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EVALUATING THE PROFICIENCY OF NURSES IN MANAGING THALASSEMIA: A CASE OF TERTIARY CARE CENTRE

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Abstract
Thalassemia is a common autosomal recessive blood disorder caused by defective synthesis of hemoglobin chains, leading to chronic anemia. It remains one of the most prevalent genetic conditions worldwide, necessitating skilled nursing care to improve patient outcomes.This study aimed to evaluate the knowledge and practices of nurses regarding the care of thalassemia major patients at a tertiary care hospital.A descriptive cross-sectional study was conducted using purposive sampling. Data were collected from nurses directly involved in the management of thalassemia patients.Among participants, 39.3% demonstrated good knowledge, 35.7% had moderate knowledge, and 25.0% exhibited poor knowledge. Regarding practices, 60.2% of nurses reported good practices, while 39.8% demonstrated poor practices.The study revealed that most nurses possessed adequate knowledge and appropriate practices concerning the care of thalassemia major patients. Nonetheless, identified gaps underscore the importance of ongoing training and professional development programs to enhance nursing competence and ensure optimal patient care.

INTRODUCTION

Thalassemia is an autosomal recessive blood disease characterized by anemia that develops because of damaged synthesis of one or more of the hemoglobin chains (Tarım & Öz, 2022). Thalassemia is one of the most prevalent genetic diseases in the world (Ahmadi et al., 2020). There are two basic groups of thalassemia disorders: alpha thalassemia and beta thalassemia, varying numbers with each of their particular globin genes mutated (Munkongdee, Chen, Winichagoon, Fucharoen, & Paiboonsukwong, 2020). Beta thalassemia, which is a major type of thalassemia, is usually caused by a defect of beta globin protein production.β thalassemia is divided into three categories: thalassemia trait, thalassemia intermedia and thalassemia major (Ropero, González Fernández, Nieto, Torres-Jimenez, & Benavente, 2022). In the first two categories, one of the beta globin genes fails and the quantity of beta globin protein in the cell is reduced by half. In thalassemia major which is also known as "Cooley anemia" the transfusion-dependent clinical phenotype of thalassemia, the absence of β-globin chain production (Shafique et al., 2021). Thalassemia major (TM) represents one of the most serious and common genetic conditions, with 23000 babies born every year (Pepe et al., 2022). Children born with thalassemia major are normal at birth, but develop severe anemia during the first year of life. Other symptoms can include: Bone deformities in the face, fatigue, growth failure, shortness of breath and yellow skin (jaundice). Severe thalassemia can cause early death (between ages 20 & 30 years) due to heart failure (A. Elewa & B. Elkattan, 2017). Annually, around 240 million cases of TM are discovered worldwide, most commonly in the Mediterranean countries and Southeastern Asia. It resulted in 36,000 deaths in 1990 and 16,800 deaths in 2015 due to iron overload in patients with

TM (Alnaami & Wazqar, 2019). B-thalassemia major (TM) is one of the most common inherited hemoglobinopathies in Pakistan, with a gene carrier rate of 5-7% and roughly a pool of 9.8 million carriers in the general population. Currently, approximately 50,000 thalassemia patients are registered with the treatment centers throughout the country (Ehsan, Wahab, Anwer, Iftikhar, & Yousaf, 2020). Nurses play a crucial role in the care of patients with thalassemia major, and their knowledge regarding this condition is essential for providing effective and safe care (Al-Awamreh & Suliman, 2019). Good nursing services given to thalassemia patients in Pakistan are not sufficient as compare to world (Jaing et al., 2021). Lack of education is a barrier to optimal care, which should be addressed in thalassemia units (Tabussam, Afzal, Sarwar, & Khan, 2022). Nursing practices for patients with thalassemia major involve a multidisciplinary approach to provide comprehensive care Perform a thorough assessment of the patient's health status, including physical, emotional, and psychosocial aspects (Bongay & Kynoch, 2022).Thalassemia patients are susceptible to infections due to their weakened immune system. Implement strict infection prevention measures, including hand hygiene, aseptic techniques during procedures, and ensuring a clean and safe environment (Sari et al., 2016). The mortality rate of thalassemia major patient increases because nurses may have inconsistencies in their practices when it comes to caring for thalassemia major patients, the quality of care will be improved if the attention would be given to the nurse's better knowledge and improved practices, so the study is amiable to be conducted to assess the knowledge and practices of nurses about the care of thalassemia major patient at a tertiary care hospital.

The cross-sectional study design conducted to assess the Knowledge and Practices of Nurses about the Care of Thalassemia Major Patient at a Tertiary Care Hospital. The purposive sampling techniques was used.The study population was staff nurses of oncology and pediatric wards of Tertiary Care hospital Lahore. The duration of this study was 9 months. The study sample was 140 calculated through proportion formula. An adapted questionnaire of knowledge and practices was used to gather the information from the study sample. The study was included all the nurses who have at least more than two-year experience. Data gathered from all staff nurses working in oncology and pediatric wards. Data was collected an adopted questionnaire of knowledge and practices of nurses about the care of thalassemia major patient. Initially, permission was taken from the respective institute going for the data collection. After that again permission was taken from the institute from where study will be conducted. After getting permission population was targeted conveniently, questionnaire was floated after the assurance of data privacy and after taking the consent. After getting the require data, data was entered on SPSS for analysis, descriptive statics will be applied. Data normality will be checked, the study tool will be check to ensure the reliability and validity of the tool in our context. Bar charts were made for qualitative variable, and tables were made. Frequency and percentages were also checked. Ethical clearance was obtained from the tertiary care hospital Lahore ethics committee. Informed consent was gained through verbal interaction with the participant and participants were allowed to voluntarily choose to participate in the study, confidentiality of participants was guaranteed and participants were told that there is no penalty for any participant who wishes to withdraw from the study at any time.

METHODS

CHAPTER ANALYSIS

Variable	Category	Frequency%
Age	25-30 years	23 (16.4%)
	31-35 years	48 (34.3%)
	36-40 years	45 (32.1%)
	41-45 years	24 (17.1)
Gender	Male	46 (32.9%)

	Female	94 (67.1%)
Marital Status	Single	75 (53.6%)
	Married	65 (46.4%)
Experience	1-5 years	45 (32.1%)
	6-10 years	59 (42.1%)
	11-15 years	36 (25.7%)
Qualification	Diploma in Nursing	66 (47.1%)
	Post RN	46 (32.9%)
	BSN (Generic)	28 (20.0%)
Department	Oncology	36 (25.7%)
	Pediatric ward	69 (49.3%)
	Others	35 (25.0%)

Table no 1. Demographic characteristics

This demographic table shows that majority of age group with 31-35 years. Majority population were female. The Majority with single marital status. Majority of nurses with 6-10 years' experience. Majority with diploma in Nursing. Majority of nurses working were in pediatrics ward.

Table 2: Knowledge questionnaires

Majority of the Participants have good knowledge regarding "Beta thalassemia major is a genetic disease". Majority of the Participants have good knowledge regarding "Beta thalassemia major leads to decrease in number of red blood cells". Majority of the Participants have good knowledge regarding "Symptoms of beta thalassemia major appears several months after birth". Majority of the Participants have good knowledge regarding "Beta thalassemia major affect growth and physical activity". Majority of the Participants have good knowledge regarding "Blood transfusion is considered the main treatment of beta thalassemia major".

Questions	Respond	Frequency %
Beta thalassemia major is a genetic disease	No	32 (22.9%)
	Yes	108 (77.1%)
Beta thalassemia major leads to decrease in number of red blood cells	No	20 (14.7%)
	Yes	120 (85.7%)
Symptoms of beta thalassemia major appears several months after birth	No	51 (36.4%)
	Yes	89 (63.6%)
Beta thalassemia major affect growth and physical activity	No	37 (26.4%)
	Yes	103 (73.6%)
Blood transfusion is considered the main treatment of beta thalassemia major	No	54 (38.6%)
	Yes	86 (61.4%)

Table 4: Practice questionnaires

Majority of the participants were poor practice regarding "Sterilize and clean the injection bottle with alcoholic swab". Majority of the participants were good practice regarding "Calculate the Desferal dosage according to the doctor prescription". Majority of the participants were good practice regarding "Withdraw Desferal as prescribed with a syringe 10cm". Majority of the participants were good practice regarding "Connect the intravenous catheter to syringe and fixed it to pump"."

Questions	Respond	Frequency%

Sterilize and clean the injection bottle with alcoholic swab	Not done	99 (70.7%)
	Done	41 (29.7%)
Calculate the Desferal dosage according to the doctor prescription	Not done	24 (17.1%)
	Done	116 (82.9%)
Withdraw Desferal as prescribed with a syringe 10cm	Not done	24 (17.1%)
	Done	116(82.9%)
Connect the intravenous catheter to syringe and fixed it to pump	Not done	15 (10.7%)
	Done	125 (89.3%)

DISCUSSION

Majority of Participants respond to correct option to the question that the ''Beta thalassemia major is a genetic disease'' were 108 (77.1%). Majority of Participants respond to correct option to the question that ''Beta thalassemia major leads to decrease in number of red blood cells'' were 120 (85.7%). Majority of Participants respond to correct option to the question that ''Symptoms of beta thalassemia major appears several months after birth'' was 89 (63.6%). Majority of Participants respond to correct option to the question that ''Beta thalassemia major affect growth and physical activity'' were 103 (73.6%). Majority of Participants respond to correct option to the question that ''Blood transfusion is considered the main treatment of beta thalassemia major'' were 86 (61.4%). Majority of nurses select the not Done option were 99 (70.7%) regarding ''Sterilize and clean the injection bottle with alcoholic swab''. Majority of nurses select the Done option were 116 (82.9%) regarding ''Calculate the Desferal dosage according to the doctor prescription''. Majority of nurses select the Done option were 116(82.9%) regarding ''Withdraw Desferal as prescribed with a syringe 10cm''. Majority of nurses select the not Done option were 125 (89.3%) regarding ''Connect the intravenous catheter to syringe and fixed it to pump''.

Conclusion

Based on the findings of my study, it is evident that the current knowledge and practices of nurses regarding the care of thalassemia major patients are already quite good. Nurses demonstrate a solid understanding of the condition and are implementing appropriate care practices. This indicates that efforts in education and training have been effective in equipping nurses with the necessary skills and knowledge to provide quality care for thalassemia major patients.

Limitation

The current study used cross- sectional study design to assess knowledge and practices of nurses about the care of thalassemia major patients.

RECOMMENDATION:

Provide nurses with continuous educational programs with evidence-based guidelines to improve their knowledge and practices regarding the care of thalassemia major patient. The future researchers can play a part to implement education programs and familiar about the care of thalassemia major patient through workshop, training programs, seminar lecture and research

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