Assessment Knowledge of Thalassemia Care Giver in Kirkuk City

Idrees Hasan Mohammed

College of Nursing / University of Kirkuk, Iraq

Abstract

Thalassemia is an inherited blood disorder, which is described by diminished synthesis or lack of globin,this synthetic defect leads to the formation of fragile abnormal red blood cells (RBC), which can be easily hemolyzed, leading to chronic anemia Quantitative design descriptive study was used to assess Knowledge Thalassemia Care givers in Kirkuk City. A non–probability / Convenience sampling technique was applied in the present study, (30) Thalassemia Care givers were participate in the study sample (Azadi Teaching Hospital) in Kirkuk City. A questionnaire was designed and constructed by researchers to measure the variables underlying the present study. Data were obtained directly by the researchers through interview technique. Content validity of the instrument was determined through the of panels which involve (5) experts to investigate the clarity. The findings in general indicated that Majority of the sample In general has good Knowledge about Thalassemia it was recorded (74,8%) were answered "I Know.

Keywords: *Assessment Knowledge of Thalassemia care giver in Kirkuk city*

Introduction

Thalassemia is an inherited blood disorder, which is described by diminished synthesis or lack of globin,this synthetic defect leads to the formation of fragile abnormal red blood cells (RBC), which can be easily hemolyzed, leading to chronic anemia [1]. This disorder isexceptionally pervasive among children in the Middle East, Mediterranean region, and South Asia,though, only a few studies on pediatric quality of life have been available from those areas [2]. The management of thalassemia contains regular blood transfusion, iron chelation treatment, and suitable management of comorbidities. These modalities led to an increase in the life expectancy of thalassemic children,therefore, stressing the significance of keeping up the personal satisfaction in kids with thalassemia [3]. Thalassemia has a negative influence on the physical functioning of children and adults. It can likewise influence social connections and emotional well-being, in the long run prompting poor school execution and general disability in the wellbeing related personal sat- isfaction. It has been accounted for that around 80% of thalassemic patients have psychiatric issues,it was accounted for already that enthusiastic pain and sickness trouble affect the personal satisfaction of patients as gloom and uneasiness related indications; nonethe- less, culture and the sort of treatment did not [4] Pediatric personal satisfaction estimation is an instrument that is utilized to evaluate the impact of ailment on a patient's prosperity,distinctive perspectives are canvassed in pediatric personal satisfaction, including physical, mental, and social working as different components can influence personal satisfaction [5,6].

General objective:

"Assessment Knowledge Thalassemia Care givers in Kirkuk City"

1.2 Specific objectives:

1- To identify socio demographic characteristics of the caregiver's

(age, gender, educational level, occupation, marital status).

2- To identify caregiver's knowledge regarding thalassemia.

Alpha thalassemia

Each human diploid cell contains four copies of

the alpha- globin gene, located on chromo-some, Alpha thalassemia is the result of reduction in the synthesis of the alpha globin chains and a form of thalassemia involving the gene HbA1 and HbA2. Two main types of alpha thalassemia are described as alpha thalassemia major and hemoglobin H disease that Alpha thalassemia major is a very serious disease of severe anemia that begins even before birth,most affected babies do not survive full gestation or die shortly after birth. Hemoglobin H disease is milder than beta thalassemia and does not generally require transfusion therapy [7]

Beta Thalassemia

The most familiar type of thalassemia is beta thalassemia. Thalassemia was first recognized clinically in 1925 when Thomas Cooley described a syndrome of anemia, splenomegaly, and bony deformities among Italian descents, Beta thalassemia or Cooley's anemia is caused by a change in the gene for the beta globin component of hemoglobin. Beta thalassemia is caused by damaged or missing genes,thalassemia can be subjected to modification in the hemoglobin genes depending on the mild and mild side effects. Beta thalassemia patients is most found in people who are from Greek, Italian, African, or Asian origin especially India, Beta thalassemia major has begun since childhood and will last until the end of the life,the severe anemia can result in severe lethargy, paleness, and insufficient growth and development, Other characteristic physical complications such as heart problems and excessive liver and spleen growth which decrease life-expectancy,this condition is becoming more prevalent in the USA as a result of Asian immigration [8].

Management of Thalassemia

Thalassemia minor

Patients with thalassemia minor generally don't require a particular treatment,educate patients that their condition is genetic andThat doctors now and then mix up the turmoil for iron insufficiency,some pregnant patients with the beta thalassemia characteristic may create simultaneous iron inadequacy and serious sickliness; they may require transfusion bolster on the off chance that they are not receptive to iron repletion modalities.(Karimi M., 2009)

Thalassemia major

The objective of long-term hypertransfusion bolster is to keep up the patient's hemoglobin level at 9 - 10 g/dL, along these lines enhancing his or her feeling of prosperity while all the while smothering upgraded erythropoiesis,this methodology treats the weakness and smothers endogenous erythropoiesis with the goal that extra medullary hematopoiesis and skeletal changes are stifled. Patients accepting long haul transfusion treatment additionally require iron chelation.(Fatimah Sharif Modawi., 2017).

Blood banking contemplations for these patients incorporate totally writing their erythrocytes for Rh and ABO antigens preceding the primary transfusion. This methodology helps future cross-coordinating procedures and limits the odds of all immunization. Transfusion of washed, leukocyte-poor red blood cells (RBCs) at roughly 8 - 15 mL RBCs for each kilogram (kg) of body weight more than 1 - 2 hours is suggested [9].

Hap good.. propose that present suggestions prompt under transfusion in guys, accordingly, guys might probably have extra medullary hematopoiesis and in this way more inclined to require splenic tomy or to create spinal rope pressure, a phenomenal however genuine complexity of Para spinalextra medullary hematopoiesis. In their investigation of 116 patients (51 guys and 65 females) with thalassemia real, guys were getting more units of RBCs per transfusion and had a higher yearly transfusion volume, however with adjustment for weight, females were accepting a higher transfused volume for each kg: 225 versus 202 mL/kg in guys (P = 0.028). [10]

Erich- repointing (EPO) levels were higher in guys: 72 versus 52 mIU/mL (P = 0.006). The frequency of splenic tomy was higher in guys (61%, versus 40% in females; P = 0.031).Allogeneic hematopoietic transplantation can be remedial in some patients with thalassemia major,the early successful allogeneic stem cell transplant from an HLA-identical sibling donor was stated in 1982, an Italian group led by Lucarelli has the most experience with this procedure,this group's research documented a 90% long-term survival rate in patients with favorable characteristics(young age, HLA match, no organ dysfunction),transplantation-related issues such as graft versus host disease, graft failure, chronic immunesuppressive treatment, and transplantation-related mortality must be cautiously considered earlier to proceeding with this method.

Surgical Treatment

Splenictome is the vital surgical system utilized for

some patients with thalassemia,the spleen is known to contain a lot of the labile nontoxic iron (i.e. stockpiling capacity) got from sequestration of the discharged iron. The spleen additionally expands RBC decimation and iron conveyance ,these realities ought to dependably be considered before the choice is made to continue with splenic tomy,what's more, with late reports of venous thromboembolic events after splenic tomy, one ought to precisely consider the advantages and the dangers previously splenic tome is supported,the spleen goes about as a store for nontoxic iron, along these lines shielding whatever remains of the body from this iron. Early evacuation of the spleen might be unsafe.

Methodology

This chapter deals with the presentation of the administrative arrangement, design of the study, setting of the sample, sample of the study, Instrument of the study, validity,pilot study, method of data collection,period of data collection statistical analysis and ,limitation of the study.

Design of the Study:

A descriptive study was carried out from February,1st, 2019to April,15th, 2019 in order to achieve the objectives of the present study.

Setting of the Study:

The study was conductedinAzadi hospitalsin Kirkuk city.

Sample of the study:

Non - Probability sampling approach (purposive sample) consists of 62 nursing staff of premature units in Azadi hospitals.

Criteria:

Inclusions*:*

Only nursing staff who were working in the premature unit in the hospitals

Instrument Construction:

1. For the purpose of the present study, a questionnaire format was constructed to assessment of the nursing staff knowledgeand practices regarding neonatal jaundice.

2. The questionnaire format was based on the review of literature and related previous studies. The questionnaire was designed in English and then translated into Arabic language. It was reviewed by supervisor and experts.

3. Formal consent was obtained from the nursing staff who agreed to participate in the study, the questionnaire was self-administer and took 10-15 minutes to be complete.

4. The study instrument of comprised of three parts, which was consisted the following variables:

1. ***Part One/*Socio-demographic characteristics**

Include: Type of hospital, Sex, Educational level, Marital status, residence, Socio-economic status, years of experience in premature unit, participation in a training course, period of the training course and the place of the training.

2. ***Part Two/*Assessment of knowledge:**

Include20items regarding knowledge of the sample. It has been consist of three scalesas ''Know'' , ''I didn't know'' and "Uncertain".

3. ***Part Three/ Assessment of practice***

Include4 items regarding practices of the study sample.

Validity of the study scale:

To ensure the validity of the scale, method and procedure were proposed to be carried out during the study. Nine experts of different specialties related to the field of the present study were chosen to review face and content validity. They were asked to review the scale format for clarity and adequacy in order to achieve the present study objectives. Those experts were allfaculty members from the College of Nursing/ University of Kirkuk,(82 %) of them had agreed that the scales were clear, relevant and adequate. Certain modifications were employed based on the experts' recommendations and suggestions .

Method of Data Collection:

Data were collected through self -administered technique, The investigators had demonstrated objectives and the significance of research and the benefit of the study to the participant. Verbal consent obtained from premature unit nursing staff.Each nurse

spends approximately (10-15min) to respond to the questionnaire.

Period of Data Collection:

Thedata collectionhas been conducted during a period of two months extending from February15th, 2019toApril15th, 2019.

Statistical Analysis

Data were analyzed in several steps. First, *descriptive statistics*, which includes frequency and percentages, and Mean score. Data are prepared, organized and entered into the computer file; Statistical Package for Social Science (SPSS)(20 version) is used for data analysis at(P. value ≤**0.05**). Data are analyzed through the application of two approaches:

Descriptive statistical data analysis:

This approach is employed through:

- **Frequency distribution**
- **Percentage (%)**

$$\% \equiv \frac{Frequencies}{sample\ \ size} x100 \text{ (32)}$$

- Mean of Scores

This computation is applied for the determination of item's significance of the assessment tool relative to each aspect. Cut-off points are used for this determination low-significant,moderate significant, and highly significant.

$$M.S = \frac{f_1 \times score_1}{n_1} + \frac{f_2 \times score_2}{n_2}$$

It is computed as follows:

M.S = Mean of score

f = Frequency

n = Number of cases

Rating and scoring of the scale:

The knowledge and practices questionnaire items were rated and scored to items as ,Know , I didn't know and Uncertain. Data of the study were ordinal according to three levels scale which were scored for each level respectively.

Result

This chapter will present the research according to the statistical analysis for the data collection during the study period. Regarding to sex, (70%) of the participants were female, while only (30%) were male. According to the educational level (10%) of the participants were Illiterate, (26.7%) of them had write & read , (20%) of them were primary school , (23,3%) of them were secondary school , while (20%) were Institution. According to marital status, (80%) of study sample were married, while (13.3%) were single , while (6,7%) were separated. Regarding to Occupation of caregiver, (10%) were Governmental employee (40%) were Non-governmental employee , and (50%) were Jobless. According to socio –economic status, (58.1%) had barely sufficient economic status and (27.4%) had sufficient economic status. Regarding to Age of caregiver (26.6%) of participants had (≥ 19 years)' experience, while (40%) of them had (20 – 29 Y) years of experience, while (30%) of them had (30 – 39 Y), while (3,4%) were (≤ 40 Y) years.

Conclusion

Thalassemia intermedia has a wide clinical spectrum, as some patients are completely asymptomatic until adult life whereas others present with the condition at 2 years of age and experience retarded growth and development. Many patients with thalassemia intermedia do not currently undergo transfu-sion therapy due to difficulties in deciding when to initiate therapy as well as the lack of a convenient and effective iron chelator. However, the availability of such a therapy may increase the use of transfusions in patients with thalassemia intermedia, allowing them to benefit from this therapeutic approach and avoid any subsequent clinical complications. As there are currently no clear guidelines for the management of thalassemia intermedia, in this paper, we present some recom-mendations based on a system-centered risk stratification mo-del to help individualize patient treatment. All patients diagnosed to have thalassemia based on High Performance Liquid Chromatography(HPLC) will be included in the study. It includes β thalassemia trait, β thalassemia intermedia, β thalassemia major, α thalassemia, double heterozygous conditions like β thalassemiaHbS, βthalassemiaHbE and β thalassemiaHbD.

Financial Disclosure: There is no financial disclosure.

Conflict of Interest: None to declare.

Ethical Clearance: All experimental protocols were approved under College of Nursing / University of Kirkuk, Iraq and all experiments were carried out in accordance with approved guidelines.

References

1. Surapolchai P. Biopsychosocial predictors of health related quality of life in children with thalassemia in Thammasat Univer- sity Hospital". Journal of the Medical Association of Thailand. 2010; 93: S65-S75.
2. Azarkeivan A., et al. "Associates of poor physical and mental health-related quality of life in beta thalassemia-major/intermedia". Journal of Research in Medical Sciences. 2009; 14: 349-355.
3. Khani H., et al. "Quality of life of Iranian beta-thalassaemia major patients living on the southern coast of the Caspian Sea". Eastern Mediterranean Health Journal 2012; 18: 539-545.
4. Nigam N, Nigam S, Agarwal M, Singh PK. β-Thalassemia: From clinical symptoms to the management IJCMR. 2015; 4(5): 1-5.
5. Hamidreza S. Critical Review on Thalassemia: Types, Symptoms and Treatment , Department of Biomedical Engineering, Sheikhbahaee University, Esfahan, Iran. 2018.
6. Karimi M. Echocardiographic finding in beta-thalassemia intermediate tote and major: absence of pulmonary hypertension follow- ing hydroxyl urea treatment in beta-thalassemia intermediate the". European Journal of Hematology 82.3 (2009): 213-218 Kaiser J. "Gene therapy. Beta-thalassemia treatment succeeds, with a caveat". Science. 2009; 326: 1468-1469
7. Rachmilewitz EA, Giardina PJ. How I treat thalassemia. Blood. 2011; 118: 3479-3488.
8. Taher A. Guidelines for the Management of Non-Transfusion Dependent Thalassemia (NTDT). Thalassemia International Foundation. 2013.
9. Fatimah S. Thalassemia Diagnoses and Management". EC Microbiology, King Khalid University, Abha, Saudi Arabia. 2017; 11: 27-34.
10. Baghianimoghadam MH. Health related quality of life in children with thalassaemia assessed on the basis of SF-20 question- naire in Yazd, Iran: a case-control study". Central European Journal of Public Health. 2011; 19: 165-169.