ABSTRACT

Pakistan have highest burden of thalassemia major patients. These patients have life expectancy of ten years in Pakistan which is very low as compare to other countries. High-quality nursing care and management of thalassemia major patients is essential. Objectives: To evaluates the understanding of nursing care quality among patients of thalassemia major which frequently have an effect on the patient’s mental and physical health harmfully. Methods: Quasi experimental study was conducted in Mayo Hospital Lahore. The study population was those nurses who were working in thalassemia care units. 30 nurses have been taken by using purposive sampling technique. Data was collected by using an adopted tool to assess the nurse's knowledge and their practices about care of thalassemia major patients. Results: Most of the nurses included in the study had a general nursing diploma (76.67%). The average experience of nurses was 6.04±3.57 years, and 97.7% of nurses did not receive any training on thalassemia. Total post knowledge was 49.37±7.686 and total practices score was 61.13±11.672. These findings revealed that continue educational program for nurses improve these variables. Conclusions: The present study depicted that majority of nurses have not received any training about nursing care of thalassemia major patients. So, teaching program had a good impact on nurse's understanding of thalassemia, as well as their practice.

INTRODUCTION

The major community problem is thalassemia over the world that is most common inherited disorder [1]. This is described as a fault in the genes which are accountable for the hemoglobin production. Hemoglobin contain alpha and beta chains. In case of intrinsic changes wait for course of activity of beta cell chains at that point beta thalassemia happens which joins scattered progression of withdrawn blood elements [2]. Alpha thalassemia happens due to deletions and point mutations in alpha-globin genes and inadequate alpha production [3]. Thalassemia major patients are born normal at birth but later they develop serious fall in HB and develop anemia in the first year of their life [4]. Thalassemia major patients suffer from heart failure can died between 20 to 30 years. Patients with thalassemia major require a significant set up management of routine blood transfusion each three to four weeks, and chelation treatment to push out iron from the body makes a refinement create well again the result [1]. Thalassemia is a challenge for thalassemia patients and thriving worry framework. Because these patients need a lifelong treatment of transfusion and chelation therapy [5]. Annual births of 5000 children every year in Pakistan. The estimated carrier rate is 11%, with 9.8 million carriers in the total population. One lakh is the most commonly expected figure of thalassemia major patients which are dependent of blood-transfusion in Pakistan. This adds to a yearly loss of 1.46 million to 2.92 million disability adjusted life years which leads a vast financial burden internationally [6].
estimated life of thalassemia major children is approximately ten years in our country which is too much low from the international standard [7]. The reason of this short life expectation can be the inappropriate nursing knowledge and nursing practices [8]. The foundation of thalassemia major patient’s care is transfusion of blood. Pakistan needs to take basic movement for improvement of nursing care of thalassemia major patients. The rationale of treatment is double toward move forward the shortcoming and to cover the inadequately erythropoiesis. Mistakes and insufficiently organization of patients during transfusion can cause to serious hazards to individuals with thalassemia major[9]. Nurses are responsible for care of patients with thalassemia major care and this is the basic part of their duty[10]. Nurses have to be outline understanding of the patients’ needs. Quality of nursing care includes that things have been done right, moving forward almost to thalassemia patients and the community [11]. The nurse plays a critical role in thalassemia major patients care of patients with disorders of hemoglobin [10]. This disease is very tough to manage properly and life threatening if it left untreated. However, this situation can be managed effectively if we share professional knowledge and expertise about its prevention and treatment [12]. Nursing care can subsequently be seen to be obliging sincerely and skillfully to fulfill the necessities of thalassemia major patients. Lack of education is a barrier to optimal care, which should be addressed in thalassemia units [13]. Thalassemia major patient’s nurses should be aware about the disease and management because nurses play an important role in every healthcare team for caring patients [14]. Good nursing services given to thalassemia patients in Pakistan are not sufficient as compare to world [15]. This study evaluates the understanding of nursing care quality among patients of thalassemia major which frequently have an effect on the patient’s mental and physical health harmfully. So, nurses having knowledge and health-related practices about thalassemia major will develop the nursing care of patients diagnosed with thalassemia major, reduce the stay of patients in hospital, and automatically it will reduce the economic burden of patients and the country.

M E T H O D S

A quasi experimental study design was adopted to evaluate the effect of nursing education, practices related to nursing care of patients diagnosed with thalassemia major. Data were collected by purposive sampling technique from thalassemia units in Mayo Hospital Lahore. The calculated sample size was 30 nurses, who are working in the pediatric medicine hematology and thalassemia care units. Male and female nurses both are included in the study. Study nurses and management level nurses were also excluded from the study. The researcher collected data about nurse's knowledge and practices regarding thalassemia patients nursing care, disease management during transfusion of blood and iron chelation. A validated tool has been used for data collection. Socio demographic features of nurses that include sex, age, marital status, education, any training about thalassemia and knowledge of nurses about caring to patient’s with thalassemia major. Knowledge total score was 100% and considered poor if it was (less than 60%), if the percentage was between (60 - 75%) it was considered average, and it was considered good if the percentage was more than 75 %. Less than (80%) practices were considered unsatisfied and considered satisfied if they were (80 % and more). Permission from the higher authorities of university as well as inform consent were taken. Data were entered and analyzed in SPSS version 25.0. Mean and standard deviation were used for quantitative variables and frequency and percentages for qualitative variables. Paired sample t- test was applied to compare the scores of knowledge and practice. P-value ≤ 0.05 is considered statistically significant.

R E S U L T S

In this study, the mean age of nurses was 28.73±3.15 years, where 60% of them were between the age group of 20-<30 years and 40% of them were 30-<40 years of age group. Out of the total 30 nurses, 01(3.3%) were male and 29(96.7%) were females. Most of the nurses included in the study had a general nursing diploma 23(76.67%). The average experience of nurses was 6.04±3.57 years, and 97.7% of nurses did not receive any training. All these results are shown in Table 1.
Discussion

A complex series of illnesses known as thalassemia is prevalent in Southeast Asia and the Mediterranean. It is very important to help thalassemia patients become aware of their disease and learn good self-management, nursing support is required, avoiding problems, using procedures, and transferring pediatric patients to the medical staff and genetic counseling. In the treatment of thalassemia patients, the nurse is essential. Therefore, it is crucial to provide a nursing service that is seamless, integrated and appropriate for patients in either acute or community settings. Furthermore, nurses are critical in assisting thalassemic patients in becoming aware of their disease and learning effective self-management techniques [16]. In the current study, thirty nurses who provided care for thalassemia patients receiving blood transfusions were included. Sixty percent of these nurses were between the ages of 20 and 30. This finding may be related to the fact that nurses in this age range frequently provide care for thalassemia patients receiving blood transfusions. The current study’s findings showed that the average experience was 6 years and 97.7% had not participated in the training. It may be related to the lack of nursing staff, which prevents these units from allowing them to attend any training sessions to prevent interruptions in work due to their absenteeism, or it may be related to the fact that the unit lacks nurse training programs [17]. Elewa revealed in his study that more than two-fifths of them had less than five years’ experience and that more than two-thirds had not participated in training programs on thalassemia and blood transfusions [18]. Regarding educational attainment, the majority of nurses in the current study were general nursing diploma holders, which may provide insight into the state of nursing qualifications today. A study showed that almost half of thalassemia patients (48.5%) were getting poor quality of care. Nurses have poor knowledge and improper practice for the management of thalassemia major patients [13]. In the current study after program implementation the success rate of nursing care was 93.33%. A study concluded that studied nurses showed an improvement in their knowledge and practices regarding blood transfusion after the implementation of guidelines. The educational programme had a positive impact on nurses’ understanding and practise of thalassemia, blood transfusion, and chelation therapy, according to study results, which enhanced the standard of nursing care for patients with thalassemia major [18]. In the current study, nurses’ knowledge was unsatisfactory, which may have been due to poor basic education preparation, a lack of interest on their part in learning new skills, work overload, or a lack of ongoing educational opportunities regarding the care of patients with thalassemia receiving blood transfusions. If nurses can transfuse blood and its components appropriately, scientifically, and safely, the likelihood of blood transfusion dangers will be minimized. Nurses play a major part in this process [19]. According to the results of the current study, there was very poor percentage of nursing practice domains of the nursing role in the initial phase of blood transfusion, during transfusion, after blood transfusion, vital sign measurement, and iron chelation therapy delivery. The findings of this study confirmed a statistically significant differences between pre- and post-educational programs with regard to nurses’ understanding and practice of thalassemia, blood transfusion, and chelation therapy. The study outcomes ensured that the educational program has had a good impact on nurses’ knowledge and practices for the management of thalassemia major patients. A study was confirmed that more than two-thirds had not participated in training programs on thalassemia and blood transfusions [18]. In the current study, the knowledge and practices of nurses caring for thalassemia major disease and blood transfusion were highly significant (P<0.05) and mean scores were improved after educational training implementation of the program.

| Items                  | Pre Program Mean ± SD | Post Program Mean ± SD | Paired t test | p-value |
|------------------------|-----------------------|------------------------|--------------|---------|
| Total Knowledge        | 26.43±1.593           | 49.37±11.642           | 11.642       | .000    |
| Total Practice         | 35.67±13.66           | 61.13±11.672           | 11.653       | .000    |

Table 1: Distribution of Nurses’ socio-demographic characteristics

Table 2: Reveals nurse's knowledge and practices about thalassemia major patients, pre and post program implantation. Post program test shows significant improvement in knowledge and practices of nurses caring for thalassemia major patients. After program implementation the success rate of nursing care was 93.33%. In this study, the knowledge and practices of nurses are about thalassemia major disease and blood transfusion were highly significant (P<0.05) and mean scores were improved after educational training implementation of the program.

Table 2: Pre & post-program implementation of nurses’ knowledge and practice

Conclusions

The study outcomes ensured that the teaching program had a good impact on nurse's knowledge and practices for the care of patients with thalassemia receiving blood transfusions. If nurses can transfuse blood and its components appropriately, scientifically, and safely, the likelihood of blood transfusion dangers will be minimized. Nurses play a major part in this process [19]. According to the results of the current study, there was very poor percentage of nursing practice domains of the nursing role in the initial phase of blood transfusion, during transfusion, after blood transfusion, vital sign measurement, and iron chelation therapy delivery. The findings of this study confirmed a statistically significant differences between pre- and post-educational programs with regard to the nurses understanding and practice of thalassemia, blood transfusion, and chelation therapy. The study outcomes ensured that the educational program has had a good impact on nurses’ knowledge and practices for the management of thalassemia major patients.
the care of thalassemia major patients. There is an urgent need to start an educational program on nursing care of thalassemia major patients based on knowledge and practices. Alternatively, the patients of thalassemia major are at risk of acquiring bacterial infection and serious reactions due to poor nurse's knowledge and their practices. Deprived of resolving the present condition, patients attain good quality nursing care is a patient's right which will remain to be violated subsequently it will cause poor patients management.

**Conflicts of Interest**
The authors declare no conflict of interest

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