

A Descriptive Cross-Sectional Study to Assess Nurses' Knowledge and Practices Regarding the Care of Thalassemia Major Patients in a Tertiary Care Hospital

Hina Rasheed (Corresponding Author)

Post RN, BSN, Department Of Nursing, Superior University, Lahore

Email: hinarasheed224@gmail.com

Rida Bashir

Post RN, BSN, Department Of Nursing, Superior University, Lahore

Email: ridabashir765@gmail.com

Nimra Shareef

Post RN, BSN, Department Of Nursing, Superior University, Lahore

Email: nimrasharif199@gmail.com

Khadija Ikram

Post RN, BSN, Department Of Nursing, Superior University, Lahore

Email: binteikram6@gmail.com

Zunira Amir

Department of Nursing, Superior University, Lahore Email: zuniraAmir@gmail.com

Rubina Jabeen

Principal, Department Of Nursing, Superior University, Lahore

Email: rubinajabeen302@yahoo.com

Abstract

Background: Thalassemia major is a chronic hereditary blood disorder requiring lifelong management, regular blood transfusions, and comprehensive nursing care. Nurses play a vital role in monitoring patients, preventing complications, and promoting adherence to treatment. Adequate knowledge and appropriate clinical practices are essential for ensuring high-quality care for patients with thalassemia major.

Aim: To assess nurses' knowledge and practices regarding the care of patients with thalassemia major and determine the association between demographic characteristics and levels of knowledge and practice.

Methods: A descriptive cross-sectional study was conducted among 140 registered nurses working in pediatric, oncology, and other clinical departments. Participants were selected using a convenient sampling technique. Data were collected through a structured

questionnaire assessing demographic characteristics, knowledge, and practices related to thalassemia major care. Data were analyzed using descriptive statistics and Chi-square tests.

Results: The findings showed that 55 (39.3%) nurses had good knowledge, 50 (35.7%) had moderate knowledge, and 35 (25.0%) had poor knowledge regarding thalassemia major care. Good practice was observed among 80 (60.2%) nurses, while 53 (39.8%) demonstrated poor practice. Educational qualification, clinical experience,

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Corresponding E-mail & Author*:

Hina Rasheed

Email: hinarasheed224@gmail.com

and department showed significant associations with knowledge and practice levels ($p < 0.05$).

Conclusion: Nurses demonstrated moderate to good knowledge and practices regarding thalassemia major care. Professional factors significantly influenced competency levels. Continuous educational programs and specialized training are recommended to enhance nurses' knowledge and clinical practices.

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 (Tarim & Öz, 2022). Hemoglobin is a protein that consists of alpha and beta chains. If the genetic mutations present in the formation of beta chains then beta-thalassemia occurs which involves abnormal development of red blood cells and eventually anemia (Al-Mosawy, 2017). Consequently, the red blood cell age of Thalassemia patients is shorter than normal and easily to break. This leads the patient to experience anemia symptoms. Thalassemia disease is found in males as well as in females (Poysungnoen & Sittisongkram, 2017).

Thalassemia is one of the most prevalent genetic diseases in the world (Ahmadi et al., 2020). There are about 300 million thalassemia patients worldwide (Sheikhi, Naderifar, Mohammad, Mastalizadeh, & Sheikhi, 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).

One of the mainstays of treatment for thalassemia is regular packed red blood cell (pRBC) transfusions. However, transfusions can lead to excess systemic iron overload with accumulation of iron in the heart, liver, spleen, and other tissues, which can lead to severe complications (Sousa, Oliveira, Pessoa, & Barbosa, 2020). Thus, managing post-transfusional iron overload with iron chelation therapy is very critical. There are three main iron chelation agents including deferoxamine (DFO), deferiprone (DFP), and deferasirox (DFX). DFO must be administered subcutaneously or intravenously

up to once a day due to poor oral bioavailability; DFP and DFX may be administered orally up to three times a day (Reddy, Locke, & Badawy, 2022).

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). Nurses should have a solid understanding of the pathophysiology of thalassemia major, including the genetic basis of the disease, the impact on hemoglobin production, and the resulting anemia. Nurses should have a solid understanding of the pathophysiology of thalassemia major, including the genetic basis of the disease, the impact on hemoglobin production, and the resulting anemia (Bajwa & Basit, 2019). They should be knowledgeable about the diagnostic procedures used to confirm thalassemia major, such as complete blood counts (CBC), hemoglobin electrophoresis, genetic testing, and prenatal screening. They should understand the significance of these tests and be able to explain them to patients and their families (Lee et al., 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).

Adequate knowledge of chelation therapy can help maintain a "safe" iron status at all time in children on a regular transfusion regime and minimize the effects of iron overload while optimizing their growth and development (Fakih, Basheer, Ateeq, Ikram, & Asad, 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 major patients require regular blood transfusions to manage their anemia (Needs, Gonzalez-Mosquera, & Lynch, 2018). Nurses play important role in ensuring safe and appropriate blood transfusion practices, including verifying compatibility, monitoring the transfusion process, and assessing for any adverse reactions (Bediako, Ofosu-Poku, & Druye, 2021).

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). These nursing practices should be modified to the individual patient's needs and may vary depending on the healthcare setting and available resources. Improved knowledge and practice among nurses can lead to better outcomes for thalassemia major patients, including improved quality of life and reduced morbidity and mortality (Jin, Ain, Li, & Chun, 2022). 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 nurses 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.

Methods

A descriptive cross-sectional study design was used to assess the knowledge and practices of nurses regarding the care of patients with thalassemia major at a tertiary care hospital. This design was appropriate because the study aimed to determine the existing level of knowledge and clinical practices among nurses at a single point in time. The study was conducted at Jinnah Hospital Lahore, which is a tertiary care hospital providing specialized services to pediatric, oncology, medical, and transfusion-related patients. The target population consisted of registered staff nurses working in oncology and pediatric wards who were directly involved in the care of patients with thalassemia major. A purposive sampling technique was used to select participants according to the study criteria. The total sample size was 140 nurses,

calculated through the proportion formula using a confidence level of 95%, expected proportion of 0.23, and margin of error of 0.07. The duration of the study was nine months. Nurses who were registered, working in clinical areas, directly involved in thalassemia care, and had at least six months of clinical experience were included. Nursing students, interns, trainee nurses, administrative nurses, non-clinical staff, and nurses with less than six months of experience were excluded.

Data Collection Procedure

Data were collected after obtaining permission from the concerned hospital authorities. The purpose of the study was explained to all eligible participants, and informed consent was obtained before data collection. Confidentiality and anonymity of the participants were maintained throughout the study. An adapted structured questionnaire was used as the data collection tool. The questionnaire consisted of sections related to demographic information, knowledge regarding thalassemia major, and practices related to nursing care of thalassemia major patients. The researcher distributed the questionnaire among eligible staff nurses in oncology and pediatric wards during duty hours. Participants were given proper guidance regarding how to fill the questionnaire, and completed forms were collected on the same day or according to participants' availability.

Data Analysis Procedure

After data collection, all questionnaires were checked for completeness and accuracy. The collected data were coded and entered into SPSS Version 27 for analysis. Descriptive statistics were used to analyze demographic variables, knowledge scores, and practice-related responses. Frequencies and percentages were calculated for categorical variables, while means and standard deviations were used for continuous variables where applicable. The findings were presented in the form of tables and charts to clearly describe nurses' knowledge and practices regarding the care of patients with thalassemia major.

Results

Demographic Analysis

Table 1

Demographic and Professional Characteristics of Participants

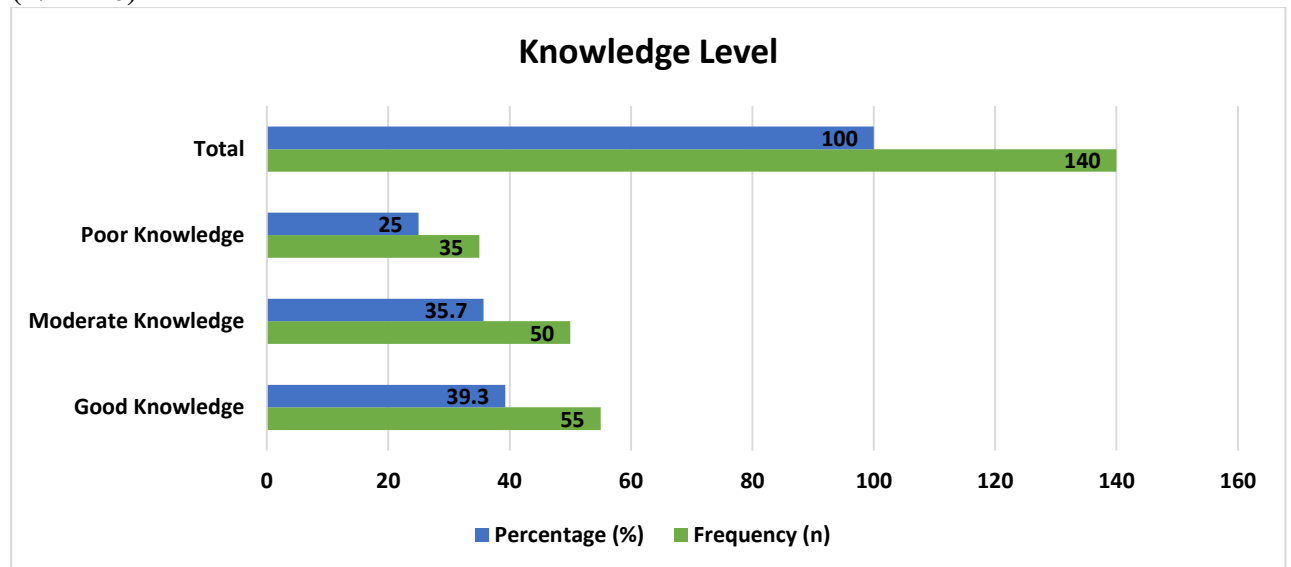
Variable	Category	Frequency (n)	Percentage (%)
Age	25–30 years	23	16.4
	31–35 years	48	34.3
	36–40 years	45	32.1
	41–45 years	24	17.1
Gender	Male	46	32.9
	Female	94	67.1
Marital Status	Single	75	53.6
	Married	65	46.4
Qualification	General Nursing Diploma	66	47.1
	Post RN	46	32.9
	Generic BScN	28	20.0
Clinical Experience	1–5 years	45	32.1
	6–10 years	59	42.1
	11–15 years	36	25.7
Department	Oncology	36	25.7
	Pediatric Wards	69	49.3
	Others	35	25.0

Interpretation:

Table 1 presents the demographic and professional characteristics of the 140

participants. Most participants belonged to the age group of 31–35 years, 48 (34.3%), followed by 36–40 years, 45 (32.1%). The majority of respondents were female, 94 (67.1%), while 46 (32.9%) were male. Regarding marital status, 75 (53.6%) participants were single and 65 (46.4%) were married. In terms of qualification, most nurses had a General Nursing Diploma, 66 (47.1%), followed by Post RN, 46 (32.9%), and Generic BScN, 28 (20.0%). Regarding professional characteristics, most nurses had 6–10 years of clinical experience, 59 (42.1%), and the majority were working in pediatric wards, 69 (49.3%).

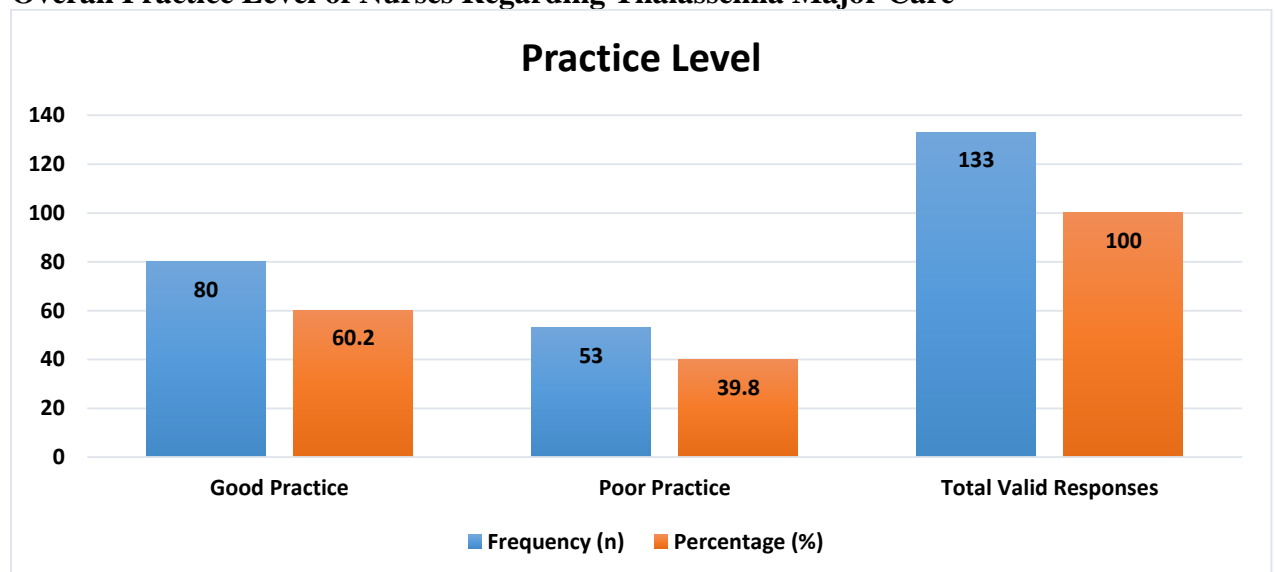
Figure 1 Overall Knowledge Level of Nurses Regarding Thalassemia Major Care (N = 140)



Interpretation:

Table 3 shows that 55 (39.3%) nurses had good knowledge regarding the care of thalassemia major patients, while 50 (35.7%) had moderate knowledge. However, 35 (25.0%) nurses had poor knowledge, indicating that a considerable proportion of nurses still required further education and training regarding thalassemia major care.

Figure 2 Overall Practice Level of Nurses Regarding Thalassemia Major Care



Interpretation:

Table 4 shows that 80 (60.2%) nurses had good practices regarding the care of thalassemia major patients, whereas 53 (39.8%) had poor practices. This indicates that

although the majority of nurses demonstrated good clinical practices, a notable proportion still showed gaps in practice performance.

Table 2
Association Between Demographic Characteristics and Knowledge Level Regarding Thalassemia Major Care

Variable	Poor n (%)	Moderate n (%)	Good n (%)	χ^2	p-value
Age				9.82	0.133
25–30 years	8 (34.8)	7 (30.4)	8 (34.8)		
31–35 years	12 (25.0)	18 (37.5)	18 (37.5)		
36–40 years	10 (22.2)	17 (37.8)	18 (40.0)		
41–45 years	5 (20.8)	8 (33.3)	11 (45.8)		
Gender				4.63	0.099
Male	15 (32.6)	16 (34.8)	15 (32.6)		
Female	20 (21.3)	34 (36.2)	40 (42.6)		
Marital Status				1.85	0.397
Single	21 (28.0)	27 (36.0)	27 (36.0)		
Married	14 (21.5)	23 (35.4)	28 (43.1)		
Qualification				12.47	0.014*
General Nursing Diploma	22 (33.3)	25 (37.9)	19 (28.8)		
Post RN	9 (19.6)	15 (32.6)	22 (47.8)		
Generic BScN	4 (14.3)	10 (35.7)	14 (50.0)		
Clinical Experience				10.96	0.027*
1–5 years	16 (35.6)	16 (35.6)	13 (28.9)		
6–10 years	13 (22.0)	22 (37.3)	24 (40.7)		
11–15 years	6 (16.7)	12 (33.3)	18 (50.0)		

Interpretation:

The Chi-square test revealed a statistically significant association between nurses' qualification ($\chi^2 = 12.47$, $p = 0.014$) and clinical experience ($\chi^2 = 10.96$, $p = 0.027$) with knowledge level regarding thalassemia major care. Nurses with higher educational qualifications and greater clinical experience demonstrated better knowledge. No statistically significant associations were found between knowledge level and age, gender, or marital status ($p > 0.05$).

Table 3
Association Between Demographic Characteristics and Practice Level Regarding Thalassemia Major Care

Variable	Poor Practice n (%)	Good Practice n (%)	χ^2	p-value
Age			5.21	0.157
25–30 years	11 (47.8)	12 (52.2)		
31–35 years	20 (41.7)	28 (58.3)		
36–40 years	14 (31.1)	31 (68.9)		
41–45 years	8 (33.3)	16 (66.7)		
Gender			2.94	0.086
Male	22 (47.8)	24 (52.2)		
Female	31 (33.0)	63 (67.0)		
Marital Status			1.29	0.255
Single	32 (42.7)	43 (57.3)		
Married	21 (32.3)	44 (67.7)		

Qualification			8.71	0.013*
General Nursing Diploma	33 (50.0)	33 (50.0)		
Post RN	13 (28.3)	33 (71.7)		
Generic BScN	7 (25.0)	21 (75.0)		
Clinical Experience			7.54	0.023*
1–5 years	23 (51.1)	22 (48.9)		
6–10 years	20 (33.9)	39 (66.1)		
11–15 years	10 (27.8)	26 (72.2)		
Department			6.89	0.032*
Oncology	17 (47.2)	19 (52.8)		
Pediatric Wards	21 (30.4)	48 (69.6)		
Others	15 (42.9)	20 (57.1)		

Interpretation:

The Chi-square test showed significant associations between qualification ($\chi^2 = 8.71$, $p = 0.013$), clinical experience ($\chi^2 = 7.54$, $p = 0.023$), and department ($\chi^2 = 6.89$, $p = 0.032$) with nurses' practice level regarding thalassemia major care. Nurses with higher qualifications, longer clinical experience, and those working in pediatric wards demonstrated significantly better practices. No significant associations were observed between practice level and age, gender, or marital status ($p > 0.05$).

Discussion

The present study aimed to evaluate the knowledge and practices of the nurses with regards to the care of the thalassemic patients who have been major. Findings showed that 25.0% of the nurses had good knowledge, 35.7% had moderate knowledge and 39.3% had poor knowledge of the care of thalassaemics. The results showed that although a number of nurses have good knowledge, there is still a lot of poor knowledge. The same has been seen by Nassim et al. (2022) in their study of patients and caregivers of people with beta-thalassemia major, which revealed a significant lack of understanding about the disease. Similarly, Maheen et al. (2015) also found low awareness and understanding of thalassemia-related problems among parents in a thalassemia center in Pakistan. The higher reported levels of knowledge may be related to structured educational programs and special clinical exposures in some settings.

The demographic characteristics revealed that the majority of the respondents were aged between 31- 40 years and female nurses. This age distribution is indicative of most healthcare facilities' nursing staff. The same distribution was found in the studies related to nursing care and patient management in chronic hematological diseases. A larger number of nurses at the mid age range could be beneficial to patient care as they are likely to have some experience and be actively involved in the clinical setting. Thalassemia major is a progressive disorder with a number of complications and management is a continuous process and requires special nursing skills (Needs et al., 2018; Shafique et al., 2021).

The study showed that there was a significant relationship between education of nurses and knowledge about the care of thalassemia major. The study revealed that nurses with higher educational level had better knowledge about the care of T.M. Post RN and Generic BScN qualified nurses were more likely to get good knowledge scores than diploma-prepared nurses. The findings are also supported by the findings by Munkongdee et al. (2020) which highlighted the complexity of thalassemia diagnosis and management, which necessitated healthcare professionals to have advanced knowledge and competencies. There is a need for constant professional education due to the growing knowledge of thalassemia including genetic aspects, laboratory diagnosis and treatment modalities. Tabussam et al. (2022) also noted that

educational interventions led to an improvement in nursing care, underscoring the crucial role of academic preparation and training.

Nurses' knowledge was significantly related with their clinical experience. There was significant improvement in knowledge among those with greater years of experience about the care of thalassemia major patients. Frequent contact with patients who require ongoing blood transfusion, complication surveillance and support services may help increase nurses' knowledge about disease management. The complexity of managing thalassemia patients was described by Quirolo and Vichinsky (2016) and the necessity of experienced health care professionals in achieving the best possible results. Practical experience is a significant source of knowledge in diagnosis of complications associated with anemia, transfusion therapy and long term disease management.

Results indicated that 60.2% of nurses had good practices related to thalassemia major care and 39.8% had poor practices related to thalassemia major care. The findings show that majority of respondents were able to carry out proper nursing care despite the differences in their level of knowledge. Good nursing care is crucial in preventing complications of thalassemia major such as iron overload and transfusion complications. Healthcare providers play a crucial role in encouraging adherence to iron chelation therapy in children and adolescents with thalassemia, as highlighted by Reddy et al. (2022) research study. Appropriate monitoring and management of iron overload is essential to patient care and is dependent upon competent nursing practices as emphasized by Sousa et al. (2020) and Piperno et al. (2020).

There was a strong correlation between types of qualification, clinical experience, department and level of practice of the nurses. The practices of the nurses working in Pediatric wards were superior to those working in other wards. Pediatric nurses are more likely to participate in blood transfusion procedures, patient assessment and family counseling, as well as monitoring for disease-related complications. Studies that have concentrated on supportive care and quality of life in children with thalassemia yield similar conclusions. Poysungnoen and Sittisongkram (2017) highlighted the need for self-care support and the role of nursing in achieving good outcomes in children with thalassemia. Sheikhi et al. (2020) also emphasized the contribution of nursing activities in reducing the anxiety levels of children in the process of blood transfusion.

There were no significant differences found among age, gender, marital status and level of knowledge and practice. The results indicate that the professional characteristics have a greater impact on the competence of the nurse than personal demographic characteristics. There is a need for specialised knowledge and clinical expertise for the care of patients with thalassemia major, irrespective of the individual's characteristics. The current literature suggests that better outcomes are more related to the number of specialists who provide care, the professional competence of the healthcare team, and multidisciplinary management approaches than to the demographic characteristics of the healthcare provider (Pepe et al., 2022; Singh et al., 2022). The major conclusions of this study highlight the significance of increasing nurses' knowledge and practices in the care of thalassemia major through higher education, clinical experience, and a specific training program.

Conclusion

The present study concluded that nurses demonstrated varying levels of knowledge and practice regarding the care of patients with thalassemia major. While a majority of nurses exhibited good clinical practices and a substantial proportion possessed good knowledge, notable knowledge and practice gaps were still identified among some participants. Educational qualification, clinical experience, and working department were significantly associated with nurses' knowledge and practice levels, indicating that professional factors play an important role in enhancing competency in

thalassemia care. Nurses with higher qualifications, longer clinical experience, and those working in pediatric wards showed better performance in caring for thalassemia patients. The findings highlight the need for continuous professional development, specialized training programs, and evidence-based educational interventions to strengthen nurses' competencies and ensure the delivery of high-quality care to patients with thalassemia major.

Recommendations

Recommendations for Nursing Practice

Regular in-service training programs and workshops should be conducted to enhance nurses' knowledge and clinical skills regarding the care of patients with thalassemia major.

Standardized clinical guidelines and protocols for thalassemia management should be made readily available in all relevant hospital units to promote evidence-based nursing practice.

Continuous competency assessments should be implemented to identify knowledge and practice gaps among nurses and provide targeted educational support.

Nurses should be encouraged to participate in multidisciplinary care teams to improve the comprehensive management of patients with thalassemia major.

Specialized orientation programs should be provided for newly recruited nurses working in pediatric and hematology-related units.

Recommendations for Nursing Education

Nursing curricula should include comprehensive content on thalassemia major, covering disease pathology, blood transfusion management, iron chelation therapy, and psychosocial care.

Nursing students should be provided with clinical exposure to hematology and pediatric units to strengthen their practical understanding of thalassemia care.

Educational institutions should incorporate simulation-based learning and case studies related to thalassemia management to improve students' clinical competencies.

Continuing nursing education programs should be promoted to ensure that practicing nurses remain updated with advances in thalassemia treatment and care.

Recommendations for Future Research

Similar studies should be conducted in multiple healthcare settings and different geographical regions to improve the generalizability of findings.

Interventional studies should be undertaken to evaluate the effectiveness of educational and training programs on nurses' knowledge and practices regarding thalassemia major care.

Future research should explore barriers and facilitators affecting nurses' ability to provide optimal care to patients with thalassemia major.

Qualitative studies should be conducted to gain a deeper understanding of nurses' experiences, challenges, and educational needs in caring for thalassemia patients.

Future studies may examine the relationship between nurses' knowledge and practices and patient outcomes among individuals with thalassemia major.

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