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ASSESSMENT OF KNOWLEDGE AND PRACTICES OF NURSES ABOUT THE CARE OF THALASSEMIA MAJOR PATIENT AT A TERTIARY CARE HOSPITAL

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ABSTRACT

Background

Thalassemia major is a genetic hematological disorder requiring lifelong management through regular blood transfusions, iron chelation therapy, and comprehensive nursing care. Nurses play a pivotal role in ensuring safe transfusion practices, patient education, and complication prevention. Assessing nurses' knowledge and practices regarding thalassemia care is essential to identify gaps that may impact patient outcomes.

Aim

The study aimed to assess the knowledge and practices of nurses regarding the care of patients with thalassemia major in tertiary care hospitals.

Methods

A descriptive cross-sectional design was employed. A total of 140 nurses were recruited through convenience sampling. Data were collected using a structured questionnaire assessing socio-demographics, knowledge, and practice items related to thalassemia care. Descriptive statistics were applied to summarize frequencies and percentages, while reliability and validity of the instrument were ensured.

Results

Most participants were female (67.1%) with an age range of 25–45 years. Knowledge assessment showed that 39.3% of nurses had good knowledge, 35.7% moderate, and 25% poor. Key knowledge gaps were noted regarding splenectomy and management of complications. In practice, 60.2% demonstrated good practice while 39.8% showed poor practice. Strengths included equipment preparation (97.1%) and site selection (92.9%), while weaknesses were observed in sterilization of vials (29.3%) and hand hygiene compliance (53.6%).

Conclusion

Although overall knowledge and practice levels were satisfactory, significant gaps remain in infection control and complication management. Educational interventions and regular training are recommended to strengthen safe transfusion practices and holistic thalassemia care.

Keywords

Thalassemia major, nursing care, knowledge, practice, blood transfusion, patient safety.

INTRODUCTION

Thalassemia refers to a genetic disorder that is passed in a recessive manner; it is an hemoglobin synthesis disorder that causes chronic anemia and other problems (Tarim & Oz, 2022). Hemoglobin is made up of alpha chains and beta chains and defects in the beta-globin gene lead to the effect of beta-thalassemia,

which includes developmental defects of red cells and premature destruction of erythrocytes (Al-Mosawy, 2017). The key terms used in this paper are thalassemia, which is an inherited condition that affects the production of hemoglobin; anemia, termed as the impaired ability of the red blood cells to carry oxygen in the body because of diminished hemoglobin or aberrant red blood cells; iron overload, the build-up process of iron in the body as a result of recurring transfusions, and chelation therapy, which refers to the medical utilization of compounds to eliminate the excess iron in the body (Sousa, Oliveira, Pessoa &

Thalassemia is among the most popular hereditary disorders on a global scale, having a substantial number of millions of people all around the world (Ahmadi et al., 2020). It is estimated that approximately 300 million people all over the globe are carrying carriers or are patients, and the highest prevalence is registered in Mediterranean countries, South Asia, and South-East Asia (Sheikhi, Naderifar, Mohammad, Mastalizadeh & Sheikhi, 2020). The prevalence of thalassemia major is approximately 23,000 children per year, which is an urgent health problem in the world (Pepe et al., 2022). In Pakistan, the incidence of 5-7 percent carrier rates of 9.8 million carriers of the 9.8 million carriers and an estimated 50,000 registered thalassemia patients is undergoing treatment at tertiary care facilities (Ehsan, Wahab, Anwer, Iftikhar & Yousaf, 2020).

There are three clinical forms of Beta-thalassemia defined as thalassemia trait, thalassemia intermedia, and thalassemia major (Ropero, Gonzales Fernandez, Nieto, Torres-Jimenez, and Benavente, 2022). Thalassemia major or Cooley anemia is the most extreme form and becomes noticeable during the first year of life with anemia, deformity of bones, underdevelopment, fatigue, jaundice, and death (A. Elewa & B. Elkattan, 2017). In individuals with untreated or poorly treated thalassemia major, dystrophic erythropoiesis stops the production of beta-globin, which requires constant transfusion of blood in order to survive (Shafique et al., 2021). Burden of disease is not only physical but also social economic as the disease affects the family through expensive treatments and psychosocial stressors due to the chronic illness (Alnaami & Wazqar, 2019).

The main method of treatment of thalassemia major is red blood cell transfusions, which maintain the health of a patient by increasing hemoglobin levels and correcting the patient of anemia (Needs, Gonzalez-Mosquera & Lynch, 2018). Chronic transfusion causes iron buildup in organs such as the liver, spleen, pancreas, and the heart, which causes problems such as cardiac failure, cirrhosis, diabetes, and endocrine dysfunction (Sousa, Oliveira, Pessoa & Barbosa, 2020). The iron chelation therapy is one of the management cornerstones and is comprised of deferasirox, deferoxamine, and deferiprone, whose use is selected on the basis of clinical condition, patient tolerance, and resources available (Reddy, Locke & Badawy, 2022). Chelation therapies are effective in decreasing the number of fatalities and enhancing the lifestyle of children and grown grownups with thalassemia major (Fakih, Basheer, Ateeq, Ikram, and Asad, 2022).

Nurses are involved in the provision of safe care and better patient outcomes concerning patients with thalassemia major (Al-Awamreh & Suliman, 2019). They will require this knowledge to inform the education of patients, early recognition of complications, and multidisciplinary care of pathophysiology of the condition, clinical issues, and treatment choices (Bajwa & Basit, 2019). Nurse duties involve observing transfusion safety, preventing infections, psychological care, and educating the families on the necessity to comply with therapy and the chronicity of the condition (Lee et al., 2019). Excellent nursing care has a direct influence on life outcomes and the quality of life of thalassemia major patients (Bediako, Ofosu-Poku & Druye, 2021).

The knowledge and services offered to the thalassemia patients by nurses is not proficient enough in Pakistan in relation to international standards (Jaing et al., 2021). The deficient education and absence of specialty education in thalassemia units are the obstacles to the successful management of patients (Tabussam, Afzal, Sarwar & Khan, 2022). Differences in clinical practice among nurses are another factor that enhances morbidity and mortality especially in a resource-limited healthcare facilities where specialized care is not readily available (Jin, Ain, Li & Chun, 2022). These gaps can only be addressed by training and knowledge enhancement programs in order to improve the role of the nurses in thalassemia care.

The multidisciplinary approach includes physical, emotional, psychosocial assessment, and an individual care plan designed to address the needs of a particular patient (Bongay & Kynoch, 2022). It has been shown that when nursing knowledge about iron chelation therapy, infection prevention, and safe transfusion strategies improves, the rate of complications and mortality rates will decrease dramatically (Sari et al., 2016). This research paper is proposed to assess the knowledge and practices of nurses of a tertiary care

hospital, to develop an understanding of gaps in awareness to align the clinical practices thus making the patient outcomes of individuals living with thalassemia major better.

Methodology

The research was modeled as cross-sectional study to determine the knowledge and how the nurses treat the thalassemia major patients. This was done at Jinnah Hospital Lahore, being a tertiary care center with special oncology and pediatric wards within a duration of nine months. The sampling method of purposive was taken since this involved the individuals directly participating in the care of thalassemia patients. Population sample was identified as staff nurses working in oncology and pediatric wards and the sample size was calculated by the use of the standard proportion formula and the resultant size was 140 nurses. Inclusion criteria were the experience of the nurses to include nurses with more than two years of practice and currently working in the pertinent wards, whereas exclusion criteria included nurses under the age category of the experience of two years or less in the work ward, nursing students, and newly employed nurses.

The data were collected using an adapted structured questionnaire of demographic data, thalassemia major knowledge, and practices. The collection of data was conducted among the participants, and its confidentiality was provided, as well as the voluntary character of participation. The results were cleaned, coded and entered into Statistical Package for Social Sciences (SPSS) version 22 and analyzed. The data was summarized by using descriptive statistics (frequencies, percentages, means and standard deviations). The knowledge and practice levels were also divided into good and poor since there were cut-off values that were set predetermined to gauge the overall competency of the nurses. This methodological approach was to make sure there was a thorough check of the knowledge and practices of the nurses in regard to the care of thalassemia patients.

Results and Analysis

The demographic analysis shows that most participants were in the 31–40 age group, indicating a relatively young and active workforce. Female nurses predominated, reflecting the gendered nature of the profession. A higher proportion of single nurses suggests possible links to workload and career commitments. Most participants held a diploma or Post RN qualification, with fewer Generic BScN graduates, showing educational gaps. Experience clustered between 6–10 years, with pediatrics as the leading department, highlighting the concentration of thalassemia care in child health services. [Table 1].

Table 1: Demographic Characteristics of Participants (N = 140)

Variable	Categories	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	Diploma in Nursing	66	47.1
	Post RN BScN	46	32.9
	Generic BScN	28	20.0
Experience	1–5 years	45	32.1
	6–10 years	59	42.1
	11–15 years	36	25.7
Department	Oncology	36	25.7
	Pediatrics	69	49.3
	Others	35	25.0

The knowledge assessment reveals that most participants demonstrated a strong understanding of beta thalassemia as a genetic disorder (77.1%) and its effect on red blood cells (85.7%). Awareness of

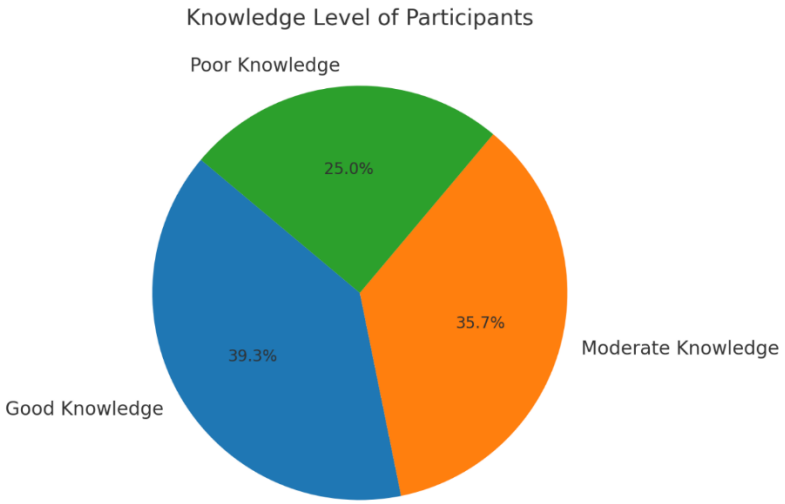
symptoms, growth effects, and splenomegaly was moderate, indicating some knowledge gaps. While a majority recognized blood transfusion as the main treatment (61.4%), misconceptions still exist among a considerable proportion. Encouragingly, preventive measures such as premarital genetic counseling (85.0%) and monitoring iron overload (72.9%) were well acknowledged. Nearly all participants (96.4%) correctly identified HIV/AIDS transmission risk through transfusion, reflecting high awareness of transfusion safety. [Table 2].

Table 2: Knowledge of Nurses Regarding Thalassemia Major (Selected Items)

Knowledge Item	Yes (%)	No (%)
Beta thalassemia major is a genetic disease	77.1	22.9
Leads to decrease in RBCs	85.7	14.3
Symptoms appear several months after birth	63.6	36.4
Affects growth and physical activity	73.6	26.4
Splenomegaly occurs	71.4	28.6
Blood transfusion is main treatment	61.4	38.6
Premarital genetic counseling can prevent thalassemia	85.0	15.0
Iron overload can be monitored by ferritin level	72.9	27.1
HIV/AIDS can be transmitted through transfusion	96.4	3.6

The analysis shows that most participants had good (39.3%) or moderate (35.7%) knowledge, while a smaller proportion (25.0%) demonstrated poor knowledge. This indicates an overall satisfactory awareness, though gaps remain that require targeted education. [Figure 1].

Figure 1: Overall Knowledge Level of Nurses (N = 140)



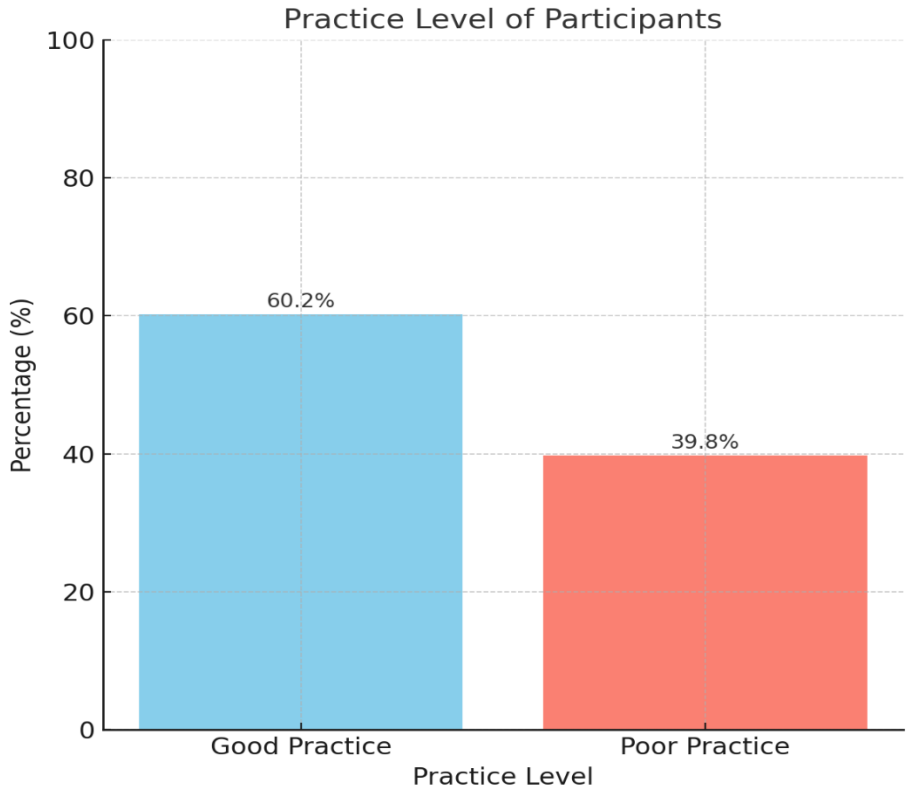
The practice findings show excellent compliance in equipment preparation (97.1%) and site selection (92.9%), reflecting strong adherence to key procedural steps. However, hand hygiene before (53.6%) and after injection (58.6%) was poorly practiced, exposing significant infection control risks. Sterilization of injection bottles was alarmingly low (29.3%), indicating a critical gap in aseptic technique. Dosage calculation (82.9%) and correct needle angle (75.0%) were well followed, though not universal. Proper sharps disposal (72.9%) and post-procedure equipment management (62.1%) highlight areas requiring reinforcement through training and stricter monitoring. [Table 3].

Table 3: Practices of Nurses in Thalassemia Care (Selected Items)

Practice Item	Done (%)	Not Done (%)
Prepared equipment before procedure	97.1	2.9
Clean and dry hands before injection	53.6	46.4
Sterilize injection bottle with alcohol swab	29.3	70.7
Calculate Desferal dose as prescribed	82.9	17.1
Select appropriate injection site	92.9	7.1
Needle at 45° subcutaneous angle	75.0	25.0
Proper disposal of sharps	72.9	27.1
Cleaning/replacing equipment after procedure	62.1	37.9
Clean and dry hands after injection	58.6	41.4

The distribution of participants' practice levels, with 60.2% demonstrating good practice and 39.8% showing poor practice. [Figure 2].

Figure 2 Practice Level of Participants



Discussion

The present study assessed the knowledge and practices of nurses regarding the care of thalassemia major patients, highlighting both strengths and gaps in clinical understanding. Findings revealed that a majority of participants had good knowledge about thalassemia being a genetic disease, its impact on red blood cells, growth, physical activity, and the role of blood transfusions. These results align with Haq et al. (2017), who also reported that nurses in Pakistan demonstrated adequate theoretical knowledge of thalassemia major. However, gaps were observed in specific areas such as awareness regarding splenectomy and transfusion-related complications, which indicates the persistence of misconceptions despite overall acceptable knowledge levels.

The study also found that 39.3% of nurses had good knowledge, 35.7% moderate, and 25% poor, suggesting a mixed but relatively positive distribution. These findings are consistent with Elewa and Elkattan (2017) in Egypt, who reported that although nurses generally recognized thalassemia as a genetic disorder

requiring lifelong care, knowledge gaps persisted regarding the management of complications and preventive strategies. Similarly, Bajwa and Basit (2019) noted that many nurses in Pakistan had sound understanding of thalassemia genetics but lacked depth in knowledge about advanced treatment protocols and chelation therapy, which mirrors the current study's findings.

In terms of practices, 60.2% of participants demonstrated good practice, while 39.8% showed poor adherence to protocols, particularly in areas like sterilizing injection bottles, hand hygiene, and equipment replacement. Comparable results were reported by Bediako, Ofosu-Poku, and Druye (2021), who identified significant gaps in safe injection and transfusion practices among nurses in low-resource settings. This similarity suggests that barriers to optimal practice may be systemic and related to resource constraints, workload, or inadequate training opportunities. In contrast, a study by Jin et al. (2022) highlighted higher compliance rates in Chinese hospitals, suggesting that better training programs and stricter institutional policies can significantly improve adherence to protocols.

The present study also demonstrated that nurses had good knowledge of chelation therapy, with most recognizing Desferal as a critical drug to manage iron overload. This is consistent with the findings of Fakih et al. (2022), who emphasized that nurse awareness of chelation therapy is essential to preventing long-term complications. However, only moderate adherence was observed in related practices such as equipment sterilization and post-injection hand hygiene. This partial discrepancy between knowledge and practice reflects the findings of Al-Awamreh and Suliman (2019), who noted that while nurses may have sufficient knowledge, practical compliance is often hindered by lack of resources, time pressure, or institutional oversight.

Another key finding of the current study was the high recognition among participants regarding the importance of premarital genetic counseling as a preventive strategy, with 85% agreeing to its role. This aligns with studies by Ropero et al. (2022) and Shafique et al. (2021), which highlighted the effectiveness of genetic counseling in reducing the burden of thalassemia. However, a contrasting report by Tabussam et al. (2022) in Pakistan revealed that many nurses remain unaware of the importance of genetic screening programs, suggesting variability in exposure and training across different healthcare institutions. (Hussain et al., 2025)

The results of this study further confirmed the nurses' awareness of blood transfusion-related risks, with the majority identifying fever, allergic reactions, and transfusion-transmitted infections like HIV/AIDS as common complications. These findings are comparable to those of Sousa et al. (2020), who highlighted nurses' role in early detection of transfusion-related reactions. Yet, gaps were observed in awareness of delayed transfusion reactions, which were underreported in the present study. This gap is consistent with Bongay and Kynoch (2022), who found that while nurses are vigilant in identifying acute transfusion reactions, long-term complications are often underrecognized due to insufficient follow-up practices.

Overall, the study's findings highlight that while nurses demonstrated strong baseline knowledge and satisfactory practices regarding thalassemia major care, significant gaps remain in specialized areas such as transfusion safety protocols, infection control, and advanced chelation practices. These results mirror the mixed findings of previous studies conducted in Pakistan, Egypt, and other low-resource countries, where adequate knowledge often coexists with inconsistent practices. Improving continuous nursing education, providing structured training on transfusion safety, and ensuring adequate resources could bridge this knowledge–practice gap. Ultimately, the results emphasize the need for standardized guidelines and ongoing professional development to improve the quality of care for thalassemia patients.

Conclusion

The study concluded that nurses working in oncology and pediatric wards at Jinnah Hospital Lahore possessed generally good knowledge about thalassemia major, with the majority correctly identifying its genetic nature, clinical manifestations, and the role of blood transfusion and chelation therapy. However, knowledge gaps were evident in specific aspects, such as awareness of splenectomy, delayed transfusion complications, and infection control measures. Nursing practices were moderately satisfactory, with strengths in preparing equipment, dose calculation, and injection site selection, but weaknesses in consistent hand hygiene, sterilization, and equipment replacement. The findings highlight that while theoretical knowledge exists, translation into consistent practice remains an area requiring improvement.

Recommendations

1. **Strengthen Continuous Education:** Regular workshops and refresher courses should be organized to enhance nurses' knowledge about thalassemia management, focusing on advanced treatment protocols, chelation therapy, and transfusion-related complications.
2. **Improve Practical Training:** Simulation-based and bedside training should be emphasized to ensure better adherence to infection control practices and safe transfusion protocols.
3. **Promote Genetic Counseling Awareness:** Nurses should be trained to advocate for premarital genetic counseling and community awareness programs as preventive strategies against thalassemia.
4. **Standardize Clinical Guidelines:** Development and implementation of evidence-based protocols for thalassemia care should be made mandatory in oncology and pediatric units.
5. **Strengthen Institutional Support:** Hospitals should ensure adequate resources, including sterilization equipment, protective gear, and monitoring tools, to facilitate safe and effective nursing practices.
6. **Encourage Research and Evaluation:** Continuous monitoring, audits, and research on nursing knowledge and practices should be encouraged to evaluate progress and identify persistent gaps.

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