International Journal of Nursing and Medical Science 2024:13(3), 01-08

IJNMS ISSN: 2454-6674

INTERNATIONAL JOURNAL OF NURSING AND MEDICAL SCIENCE

Nursing Education Health Science Research

PANACEA INTERNATIONAL JOURNAL PRL PUBLISHER

Original Research Article Volume 13 Issue 3 May-June 2024

A STUDY TO EXPLORE LIVED EXPERIENCE AND QUALITY OF LIFE OF THALASSEMIA CHILDRENIN SELECTED HOSPITALS OF RAJASTHAN

Mr. Manohar Singh Chouhan

PhD Nursing Scholar

Introduction-

According to World Health Organization as Human beings- Health and health need are a matter of daily concern. Regardless of age, gender, socio-economic or ethnic background, health is considered to be a most basic and vital asset for everyone's life. On the other hand, sickness can keep away from going to work, from attending family functions and from participating in the activities of the community. By the same time, we are ready to do many more sacrifices if only that would ensure us and our family for a longer and healthier life. In short, when talk about well-being, health is often what and how we are taking it seriously.

Thalassemia is a heterogeneous group of blood disorders affecting the hemoglobin genes and resulting in ineffective erythropoiesis. The decreased production of hemoglobin results in anemia in early age and frequent blood transfusions are required to keep up the hemoglobin levels.

Thalassemias are a heterogeneous grouping of genetic disorders that result from a decreased synthesis of alpha or beta chains of hemoglobin (Hb). Hemoglobin serves as the oxygen-carrying component of the red blood cells. It consists of two proteins, an alpha, and a beta. If the body does not manufacture enough of one or the other of these two proteins, the red blood cells do not form correctly and cannot carry sufficient oxygen; this causes anemia that begins in early childhood and lasts throughout life. Thalassemia is an inherited disease, meaning that at least one of the parents must be a carrier for the disease. It is caused by either a genetic mutation or a deletion of certain key gene fragments.

Research Statement

A study to explore the lived experience and quality of life of thalassemia children in selected hospitals of

Aim of the study:

The study aims to explore the lived experience and quality of life of thalassemia children in selected hospitals in Rajasthan

Objectives of the study:

1. To assess the Quality of life of thalassemia children in selected hospitals in Rajasthan
2. To explore the lived experience of thalassemia children in selected hospitals of Rajasthan
3. To find out the association between quality of life with selected demographic variables

Hypotheses:

All at 0.05 level of significant

- H_1: There will be significant relationship between quality-of-life scores and thalassemia children
- H_2: There will be a significant association between the quality of life of thalassemia children with selected demographic variables.

Assumptions:

- Thalassemia children have varying levels of fear and anxiety.
- Thalassemia children have varying levels of quality of life.
- Thalassemia children have varying levels of physical, emotional social and educational difficulties.

Operational Definitions:

Explore: It refers to systematic examination of quality of life and lived experience among thalassemia children.

- **Lived Experience:** It refers to the subjective perception of thalassemia children towards their health and illness.
- **Quality of life:** It refers to the extent to which life is comfortable or satisfying among thalassemia children concerning physical, psychological, emotional, social, and educational domains.
- **Thalassemia children:** It refers to children with inherited blood disorders characterized by the deficiency of specific globin chains in hemoglobin.

Limitations of the study:

- The study was limited to thalassemia children only it can be done on other problems like hemophilia, and leukemia.
- The study was limited to 200 samples only
- This study was limited to selected hospitals of Rajasthan only it can be done at the national level or international level.

Summary-

This study attempted to explore the lived experience and quality of life of thalassemia children of selected hospitals Rajasthan, Total of 200 thalassemia children were selected who fulfilled the inclusion criteria. Formal permission from the concerned authorities was obtained before the data collection. The researcher had identified the mixed method research approach and explanatory sequential research design to explore lived experience and quality of life of thalassemia children. Non probability purposive sampling technique was used to collect the quantitative data and systemic random sampling technique used to collect qualitative data. Written consent was taken from the parents and willingness of the participants was gained. Children made comfortable during the data collection. Their routine was not disturbed due to the data collection procedure researcher has planned accordingly, Period of data collection were from June

Data collection tool considered demographic variable, disease related variables, and structured questionnaire was formulated to assess the quality of life. The tool was prepared through extensive review and validated by various subject experts. The quality of life assessment scale prepared with physiological, physical, psychological,

emotional an educational domains; each domain consisted of 10 items. Semi semi-structured interview was scheduled to explore lived experience for the five open-ended questions formulated. 30 to 40 minutes spent to each child to explore lived experience. Theme and subtheme were extracted.

The tool was administered to participants and data were collected. Descriptive and inferential statistics were carried out to analyze the quantitative findings. Conventional content analysis carried out for qualitative findings

The result of the study revealed highest 51% of thalassemia children had an Average quality of life 29% of thalassemia children had a good quality of life and 20% of children had poor quality of life. There was a significant association between quality of life and selected demographic variables (habitat) There was no significant association between quality of life and age, gender, Religion, standard of school education, age at which thalassemia was diagnosed, serum ferritin level and frequency of blood transfusion per year.

Major Findings of the study were:

- **Age in years:** Majority 32% respondents were in the age group of 10-11 years, 27% were in the age group of 16-17 years, 25% were in the age group of 14-15 years and the least 16% respondents were in the age group of 12-13 years.
- **Gender:** Majority of respondents 59.5% were male whereas 40.5% were female.
- **Religion:** Majority of respondents 64.5% were Hindus, 33% were Muslim and the least 2.5% respondents were from other religion
- **Habitat:** Equal distribution 37.5% were the residents of urban and rural, whereas least 25% respondents were living in semi urban area.
- **Monthly family income (Rs.):** Majority 46.5% respondents had 10,001-15,000/-monthly family income, 39.5 % had 15,001-20,000/- monthly family income and the least 12% respondents had 20,001-25,000/- monthly family income.
- **School Education:** Majority 74% respondents had primary education, 31%

had secondary education 20% had higher secondary education and only 10% respondents were not at school or school dropout.

- **Age at which thalassemia was diagnosed**: Majority 73% respondents had diagnosed thalassemia < 1 year, 24% had diagnosed thalassemia at 1-2 years and the least 2.5% respondents had diagnosed thalassemia at 3-4 years.
- **Type of thalassemia**: All respondent had Beta thalassemia.
- **Serum ferritin level (µg/L)**: Majority 45.5% respondents had > 2500, 26.5 % had > 5000 serum ferritin level and the least 28 % respondents had < 2500 serum ferritin level.
- **Frequency of blood transfusion per year**: Majority 65.5% respondents had required 12-24 times blood transfusion per year, 18% had required blood transfusion < 12 per year and the least respondents 15.5% required blood transfusion >24 times per year.
- **Splenectomy been performed:** Only 5% of respondents had under gone splenectomy where as remaining 95% had not undergone splenectomy.
- **Family History of Thalassemia:** All the respondents had a family history of thalassemia.

Objective 1: To assess quality of life of thalassemia children

Majority 51% of thalassemia children had average quality of life, 29% of thalassemia children had good quality of life and 20% of thalassemia children had poor quality of life. Domain wise level of quality of life: Physiological domain mean scores were 28.89 with mean % 16.9, physical domain mean scores were 28.74 with mean % 16.8, psychological domain mean scores were 28.57 with mean % 16.0, Emotional domain mean scores were 27.29 with mean % 16, social domain mean scores were 29.44 with mean % 17.2, educational domain mean scores were 27.27 with mean % 16.0. Emotional and educational mean score was lower than other domain mean score. It's indicated that thalassemia children had emotional and educational difficulties, calculated value of each domain greater than tabulated value its shows there was significant relation of each domain with total quality of life score.

Objective 2: To explore lived experience of thalassemia children Theme and subtheme identified after semi structured interview

Physical distress- Physical problems, psychological suffering- Confusion, Emotional Exhaustion- Painful emotion, Frustration with treatment- Burden of treatment and investigation, learning impact- school absenteeism.

Objective- 3 To find out association between quality of life with socio demographic variables & disease related variables.

Researcher found significant association between the quality of life and demographic variables (habitat). There was no significant association between the quality of life with other socio-demographic variables and disease related variables as the calculated chi-square values was less than the tabulated value at the 0.05 level of significance.

Overall experience of conducting the research, Thalassemia is a chronic debilitating disease and severely affects the quality of life, for them Life is not so easy to live with over burden of treatment and investigations still they have strong will power to fight with thalassemia, The need for good coping strategies: they tried to cope with their suffering. The coping strategies focused on improving the childr en's lives and well - being. They suffers Physically, mentally, socially, emotionally and educationally, This children are also the future citizen so it is our responsibility to care, respect them, and do the blood donation regularly. We should make aware the general public to get screening of thalassemia. So we can prevent the transmission of thalassemia.

CONCLUSION

The study was conducted to Explore lived experience and quality of life of thalassemia children in selected hospitals of Rajasthan thalassemia children from various hospitals and transfusion center were selected as sample by purposive and systemic random sampling technique.

The research approach adopted for the study was mixed method with explanatory sequential research design to assess quality of life and explored lived experience of thalassemia children. The data was gathered by the use of data instrument which contain Section- A Socio demographic data, Section-B Disease related variables, Section: C Structured quality of life assessment scale, Section- D Semi structured

interview through open ended questions.

On the basis of finding the study below said conclusion were drawn-

Majority 51% of thalassemia children had average quality of life, 29% of thalassemia children had good quality of life and 20% of thalassemia children had poor quality of life mean score was 170.2 ± 30.51 with mean percentage 56.73%, standard deviation was 30.51 %

Domain wise level of quality of life: physiological domain mean scores were 28.89 with mean % 16.9, physical domain mean scores were 28.74 with mean % 16.8, psychological domain mean scores were 28.57 with mean % 16.0, Emotional domain mean scores were 27.29 with mean % 16, social domain mean scores were 29.44 with mean % 17.2, educational domain mean scores were 27.27 with mean % 16.0.

Thalassemia is a chronic debilitating disease and severely affects the quality of life. According to the result of this study thalassemia children faced many challenges in their life. Children with thalassemia have the average quality of life in physical, emotional, psychological, social and educational domain. Improvement in quality of life requires consolidated efforts on part of doctors, parents, school authorities and policy makers. Parents, school authorities and health providers have to come together transfusion center and could provide transfusion services on weekends to reduce the frequent absenteeism in the school. In school teachers gives proper attention on thalassemia children, be approachable for them. A nurse who gives care of thalassemia children minimizes pain and maximizes the comfort. Create child centred environment in the ward. By increasing the awareness and knowledge regarding thalassemia among parents, it can help get better care locally and thus improve the quality of life. Early detection of associated complications and adverse transfusion reactions in thalassemia patients would be quite helpful in reducing the burden of disease through preventive measures. Every chapter was prepared with the help of a guide in the meaning of a very constructive way to explore lived experience and quality of life of thalassemia.

REFERENCES

1. King CR, Hinds PS. Quality of Life, from nursing and patient perspective, Theory, Research, Practice. 1st edition. Appleton and Lange, 2007.

2. Mohammad Abu S. Needs and concerns of Jordanian mothers with thalassemia children. Journal of American Science 2014; 10(1).
3. Ismail M, Yin Chun C, Mohd Yusoff N et al. Quality of life among thalassemia children. adolescent and their caregivers 2013; 42(3): 373-380.
4. Talsania S, Talsania N, Nayak H et al. A cross sectional study of thalassemia in Ahmedabad City, Gujarat(Hospital based). Healthline 2011; 2(1): 48-51.
5. Cunningham MJ, Macklin EA, Neufeld EJ. Complications of beta-thalassemia major in North America. Am Soc Haematol 2004; 104: 34-39.
6. Adaay MH, Al-Anzy MM, Al-Tikriti KA. Some observations on the occurrence of Î²-thalassemia in mosul. Iraq Joinerysoft Microsoft Pinpoint 2011; 9: 270-274.
7. Mehrnoosh Doroudchi, Ali Akbar Asadi Pooya. Thalassemia major and consanguinity in shiraz city, Iran. Turk J Hematol 2004; 21: 127-130.