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Original Article

Assessment of Nursing Knowledge About Care of Patients Diagnosed with Thalassemia Major

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INTRODUCTION

Thalassemia is a major genetic blood syndrome caused by a lack of or dysfunctional hemoglobin [1]. Hemoglobin (Hb) is a protein in red blood cells, which involves four subunits and each unit consists of heme and globin chains [2]. There are two types of globin chains, alpha and beta chains. If genetic mutations prevent beta chain formation, beta-thalassemia develops, resulting in abnormal red blood cell development and, eventually, anemia and alpha-thalassemia are produced by a transformation in the alpha-globin gene [3]. The thalassemia genotype can cause an individual to be either a carrier or a patient [4]. According to the World

ABSTRACT

Thalassemia is a life-threatening disease and patients with this require whole-life medical care. Nurses play the most important part in the care of such patients. **Objective:** To assess the knowledge among nurses who are dealing with and their role in the management of thalassemia patients. **Methods:** In this study, a pre-test and a post-test were conducted among nurses. In the study, a questionnaire was given to 150 nurses to fill out before and after the awareness session who were included in the study. Pre and post-mean score differences were found using the Wilcoxon test, and a relationship was determined between post-mean score and level of experience using Spearman correlation. **Results:** The mean age of the participants was 28.73 \pm (3.15) years. Comparison of the nurses' pre- and post-session mean knowledge scores revealed that the nurses' post scores in knowledge (39.48 \pm 2.08) were higher than their pre-receiving guide scores (21.18 \pm 3.47) and that the difference was statistically significant (Z = -10.62, P = 0.000). **Conclusions:** According to the facts of this study, on the post-test, the level of thalassemia knowledge was higher among nurses who had received nursing care protocol training than among those who had not. Nursing level of experience and post-training sessions had a significant relationship.

Health Organization in 2018, 5.2% of people were thalassemia carriers, globally. It was estimated that worldwide almost 1.1% of couples having children with an Hb disorder were at risk and that 2.7 out of 1,000 conceptions were harmed. The occurrence of Hb disorders in over 170 million people has been known for a long time in the Pakistani population [5]. There are ten million carriers of thalassemia in Pakistan and the frequency of beta-thalassemia in Pakistan ranges between 5-7%. This number increases day-by-day, due to poor management of blood transfusion in thalassemia patients.

In Pakistan, almost five thousand children are identified to transmit β -thalassemia most important [6]. The majority of the population belongs to the lower socioeconomic strata, and family units are large, making it difficult to afford the treatment and monitoring of their thalassemic child. There is currently no thalassemia prevention program available in Pakistan at the national level [7]. Though some initiatives have been taken at the provincial level, with legislation for before-marriage screening approved in Khyber Pakhtunkhwa (KPK), Sindh, and Baluchistan, the execution is still difficult [8]. Nurses play an essential role in controlling the quality of life of thalassemia patients, by instructing patients and their families on how to identify and report significant symptoms like fever or pain and highlighting the value of hygiene. Providing timely treatment to thalassemia patients reduces the risk of complications [9]. Lack of nursing knowledge about different aspects of blood transfusion and care of thalassemia patients could be a serious lifesaving threat. Patient gratification has been proposed as an outcome measure of excellent nursing care, along with effective communication, adequate skill, efficient organization, caring attitudes, effective participation, and management systems [10]. Nurses must understand that high-quality care cannot be provided unless the patient is comfortable. Nurse edification is the theoretical and practical exercise given to nurses in order to prepare them for their roles as professional nurses [11]. This study aimed to assess the knowledge among nurses who are dealing with and their role in the management of thalassemia patients. Nurses knowing about thalassemia major could improve the quality of nursing care, reduce the stay of patients in hospital, and automatically reduce the economic burden on patients and the country.

METHODS

It was a comparative cross-sectional study conducted at the pediatric medicine hematology and thalassemia care units of Mayo Hospital Lahore. The study duration was three months and data were collected from March-May, 2022. A purposive sampling technique was used for data collection. The sample size was determined using the Slovene formula by taking a margin of error of 5%. Ethical approval was sought from the Institutional Review Board, University of Lahore prior to the collection of data. Informed consent was taken from all the study participants. Nurses who are working as clinical nurses in the pediatric hematology and thalassemia care units having 1-30 years experience, MSN, Generic BSN, and Diploma holder between the ages of 20-50 years, and those nurses included in the study who have poor knowledge scores in the pre-assessment phase of inclusion. The participants excluded from the study who had attended any additional educational sessions regarding thalassemia care before the research period and student nurses and management-level nurses were excluded from the study. Data were collected through the knowledge assessment questionnaire. Routine Blood Transfusion Knowledge Questionnaire (RBTKQ)[12], was developed to evaluate the nurse's knowledge about thalassemia. These factors were part of the study, sociodemographic characteristics of nurses including gender, age, marital status, qualifications, and training about thalassemia. Data were entered and analyzed in SPSS version 25.0. Quantitative variables were presented in the form of Mean \pm SD. Qualitative variables are presented in the form of frequency and percentages. Wilcoxon signed-rank test was applied after assessing the normality through the Shapiro-Wilk test, to compare the scores of knowledge. To determine the relationship between post mean score with age, and level of experience, the Spearman correlation was applied. P-value ≤ 0.05 was considered statistically significant.

RESULTS

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 150 nurses, 05(3.3%) were male and 145(96.7%) were females. Most of the nurses included in the study had a general nursing diploma of 125(83.34%). 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.

Variables	Frequency (%)			
Age (in years)				
20-<30	90 (60)			
30-<40	60(40)			
Mean±SD	28.73±3.15			
Gender				
Male	05(3.3)			
Female	145 (96.7)			
Eduactional Level				
General Nursing Diploma	125(83.34)			
Bachelor of Science in nursing	10 (6.67)			
Masters degree	05 (3.33)			
Speciality (any)	10 (6.67)			
Years of experience				
1-5	80 (53.33)			
6-10	35(23.33)			
Above 10	35(23.33)			
Average experience	6.04±3.57			
Training program				
Yes	05(3.3)			
No	145 (97.7)			

Table 1: Demographic Characteristics of Nurses'

Table 2, reveals the pre and post-program implantation of nurses' knowledge about thalassemia. The nurses' prescore was (21.18 ± 3.47) and the post-knowledge score was (39.48 ± 2.08). Significant improvement was seen in pre and post-knowledge (z=-10.62, p=0.000).

Table 2: Mean knowledge scores of the nurses' pre- and postawareness session

Variables	n	Mean±SD	Z /p
Age (in years)			
Before the session mean knowledge scores	150	21.18±3.47	Z=-10.62
After receiving the awareness mean knowledge scores	150	39.48±2.08	p=0.000

The correlation between the nurses' mean knowledge scores with age, and experience in the field was compared, statistical significance difference was determined by the level of experience(p < 0.005)(Table 3).

Table 3: Correlation between the nurses' knowledge scores

Variables	Post-receiving guide mean score	p-value
Age	r=-0.015	0.853
Experience in the field	r=0.557	0.000

DISCUSSION

The results of this study showed a remarkable difference between pre and post-mean scores of nursing knowledge. In the current study, the nurses' post scores in knowledge (39.48±2.08) were higher than their pre-receiving guide scores (21.18±3.47). In Akyol et al., study (2019), the mean pre-score was (42.86 ± 13.84) and the post-course score was (68.90 ± 6.08) [13]. In this study, the post-mean score was higher than their pre-course scores, but in our study, the pre-score was higher than post score and it showed better results. In another study conducted in 2014 by Kaur et al., in the pre-training assessment, the mean score was 51% while in the post-training assessment, the mean score was 85.4% and the difference was statistically significant [14]. Aslani et al., in their study, showed that 18.8% of the nurses correctly responded to the questions related to blood components and blood transfusion [15]. In a study conducted in 2016, it was found that for all the questions the overall mean score and the correct response rate was 60.7% [16]. It was revealed in a study that almost the majority of the nurses lack knowledge related to blood transfusion in thalassemia patients [17]. The gaps in nurses' knowledge and practice could be improved by updating their theoretical knowledge and practical skills through different pieces of training. Nurses should be encouraged to participate in educational programs and such programs may include workshops, distance learning programs, and practical sessions. As in our study, the posttest showed improvement in nursing knowledge, this result was also supported by Abolwafa et al., who investigated in their study the quality of nursing care with Thalassemia [18]. One of the significant parameters in patient care is the participants' less than five years' length of service in their profession and their existing position was thoughtless, which did not provide them with the expertise to have knowledge and skill of blood transfusion and patient care. In the current study, the post-mean scores of the individuals included in this study according to their length of service were statistically significant (p<0.05), and moderately correlated r=0.557. Experience varies from 1 year to 14 years in the present study. The findings of Oznur's study are different from our study. In his, study postsession mean scores of the contributors were statistically insignificant p>0.05, and the duration of service was less than 4 years or 5 or more [13]. Dubey's study determined that the nurses' knowledge levels related to the care of thalassemia patients and blood transfusion was insignificant whose clinical practice was less than five years and more than five years [19]. According to the Thalassemia International Federation's guidelines, patients meet nurses first and spend more time with them as a result, they will have more trust and confidence in them. Nurses do not educate the patients but give them care to patients. The nurse's role is to guide the patients about their best care, self-management techniques, and prevention of complications [20]. The result of this study revealed that training is necessary to increase nursing knowledge and to fulfill in order to provide special care. In the current study, 97.7% of nurses do not have any training. In a study, it was clarified about the importance of nursing knowledge and educational programs to gain practice in the management of the patient and the disease. In a study, 80.0% of nurses did not attend any training regarding thalassemia [21]. This is the major drawback of our study and in a previous study as well. According to the researchers, there has been a lack of recent advances in the care of thalassemia children. Medical professionals and nursing must constantly apprise their knowledge and keep up with innovative inclinations in hereditary disease management. As we know that the results of this study about the significant change between pre and postnursing knowledge, these findings demonstrated that nurses' devotion to evidence-based care during their practice is critical for the improvement of paediatric children's health. Elawa demonstrated in his study that education training programs improved nurses' knowledge and had a positive effect on nursing practice related to thalassemia, blood transfusion, and other related therapies. Therefore, this increased patient satisfaction and nursing care quality [22].

CONCLUSIONS

In our study post knowledge mean score and experience of nurses both are statistically significant. It means both

factors contribute to the overall nursing care in their fields. So, we concluded that according to the facts of this study, on the post-test, nurses who had acknowledged nursing care protocol education had a higher level of knowledge about thalassemia than those who had not. Nursing level of experience and post-training sessions had a significant relationship.

Authors Contribution

Conceptualization: ST Methodology: ST, IS, ZK Formal analysis: HN, HUR Writing-review and editing: TK

All authors have read and agreed to the published version of the manuscript.

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