

Nurses' Knowledge and Role on Care of Children with Thalassemia

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ABSTRACT

Thalassemia is one of the world wide genetic hemoglobinopathies caused by a defect in the genes responsible for hemoglobin synthesis. Nurses also play a critical role in managing the patient's quality of life by helping to prevent unnecessary complications and providing treatment. Non-adherence is recognized as a serious problem in chronic diseases especially hemoglobin disorders which may lead to serious or fatal complications. The role of the nurse in promoting adherence is reported as being to clarify and explain both the complications of thalassemia and the effects of non-adherence to the chelation therapy. The present study aims to assess the knowledge and role of nurses on care of children with thalassemia at selected hospital, Udaipur, Rajasthan. A total sample of 98 staff nurses were participated in this study. Self structured knowledge questionnaire and checklist was used for data collection. Results revealed that majority 59.2% of nurses had poor knowledge, 34.7% had average knowledge and only 6.1% had good knowledge whereas role of nurses showed that 96.9% of nurses were incompetent and only 3.1% of nurses were competent in care of children with thalassemia. The study concluded that nurses were lacking knowledge and skills in caring children with thalassemia and needs engagement in continuous training about thalassemia. Study suggests that guidance and support for continuous education and training is required in order to enable nurses to fulfill their potential. Continuous education is necessary to facilitate the nurses to provide enhanced physical, psychological and genetic care to children with thalassemia.

Keywords: thalassemia, genetic hemoglobinopathies, nurses, children

INTRODUCTION

Thalassemia is a genetic, autosomal recessive haemoglobinopathic disease, it is found worldwide, but most commonly in the Mediterranean, Thalassemia is the most common inherited disorder in the world that represents a major public concern. It is characterized by a defect in the genes responsible for production of hemoglobin.¹ Hemoglobin is a protein that consists of alpha and beta chains. If the genetic mutations prevent any formation of beta chains then beta-thalassemia occurs which involves abnormal development of red blood cells and eventually anemia. Beta-thalassemia is caused by any of more than 200 mutations that affect different levels of

the beta-globin gene expression by a variety of mechanisms.²

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).³ Beta-thalassemia major is a chronic disorder of blood, having an extensive impact on life and presenting with hemolytic anemia, growth retardation, hepato-splenomegaly and skeletal abnormalities. It often requires regular blood transfusions, iron chelation therapy and sometimes splenectomy for its management. Thus, the therapeutic regime

is complex, lifelong and inconvenient, requiring repeated hospitalizations and blood transfusions, which often affects the child's physical and mental health negatively.⁴

Blood transfusion is the mainstay of the care for individual with thalassemia major and many with intermediate. The purpose of transfusion is twofold: to improve the anemia and to suppress the ineffective erythropoiesis. Chronic transfusions prevent most of the serious growth, skeletal and neurological complications of thalassemia major. In spite of its vital role in saving lives and enhancing patients' lives, blood transfusion is associated with risks. Making mistakes in blood transfusion and insufficient control of patients who receive blood during the transfusion can lead to death for such patients. Nurses being responsible for the final bedside check before transfusion, have the final opportunity to prevent a miss transfusion. An understanding and knowledge of the pathophysiology of transfusion reactions, symptoms and treatment is essential to safely administer and monitor transfusions.⁵

Quality of care is indicating that the right things are being done right, improving the outcomes for patients, their families and their communities. The criteria used to assess quality could address structure, process or outcome. It is an optimal balance between possibilities realized and a framework of norms and values. Optimal nurse staffing is a critical component in improving the quality of patient care and preventing complications. The quality of nursing care makes a vital difference in patient outcomes and safety.⁶

Patient's satisfaction has been advocated as an outcome measure of quality nursing care which include: adequate skill, caring attitudes, effective communication, efficient organizational and management systems and effective participation. Nurses need to understand that care cannot be of high quality unless the patient is satisfied. So, patient's satisfaction should thus remain

a requirement for obtaining health care goals.⁷ The nurse should be aware of his/her responsibility for the quality of care provision to the patients, the institution, ethics, laws and professional standards, as well as performance that contributes to the evaluation of care and the patients' satisfaction. The nurse plays a critical role in any team of healthcare professionals involved in the care of patients with chronic diseases including hemoglobin (Hb) disorders such as thalassemia and sickle cell disease.⁸

Nurse's education consists of the theoretical and practical training provided to nurses with the purpose to prepare them for their duties as nursing care professionals. It is very important for nursing staff to engage in plenty of ongoing training as well the needs of patients continue to change and there are new developments in procedure, the education of nurses never stops as they are required to continually master new skills and concepts throughout their career.⁹

Statement Problem:

A descriptive study to assess the knowledge and role of nurses on care of children with thalassemia at selected hospital, Udaipur, Rajasthan.

Aim of study:

To assess the knowledge and role of nurses on care of children with thalassemia

Objectives:

1. To assess the knowledge and role of nurses on care of children with thalassemia.
2. To find correlation between knowledge and role of nurses on care of children with thalassemia
3. To find out association between knowledge and role of nurses on care of children with thalassemia with their selected demographic variables.

METHODOLOGY

Research Approach

For the present study quantitative research approach was adopted to assess the nurse's knowledge and role on care of children with thalassemia.

Research Design

Descriptive study design was adopted to accomplish the objectives of the study

Research Setting

The present study was conducted at Maharana Bhupal Bal Chikitsalaya Hospital, Udaipur, Rajasthan.

Variables under study

Independent variables: Knowledge and role of nurses on care of children with thalassemia.

Population

The population of the present study was Nurses working in medical ward, surgical ward, pediatric ward and maternity ward were selected for this study.

Sample size:

The sample size for the study was 98 staff nurses selected based on inclusion criteria of this study.

Sampling technique:

Convenience sampling technique was used to select the samples for this study.

Inclusion Criteria: Staff nurses who are:

- Co-operative and willing to participate in study.
- working for at least 6 months
- Available at the time of data collection.

Exclusion Criteria: Staff nurses who are:

- not willing to participate in study
- not present during time of data collection.

Description of tool:

Part- A: Socio demographic profile of staff nurses. Socio demographic data includes age, sex, education, experience, work area and care of thalassemia children.

Part- B: Self structured knowledge questionnaire on care of children with

thalassemia which includes 25 items related to Definition, causes, transmitted by blood, types, meaning of carrier, symptoms of diseased & carrier, diagnosis, blood transfusion and treatment.

PART C: Self structured checklist to assess the role of nurses on care of children with thalassemia which includes questions related to administration of drugs and Intravenous therapy, blood transfusion and documentation.

Reliability:

The reliability for the knowledge questionnaire was measured using Guttman Lambda method ($r=0.725$) and checklist questionnaire was measured using Cronbach's alpha method ($r=0.704$). Tool was found to be reliable.

Ethical Consideration:

Formal approval was obtained from ethical committee of the institution and permission was obtained from concerned authority of the hospital, Udaipur. Written informed consent was obtained from all the participants and anonymity was maintained.

Results and Discussion:

Table 1: Frequency and percentage distribution of demographic variables N=98

S. No	Demographic variables	Frequency	Percentage
1	Age in years		
	21-25 years	30	30.6
	25-30 years	34	34.7
	31-35 years	23	23.5
	Above 35 years	11	11.2
2	Gender		
	Male	16	16.3
	Female	82	83.7
3	Educational qualification		
	GNM	25	25.5
	B. Sc Nursing	58	59.2
	Post B. Sc Nursing	15	15.3
4	Professional Experience		
	< 1 year	30	30.6
	1-5 years	26	26.5
	5-10 years	25	25.5
	> 10 years	17	17.3
5	Work area		
	Medical ward	19	19.4
	Pediatric ward	39	39.8
	Maternity ward	28	28.6
	Surgical ward	12	12.2
6	care of children with thalassemia		
	Yes	21	21.4
	No	77	78.6

Table 1 depicts the distribution of demographic variables of the nurses. 34.7% of nurses were in 25-30 years of age with mean age was 28.35±5.67. Regarding gender 83.7% of nurses were females, 59.2% of nurses had B. Sc Nursing degree, 30.6% of nurses had less than one year of experience, 39.8% of nurses was working in pediatric department and only 23% of nurses reported that they have given care for children with thalassemia.

Table 2: Nurses knowledge on care of children with thalassemia N=98

Knowledge	f	%	Mean	SD
Good	6	6.1	12.74	4.971
Average	34	34.7		
Poor	58	59.2		
Total	98	100		

Table 3: Role of nurses on care of children with thalassemia N=98

Role of Nurses	f	%	Mean	SD
Competent	3	3.1	8.46	1.996
Incompetent	95	96.9		
Total	98	100		

Table 2 illustrates the nurses' knowledge on thalassemia and blood transfusion. This table reveals that majority 59.2% of nurses had poor knowledge, 34.7% had average knowledge and only 6.1% had good knowledge regarding thalassemia with mean score for knowledge was 12.74±4.97. Ghazanfari Z, Arab M, Pouraboli B. (2013)¹⁰ conducted a study on knowledge of nurses about thalassemia revealed that 65.4% of nurses had inadequate knowledge and 34.6% had adequate knowledge with mean knowledge score 14.53±5.85.

Table 2 depicts the role of nurses on care of children with thalassemia. This table reveals that 96.9% of nurses were incompetent and only 3.1% of nurses were competent. About administration of drugs (5.4±2.9), IV therapy (4.3±1.9), blood transfusion (5.6±2.4) and documentation (4.1±1.82) with overall mean score was 8.48±1.99. Mausumi Basu (2015)¹¹ conducted a study on knowledge and practices of nurses on care of children with

thalassemia showed that nurses were having 56.9% had adequate knowledge and 43.1% had inadequate knowledge and regarding practices 74% had poor practices and 26% had good practices on caring children with thalassemia.

Table 4: Correlation between knowledge and role of nurses on care of children with thalassemia N=98

Correlation	Mean	SD	r value	p value
Knowledge of Nurses	2.74	4.97	0.542	0.451
Role of Nurses	8.46	1.99		

Table 4 depicts the correlation between knowledge and role of nurses on care of children with thalassemia revealed that (r=0.542) indicates moderate positive correlation between knowledge and role of nurses on care of children with thalassemia and (p=0.451) shows statistically non significant. Pary M, Farida A, Janet Kelsey (2015)¹² stated that there was positive correlation between knowledge and role of nurses in the management of thalassemic patients.

Table 5 depicts the association between knowledge of nurses on care of children with thalassemia with their demographic variables reveals that statistically no significant association found between knowledge of nurses with their demographic characteristics.

Table 6 depicts the association between role of nurses on care of children with thalassemia with their demographic variables reveals that statistically no significant association found between role of nurses with their demographic characteristics.

Nagat Farouk, Amal H.M, Yosria El Hossein (2018)¹³ conducted a study on nurses knowledge and practices about thalassemia and blood transfusion. Results revealed that age of nurses, education and experience was statistically significant with knowledge (p= 0.01, 0.02 and 0.01) respectively and practices of nurses (p=0.02, 0.03 and 0.02) respectively.

Table 5: Association between knowledge of nurses on care of children with thalassemia with their demographic variables. N=98

S. No	Demographic variables	Level of knowledge			X ² value	df	p value
		Poor	Average	Good			
1	Age in years				2.905	6	0.821 ^{NS}
	21-25 years	18	10	2			
	25-30 years	21	10	3			
	31-35 years	13	10	0			
	Above 35 years	6	4	1			
2	Gender				0.072	2	0.965 ^{NS}
	Male	9	6	1			
	Female	49	28	5			
3	Educational qualification				3.404	4	0.493 ^{NS}
	GNM	16	6	3			
	B. Sc Nursing	34	22	2			
	Post B. Sc (N)	8	6	1			
4	Professional Experience				1.104	6	0.981 ^{NS}
	< 1 year	17	12	1			
	1-5 years	16	8	2			
	5-10 years	15	8	2			
	> 10 years	10	6	1			
5	Work area				4.616	6	0.594 ^{NS}
	Medical ward	12	5	2			
	Pediatric ward	21	16	2			
	Maternity ward	19	7	2			
	Surgical ward	6	6	0			
6	care of children with thalassemia				5.048	2	0.080 ^{NS}
	Yes	14	4	3			
	No	44	30	3			

Table 6: Association between knowledge regarding care of children with thalassemia among nurses with their demographic variables. N=98

S. No	Demographic variables	Level of competence		X ² value	df	p value
		Competent	Incompetent			
1	Age in years			2.389	3	0.496 ^{NS}
	21-25 years	28	2			
	25-30 years	33	1			
	31-35 years	23	0			
	Above 35 years	11	0			
2	Gender			0.604	1	0.437 ^{NS}
	Male	16	0			
	Female	79	3			
3	Educational qualification			0.577	2	0.749 ^{NS}
	GNM	24	1			
	B. Sc Nursing	56	2			
	Post B. Sc (N)	15	0			
4	Professional Experience			2.694	3	0.441 ^{NS}
	< 1 year	28	2			
	1-5 years	25	1			
	5-10 years	25	0			
	> 10 years	17	0			
5	Work area			0.746	3	0.862 ^{NS}
	Medical ward	18	1			
	Pediatric ward	38	1			
	Maternity ward	27	1			
	Surgical ward	12	0			
6	care of children with thalassemia			0.844	1	0.358 ^{NS}
	Yes	21	0			
	No	74	3			

CONCLUSION

The study concluded that nurses were lacking knowledge and skills in caring children with thalassemia and needs engagement in continuous training about thalassemia. Study suggests that guidance and support for continuous education and training is required in order to enable nurses to fulfill their potential. Continuous

education is necessary to facilitate the nurses to provide enhanced physical, psychological and genetic care to children with thalassemia.

Recommendations:

Based upon the results of the current study, the following recommendations are suggested - A specialized orientation

program should be developed for newly appointed nurses to prepare them before working at the pediatric departments. Further studies should be conducted to improve nurses' knowledge and practices regarding to blood transfusion and care of children with thalassemia. Developing and performing an in-service training program for nurses emphasizing to increase their knowledge and practices in providing quality care for children with thalassemia.

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