"A STUDY TO ASSESS THE CLINICAL AND PSYCHOLOGICAL FACTORS AFFECTING QUALITY OF LIFE AMONG CHILDREN SUFFERING WITH THALASSEMIA AT THALASSEMIA CENTER OF HSK HOSPITAL AND RESEARCH CENTER, BAGALKOT."

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Abstract

Background: Thalassemia is a major health problem that disturbs the lifestyle of the affected patient. The assessment of quality of life in children, especially in those with chronic illness such as thalassaemia, is particularly important. It differs from other forms of medical assessment in that it focuses on the individuals' own views of their well-being and other aspects of life, giving a more holistic view of well-being. The aim of this work is to find out the level of depression of patients with thalassemia disease condition. **Objectives:** To assess the clinical and psychological factors affecting quality of life among children suffering with thalassemia in thalassemia centre of HSK Hospital and research centre at Bagalkot. **Methods:** A study was conducted with a sample of 100 students in the age group of 6 – 15 years was selected by convenient sampling technique. The data was collected by using Centre for epidemiological studies Depression scale for children [CES-DC] & Paediatric quality of life inventory scale. The data was entered in MS excel sheet and transferred to SPSS 25 for analysis. **Results:** Among 100 samples 44% were males and 56% were females. Among 100 participants 35% children are in between the age group of 6 to 8 year, 63% of children are suffering with the thalassemia major, 93% of children are at risk for depression according to the epidemiological studies depression scale for children, the mean and standard deviation is 45.61 and ±7.7 of paediatric quality of life inventory scale.
Conclusion: Thalassemia has a negative impact on perceived physical, emotional, social and school functioning in thalassemia patients. Children are at more risk of having depression according to the scale.
Keyword: Quality Of life, children, thalassemia, clinical, psychological factors.

INTRODUCTION

Thalassemia's are inherited disorders of Haemoglobin synthesis that result from an alteration in the rate of globin chain production. A decrease in the rate of production of a certain globin chain or chains (α, β, γ, δ) impedes Hb synthesis and creates an imbalance with the other, normally produced globin chains.[1] The most severe form is the β-thalassemia major, which is characterized by a severe microcytic, hypochromic anaemia (Cooley's anaemia), whose symptoms appear usually within the first 2 years of life. Infants become pale and asthenic, have poor appetite, grow slowly, and often develop jaundice; spleen, liver and heart may also be enlarged. School age [6 to 15] with the most severe form may experience delayed puberty.[2] Significant advances in treatment modalities and improved clinical management have led to a substantially higher life expectancy of these patients.[3] Children with thalassemia major have good survival but little is known about their quality of life.[4] Children are less able to voice their concerns and are more vulnerable than adults.[5]The assessment of quality of life (QOL) in children especially in children with chronic illness such as thalassaemia is particularly important.[6] An assessment of QOL differs from other forms of medical assessment in that it focuses on the individuals' own views of their well-being and assesses other aspects of life, giving a more holistic view of well-being [6] It is important to understand more about quality of life in paediatric population to evaluate and improve the care patients receive. Children with chronic physical illness exemplified thalassemia are vulnerable to emotional and behavioural problems leading to poor quality of their lives. The disease may cause a sense of stigmatization in the child leading to feeling of shame and rejection. It also may affect social relations, school interactions, and self-esteem. So, great attention has to be taken especially by the nurse during treatment, monitoring and follow up.1

Methods: Descriptive co-relational design was used for the present study. The aim of study was to find out the level of depression among children with thalassemia disease condition. Setting of the study was Thalassemia centre of HSK Hospital and research centre at Bagalkot. A sample of 100 children in the age group of 6 – 15 years were selected by using Purposive sampling technique.

Study participants: The study participants were children from 6-15 years of age group residing in Thalassemia centre of HSK Hospital and research centre at Bagalkot District.

Setting of the data: Based on the investigator's familiarity, availability of the subjects and feasibility to conduct the study, the present study was conducted in Thalassemia centre of HSK Hospital and research centre at Bagalkot.

Sampling technique: The sample was selected by Purposive sampling technique. will be used to select the sample for Selecting in Thalassemia centre of HSK Hospital and research centre at Bagalkot **Sample size estimation:** The sample size for the present study was estimated using the following formula based on result of pilot study.

Sample size = Zvalue^2. × SD^2 /d^2

where, **Z** = the value of normal variant at 95% confidence level i.e. Z value = 1.96.

SD = Standard Deviation

D = Expected allowable error in the mean (i.e. 5%of mean)

Mean =13.5**SD** = 3.14**d** =5×13.5/100 **d**= 0.67

The value of normal variant at 95% confidence level i.e. **Z** valve = 1.96.

Hence, Sample size (n) = Z value ^{2} × SD^2 / d ^{2} Sample size (n) = $(1.96)^2$× $(3.14)^2$ / $(0.67)^2$

Sample size (n) = 3.84 × 9.85/ 0.44

Sample size (n) = 85.96

Hence the calculated sample size was 85.96 as round off the researcher selected 100 school age children in Thalassemia centre of HSK Hospital and research centre at Bagalkot.

DATA COLLECTION INSTRUMENTS

- Centre for epidemiological studies Depression scale for children [CES-DC]
- Paediatric quality of life inventory scale.

Translation and reliability of data collection instruments

The instruments were translated in to Kannada language and retranslated in to English. Similarity between original and translated tool were ascertained by linguistic experts. The reliability of all 2 tools was established by test-retest method. The tools were administered to 10School age children and the same tools were administered to same group with a gap of seven days. Spearman's rank order correlation co-efficient for baseline proforma was R=1. For Centre for epidemiological studies Depression scale for children [CES-DC] [r=0.79] and for Paediatric quality of life inventory scale [r= 0.81] suggesting all the tools were reliable for conducting the study.

Data collection procedure: Data collection was done from 27/11/2023and 02/12/23 at in Thalassemia centre of HSK Hospital and research centre at Bagalkot. A formal Permission was obtained from the Principal of Sajjalashree Institute of Nursing Sciences Navanagar, Bagalkot. Then permission was obtained from the medical superintendent of HSK Hospital and research centre at Bagalkot. The investigator given self-introduction explained the purpose of data collection to the subjects and subject's willingness to participate in the study was ascertained. The subject was assured the anonymity and confidentiality of the information provided by them.

Ethical clearance: Ethical clearance certificate was obtained from Institutional ethical clearance committee, B.V.V.S Sajjalashree Institute of Nursing sciences, Bagalkot (ref No. BVVSSIONS-IEC/2022-23/1015 Dt:12/08/2023) written consent of participation was obtained from participants before data collection.

Statistical analysis: The data was analysed using SPSS version 25. The obtained data was entered in MS excel sheet. The data was edited for accuracy and completeness. The categorical responses were coded with numerical codes. The data was presented with frequency and percentage distribution tables and diagrams. The description of level of depression and Quality of life. was presented with frequency, and percentage distribution, mean, median and standard deviation, range etc. Spearman's correlation formula used to find out the co-relation between the level of depression and Quality of life. The chi-square (X2) test will be used to find out the association between the demographic variables with the level of depression and Quality of life.

RESULTS

Table I: Description of Socio-demographic characteristics of children suffering with thalassemia. N=100

AGE IN YEARS	**FREQUENCY**	**%**
6 to 8	35	35%
9 to 1	23	23%
11 to 12	23	23%
13 to 15	19	19%
TOTAL	100	100
GENDER	**FREQUENCY**	**%**
Male	44	44%
Female	56	56%
Transgender	0	0%
TOTAL	100	100
RELIGION	**FREQUENCY**	**%**
Hindu	75	75%
Muslim	12	12%
Christian	8	8%
Others	5	5%
TOTAL	100	100
EDUCATION OF CHILD	**FREQUENCY**	**%**
School	85	85%
High school	15	15%
TOTAL	100	100
EDUCATION OF FATHER	**FREQUENCY**	**%**
Literate	81	81%
Illiterate	19	19%
TOTAL	100	100
EDUCATION OFMOTHER	**FREQUENCY**	**%**
Literate	59	59%
Illiterate	41	41%
TOTAL	100	100
OCCUPATION OF FATHER	**FREQUENCY**	**%**
Unemployed	0	0
Employed	66	66%
Self-employment	20	20%
Coolie	2	2%
Agriculture	12	12%
TOTAL	100	100
OCCUPATION OF MOTHER	**FREQUENCY**	**%**
House wife	60	60%
Employed	18	18%
Self-employment	13	13%
Coolie	2	2%
Agriculture	7	7%
TOTAL	100	100
FAMILY MONTHLY INCOME	**FREQUENCY**	**%**
Less than 10,000	0	0
10,000 - 20,000	49	49%
20,000 – 30,000	29	29%
More than 30,000	22	22%
TOTAL	100	100
TYPE OF FAMILY	**FREQUENCY**	**%**
Joint	27	27%

Nuclear	73	73%
Extended	0	0%5
TOTAL	100	100
AREA OFRESIDENCE	**FREQUENCY**	**%**
Urban	61	61%
Rural	39	39%
TOTAL	100	100

Table 1 shows the Description of Socio-demographic characteristics of children suffering with thalassemia.

Table II: clinical characteristics of children suffering with thalassemia.

Types of Thalassemia	**Frequency**	**%**
Thalassemia major	63	63%
Thalassemia intermedia	37	37%
TOTAL	100	100

Table III shows the clinical characteristics of children suffering with thalassemia.

Table III: Shows the clinical characteristics of children suffering with thalassemia

Age at diagnosed in year	**Frequency**	**%**
Below 4 months	2	2%
4 – 11 months	84	84%
1 year – 3 years	8	8%
4 year – 6 years	5	5%
7-year -10 year	1	1%
Above 10 years	0	0
TOTAL	100	100
Age at first blood transfusion	Frequency	%
Below 4 months	2	2%
4 – 11 months	84	84%
1 year – 3 years	8	8%
4 year – 6 years	5	5%
7-year -10 year	1	1%
Above 10 years	0	0
TOTAL	100	100
Oral iron Chelation Thera	Frequency	%
Yes	7	7%
No	93	93%
TOTAL	100	100
Age at first chelation in year	**Frequency**	**%**
Below 4 months	0	0
4 – 11 months	2	2%
1 year – 3 years	2	2%
4 year – 6 years	2	2%
7-year -10 year	1	1%
Patient with no chelation therapy	93	93%
TOTAL	100	100
Hepatitis c infection	**Frequency**	**%**
Positive	3	3%
Negative	97	97%
TOTAL	100	100
Frequency of blood transfusion	**Frequency**	**%**

< 6 times / year	2	2%
> 6 times / year	98	98%
TOTAL	100	100
Pre transfusion Hb level	**Frequency**	**%**
Below 4	0	0
4 – 7 g/dl	64	64%
8 – 10 g/dl	36	36%
TOTAL	**100**	**100**
Serum ferritin level test	**Frequency**	**%**
Yes	3	3%
No	97	97%
TOTAL	100	100

Table IV shows the clinical characteristics of children suffering with thalassemia

Table IV: Centre for epidemiological studies depression scale for children (CES-DC) N = 100

LEVEL OF DEPRESSION	SCORE	FREQUENCY	%
No significant depression	Less than 16	7	7%
Significant clinical depression	More than 16	93	93%
TOTAL		100	100

Table no 4 depicts the Percentage wise distribution of children with thalassemia according to the depression level, (93%) of children were under the risk of depression and 7% of children were normal.

Table V: paediatric quality of life inventory child version N = 100

SL NO	Qualities	Mean	Standard deviation
1	Health and activities	15.5	6.3
2	Feelings	9.42	2.8
3	Along with others	8.94	2.8
4	About school	11.8	4.2
5	Over all	45.61	7.7

The above table no 5 shows the distribution of children with thalassemia according to their paediatric quality of life inventory of child, health and activities mean and standard deviation is 15.5, ± 6.3, feelings of children mean and standard deviation is 9.42, ±2.8, along with the others mean and standard deviation is 8.94, ±2.8, about school mean and standard deviation is 11.8 ±,4.25 and over all mean and standard deviation is 45.61, ±7.7.

Table VI: Association between the Quality-of-life school age students with their selected socio-demographic variables. N=100

Sl.No	Socio-demographic variables	Df	χ2 value	P Value
1	Age in year	3	6.38	0.0945
2	Sex	1	2.82	0.0931
3	Religion	1	3.9	**0.0483***
4	Education of child	1	2.6	0.1069
5	Education of father	1	1.83	0.1761
6	Education of mother	1	0.61	0.4348
7	Occupation of father	2	3.61	0.1645
8	Occupation of mother	2	3.688	0.1588
9	Family monthly income	2	0.06	0.9704
10	Type of family	1	0.37	0.543
11	Area of residence	1	5.35	**0.0207***

* Significant p<0.05

Table –VI shows the Association between the Quality-of-life school age students with their selected socio-demographic variables

Table VII: Association between the level of QOL of children with their selected clinical characteristics. N=100

Sl.no	Clinical characteristics	D f	χ2 value	P Vale
1	**Types of Thalassemia**	1	2.8	0.1079
2	**Age at diagnosed in year**	5	6.43	0.0965
3	**Age at first blood transfusion year**	5	2.72	0.0917
4	**Oral iron Chelation Therapy**	1	3.8	**0.0471***
5	**Age at first chelation in year**	5	3.71	0.1665
6	**Hepatitis c infection**	1	0.07	0.9717
7	**Frequency of blood transfusion**	1	5.45	**0.0221***
8	**Pre transfusion Hb level (g/dl)**	2	0.51	0.4308
9	**Serum ferritin level test(ng/ml)**	1	1.93	0.1781

* Significant p<0.05

Table VII shows the Association between the level of QOL of children with their selected clinical characteristics.

Table VIII: Association between the level of QOL of children with their score of depression scale.

Sl.no	Level of Depression	D f	χ2 value	P Vale
1	Risk for depression	1	0.01	0.9203

* Significant p<0.05

Table VIII shows the Association between the level of QOL of children with their score of depression scale.

DISCUSSION

It is a co-relation study to assess the clinical and psychological factors affecting quality of life among children suffering with thalassemia. "A similar cross-sectional study was conducted to assess the factors influencing quality of life of these children and how it can be improved. The study concluded that the results showed Factors improving the quality of life were control of iron overload and adverse effects of ICTs, management of co morbidities and fewer hospital visits.[7]A similar descriptive cross-sectional study was conducted to examine factors associated with HRQOL among children and adolescents with thalassemia in Thailand the results of the study show that the mean (SD) of the total summary score was 76.67 (11.40), while the means (SD) for the Physical Health Summary score and Psychosocial Health Summary score were 78.24 (14.77) and 75.54 (12.76), respectively. The school functioning subscale scored the lowest, with a mean of 67.89 (SD = 15.92) the study concluded that to improve HRQOL of thalassemia patients, suitable programs aimed at providing psychosocial support and a link between the patient, school officials, the family and the physician are important, especially in terms of improving the school functioning score.[8]

A similar descriptive cross-sectional study was conducted to assess the quality of life in children with thalassemia major at Center for Special Diseases of valiasr hospital in Birjand. the results showed mean score of 70.37±9.88 for quality of life, 25±3.06 for physical health, 18.12±3.22 for mental health, 21.3±4.43 for living environment, and 5.95±1.58 for sociability. There was no significant correlation between quality of life and demographic variables. Correlation between social relationships and education level was significant (P-value<0.0001). the study concluded that the quality of life of the patient was above average in three dimensions of physical health, psychological health, and environmental health, and in order to improve quality of life in these children, appropriate programs should be implemented to support them physically, mentally and socially, and improve patient's relationship with Center for Special Disease[9]A similar descriptive study was conducted to assess the Quality of life (QoL) and the factors affecting it in transfusion-dependent thalassaemic children. The result of the study concluded that Factors related with low QoL in current study were higher age, increased transfusion frequency and injectable mode of chelation. In order to improve the QoL in thalassaemic children appropriate programmes and interventions should be started targeting above domains.[10] A similar study was conducted in vijayapur. Thalassemia is a group of hemoglobinopathies characterized by defect in hemoglobin synthesis. It is chronic disease, where the patients should undergo regular blood transfusion and take iron chelation to maintain their health status. The authors aimed to bring the comprehensive view of overall health related quality of life and find out the various factors associated with their quality of life. The findings from various studies revealed that all the domains of health-related quality of life is been affected. The most common factors which had impact on QoL include chelation therapy, repeated hospitalization, educational status of parents and financial factors.[11]A similar study was conducted to assess the factors affecting health-related quality of life among paediatric patients with thalassemia. Results indicated factors affecting the quality of life among thalassaemia patients and its implications in the essential core domains for paediatrics health-related quality of life measurements: physical, emotional, social and school functioning. It also empowers a better understanding regarding thalassaemia and assists as a foundation for the development of the effective preventive strategies for it.[12]

A similar cross-sectional studyaims to assess systematically evaluate the psychiatric morbidity and quality of life in relation

to demographic- and illness-related variables among Sri Lankan patients with thalassemia. The study concluded that Several factors may influence the psychological state and well-being of patients with thalassemia in Sri Lanka. Specific service innovations (some gender-specific) may help to address these factors to improve treatment outcome and well-being.[13]A similar study was conducted to assesses the QOL and the factors that affect it in children with β-TI and to determine the impact of the patients' and their mothers' perceptions of the illness on patients' QOL. the study concluded that QOL is significantly affected in β-TI patients; maintaining a suitable hemoglobin level and standard levels of body iron are associated with better QOL. Patients' and their mothers' perceptions of the illness play an important role in QOL.[14]A similar study was conducted to Quality of Life and Social Support among Mothers of Children with Thalassemia. The study concluded that there was a positive correlation between total quality of life and total social support among the studied mothers. It was recommended that, an educational program should be given for the mothers of children with thalassemia to maintain their psychological and physical health, as well as improve their quality of life as a whole. [15]

CONCLUSIONS

Thalassemia has a negative impact on perceived physical, emotional, social and school FUNCTIONING in thalassemia patients. Children are at more risk of having depression according to the scale. Study in large scale, and true experimental research also should be carried out. More and more educational campaigns also should be conducted in this field.

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