



Effectiveness Of Life Style Modification Program On Knowledge Regarding Improvement Of Quality Of Life Among Children Diagnosed With Thalassemia In Btct Hospital Sagar”

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Abstract

Introduction: Thalassemia, a chronic blood disorder, casts a long shadow over the lives of affected children, often throwing a wrench into their day-to-day well-being. While medical treatments play a crucial role, it's increasingly clear that they are only one piece of the puzzle. This study, conducted at BTCT Hospital Sagar, sets out to examine how lifestyle modification programs can turn the tide, equipping children with the knowledge needed to take the bull by the horns and improve their quality of life. By empowering young patients through education and practical changes, the research aims to kill two birds with one stone boosting both awareness and well-being. In a nutshell, it seeks to highlight whether informed lifestyle choices can help these children not just survive, but thrive.

Aims: To assess the effectiveness of a lifestyle modification program in boosting knowledge and enhancing the quality of life among children diagnosed with thalassemia at BTCT Hospital, Sagar—aiming to turn the tide in their daily well-being and help them lead a life less burdened."

Objectives: 1) To assess the pretest level of knowledge regarding quality-of-life improvement among children diagnosed with thalassemia in BTCT Hospital, Sagar. 2) To develop a lifestyle modification program to improve knowledge and quality of life among children diagnosed with thalassemia. 3) To administer the lifestyle modification program among children diagnosed with thalassemia in BTCT Hospital, Sagar. 4) To

assess the post-test level of knowledge regarding quality-of-life improvement among children diagnosed with thalassemia in BTCT Hospital, Sagar. 5) To find out the effectiveness of the lifestyle modification program on knowledge regarding improvement of quality of life among children diagnosed with thalassemia. 6) To determine the association between pretest level of knowledge and selected demographic variables of children diagnosed with thalassemia.

Materials and Methods: The study was conducted at Bhagyoday Tirth Charitable Hospital, Sagar (M.P.), with due permission and ethical clearance, ensuring everything was above board. A total of 30 children diagnosed with thalassemia were selected using non-probability convenient sampling—just a drop in the ocean compared to the larger population. The independent variable was the lifestyle modification program, and the dependent variable was the children's knowledge regarding quality of life, while socio-demographic factors acted as extraneous variables. Tools included a self-structured, expert-validated knowledge questionnaire with 30 multiple-choice questions, scoring one point per correct answer, with results classified as inadequate (1–10), moderate (11–20), or adequate (21–30). Data was collected from 15/06/2025 to 20/06/2025 after obtaining verbal consent, with questionnaires administered face-to-face. All efforts were made to ensure participants were selected fairly, confidentiality maintained, and no stone left unturned in meeting the study objectives.

Findings: The demographic analysis of children diagnosed with thalassemia (N=30) revealed that the majority, 24 (80%), were aged 19–<22 years, while 6 (20%) fell in the 23–<26 years group. In terms of religion, most were Hindu 21 (70%), followed by Muslims 9 (30%). Regarding family structure, 24 (80%) belonged to nuclear families and 6 (20%) to joint families, while monthly income data showed 13 (43.33%) families earned ₹15,001–20,000 and 11 (36.66%) earned ₹5,000–10,000. With respect to area of residence, 23 (76.66%) lived in urban areas, and 7 (23.33%) in rural. When it came to prior awareness of thalassemia, 19 (63.33%) reported no prior knowledge, while 11 (36.66%) did; among those, 12 (40%) cited mass media, 9 (30%) health personnel, and 9 (30%) family members as their information sources. Pre-test knowledge scores revealed that 20 (66.66%) had inadequate knowledge (mean = 8.96, SD = 4.74), 8 (26.66%) had moderate, and only 2 (6.66%) had adequate knowledge. After the lifestyle modification program, post-test scores showed a marked improvement: 26 (86.66%) had adequate knowledge, 4 (13.33%) had moderate, and none scored in the inadequate range (mean = 22.69, SD = 3.051). The mean difference in knowledge scores was 14, with a 't' value of 5.255 ($p \leq 0.05$), indicating statistically significant effectiveness of the intervention. Furthermore, a significant association was found between knowledge score and the variables "any previous information on thalassemia" (DF=2, $\chi^2=7.396$) and "source of information" (DF=4, $\chi^2=30.69$), whereas age, religion, family type, income, and area of residence showed no significant relationship, highlighting that prior exposure to information had a pivotal role in knowledge improvement.

Conclusion: In a nutshell, the study hit the nail on the head by proving that the lifestyle modification program worked wonders in enhancing the knowledge of children diagnosed with thalassemia regarding their quality

of life. The dramatic shift from inadequate to adequate knowledge post-intervention shows that the program wasn't just a shot in the dark—it paid off handsomely. While some demographic factors didn't make waves, prior information and its sources clearly tipped the scales, underlining the power of awareness. All in all, the findings speak volumes: timely, targeted education can be a game changer, helping children with thalassemia take the bull by the horns and lead a better, more informed life.

Keywords: Thalassemia, Lifestyle Modification Program, Quality of Life, Knowledge Improvement, Children, BTCT Hospital, Sagar, Health Education, Chronic Illness Management, Pediatric Care.

INTRODUCTION

Thalassemia, a chronic genetic blood disorder, has long been a thorn in the side of affected children and their families, often casting a shadow over their quality of life. In the face of this lifelong condition, knowledge truly is power—arming patients with the tools to manage their health more effectively and live life to the fullest. With the rise in thalassemia cases and the day-to-day challenges these children face, it's high time to turn the tide through structured educational interventions. A lifestyle modification program can serve as a silver lining, guiding children to adopt healthier habits and empowering them to take charge of their well-being. This study, conducted at BTCT Hospital, Sagar, set out to leave no stone unturned in assessing whether such a program could hit the mark in boosting knowledge and improving quality of life. In a world where prevention is better than cure, and awareness can make or break outcomes, this research aimed to prove that a little guidance goes a long way in lighting the path to better health for children with thalassemia.

Background of the Study

Thalassemia, a genetic blood disorder that's no stranger to developing countries like India, continues to rear its ugly head despite advances in medical science. With an estimated 100,000 patients and around 10,000–12,000 children born each year with thalassemia major in India alone, the condition is spreading like wildfire, particularly in regions with poor awareness and limited access to preventive education. According to WHO, nearly 4% of the global population are carriers of thalassemia, and in India, the carrier rate is 3–17% depending on the region. Children diagnosed with thalassemia often bear the brunt of not just medical complications but also a compromised quality of life due to lack of knowledge about lifestyle adjustments, creating a vicious cycle of poor health and limited social participation. While treatment options like blood transfusions and chelation therapy keep the disease at bay, without adequate awareness, families and patients are left groping in the dark. This study is a step in the right direction, aiming to break the silence and fill the knowledge gap through a lifestyle modification program—because when it comes to chronic conditions like thalassemia, knowledge isn't just power, it's a lifeline.

Significance and Need for the Study

Thalassemia, a lifelong inherited blood disorder, continues to be a thorn in the side of pediatric healthcare in India, with an estimated 10,000–15,000 children born with the condition each year and nearly 100,000 patients currently living with it nationwide. Despite advances in treatment, many children and their caregivers are still in the dark about managing the disease and enhancing quality of life through simple lifestyle changes. This study was not undertaken on a whim but stemmed from the growing realization that knowledge is power especially in chronic illness management. With Madhya Pradesh being one of the states carrying a significant thalassemia burden, the need of the hour was to develop a structured educational intervention to bridge the glaring knowledge gap. By shining a light on lifestyle modification as a practical tool for empowerment, this study aims to turn the tide and give affected children a fighting chance at a healthier, more informed life. Hence, this research doesn't just fill a gap—it hits the ground running toward a more proactive, patient-centered approach.

Statement of the Problem

A study to evaluate the effectiveness of Life Style Modification Program on knowledge Regarding improvement of quality of life among children diagnosed with Thalassemia in BTCT Sagar”

Objectives of the Study

- To assess the pretest level of knowledge regarding quality-of-life improvement among children diagnosed with thalassemia in BTCT Hospital, Sagar.
- To develop a lifestyle modification program to improve knowledge and quality of life among children diagnosed with thalassemia.
- To administer the lifestyle modification program among children diagnosed with thalassemia in BTCT Hospital, Sagar.
- To assess the post-test level of knowledge regarding quality-of-life improvement among children diagnosed with thalassemia in BTCT Hospital, Sagar.
- To find out the effectiveness of the lifestyle modification program on knowledge regarding improvement of quality of life among children diagnosed with thalassemia.
- To determine the association between pretest level of knowledge and selected demographic variables of children diagnosed with thalassemia.

Research Hypothesis

RH1: There will be a significant difference in the knowledge level regarding improvement of quality of life among children diagnosed with Thalassemia in the experimental group after the administration of the Lifestyle Modification Program in BTCT, Sagar.

RH2: There will be a significant association between the pre-test level of knowledge regarding improvement of quality of life and selected socio-demographic variables among children diagnosed with Thalassemia in BTCT, Sagar.

Null Hypothesis

H₀1: There will be no significant difference in the knowledge level regarding improvement of quality of life among caregivers of children diagnosed with Thalassemia in the experimental group after the administration of the Lifestyle Modification Program in BTCT, Sagar.

H₀2: There will be no significant association between the pre-test level of knowledge regarding improvement of quality of life and selected socio-demographic variables among caregivers of children diagnosed with Thalassemia in BTCT, Sagar.

Assumptions

- Caregivers of children diagnosed with Thalassemia have varying levels of baseline knowledge regarding the disease and factors that influence the quality of life.
- A structured Lifestyle Modification Program (LSMP) can improve the knowledge of caregivers regarding practices that enhance the quality of life in children with Thalassemia.
- Increased knowledge among caregivers leads to better lifestyle-related practices that positively impact the child's physical, emotional, and social well-being.
- Socio-demographic variables may influence caregivers' knowledge towards lifestyle modification.
- Participants will respond honestly and accurately to the knowledge assessment tools used during pre-test and post-test evaluations.
- All participants will receive the same Lifestyle Modification Program, ensuring consistency in intervention delivery.
- The tools used for knowledge assessment are valid and reliable for measuring the intended constructs in this population.
- No major external factors will influence the participants' knowledge other than the intervention provided during the study period.

Operational Definitions

Evaluate: In this study, evaluate refers to the process of assessing the change in knowledge scores of participants before and after the implementation of the Lifestyle Modification Program, using a structured knowledge questionnaire.

Effectiveness: Effectiveness refers to the extent to which the Lifestyle Modification Program results in a statistically significant improvement in the knowledge scores of participants regarding the improvement of quality of life, as measured by a pre-test and post-test.

Lifestyle Modification Program: A Lifestyle Modification Program in this study refers to a structured educational intervention designed by the researcher. It includes information on diet, physical activity, medication adherence, infection prevention, and emotional support aimed at improving the quality of life of children with Thalassemia. The program is delivered through teaching sessions, visual aids, and interactive discussions over a defined period.

Knowledge: Knowledge refers to the awareness and understanding of children and/or their caregivers about Thalassemia, its complications, and measures to improve quality of life, as assessed through a validated structured questionnaire designed by the researcher.

Improvement of Quality of Life: Improvement of quality of life refers to better management of physical, psychological, and social aspects of living with Thalassemia, indicated indirectly by enhanced knowledge levels post-intervention.

Children Diagnosed with Thalassemia: In this study, children diagnosed with Thalassemia refers to boys and girls aged below 18 years, who have been medically diagnosed with Thalassemia, and are receiving care at BTCT, Sagar.

Delimitations

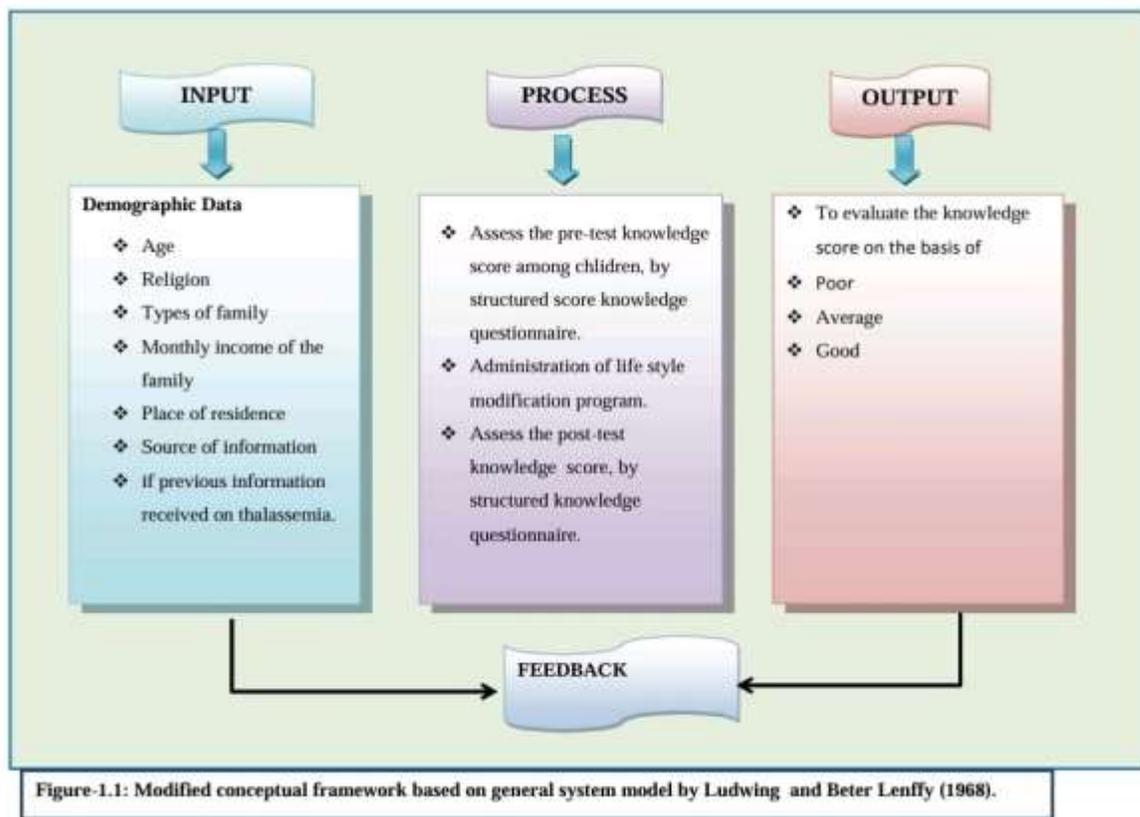
- ❖ The study is done only at BTCT Sagar.
- ❖ It includes only children with Thalassemia, not adults.
- ❖ Only the effect of a Lifestyle Modification Program is studied — no other treatments are considered.
- ❖ The study checks only the knowledge about improving quality of life, not the actual health or physical changes.
- ❖ The effectiveness is measured within a short time after the program, not over months or years.
- ❖ A questionnaire made by the researcher is used to collect data.
- ❖ Only children or caregivers who understand the language used in the program and questionnaire can take part.
- ❖ Only those who agree to participate (give consent) are included in the study.

Scope of the Study

- ✓ The study focuses on children diagnosed with Thalassemia who are receiving treatment at BTCT Sagar.
- ✓ It aims to improve their knowledge about managing their condition through a Lifestyle Modification Program.
- ✓ The study includes areas like diet, exercise, medication, hygiene, and emotional support as part of the lifestyle changes.
- ✓ It helps understand whether education and awareness can lead to better understanding of how to live a healthier life with Thalassemia.

- ✓ The study can help healthcare providers, parents, and children by offering a structured educational approach.
- ✓ Results of the study may be used to develop similar programs in other healthcare settings for children with chronic conditions.
- ✓ The study contributes to nursing and public health education by showing how lifestyle education can support quality of life in children with chronic illnesses.

Conceptual Framework



RESEARCH METHODOLOGY:

Research approach: Quantitative Evaluative Research Approach.

Research design: Pre – experimental one group pre – test post – test research design.

Variables:

Dependent variables: Knowledge of children with diagnosed thalassemia regarding improvement of quality of life among children diagnose with thalassemia.

Independent variables: Life style modification program on knowledge regarding improvement of quality of life.

Extraneous Variables:

- ✓ Age of the children
- ✓ Educational level of the child
- ✓ Parental education and involvement
- ✓ Previous knowledge about Thalassemia
- ✓ Socioeconomic status
- ✓ Language and communication ability
- ✓ Frequency of hospital visits
- ✓ Health status during the study
- ✓ Family support system
- ✓ Exposure to other educational resources

POPULATION

Target Population: Children at BTCT Sagar, Madhya Pradesh.

Accessible Population: Children diagnosed with Thalassemia who are taking treatment at BTCT Sagar, Madhya Pradesh.

SAMPLE SIZE

A total of 30 children diagnosed with Thalassemia.

SAMPLING TECHNIQUE

Convenient sampling technique was used to select participants based on availability and willingness to participate.

CRITERIA FOR SAMPLE SELECTION**Inclusion Criteria:**

Children diagnosed with Thalassemia who:

- ✓ Are taking treatment at BTCT, Sagar.
- ✓ Can understand Hindi or English.
- ✓ Are willing to participate in the study.

Exclusion Criteria:

Children diagnosed with Thalassemia who:

- ✓ Are not taking treatment at BTCT, Sagar.
- ✓ Do not understand Hindi or English.
- ✓ Are not willing to participate in the study.

DEVELOPMENT AND DESCRIPTION OF TOOL

According to Polit & Beck (2012), data collection tools are the instruments, procedures, scales, and observations used by the researcher to measure the key variables in a study.

Sequence of Tool Development:**Section A: Demographic Variables**

This section includes demographic information directly or indirectly related to the study, such as:

- ❖ Age (in years)
- ❖ Religion
- ❖ Type of family
- ❖ Family monthly income
- ❖ Previous knowledge regarding the topic
- ❖ Source of information
- ❖ Any previous information received on Beta Thalassemia

Section B: Self-Structured Knowledge Questionnaire

This section consists of 30 self-structured multiple-choice questions designed by the researcher to assess knowledge related to improvement of quality of life among children diagnosed with Thalassemia.

PILOT STUDY

A pilot study is a small-scale preliminary investigation conducted with the same general characteristics as the main study.

The purpose of the pilot study was to:

- Test the feasibility of the research design and tools.
- Assess the practicality of the methodology.
- Ensure the reliability and validity of the tool for measuring knowledge on quality of life improvement among children with Thalassemia.

PROCEDURE FOR DATA COLLECTION

The present study was carried out at Bhagyoday Tirth Charitable Hospital, Sagar (M.P.), where the investigator was granted permission to collect data in a setting well-suited for the task at hand. The wind was taken out of no one's sails, as ethical clearance and participant consent were ensured prior to data collection. A non-probability convenient sampling technique was used to rope in 30 children diagnosed with thalassemia, forming the sample that represented the tip of the iceberg of the hospital's broader patient population. These participants, the accessible population, were selected based on clearly drawn inclusion and exclusion criteria, ensuring no stone was left unturned. The independent variable under scrutiny was the lifestyle modification program designed to boost knowledge related to improving quality of life, while the dependent variable was the knowledge level of these children, which was expected to change by leaps and bounds post-intervention. Socio-demographic details like age, religion, type of family, and income, acting as extraneous variables, were considered to avoid muddying the waters. The study hinged on a self-structured knowledge questionnaire consisting of 30 multiple-choice questions, meticulously developed and validated by a panel of six experts in medical-surgical nursing, ensuring the tool hit the nail on the head in terms of relevance and clarity. Scoring was straightforward: each correct answer earned one mark, and knowledge levels were graded as inadequate, moderate, or adequate. With all systems go, data collection took place from 15/06/2025 to 20/06/2025, during which the investigator provided a brief about the study, obtained verbal consent, and distributed the questionnaires among willing participants, making sure that confidentiality was maintained and participation was strictly voluntary. Thus, the groundwork was laid methodically, keeping all variables in check and making sure the study did not go off the rails.

DATA ANALYSIS AND INTERPRETATION OF DATA:**SECTION I Description of demographic variables of the children diagnose with thalassemia in BTCT Sagar.**

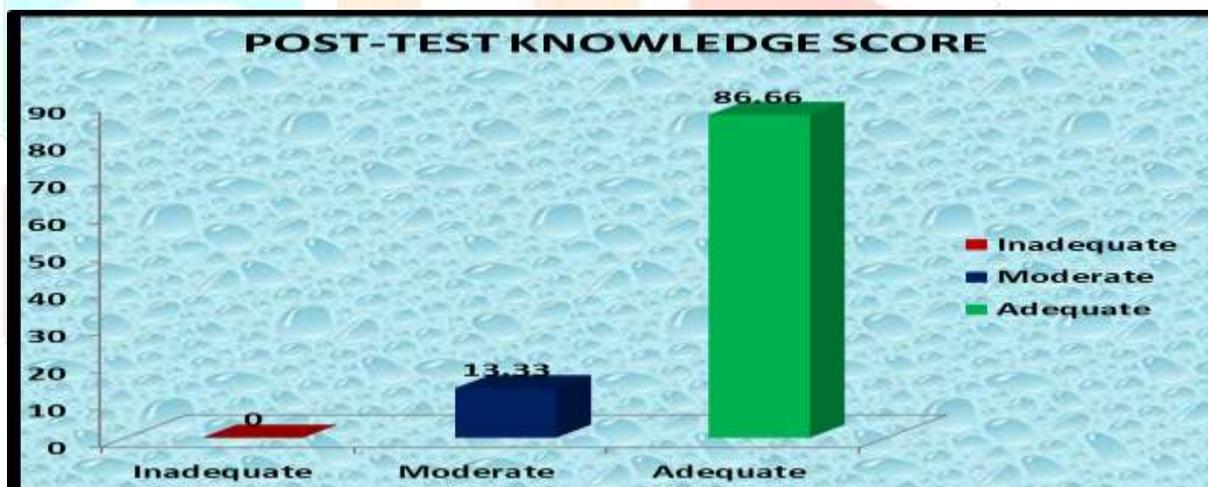
S. NO.	DEMOGRAPHIC VARIABLES	Frequency (f)	Percentage (%)
1.	Age in years		
	a) Birth to 10 years	24	80
	b) 10 to 18 years	6	20
2.	Religion		
	a) Hindu	21	70
	b) Muslim	9	30
	c) Christian	0	0
	d) Others	0	0
3.	Types of family		
	a) Joint	6	20
	b) Nuclear	24	80
	c) Extended family	0	0
4.	Monthly income of the family (Rs)		
	a) 5000- 10000	11	36.66
	b) 10001-25000	6	20
	c) 15001-20000	13	43.33
	d) 20001 and more	0	0
5.	Area of Residence		
	a) Rural	7	23.33
	b) Urban	23	76.66
	c) Semi-Rural	0	0
	Any previous information received on thalassemia		
	a) Yes	11	36.66
	b) No	19	63.33
7.	If yes (source of information)		
	a) Health person	9	30

b) Parants/ Family/ relatives	9	30
c) Mass media	12	40

Pretest level of knowledge regarding quality-of-life improvement among children diagnosed with thalassemia in BTCT Hospital, Sagar.

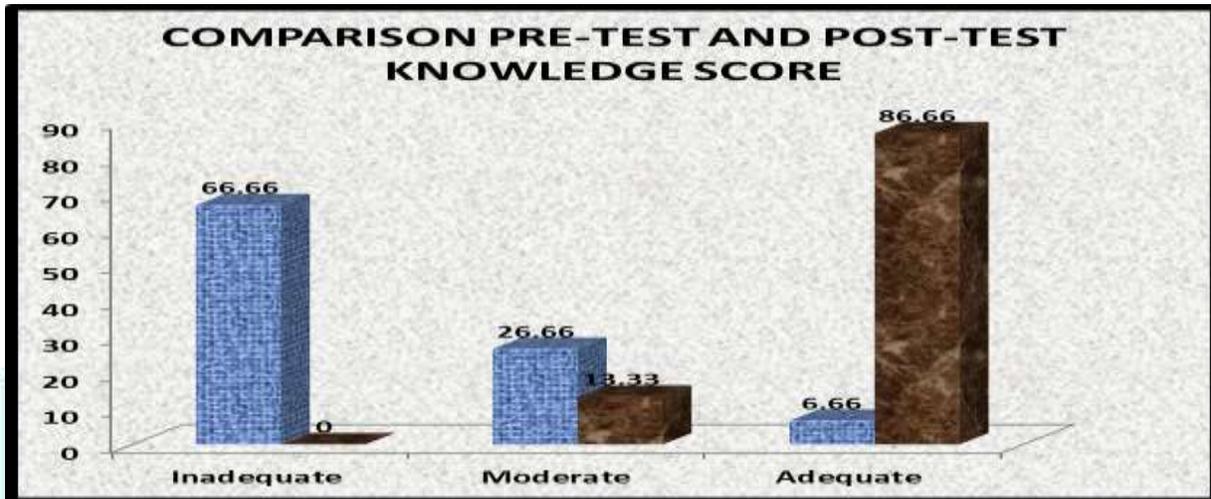


Posttest level of knowledge regarding quality-of-life improvement among children diagnosed with thalassemia in BTCT Hospital, Sagar.



Comparison of pre-test and post-test knowledge score regarding improvement of quality of life among children with diagnose thalassemia.

Score	Mean	Mean Difference	Mean percentage	Standard deviation	't' Value
Pre test	8.96	14	28.070	4.74	5.255
Post test	22.96		71.929	3.051	



Association between pretest level of knowledge and selected demographic variables of children diagnosed with thalassemia.

S. No.	Demographic variables	Category	Inadequate	Moderate	Adequate	df	Chi square
1	Age in years	Birth to 10 years	14	6	2	2	0.625
		11 to 18 years	4	2	0		
2	Religion	Hindu	12	7	2	2	2.974
		Muslim	8	1	0		
		Christian	0	0	0		
		Others	0	0	0		
3	Types of family	Joint Family	2	3	1	2	3.6306
		Nuclear Family	18	5	1		
		Extended family	0	0	0		
4	Monthly income of the family	5000-10000	6	4	1	3	4.088
		10001-	3	2	1		

		25000					
		15001-20000	11	2	0		
		20001 and more	0	0	0		
5.	Area of residence	Rural	5	2	0	2	0.7374
		Urban	15	6	2		
		Semi-Rural	0	0	0		
6.	Any previous information received on thalassemia	Yes	5	6	0	2	7.396*
		No	15	2	2		
7.	If yes (source of informant)	Health person	5	3	1	4	30.69*
		Parents/ Family/ relatives	8	4	0		
		Mass media	7	1	1		
		No other information					

SUMMARY

The study set out to shed light on how a Lifestyle Modification Program can make a difference in the knowledge levels of children diagnosed with Thalassemia, particularly those receiving treatment at BTCT Sagar. With a hand-picked sample of 30 children selected through convenient sampling, the research aimed to assess whether structured education could turn the tide in improving their understanding of how to enhance their quality of life. By using a self-structured knowledge questionnaire and gathering insights through demographic data, the researcher left no stone unturned in ensuring the tool was both relevant and reliable. A pilot study was conducted to test the waters, ensuring that the approach was feasible and the tool effective before diving into the main study. In short, this research sets the stage for more informed care and practical interventions in the lives of children battling Thalassemia.

NURSING IMPLICATIONS

The findings of this study hold significant nursing implications, as they underscore the vital role nurses play in educating and empowering children with Thalassemia and their families. By implementing lifestyle modification programs, nurses can help these children turn over a new leaf in managing their condition, enhancing not just their knowledge but also their quality of life. With the right guidance, nurses can teach families to nip complications in the bud, promote adherence to treatment, and foster healthier habits. This study drives home the point that structured education is not just a support tool but a game changer in pediatric chronic illness care. Nurses, being at the frontline, can bridge the gap between medical treatment and day-to-day wellness, making a lasting difference in these children's lives.

Nursing Education

- Include real-life examples in teaching to "bridge the gap between theory and practice."
- Encourage nurses to educate patients regularly – "make health teaching second nature."
- Focus on relevant content – "hit the nail on the head" with practical knowledge like lifestyle changes for Thalassemia.
- Keep nursing students updated – "stay ahead of the curve" in chronic disease management.
- Teach effective communication in simple language – "don't talk over their heads."
- Highlight the importance of patient education – "knowledge is power – share it."
- Encourage students to lead by example – "practice what you preach."
- Adapt education to the learner's needs – "one size doesn't fit all."
- Cover all important areas of health education – "leave no stone unturned."
- Use the right time for teaching – "strike while the iron is hot."

Nursing Practice

- Provide health education about Thalassemia and lifestyle modifications.
- Develop individualized care plans for affected children.
- Identify knowledge gaps and provide appropriate guidance.
- Offer emotional support and counseling to children and families.
- Monitor adherence to lifestyle changes and treatment plans.
- Promote healthy habits like balanced diet, hygiene, and rest.
- Involve parents and caregivers in the child's care and education.
- Advocate for better resources and care for Thalassemia patients.
- Document teaching, progress, and outcomes accurately.
- Collaborate with other healthcare professionals for holistic care.

Nursing Administration

- Ensure availability of trained staff to educate and care for Thalassemia patients.
- Organize regular training programs on lifestyle modification and chronic illness care.
- Provide necessary educational materials and resources for nurses and patients.
- Establish protocols for health education and follow-up care.
- Monitor and evaluate the quality of nursing care provided to Thalassemia patients.
- Allocate appropriate time and staff for health teaching sessions.
- Support implementation of awareness programs in the community.
- Facilitate multidisciplinary team collaboration within the healthcare setting.
- Encourage documentation and use of evidence-based practices.
- Promote continuing education and skill development among nursing staff.

Nursing Research

- Encourage research on lifestyle interventions for children with Thalassemia.
- Promote evidence-based practice by applying research findings in clinical care.
- Identify gaps in knowledge related to quality of life in chronic illnesses.
- Develop and validate tools to assess knowledge and lifestyle practices.
- Support replication of similar studies in different settings to generalize findings.
- Share research outcomes to improve nursing practices and policies.
- Motivate nurses to participate in research activities and training.
- Use research findings to create guidelines for patient education programs.
- Conduct follow-up studies to assess long-term impact of lifestyle programs.
- Collaborate with interdisciplinary teams in research related to child health and chronic diseases.

Recommendations:

- Lifestyle Modification Programs should be implemented regularly for children with Thalassemia.
- Nurses should conduct ongoing health education sessions for children and their caregivers.
- Educational materials (leaflets, posters, videos) should be developed in simple language (Hindi/English).
- Similar studies should be conducted on a larger sample to strengthen the findings.
- Long-term follow-up studies should be done to assess sustained improvement in quality of life.
- Regular training should be given to nursing staff on chronic illness management and patient education.

- Community awareness programs should be organized to reduce stigma and increase support for Thalassemia.
- Schools should be involved in supporting the academic and emotional needs of Thalassemic children.
- Government and NGOs should collaborate to improve access to treatment and educational support.
- Research on other aspects like psychological well-being and coping strategies in Thalassemia should be encouraged.

CONCLUSION

In conclusion, the study clearly shows that the Lifestyle Modification Program was a game changer in enhancing knowledge among children diagnosed with Thalassemia regarding improvement of their quality of life. The findings indicate that when it comes to health education, a little effort can go a long way. The program helped bridge the knowledge gap and empowered participants to take life by the horns, despite their condition. As the saying goes, "knowledge is power," and in this case, it became the key to unlocking better health practices and a brighter outlook. All in all, the results speak volumes and prove that prevention is better than cure when managing chronic illnesses like Thalassemia.

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