

Effect of an Educational program on Nursing Care Practices regarding Pediatric Transfusion-Dependent β -Thalassemia Major

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Abstract: Pediatric β -thalassemia major must be treated with life-long blood transfusions. Therefore, pediatric nurses should have safe and competent practices. **Aim:** The study aimed to evaluate effectiveness of an educational program in improving nursing care practices regarding pediatric transfusion-dependent β -thalassemia major. **Design:** A quasi experimental design was utilized to conduct this study. **Settings:** The study was conducted at in-patient and out-patient Pediatric departments affiliated to both Suez Canal University Hospitals and Ismailia General Hospital. **Subjects:** A convenient sample comprised 60 nurses from the previously mentioned settings. **Tools:** Three tools were used to collect data: *Tool (1)*, A structured interviewing questionnaire sheet concerned with nurses' personal data and their knowledge regarding pediatric transfusion-dependent β -thalassemia major. *Tool (2)*, Routine Blood Transfusion Knowledge Questionnaire to assess nurse's knowledge about blood transfusion. *Tool (3)*, Observational checklists to assess nurses' practices regarding pediatric transfusion-dependent β -thalassemia major. **Results:** The results revealed that, statistically significant improvement in the knowledge and practices of the studied nurses regarding pediatric transfusion -dependent for pediatric β -thalassemia major post implementation of the program than pre-program. Also, there was a positive correlation between total nurses' knowledge and practices post-implementation of the educational program. **Conclusion:** Studied nurses' total knowledge and practice scores regarding pediatric transfusion-dependent β -thalassemia major were improved post-implementation of the educational program than pre-program implementation. **Recommendation:** The study, emphasized on the importance of continuous training programs for pediatric nurses regarding pediatric transfusion-dependent β -thalassemia major

Keywords: Educational program, Pediatric transfusion-dependent β -thalassemia major, Nursing care practices.

1. INTRODUCTION

Thalassemia is a genetic disorder that involves abnormal hemoglobin formation (Quirolo and Vichinsky, 2016). Hemoglobin comprises of alpha and beta chains. In children with thalassemia, problems arise because there is a lack of healthy hemoglobin that the body requires for it to become properly oxygenated. The main cause behind thalassemia is always the defective synthesis of alpha or beta chains (Moghaddam et al., 2012). There are two main categories of thalassemia which are alpha and beta thalassemia that are then divided into further subcategories (Arbabisarjou et al., 2015).

β -thalassemia major is a common health problem in Egypt; it has been estimated that 1000 children with β -thalassemia are born annually for every 1.5 million live births. The carrier's rate of β -thalassemia in Egypt was reported to be 9–10%. β -thalassemia imposes serious physical, socio-mental, congenital and economic effects to the children and their families (Tubman et al., 2015). Physical Problems such as chronic anemia, bone deformation, growth change, short height and delayed physical maturing on the one hand and unpleasant as well as long and repetitive therapies on the other hand affect different life aspects of the children (Wong et al., 2016).

β -thalassemia must be treated by life-long regular blood transfusions (Coifman et al., 2014). Long-term blood transfusions may generate iatrogenic hemosiderosis, resulting from the accumulation of iron in different tissues which are fatal for thalassaemic children (Shahramian et al., 2013). Iron chelation therapy is the mandatory method of preventing further organ damage as a serious complication caused by iron accumulation from blood transfusions (Elalfy et al., 2012; Kwiatkowski, 2012).

The pediatric nurse can play a vital role in the care of children with β -thalassemia (Baraz et al., 2016). Nurses provide experienced, skilled support and encouragement throughout an often standardized treatment regime. In particular, nurses should be sure that children and their families are educated about their disease and about the treatment options available (Ahmadi et al., 2014).

Pediatric nurse practitioners are trained to treat children with β -thalassemia, meet their specific needs and counsel all family members on preventive treatment measures and serious complications. Pediatric nurse practitioners evaluate every child with thalassemia during visits for their routine transfusions under the supervision of a hematologist (Kiani et al., 2016). A nurse provides continuing education and monitors compliance with chelation therapy (Shahramian et al., 2013). They also provide support regarding the diagnosis and therapy, and identify all necessary resources for the family (Baraz et al., 2016).

Significance of the study

β -thalassemia major is a severe early-onset form of blood disorders characterized by severe anemia requiring regular blood transfusions (Arbabisarjou et al., 2015). In Egypt, β -Thalassemia is the most frequent hemoglobinopathy. The carrier rate of this disease varies between 5.3-9% and the gene frequency is 0.03%. It was estimated that 1000/1.5 million per year live birth born with thalassemia disease (Tubman et al., 2015). Children with transfusion-dependent thalassemia typically should undergo blood transfusions once or twice a month depending on the severity of the illness. This may force them to spend the entire transfusion day at the hospital with subsequent disruption in education and social activities (Coifman et al., 2014). So that, the current study was conducted to evaluate the effect of an educational program in improving nursing care practices regarding pediatric transfusion-dependent β -thalassemia major.

Aim of the study:

The study aimed to evaluate effectiveness of an educational program in improving nursing care practices regarding pediatric transfusion-dependent β -thalassemia major. This will be achieved through:

1. Assessing nurses' knowledge about pediatric transfusion-dependent β -thalassemia major
2. Assessing nurses' practices regarding pediatric transfusion-dependent β -thalassemia major.
3. Evaluating effectiveness of an educational program on nursing care practices regarding pediatric transfusion-dependent β -thalassemia major.

2. SUBJECT AND METHOD

Design: A quasi experimental research design was utilized to achieve the purpose of the study.

Research hypotheses: Pediatric nurses who received the educational program regarding pediatric transfusion-dependent β -thalassemia major expected to have higher mean scores of knowledge and practices post implementation of the educational program compared with pre implementation.

Setting: The study was conducted at in-patient and out-patient Pediatric departments affiliated to both Suez Canal University Hospitals and Ismailia General Hospital.

Sample: A convenient sample comprised 60 nurses (45 nurses working at Suez Canal University Hospitals and 15 nurse working at Ismailia General Hospital). They were recruited in the study regardless their gender, educational level and years of experience. The study sample also included 50 child diagnosed with β -thalassemia major and treated at the previously mentioned settings.

Tools of data collection:-

Tool 1. A structured interviewing questionnaire was designed by the researchers in simple Arabic language after reviewing related literature. It consisted of two parts. **The first part** concerned with personal characteristics of both

studied nurses and children as age, gender, educational level, years of experiences, previous training, duration of illness and frequency of blood transfusion. **The second part** concerned with assessing studied nurses' knowledge in relation to definition, causes, clinical manifestations, diagnostic evaluation, complications and management of thalassemia major in children.

Tool 2. Routine Blood Transfusion Knowledge Questionnaire (RBTQ) was used to assess nurses' knowledge about blood transfusion it was developed by **Hijji, et al., (2012)**. It consisted of 32 items that measure nurse's knowledge about blood transfusion (2 true-false, 20 MCQ & 10 open ended questions). It is concerned with assessing nurses' knowledge blood bag collection from blood bank, child preparation before transfusion, nursing responsibilities pre & post blood transfusion as well as its complications.

Scoring system: Mean scores of studied nurses' knowledge were calculated, as each correct answer was given one point and incorrect answers were given zero.

Tool 3. Observational checklists were used to assess studied nurses' practices regarding pediatric transfusion-dependent β -thalassemia major.

Blood transfusion observational checklist was adopted from **Cowell, (2009)** and **de Mattia, (2016)**. It was used to assess nurses' practices as regards care of children receiving blood transfusion, nurses' practices prior to blood transfusion (11 items), during blood transfusion (10 items) and after blood transfusion (8 items).

a) Vital signs measurements and administration of I.V iron chelation therapy observational checklists were adopted from **Taylor et al., (2008)**.

Scoring system: Mean scores of studied nurses' practices were calculated as a score of one was given for complete done and a score of zero was given for incomplete done/not done.

Content validity: Content validity of the study tools was assessed and ascertained by a panel of five experts including three in Pediatric Nursing field and two in Pediatrics field to validate its format, layout, consistency, accuracy and relevance. Internal consistency reliability of all items of the tools was assessed using Cronbach's Alpha test. It was 0.83 for the structured interviewed questionnaire sheet and 0.86 for the observational checklists.

Ethical considerations: An official permission was obtained from directors of the previously mentioned settings before starting the study. The researchers obtained oral consent from the studied nurses to participate in the present study after informing them about the nature and aim of the study. Confidentiality was ensured throughout the study process and their data was used for research purpose only and had the right to withdraw from the study at any time.

Pilot study: A pilot study was carried out on 6 nurses who represents 10% of the studied nurses in order to test feasibility, applicability and clarity of the study tools and time needed to complete it as well. According to the results of the pilot, no modifications were required. The nurses participated in the pilot study were included in the study total sample.

Field work: Data collection period was extended over 6 months, from the beginning of October 2018 to the end of March 2019. The researchers were available four days per week (from Sunday to Wednesday) during morning and afternoon shifts. The educational program was implemented through the following phases:

Assessment phase: This phase started with meeting the studied nurses, at the beginning of the interview the researchers introduced themselves to the studied nurses and explained the nature & aim of the study as well as content of the educational program. Each nurse was interviewed individually to assess her knowledge regarding pediatric transfusion-dependent β -thalassemia major using the structured interviewing questionnaire (tool 1 and tool 2). The average time required for completion of both tools was around 20-30 minutes. Meanwhile, studied nurse's practices regarding pediatric transfusion-dependent β -thalassemia major were assessed by the researchers during their actual practices with children, this part took about three weeks. Then studied nurses were divided into ten groups, each group was consisted of 6 nurses.

Planning phase: The educational program was designed by the researchers, after reviewing the related literatures based on results obtained during the assessment phase. It was designed to improve nurse's knowledge and practices regarding pediatric transfusion-dependent β -thalassemia major

Implementation phase: The educational program was implemented for 4 days per week. It was provided in 4 sessions (2 theoretical and 2 practical). Each session ranged between 45 - 60 minutes including time for discussion. The theoretical sessions was prepared to cover items related to definition of β -thalassemia major, its causes, clinical manifestations, complications and management, in addition to precautions and hazards of blood transfusion for pediatric B-thalassemia major. Nursing care practices prior to, during and after blood transfusion as well as measuring vital signs and IV iron chelation therapy were demonstrated to the studied nurses during the practical sessions. Each group of the studied nurses was given the opportunity to choose their optimal time for receiving the program according to their workload and mitigating circumstances of the study setting. Each nurse obtained a copy of the educational program booklet that, included all the training materials. At the beginning of the first theoretical session, an introduction about the objectives of the educational program was given, each session usually started by a summary of what has been taught during the preceding sessions and the objectives of the new one. Different teaching methods were used as: lectures, demonstration and re-demonstration. The training sessions were guided by the material of the educational program prepared by the researchers. Suitable teaching media were prepared and used during the implementation phase as data show, real equipment (for demonstration and demonstration), posters and pictures.

Evaluation phase: At this phase, the researchers utilized results of the analyzed data which obtained during assessment phase as a base for continued intervention, and reevaluate the studied nurses using the same tools to evaluate effect of the educational program on nursing care practices regarding pediatric transfusion-dependent β -thalassemia major.

Statistical analysis: Data obtained from the studied nurses were organized, revised, coded and entered using personal computer. The Statistical Package for Social Sciences (SPSS version 20.0) was used for data analysis. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables and means & standard deviations for quantitative variables. Quantitative continuous data were compared by using t-test to test significance differences between the mean scores of the studied nurses' knowledge and practices pre and post implementation of the educational program. Pearson correlation analysis used for assessing correlation between the studied nurses' knowledge and practices and their personal characteristics. A statistically significant difference was considered at P-value ≤ 0.05 , and a highly statistically significant difference was considered at P-value ≤ 0.001 .

3. RESULTS

Table (1): Percentage distribution of the studied nurses according to their personal characteristics (n=60)

Items	No.	%
Age/ Year		
- < 20	15	25
- 20 < 30	32	53.3
- 30 \geq 40	13	21.7
$\bar{X} \pm SD$		24.9 \pm 5.1
Nursing qualification		
- Diploma in nursing	17	28.3
- Technical institute in nursing	33	55
- Bachelor in nursing science	10	16.7
Years of experience		
- < 3	18	30
- 3 < 6	29	48.4
- \geq 6	13	21.6
$\bar{X} \pm SD$		3.98 \pm 1.9
Place of work		
- Suez Canal University Hospitals	45	75
- Ismailia General Hospital	15	25
Previous training		
- No	60	100
- Yes	0	0

Table (1): clarifies that, 53.3% of the studied nurses were aged between 20 to less than 30 years, with a mean age of 24.9 years, while 55% of them had technical institute in nursing. It also, shows that 48.4% of nurses' years of experience were between 3 to less than 6 years, with the mean years of experience 3.98 years. Concerning place of work 75% of the studied nurses worked at Suez Canal University Hospitals. Also; all of the studied nurses had no previous training regarding pediatric transfusion-dependent β -thalassemia major.

Table (2): Percentage distribution of the studied children according to their personal characteristics (n=50)

Items	No.	%
Age/ Year		
- < 6	18	36
- 6 < 12	22	44
- 12 ≤ 18	10	20
$\bar{X} \pm SD$		8.27 ±3.99
Gender		
- Male	22	44
- Female	28	56
Educational level		
- Not yet enrolled	18	36
- Primary school	22	44
- Preparatory school	6	12
- Secondary school	4	8
Duration of illness per year		
- < 5	16	32
- 5 < 10	10	20
- 10 < 15	12	24
- ≥ 15	12	24
$\bar{X} \pm SD$		9 ±5.38
Frequency of blood transfusion per year		
- < 6 times	15	30
- > 6 times	35	70

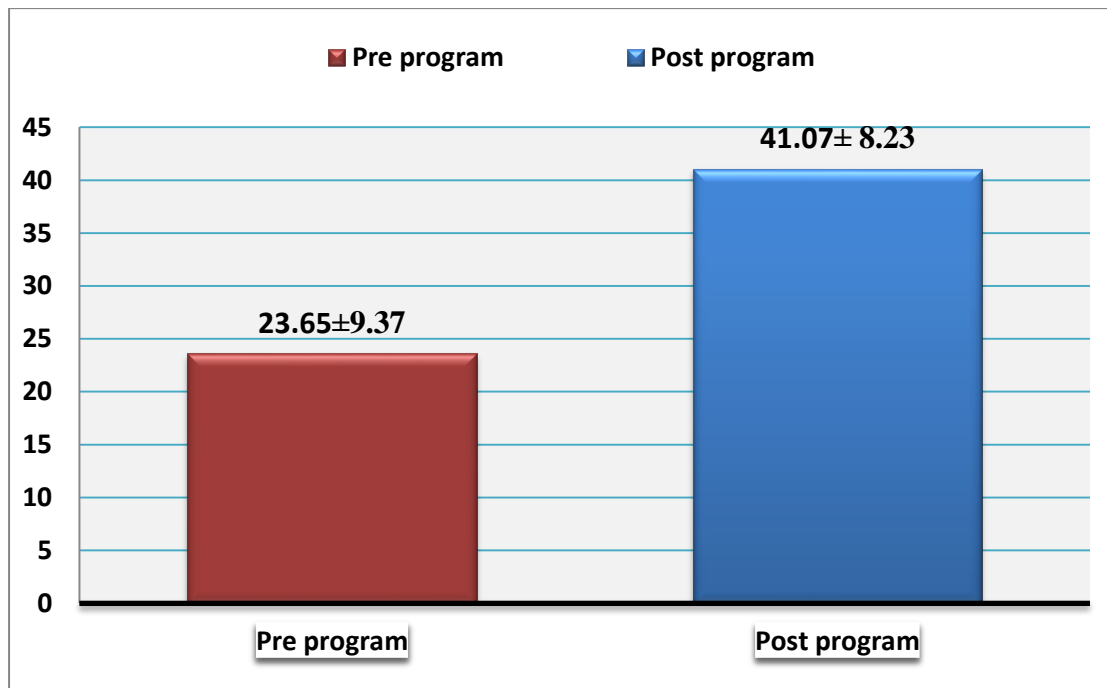
Table (2): shows that, 44% of the studied children were aged between 6 to less than 12 years, with a mean age 8.27 years, while 56% of them were females. It also, illustrates that, 44% of studied children's were in primary school. Regarding duration of illness, 32% of the studied children were diagnosed as β -thalassemia major children for less than 5 years, with a mean duration 9 years. Also, 70% of the studied children were receiving blood more than 6 times per year.

Table (3): Mean scores of the studied nurses' knowledge regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion pre/post- program implementation (n=60)

Item	Pre Mean ±SD	Post Mean ±SD	Significance	
			T-test	P value
Definition	2.79±1.14	4.88±1.22	10.678	.005**
Causes	3.69±2.30	6.09±2.06	12.258	.001**
Clinical manifestations	6.38±2.49	12.57±4.13	13.487	.000**
Diagnostic evaluation	7.08±3.68	13.03±3.67	11.915	.001**
Management and instruction given to children and their parents	2.00±0.94	3.26±1.01	6.553	.015*
Complications	1.57±0.49	2.46±0.67	6.452	.021*
Precautions of blood transfusion	1.38±0.55	2.63±0.81	9.320	.009**
Hazards associated with blood transfusion	1.42±0.71	2.39±0.74	11.320	.003**

*P-value<0.05 ----- statistically significant

Table (3): clarifies that the studied nurses had the high mean scores of knowledge regarding pediatric β -thalassemia major and blood transfusion post program implementation compared to preprogram implementation as regards definition, causes, clinical manifestations, diagnostic evaluation, management and instruction given to children and their parents, complications of β -thalassemia major, precautions of blood transfusion and hazards associated with blood transfusion with a statistical significance difference between pre/post phases of implementation of the educational program at $P < 0.05$.



*P-value < 0.05 ----- statistically significant

Figure (1): Total mean scores of the studied nurses' knowledge regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion pre/post- program implementation (n=60)

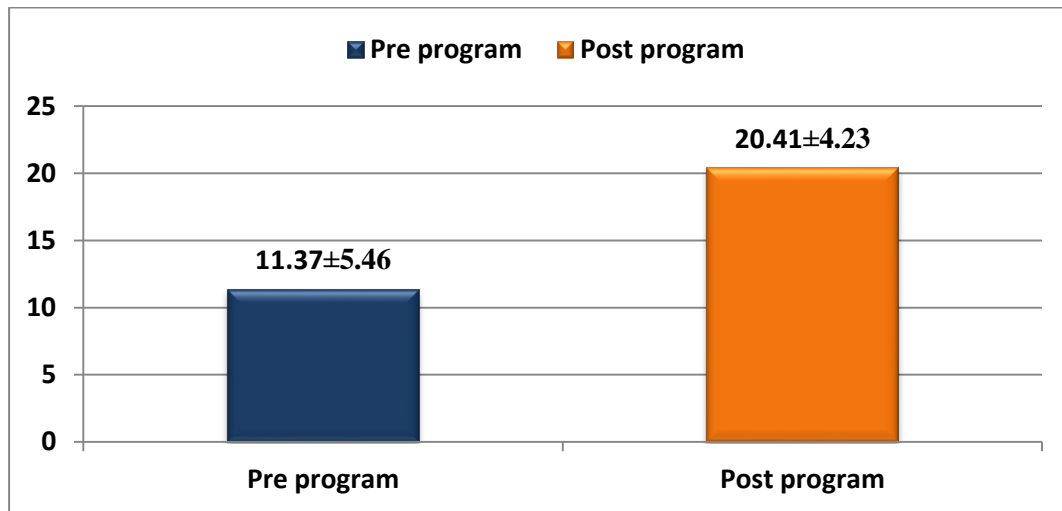
Figure (1): illustrates that, the studied nurses had the high total mean scores of knowledge pediatric transfusion-dependent β -thalassemia major and blood transfusion post program implementation (41.07 ± 8.23) compared to pre program implementation (23.65 ± 9.37).

Table (4): Mean scores of the studied nurses' practices regarding pediatric transfusion-dependent β -thalassemia and blood transfusion pre/post- program implementation (n=60)

Nurses' practice	Pre Mean ±SD	Post Mean ±SD	Significance	
			T-test	P value
Measuring vital signs	5.26±3.06	9.57±2.18	13.602	.001**
Preparation for blood transfusion	2.89±1.91	4.70±2.11	9.014	.005**
During blood transfusion	3.08±1.35	7.99±1.13	10.201	.003**
After blood transfusion	7.59±3.38	9.51±4.38	8.313	.011*
Administration of iron IV chelation therapy	6.99±4.16	11.67±3.81	12.243	.001**

*P-value < 0.05 ----- statistically significant

Table (4): shows that, the studied nurses had the high mean scores of practices regarding pediatric transfusion-dependent β -thalassemia major post program implementation compared to pre program implementation as regards measuring vital signs, preparation for blood transfusion, during blood transfusion, after blood transfusion, administration of iron IV chelation therapy with a statistical significance difference between pre/post phases of implementation of the educational program at $P < 0.05$.



*P-value<0.05 ----- statistically significant

Figure (2): Total mean scores of the studied nurses practices regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion pre/post- program implementation (n=60)

Figure (2): clarifies that, the studied nurses have the high total mean scores of practices regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion post program implementation (20.41±4.23) compared to pre program implementation (11.37±4.64).

Table (5): Correlation between studied nurses' total mean scores of knowledge and practices regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion pre/post- program implementation (n=60)

Items	Total mean scores of knowledge			
	Pre		Post	
	r	P value	r	P value
Total mean scores of practice pre	0.295	0.05*		
Total mean scores of practice post			0.431	0.001*

* P-value <0.05 ----- statistically significance

Table (5): clarifies that, there was a positive statistical significant correlation between total scores of nurses' knowledge and their total practices' scores regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion pre/post- program implementation at $p < 0.05$.

Table (6): Correlation between studied nurses' knowledge and practices regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion post- program implementation and their personal characteristics (n=60)

Nurses' personal characteristics	Nurses' knowledge		Nurses' practice	
	r	P value	r	P value
▪ Age	0.578	0.012*	0.618	0.011*
▪ Educational level	0.418	0.001*	0.547	0.014*
▪ Years of experience	0.412	0.013*	0.649	0.015*
▪ Previous training	0.529	0.001*	0.528	0.001*

* P-value <0.05 ----- statistically significance

Tables (6): illustrates a significant statistical correlation between total knowledge and practice of the studied nurses and their personal characteristics (age, educational level, years of experience & previous training) pre and post implementation of the educational program ($P < 0.05$).

4. DISCUSSION

B-thalassemia major is one of the commonest recessive genetic diseases that results in a severe anemia. Therefore, children with β -thalassemia major need regular blood transfusions in order to live (**El sayed and Abd El-Gawad, 2015**). Pediatric Nurses play an integral role regarding blood transfusion for children with B-thalassemia. Thus nurses must have adequate knowledge and skills that ensure and maintain child 'safety (**Abd Elhy and Kasemy, 2017**).

Concerning the personal characteristics of the studied nurses, the study results revealed that, half of the studied nurses were aged between 20 to less than 30 years with a mean age of 24.9 years, graduated from technical institutes of nursing and having years of experience ranged between 3 to less than 6 years. It also revealed that, three quarters of them working at Suez Canal University Hospital and all of them had no previous training regarding blood transfusion for pediatric B-thalassemia major. These results were not in the same line with those of **Elewa and Elkhattan, (2017)** whom evaluated the Effect of an Educational Program on Improving Quality of Nursing Care of Patients with Thalassemia Major as Regards Blood Transfusion. They found that almost half of the studied nurses were aged between 30 to less than 40 years, with years of experience less than 5 years. While three quarters of them had nursing diploma and didn't receive previous training about thalassemia and blood transfusion.

The findings of the study clarified that, the studied children had a mean age of 8.27 years, more than half of them were females, two fifth were enrolled in primary schools, about one third had a duration of illness for less than 5 years and more than two thirds of them had a frequency of blood transfusion for more than 6 times per year. This was in agreement with those of **Abu Samra et al., (2015)** whom investigated the Impact of Educational Program regarding Chelation Therapy on the Quality of Life for B-thalassemia Major Children, and found that, about two-thirds of the studied children were aged between 8 to less than 12 years and more than half of them were girls and were in primary school. They also found that, 32.9% of them had the disease for about 12–15 years and two thirds of them received blood twice per month.

On assessing studied nurses knowledge regarding pediatric transfusion-dependent β -thalassemia major, the study results showed a highly statistical significant improvement in nurses' knowledge regarding definition of β -thalassemia major, its causes, clinical manifestations, management, precautions of blood transfusion and its hazards post implementation of the educational program compared with pre implementation. Also, there were significant improvement regarding total mean scores of the studied nurses knowledge regarding pediatric transfusion-dependent β -thalassemia major and blood transfusion throughout the study phases. These results could be attributed to lack of continuous training and education of the studied nurses, as well as lack of sources of knowledge and guidelines of nursing care. These results were similar to **Abolwafa et al., (2018)** whom conducted a study about Improving Quality of Nursing Care among School Age Children with Thalassemia Major as regards Blood Transfusion. They found a significant improvement in all items of knowledge among the studied nurses after implementation of the educational program. As stated by **Khouri et al., (2011)** that, education could enhance nurses' ability to be more effective as a direct care provider.

In relation to studied nurses practices regarding pediatric transfusion-dependent β -thalassemia major, the study results illustrated a highly significant improve in the total mean scores of the studied nurses practices (prior, during & after blood transfusion, vital signs measurements and IV iron chelation therapy) post implementation of the educational program compared with pre implementation. From the researchers point of view, these findings could result from shortage of both qualified nurses and training programs which, emphasizes the importance of on job training in improving nurses performance. These results was concurrent with those of **Abolwafa et al., (2019)** in their study about Quality of Nursing Care among School Age Children with Thalassemia as regards Blood Transfusion and Self Concept. They found a statistically significant improvement in the studied nurses' practices after program implementation. Furthermore, a study conducted by **Khalaf et al., (2017)** was in accordance with the current study findings and found that, studied nurses demonstrated very low level of competent practice towards caring for children receiving blood transfusion before implementation of the educational program. As stated by **Hijji et al., (2010)** that poor blood transfusion practice among nurses is one of the main causes of the morbidity and mortality of patients who receive blood transfusion. So that, there is a need for blood transfusion policy and current practical guidelines.

The current study findings illustrated a highly significant positive correlation between studied nurses' total knowledge and practices regarding pediatric transfusion-dependent β -thalassemia major pre and post program implementation. These results were similar to **Elewa and Elkhattan, (2017)** whom found a highly statistically significant correlation between nurses' knowledge and their practice in pre- and post-program implementation phases. These findings emphasize on the fact that, the level of practice influenced by the level of knowledge and without correct, sufficient knowledge nurses practices will become more hazardous and inefficient. Furthermore, **Vaghar, (2018)** reported that, training and education are essential for all staff nurses involved in the transfusion procedure as it minimize transfusion errors.

The current study results found a highly statistical significant correlation between studied nurses' knowledge and practices regarding pediatric transfusion-dependent β -thalassemia major post- program implementation and their personal characteristics (age, educational level, years of experience and previous training). These results were supported by **Abed El-Hay et al., (2018)** whom studied the Effect of Educational Guidelines on Nurses` Performance Regarding Management of Patients Undergoing Bone Marrow Transplantation, and found a statistical significant positive correlation among nurses' knowledge and practice and their socio-demographic characteristic. These results could be attributed to the positive relation between level of education and both nurses' knowledge and nursing practice as being stated by **Deborah and Corcoran (2011)**. In addition, **Shafik and AbdAllah (2015)** reported that, the greater the years of experience of the nurses, the greater their knowledge and practices.

5. CONCLUSION

Based on the findings of the current study, there were statistical significant improvements in nurses' knowledge and practices regarding pediatric transfusion-dependent β -thalassemia major post program implementation than pre implementation. Also, there was statistical significant correlation between studied nurses' personal characteristics and their total knowledge and practices scores post program implementation.

6. RECOMMENDATION

The study findings emphasize the importance of implementing planned continuous training programs regarding blood transfusion for pediatric B-thalassemia major for nurses. Plus, clinical protocols of nursing care regarding blood transfusion for pediatric β -thalassemia major should be followed to improve nursing management. Further studies should be conducted to improve pediatric nurses' knowledge and practices regarding blood transfusion for pediatric B-thalassemia major as well in different settings and large samples.

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