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"A COMPARATIVE STUDY TO ASSESS THE QUALITY OF LIFE AMONG THALASSEMIA CHILDREN AND SICKLE CELL CHILDREN (8-14 YEARS) WITH A VIEW TO DEVELOP AN INFORMATIONAL BOOKLET"

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ABSTRACT

Pediatric blood disorders are a group of noncancerous diseases, including bone marrow failure syndromes and hemoglobinopathies, which can affect the functioning and quality of life of infants, children, and adults. In some cases, these disorders can be life-threatening. Bone marrow failure syndromes are rare and involve low blood counts due to problems with the bone marrow – the tissue inside bones that produces hematopoietic stem cells. Hematopoietic stem cells are the parent cells of all blood cells, giving rise to oxygen-rich red blood cells, infection-fighting white blood cells, and blood clot-forming platelets that help stop bleeding. The failure of a child's bone marrow to produce certain blood cells can be inherited through mutations (changes) in genes, or it can be acquired during a child's life time

Keywords: Structured teaching program, thalasemia, and sickle cell anaemia children, information booklet

INTRODUCTION

The term sickle cell disease (SCD) describes a group of inherited red blood cell disorders. People with SCD have abnormal hemoglobin, called hemoglobin S or sickle hemoglobin, in their red blood cells. Hemoglobin is a protein in red blood cells that carries oxygen throughout the body."Inherited" means that the disease is passed by genes from parents to their children. SCD is not contagious. A person cannot catch it, like a cold or infection, from someone else. People who have SCD inherit two abnormal hemoglobin genes, one from each parent. In all forms of SCD, at least one of the two abnormal genes causes a person's body to make hemoglobin S. When a person has two hemoglobin S genes, Hemoglobin SS, the disease is called sickle cell anemia. This is the most common and often most severe kind of SCD. Chhattisgarh is one of the creating states of India where state level population based screening for Thalassemia yet not done. Above information show that in 2012 transporter recurrence is acquired that 10.61% of screened population and in 2013 it is figured as 14.65% and finally in 2014 it is turned into 17.95%. Accordingly, we watch that Thalassemia carrier frequencies are expanding year by year in Chhattisgarh.

REVIEW OF LITERATURE

SECTION A: STUDIES RELATED TO THE PREVALENCE OF THALASSEMIA CHILDREN AND SICKLE CELL CHILDREN

SECTION B: STUDIES RELATED TO QUALITY OF LIFE OF THALASSEMIA CHILDREN.

SECTION C: STUDIES RELATED TO QUALITY OF LIFE OF SICKLE CELL CHILDREN.

SECTION D: A COMPARATIVE STUDY RELATED TO THALASSEMIA CHILDREN AND SICKLE CELL CHILDREN.

OBJECTIVES OF THE STUDY

1. To assess the quality of life among Thalassemia children and Sickle cell children.
2. To compare the quality of life of Thalassemia children and Sickle cell children.
3. To develop and distribute the informational booklet.

METHODOLOGY

An extensive review of literature was undertaken. The conceptual frame work adopted this studies based on Health belief model theory A quantitative non-experimental Comparative research approach was adopted for the study as the present study aim to assess the quality of life among thalassemia children and sickle cell children.

The research approach used will be quantitative non - experimental (comparative research approach) is considered appropriate for the study . In the present study, Quantitative non-experimental comparative research design was used since it aided in attaining first hand information and enhanced obtaining accurate and meaningful data. The study will be conducted in the out patient and in patient pediatric medicine ward in B.R.A.M Hospital Raipur which is a hospital having 1200 beds. The sample of the present study comprised of 50 thalassemia children and 50 sickle cell children in B.R.M.A hospital Raipur &Sickle Cell Institute of Chhattisgarh, Raipur. non-probability purposive sampling technique was used. The study to assess the quality of life among thalassemia children and sickle cell children. The tool include socio demographic data , modified health related quality of life assessment scale. The researcher used modified health related quality of life assessment scale, which consists of 35 questions to assess quality of life of thalassemia children and sickle cell children.

The data tool collection is consist of self structured questionnaire and rating scale is used . the reality of the tool was calculated using Karl Pearson methods and a reliable tool was found r=0.8. analysis and interpretation of the data was done using descriptive and inferential statistics

DEVELOPMENT & DESCRIPTION OF THE TOOL

Data collection tools are the procedures or instruments used by the researcher to observe or measure the key variables in the research problem **(Burns.N,Grove. K,2002).**

After wide reading, the researcher developed the tool as per the following:-

SECTION-A: Deal with socio demographic variables .

SECTION B: self-structured based questionnaire

CRITERIA MEASURING SCORE

0-4 point rating scales are used to assess quality of life of Thalassemia and sickle cell children.

The score of quality of life is categorized as -

S.NO.	SCORING	QUALITY OF LIFE
0	0-27	Very poor quality of life
1	28-55	Poor quality of life
2	56-83	Average quality of life
3	84-111	Good quality of life
4	112-140	Excellent quality of life

RELIABILITY

The value of r was found to be Thalassemia children (0.77) &sickle cell children (0.92) .

Reliability 0.8 lies within the acceptable range of reliability of tools that is 0.77 & 0.92.

The score that indicate perfect reliability. This indicate the tool is highly Reliable

PILOT STUDY

In order to establish the reliability of the tool it was administered to 5-Thalassemia and 5-sickle cell children In patient department of Bal Gopal children Hospital and research institute of Raipur Chhattisgarh .

The split half method was used to test the reliability of the tool. The test was first divided into two equivalent half then half 3 odd number sample kept in X and even numbers samples kept in Y and calculated by using Karl pearson's correction co-efficient formula and score of the test was 1that shows highly reliability of tool was established and was found to be statistically reliable for present study.

DATA COLLECTION PROCEDURE

- The investigator will obtain written permission from the hospital authority .
- Formal permission will be obtained from the HOD of the pediatric department ,the Director General Sickle Cell Institute Of Chhattisgarh, Raipur department to collect data.

- After verifying the records, informed consent will be taken and children who fulfills the inclusion criteria will be selected by using non-random (convenience) sampling technique. The researcher had taken permission from patient under study, prior to interview. The investigator first introduces herself to the respondent and explains the purpose of gathering of data.
- Data collection for the study was carried out from 25/07/2018 to 05/08/2018.
- Baseline variables will be collected using self-structured interview schedule and modified health related quality of life assessment scale 0-4 generic core questionnaire will be administered using structured interview schedule among Thalassemic children and Sickle cell children for 30-45 minutes. At the end of interview 3-5 minute were utilized to give health teaching regarding coping with disease related problem and issues

PLAN FOR DATA ANALYSIS AND INTERPRETATION

Data will be analyzed by using descriptive and inferential statistics.

- Organization of data in master sheet.
- Calculate the frequency and percentage to show the distribution of subjects according to the baseline variables
- Calculate mean, standard deviation of the domains of quality of life and independent t - test for comparison between the two groups.
- Value to compare at 5% level of significant for corresponding degree of freedom .

- Data will be expressed in table and figure for better clarification

RESULT

Finding related to Assess the Overall Quality of life among Thalassemia children and Sickle cell children. The comparison between Thalassemia children & Sickle cell children according to Assessment of overall quality of life in percentages. In Thalassemia (70%) Children's are belong to the Good quality of life & (30%) children belong to the Average quality of life. In Sickle cell (54%) children are belong to the good quality of life and (38%) are children belong to the Average quality of life and (8%) children belong to the excellent quality of life the comparison between Thalassemia children & Sickle cell children according to Assessment of overall quality of life in percentages. In Thalassemia (70%) Children's are belong to the Good quality of life & (30%) children belong to the Average quality of life. In Sickle cell (54%) children are belong to the good quality of life and (38%) are children belong to the Average

quality of life and (8%) children belong to the excellent quality of life.

CONCLUSION

After the detail analysis, this study reveals or concluded that:

Majority of Sickle cell children had better quality of life than the Thalassemia children by using the descriptive and inferential statistics.

RECOMMENDATIONS

- Improving awareness of children & parents regarding Thalassemia and Sickle cell disease that help in enhancement children's quality of life.
- Develop an educational program for children and their parents about the prevention of Thalassemia and Sickle cell crises.
- Future studies needed with larger samples of Thalassemia & sickle cell and on other age groups.
- Improving knowledge, attitudes and practices of thalassemia & sickle cell children's parents about importance of premarital examination and genetic counseling services.
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