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The Impact of the SCOPE Programme on the Health-Related Quality of Life and Health Status of Thalassemic Children at a Selected Hospital in Berhampur, Odisha

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Abstract:

Thalassemia, a hereditary blood condition, reduces hemoglobin synthesis and oxygen delivery. Mutations in the genes that produce the alpha and beta hemoglobin subunits cause alpha and beta thalassemia, respectively. Anaemia, tiredness, and jaundice are signs. Blood transfusions, chelation, and bone marrow transplants are treatments. Mediterranean, African, and Southeast Asian individuals have the most thalassemia. The severity of thalassemia relies on the number of defective genes inherited in alpha-thalassemia and the hemoglobin molecule affected in beta-thalassemia. Severe instances may need blood transfusions. Beta thalassemia major children need lifelong blood transfusions, which may harm their physical, mental, and social health. Dental, orthopedic, and cardiac disorders might occur. Thalassemia-afflicted children have poor health. Thalassemia causes weariness, weakness, pale or yellowish complexion, facial bone abnormalities, delayed development, abdominal swelling, and black urine. Symptoms may appear at birth or within two years. However, thalassemia patients and families are empowered and supported. Thalassemia patients in Berhampur, India, get regular hospital care under the scope programme. The research examines Berhampur's thalassemia empowerment trend. Senior patients educate younger patients about thalassemia treatment. Thalassemia, a hereditary blood illness that inhibits hemoglobin production, causes anaemia and other symptoms. Transfusions and other treatments manage symptoms. Patients with thalassemia are empowered and supported.

Keywords: Effectiveness, quality of life, health status, thalassemia Berhampur, Odisha.

Introduction:

Thalassemia is a genetic condition that is passed down through families in an autosomal recessive manner. It causes red blood cells to oxidase prematurely because they do not produce enough hemoglobin. Because of a genetic blood disorder known as thalassemia, which is handed down from parent to kid, an abnormally low amount of hemoglobin is produced by the body. Because they contain hemoglobin, red blood cells are able to transport oxygen across the body. People who have thalassemia have an alteration in the DNA of the cells that create hemoglobin, the component of red blood cells that is responsible for transporting oxygen throughout the body.

Thalassemia is a genetic disorder that is caused by mutations that are handed down from parents to offspring. Both the alpha and

beta chains, which together form hemoglobin molecules, are susceptible to undergoing mutations (1, 2). One may be diagnosed with the kind of thalassemia known as alpha- or beta-thalassemia when either the alpha or beta chains are not produced in sufficient quantities (Figure a). The severity of an individual's alpha-thalassemia is determined by the amount of gene mutations they inherited from each of their parents. The severity of thalassemia correlates directly with the number of genes that are altered. The severity of beta-thalassemia is directly proportional to the portion of the hemoglobin molecule that is affected by the disease. If you are unable to attend to school or receive an education, this may lead to poor physical and mental health. Some of the issues that can contribute to this include not having enough erythropoietin, blood injections, and other things (3-5). These youngsters may also have a higher risk of developing issues with their hearts, bones, and teeth. Babies that are born with thalassemia have a poor quality of life and are not in excellent health on the whole, which is something that can be stated about the condition as a whole. Thalassemia may take on a variety of distinct appearances. There are a variety of indications and symptoms associated with the illness, including lethargy and a deficiency in energy, although these may take on a variety of forms depending on the nature and severity of the condition. a complexion that is pasty or yellow, as well as facial bones that are misaligned. A lack of development, an enlarged stomach, urine that is black, etc. Some infants exhibit symptoms of thalassemia before they are even born, while others don't show any symptoms until they are between the ages of one and two (6, 7).

Literature Review:

Every year, May 8 is celebrated as World Thalassemia Day. The major purpose of this day is to increase awareness about thalassemia among the general population. This is an example of a hereditary condition that may be passed on from parents to their children. since of this, childhood as a whole is negatively impacted since a significant number of youngsters need to need frequent blood transfusions in order to stay alive. As a direct consequence of this, they are required to go to the hospital or clinic on a regular basis (8). In 2018, the government of Maharashtra came to the conclusion that this was the best course of action for individuals who suffer from blood diseases. The state government recognised in a public resolution that was passed that hemophilia, thalassemia, and sickle cell disease was all conditions that were within the umbrella of the category of disabilities (9). There are around 600 to 800 people living in Odisha who have thalassemia major. The Thalassemia Society of Maharashtra was able to provide assistance to 70 people living in western Maharashtra and Odisha so that they could receive a disability certificate. Despite the passage of this General Resolution, people who suffer from blood disorders such as thalassemia and hemophilia are not aware of the advantages that the Rights of Persons with Disabilities

Act of 2016 provides (10). According to the GR, these persons are now able to submit applications for benefits including infirmity certificates, job and educational adjustments, and so on. In order to educate and advise patients on equality, national health authorities have cooperated with hospitals, non-governmental groups, and the Thalassemia Societies of Maharashtra and Odisha. There is a higher prevalence of this illness among some communities in India, such as the Gujrathis, Panjabis, and Sindhis; this may be attributed to the fact that they marry within their own families. But since there are now more marriages between people of different castes, the sickness has spread to every culture. Hundreds of infants are born with thalassemic conditions in our countries each year, and millions of individuals possess the gene that causes the condition. At the National Headquarters of its blood bank, the Indian Red Cross Society has a facility called the Thalassemia Screening and Counseling Centre (11). The purpose of this facility is to inform members of the general public about the risk of contracting this condition. Children under the age of 14 make up 27.34% of India's total population, with male children making up 186,087,665 and female children making up 164,398,204, as stated in India's demographic profile for 2018. It is important that children do not get the impression that adults are less capable than they really are. It is not possible to make considerable adjustments to these medical criteria for children and adolescents. The study of children is an exciting field of study, and it is clear which elements, taken together, contribute to the disorders that children experience. There is a possibility that the clinical symptoms of illnesses will be different in newborns compared to adults. According to the findings of scientific study, the recommended drug doses for children are different from those for adults (12-14).

Methodology:

Research Approach:

Quantitative research methodology will be used to undertake the present investigation.

Research Design:

This study employed a Randomized Controlled Trial (RCT) with a pre-test and post-test design based on the principles of randomization and control.

Variables under Study:

Independent Variable:

In experimental studies, the independent variable is the variable that is manipulated or varied to examine its effects. It is referred to as "independent" because it is not affected by any other study variables (15). In this study, the independent variable is the scope program's efficiency.

Dependent Variable:

A dependent variable is one that changes in response to a change in an independent variable. Your dependent variable "depends" on the outcome you wish to measure. The dependent variables were the quality of life and health status of thalassemic children, while the demographic factors were their age, gender, religion,

family type, mother's education level, current weight, and family income (16).

Setting of the Study:

It refers to the precise location where the study will be conducted. The setting provides the physical, social, and cultural context in which the study is conducted. The research environment has a significant impact on the study's samples, data categories, and outcomes. The Thalassemia ward at M.K.C.G.M.C.H., Berhampur, Ganjam, Odisha will serve as the site for the current investigation (Figure b).

Study Population:

In this research, populations will consist of thalassemic minors admitted to MKCG MCH at the moment of data collection.

Sample:

In the present research, samples will be collected from thalassemic minors admitted to the M.K.C.G., Medical College & Hospital in Berhampur, Odisha.

Sample Selection Criteria

Inclusion Criteria:

Thalassemic minors aged 8 to 18 years and their caretakers from select Thalassemia centers at M.K.C.G., Medical College & Hospital are eligible for this study:

1) Regularly receiving blood transfusions at the Thalassemia centre.
2) Willing to take part in the research.
3) Children ages 8 to 18 and their parents or guardians.
4) Available during the data collection period.
5) Be conversant in Marathi, Hindi, and English.

Exclusion Criteria:

Thalassemic minors aged 8 to 18 years and their caretakers from select Thalassemia centers at M.K.C.G., Medical College & Hospital are eligible for this study:

1) Not receiving regular transfusions of blood from the Thalassemia centre.
2) Unwilling to take part.
3) Children younger than 8 years old and older than 18 years old.
4) Who has life-threatening conditions.
5) Lack language proficiency in Marathi, Hindi, and English

Sampling Technique:

The participants in the study will be arbitrarily assigned to experimental and control groups using a computer-based random number generator (17). It is the selection of samples from the available population.

Sample size:

It is a crucial aspect of the research that every researcher must take into account. It should be determined prior to conducting the investigation. The intended sample size will be determined by statistical principles. Thus, the researcher has included 100 cases in the study group.

Tool:

The socio-demographic information was compiled using semi-structured questionnaires after a comprehensive literature review and consultation with subject matter experts. Participants' information was collected using the

Paediatric Quality of Life Inventory, version 4.0, and the clinical profile (18).

Ethical Consideration:

- The study will be conducted in accordance with the human rights guidelines for nurses conducting clinical and other forms of research (19).
- The institutional research committee of the MKCG Medical College will authorize this research project.
- The prerequisites will be met and permission to conduct the study will be obtained from the chosen hospital. The relevant authorities and departments will be notified about the study.

Result and Discussion:

Demographic variables of thalassemic children in M.K.C.G.M.C.H., Berhampur:

This section presents a prevalence and percentage distribution of respondents according to sociodemographic variables of thalassemia infants. Table (a) displays the distribution of respondents by age in years, with the preponderance of respondents falling within the oldest age bracket. 35% of respondents fell within the age range of 8-12 years, 26% fell within the age range of 5-7 years, 24% fell within the age range of 2-4 years, and less than 10% fell within the age range of 13-18 years. The gender distribution of respondents; 56% of respondents were male and 40% were female. The religious distribution of respondents; 64.5% of respondents were Hindu, 33.0% were Muslim, and 2.5% were of other faiths.

Demographic variables of thalassemic children'sparents in M.K.C.G.M.C.H., Berhampur:

In Table b, the sociodemographic traits of the parents of children with thalassemia are shown in terms of the number and proportion of responders in this area. In the groups that got regular therapy (RT) and alternative therapy (AT), 98.2% and 96.4% of the dads were the only ones who paid. About 4% of moms with AT children were the only wage earners in the family, while only 1.8% of parents with RT children were the only wage earners. Families in the RT and AT groups had monthly incomes that were 8.2% and 14.5% less than Rs. 8,000, respectively. 8–9% of families in both treatment groups made more than Rs. 16,000/- per month. Families with children in the RT group make 82.7% of their pay in this range. Families with children in the AT group make only 77.3%. Children in the RT group came from both large homes (62.7% of them) and smaller ones (37.3%). This number was higher than 50% in the AT group, and 51.8% of families were made up of two or more people. In the RT group, almost 60% of families have two children, but only 30%.9% of families in the AT group have two children. In the AT group, 52.7% of families only have one child, but only 26.4% of families in the RT group only have one child. Families with three or more children make up 12.7% and 16.4% of the RT and AT groups, respectively. In the AT group, 94.5% of families only had one child with thalassemia major. In the RT group, only 77.3% of

families had only one child with thalassemia major. In the RT group, 2.9% of families with 2 or more affected children and 3.6% of families with 1 affected child have a child with thalassemia major. Only 5.5% of AT group families have two people with severe thalassemia. Table (b) shows what kind of people the parents of children with severe thalassemia.

Health related Quality of Life Score:

In terms of both physical and social health, the average scores of the study group and the control group were significantly different. However, there was little difference between the experimental and control groups in terms of how well the thalassemic children performed in school and with their peers (Table c).

Effectiveness of SCOPE Program on Health Related Quality of life of Children:

The health condition of thalassemic children was determined by determining whether or not they had clinical difficulties, as well as their pre-transfusion hemoglobin (Hb) levels and body mass index (BMI). The majority of the children who participated in the pre-test presented with symptoms such as fever, pallor, lethargy, lack of appetite, weight loss, bodily discomfort, congestion, coryza, abdominal distention, irritability, hepatomegaly, splenomegaly, bone and joint pain, and jaundice (table d). According to the data shown in Tables (f) and (g), there was not a statistically significant difference between the two groups in terms of pre-transfusion levels of Hb ($t=0.378$, $P=0.713$) or BMI ($t=0.426$, $P=0.679$). The findings of the post-test showed that the health status of thalassemic children who were exposed to the SCOPE Programme improved considerably compared to the group that served as the control ($F = 10.824$, $P = 0.001$) (table h). Nutritional therapy and health education with a focus on families, particularly in reference to the care of thalassemic children at home, both contributed to an improvement in this group's overall health. The difference was found when the mean score for health concerns was compared between the experimental group and the control group four months following the intervention. The experimental group had a mean score of 4,500, with a standard deviation of 2,8810, whereas the control group had a mean score of 25,183, with a standard deviation of 3,4925.

Figures and Tables:

Figures:

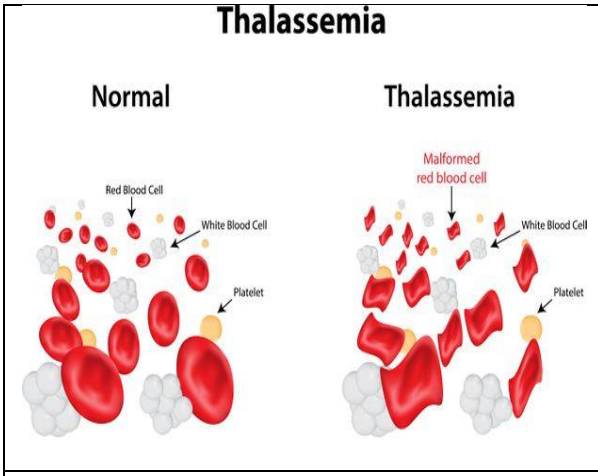

Figure (a) Thalassemia

Figure (b) M.K.C.G.M.C.H., Berhampur, Ganjam, Odisha

Tables:

Table (a)Distribution of respondent's ages, genders, and religions according to the survey N=100

Sr. No.	Socio – demographic variables	Categories	Frequency	Percentage (%)
1	Age (Years)	13-18 8-12 5-7 2-4	10 35 26 24	10 % 35 % 26 % 24 %
2	Gender	Male Female	56 40	56% 40 %
3	Religion	Hindu Muslim Christian Others	66 00 05	33% 00 2.5%

Table (b)Distribution of respondents by habitat, monthly family income, and educational attainment N=100

Sr. No.	Socio - demographic Variables	Categories	Frequency	Percentage (%)
1	Habitat	Rural	40	40 %
		Urban	40	40 %
		Semi urban	20	20 %
2	Monthly family Income (Rs.)	5000-15000	51	51 %
		< 5000	37	37 %
		>15000	9	9 %
3	School education	Primary	67	67 %
		Secondary	13	13 %

		Higher secondary	7	7 %
		Not at school/school drop out	9	9 %
4	Educational status of the mother	Profession/honors	2	1.8 %
		Graduate/postgraduate	8	7.3 %
		Intermediate/ diploma	31	28.2 %
		High school certificate	28	25.5 %
		Middle school certificate	33	30.0 %
		Primary school certificate	8	7.3 %
5	Occupation of the Father	Professional	7	6.4 %
		Semi-professional	19	17.3 %
		Skilled worker	12	10.9 %
		Semi-skilled worker	28	25.5 %
		Unskilled worker	28	25.5 %
		Unemployed	16	14.5 %
6	Occupation of the Mother	Professional	0	0.0 %
		Semi-professional	0	0.0 %
		Skilled worker	1	0.9 %
		Semi-skilled worker	1	0.9 %
		Unskilled worker	3	2.7 %
		Unemployed	105	95.5 %
7	Earning member of the family	Father	108	98.2 %
		Mother	0	0.0 %
		Both	2	1.8 %
8	Type of the family	Joint	69	62.7
		Nuclear	41	37.3
		Extended	0	0.0
		Single parent	0	0.0
9	Number of children in the family	One	29	26.4
		Two	67	60.9
		Three	13	11.8
		More than three	1	0.9
10	Number of children diagnosed with Thalassemia in family	One	85	77.3
		Two	21	19.1
		More than Two	4	3.6

Table (c)Health related Quality of Life Score levels of the experimental and control groups at pre-test. N=100

	t-test for Equality of Means		
	t value	**df**	**Level of significance (2-tailed)**
Physical functioning	-.215	10	.834
Emotional functioning	-1.697	10	.121
Social activities	.094	10	.927
School activities	2.236	10	.049

Table (d)Impact of the SCOPE Programme on Children's Health-Related Quality of Life N=100

Domain	Source	Sum of squares	Df	Mean square	F	Significance
Physical functioning	Within group Between group	170.267 365.067	4 1	42.567 365.067	9.167 10.824	.001 .008
Emotional functioning	Within group Between group	22.100 228.150	4 1	5.525 228.150	6.255 19.868	.001 .001
Social activities	Within group Between group	49.233 72.600	4 1	12.308 72.600	5.810 2.227	.001 .166
School activities	Within group Between group	64.500 3.750	4 1	16.125 3.750	3.300 .065	020 .804

Table (e)Mean score and standard deviation for the presence/absence of clinical characteristics used to assess the health status of thalassemic children N=100

Observation	Mean score	Standard deviation
Pre-test(O1) Exp.group Con.group	9.83 10.33	2.137 2.160
Post-test(O2) Exp.group Con.group	8.17 9.67	3.656 1.966
Post-test(O3) Exp.group Con.group	5.33 9.83	2.805 1.722
Post-test(O4) Exp.group Con.group	5.17 9.33	2.787 1.033
Post-test(O5) Exp.group Con.group	4.500 25.183	2.8810 3.4925

Table (f)Hemoglobin level before transfusion among thalassemic children N=100

Pre-transfusion Hemoglobin level	Mean Hb (gm%)	Standard deviation (gm%)	df	t test value	P value
Experimental group	4.933	0.972	10	0.378	0.713
Control group	4.700	1.183			

Table (g)BMI at testing among thalassemic infants N=100

Pretest level of BMI	Mean score	Standard deviation	df	t value	P value
Experimental group	13.555	0.972	10	0.426	0.679
Control group	13.896	1.705			

Table (h)Impact of the SCOPE programme on the welfare of thalassemic adolescents N=100

Source	Sum of squares	df	Mean square	F	Significance
Within group	814.041	4	203.510	71.492	.001
Between group	589.693	1	589.693	26.891	.001

Conclusion:

During the preliminary assessment, the health-related quality of life (HRQOL) of both groups of thalassemic children was subpar. It is said that thalassemic youngsters had a much inferior quality of life, and the

most severely impacted aspect of school functioning was academic performance (20). The overall health-related quality of life score of the thalassemic teenagers who participated in the present study's experimental group rose after the introduction of the SCOPE Programme. The quality of life ratings of children diagnosed with thalassemic saw an improvement when they got free chelating drugs (Desirox), blood donors, and health advocacy for the treatment of transfusions. Previous research has also arrived to similar findings and conclusions (21). Teenagers who suffer from thalassemic anaemia have a worse quality of life in terms of their health compared to their peers. There is a possibility that interventions such as the SCOPE Programme will improve both their general health and their quality of life. However, owing to the limited number of participants in the study, these results cannot be generalized (22).

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