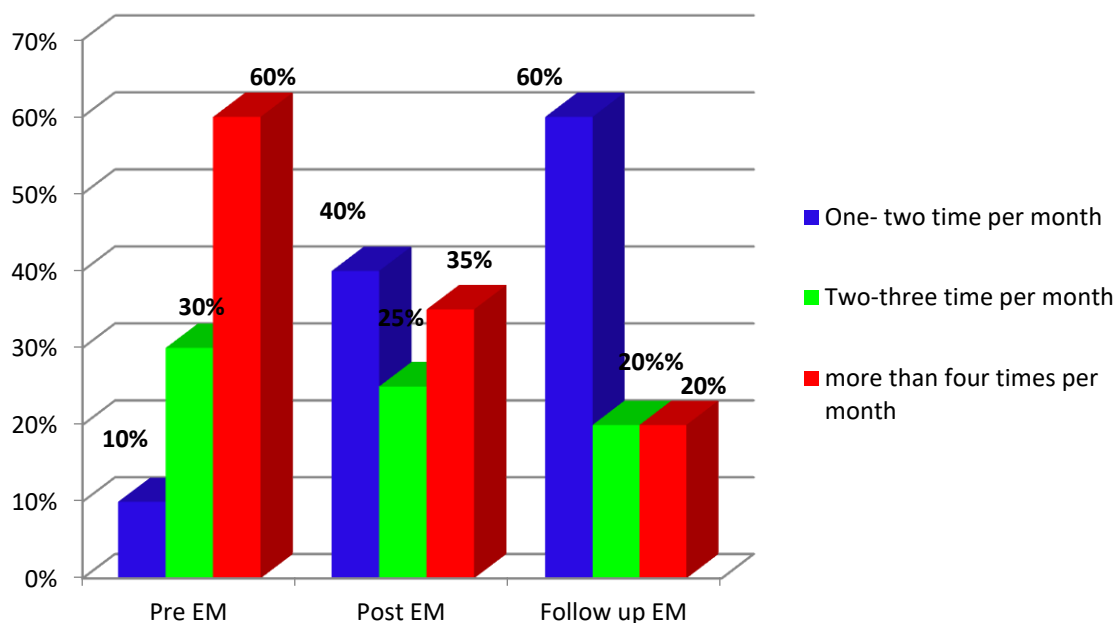


Figure (4): This table demonstrates that, 60% of the studied children had hospitalized more than four times per month pre self learning module implementation compared to, 35 % & 20 % of them post and follow up self learning module implementation respectively.

4. DISCUSSION

Blood diseases are one of the most common human genetic diseases in the world and it causes many problems for pediatric patients, families and health care system. Thalassaemic children must be cared continuously throughout their lives. However, they need to be given a helping hand by their families for continuous treatment of regular or occasional blood transfusions and iron chelators. Hemophilia is lifelong condition so; caregivers and their children need to learn about the condition in order to live a positive manner with the situation. Educations about practices related to care of hemophilic children, make caregivers in good deal with their children to live healthy and normal life (**Prasomsuk et al., 2007 and Header et al., 2016**).

This study aimed to evaluate the effect of self learning module on caregivers of children with common blood disorders through assessing knowledge, practices and attitude of caregivers about common blood disorders, designing and implementing self learning module about common blood disorders and evaluating the effect of self learning module on caregivers of children with common blood disorders post and follow up self learning module.

As regards the age of the studied caregivers, the present study clarifies that, all of caregivers were mothers and near to half (42.5%) of them, their age ranged between 25<35 years old with mean age 35.60 ± 10.2 year. This result is supported by (**Radha et al., 2015**) who found in their study entitled (burden of caregivers care for children with thalassemia) that, almost of caregivers (mothers) their age ranged between 18 to less than 38 years old . Also, this result is in agreement with (**Schwartz et al., 2017**) who revealed in their study entitled (measuring hemophilia caregiver burden: validation of the hemophilia caregiver impact measure) that, mean age of the studied caregivers was 39.24 ± 8.66 .

The result of current study illustrates that, majority (82.5%) of studied caregivers live in rural area, this result is in an accordance with (**Biswas et al., 2018**) who reported in their study entitled (knowledge of caregivers of thalassemic children regarding thalassemia) that, most of the studied caregivers live in rural area. It can be explained in the light of ignorance or limited health service which provided in rural communities. Also, this finding is in agreement with (**Atwa et al., 2016**) whose study about (joint health in Egyptian children with hemophilia). It was found that, more than half of studied children and their parent lived in rural area.

Concerning occupation of the studied caregivers, the present study demonstrates that, high percentages of them (82.6%) are housewife. This result is in the same line with (**Pouraboli et al., 2018**) who reported in their study that, most of the caregivers caring children with thalassemia were housewife. It can be explained that most of mother terminate their work to spend their time to provide care for their children especially if their children have chronic illness

Regarding educational level of the studied caregivers, the result of current study illustrates that, about one third of the studied caregivers had diploma. This result is in accordance with (**Mashayekhi et al., 2016**) who stated in their study about (caregivers' burden and social support in mother with thalassemia) that, high percentage of caregivers had diploma degree.

As regarding age of the studied children, the current study illustrates that, 61.5% & 57.1% of thalassemic and hemophilic children respectively, their age are less than 10 years old. This result is in agreement of (**Header et al., 2016**) who reported in their study that, high percentage of the studied children with hemophilia their age less than 10 years. The present study shows that, 77% & 71.4% of thalassemic and hemophilic children respectively at primary school. This result is supported by (**Shaligram et al., 2014**) who stated in their study about (psychological problems and quality of life in children with thalassemia) that, high percentage of the study sample were in primary school.

The current table clarifies that, most of thalassemic and hemophilic children (77% & 85.7%) respectively, their age at onset of disease, less than one year old. This result is in agreement with the results of (**Dakhkhny, et al., 2011**) who conducted study about (quality of life of school age thalassemic children at Zagazig city) that, the majority of the studied children were diagnosed as thalassemia by the first year of life. On the other hand, the findings of present study illustrated that high percentage (54% & 71%) of the thalassemic and hemophilic children respectively are second birth order, this result was matched with (**Abo Samra et al., 2016**) who clarified in their study that, birth order of the affected child in the family was the second. Also, this result goes in the same line with (**Header et al., 2016**) who conducted study entitled (assessment of mothers' practices regarding their children with hemophilia in blood disease) that, high percentage of the affected child in the family was second birth order.

Concerning school attendance of the studied children, the current study illustrates that, 53.8% & 78.6% of thalasemic and hamophillic children respectively are irregular in school attendance. This result was in the same line with **(El - Dakhakhny et al., 2011)** who found that, most of the thalasemic children had low quality of life regarding school functioning and missing school to go to hospital. Also, this result is supported by **(El - Dakhakhny et al., 2014)** who conducted study about (impact of health instructions on improving knowledge and practices of haemophilia in adolescents) that, 60% of the children were irregular at school. It may be due to child hospitalization or fear of mother form bleeding episodes at school.

Also, the finding of the current study reveals that, 69.2% & 78.6% of thalasemic and hamophillic children respectively are irregular in compliance to their treatment. This result is consistent with **(Elsaid, 2009)** whose study findings revealed that studied sample was not compliant with treatment plan. This may be due to the painful procedure, long periods of infusion or limited activity during the use of desferral bump, and also side effects of oral chelators as abdominal pain, diarrhea and vomiting.

As regards history of consanguinity, the current study illustrate that, there are positive history of consanguinity among 69.2% & 85.7 % of hamophillic and thalasemic children respectively. This result is in an accordance with **(Shawky et al., 2013)** who found in their study which examines the effect of consanguineous marriage on genetic diseases that, consanguineous marriage had detected in more than two thirds of cases with blood diseases. It can be explained in light of our habits and tradition that the marriage should be within the family or relative.

Concerning family history of the studied children, the present study illustrates that, 76.9% & 71.4% of thalasemic and hemophillic children respectively had positive family history, this result is consistent with **(Arif et al., 2008)** whose result about (awareness among parents of children with thalassemia major) clarified that, 40.8% of the cases had positive family history.

The findings of present study clarifies that, 50 % & 70 % of thalasemic and hemophillic children respectively have positive family history in their sibling, this result is almost in an accordance with **(Hashim, 2006)** who conduct study concerning thalasemic children that, there was a positive family history among 40% of siblings. Also, this result is supported by **(Price and Gwin, 2008)** who stated that the child's family history is of particular importance in the diagnosis of hemophilia. When hemophilia is present in the family and the pediatric patient has had periods of abnormal bleeding from early childhood, the determination is relatively easy.

It is recommended in current practice for transfusion therapy in Arabian Gulf countries that regular blood transfusions is administered for every 2–5 weeks in order to maintain the pre-transfusion Hb level above 9.5–10.5 g/dl. **(Cappellini et al., 2008)**. The findings of present study illustrates that, near to three quarters of studied children received blood transfusion twice per month, this result is in an agreement with **(Eissa and El-Gamal, 2014)** who illustrated in their study that, majority of the studied thalasemic children had regular blood transfusion at a rate of twice / month. It may be due to severity of the disease and level of heamoglobin pre transfusion

Concerning bleeding episodes among hemophillic children, the result of the present study illustrates that, 37.8% of hemophillic children had bleeding episodes three - four episodes per month, this result is in an accordance with **(Dakhakhny et al., 2014)** who found in their study entitled (impact of health instructions on improving knowledge and practices of haemophilia A adolescents) that bleeding frequency represents three – four episodes / month among 36% of hemophillic children.

The result of present study reveals that, one third of caregivers (30%) achieves good knowledge level pre self learning module. Meanwhile, follow up of self learning module clarifies that, more than half (52.5%) of caregivers have good knowledge levels. Therefore, total knowledge of caregivers' (mothers) about disease and its management were significantly improved after self learning module implementation, this result is in an accordance with **(Najafi, et al., 2011)** who reported in their study entitled (the effect of centered empowerment on the mothers' knowledge and attitude about thalassemia disorder) that, there was statistical significant difference towards mothers awareness before and after intervention. Additionally, **(Wacharasin, et al., 2015)** who illustrated in their study which aimed to examine the usefulness of an empowerment program on beliefs of families caring for a child with thalassemia that, the empowerment programme helped families to develop their ability to provide care for their chronically ill child. Also, the result of present study is supported by **(Kang et al., 2010)** who stated that, self-help programme for mothers of haemophilic children could improve their knowledge and quality of life.

The current study demonstrates that, pre self learning module implementation, only 20% of the studied caregivers have satisfactory reported practice towards caring child with common blood disorders meanwhile, in follow up of self learning module, 65% of them have satisfactory reported practice. This result is in an accordance with (Hussein et al., 2013) who had found in their study that, mother practice regarding hemophilia improved after implementation of educational program compared to their practice before the programme. Moreover, (Qadir and Hussein, 2013) had reported in their study that there was improvement in mothers' practice regarding care of their thalasemic children after programme implementation compared to their practice before the programme.

Concerning attitude of the studied caregivers, the current study illustrates that, only 30% of the studied caregivers have positive attitude pre self learning module implementation. Meanwhile, in follow up self learning module, more than half of caregivers (57.5%) have positive attitude towards caring of their children with common blood disorders. This result is in the same line with, (Pourdehkordi et al., 2008) who investigate the effect of booklet method on improving attitude and awareness of parent of children with thalassemia major, it was found that attitude of their parent had improved after receiving booklet compared to their attitude before intervention. On the other hand, the finding of current study is supported by (Khanam, 2015) who found in his study that, health programme was able to improve maternal knowledge and attitude about thalassemia disorder.

The current study clarifies that, there are statistical significance differences pre, post and follow- up of self learning module implementation towards indicators of its effectiveness namely: frequency of blood and plasma transfusion ($X^2=5.33$, P value <0.05). Meanwhile, there are highly statistical significance differences towards bleeding frequency, school attendance and compliance in treatment ($X^2=40.00$ & 52.28 & 26.17 , P value <0.001). This result is consistent with, (Elsayed, 2015) who found in her study that, there are statistical significant difference pre, post and follow up of self learning package as regards indicator of SLP effectiveness namely: frequency of blood transfusion and school attendance .

As regarding frequency of hospitalization, the result of present study clarifies that, 60% of the studied children had hospitalized more than four times per month pre self learning module implementation compared to 35 % & 20 % of them, post and follow up self learning module implementation respectively. This result is in an accordance with (El-Sayed and Hussein, 2002) who found in their study that frequency of hospitalization of thalasemic children dropped after implementation of educational intervention on maternal management of children with Beta thalassemia.

5. CONCLUSIONS

There was a positive effect of self learning module on improving knowledge, practice and attitude of the caregivers of children with common blood disorders.

6. RECOMMENDATIONS

1. Establish a regular self learning module for caregivers of children who are newly diagnosed by chronic blood disorder.
2. Apply self learning module based on information technology for caregivers of children with other blood disorders to relieve stressors among families caring children with blood disorders.
3. Encourage caregivers and their children to carry the I.D, when they went to school to identify their conditions, if they had any accident or bleeding episodes away from home.
4. Further researches should be done for caregivers of children having chronic blood disorders to cope positively with the disease as well as maintaining knowledge and practice up to date.

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