

**Effectiveness of an Educational Intervention on Parental Knowledge in Management of Children with Beta Thalassemia**

Nilamadhaba Panda<sup>1</sup>, Jyoti Ranjan Behera<sup>2</sup>, Snigdha Rani Panigrahy<sup>3</sup>, Sadhana Panda<sup>4</sup>, Bharata Chandra Choudhury<sup>5</sup>, Narendra Behera<sup>6</sup>

<sup>1</sup>Assistant Professor, Department of Paediatrics, MKCG Medical College and Hospital, Berhampur, Ganjam

<sup>2</sup>Assistant Professor, Dept of Paediatrics, MKCG Medical college and Hospital, Berhampur, Ganjam

<sup>3</sup>Assistant Professor, Department of Pharmacology, MKCG Medical College and Hospital, Berhampur, Ganjam

<sup>4</sup>Professor & HOD, Department of Pediatrics, Dharanidhar Medical College & Hospital, Keonjhar

<sup>5</sup>Senior Resident, Department of Pediatrics, MKCG Medical College & Hospital Berhampur, Ganjam

<sup>6</sup>Superintendent, Government Medical College & Hospital, Phulbani

Received: 01-10-2025 / Revised: 15-11-2025 / Accepted: 21-12-2025

Corresponding author: Dr. Nilamadhaba Panda

Conflict of interest: Nil

**Abstract**

**Introduction:** The study evaluate the impact of an educational intervention on the knowledge, attitude, and practice (KAP) of parents of children with beta thalassemia. The study involved 147 participants, providing a comprehensive overview of how targeted educational efforts can enhance understanding and management of the disease. Overall, the study emphasizes the value of education as a tool for enhancing health literacy and promoting proactive health behaviours among parents of children with beta thalassemia. By continuing to invest in and develop such educational initiatives, we can significantly improve the quality of life for affected families and contribute to better disease management and prevention strategies.

**Material And Method:** A hospital based Prospective Quasi-experimental Pre- Post test design to evaluate the Effectiveness of an educational intervention. Beta-thalassemia Children of age 6 month to 14 years with their parents (care giver) presented to MKCG Medical College & Hospital for regular blood transfusion This prospective quasi-experimental study was conducted in the department of paediatrics, MKCG, MCH, Berhampur from the period of October 2022 to September 2024. Study population included parents or care givers of thalassemia children of age group 6 month to 14 year.

**Result:** More number of questionnaire regarding KAP about thalassemia will helpful on strength of the study. Scoring or Grading of KAP could may give more light on the performance of the Study. Long term follow up will yield better result in assessing KAP of thalassemia parents. Smaller sampling size will give more bias in the study and large size of the sample will give better result in KAP assessment regarding thalassemia.

**Conclusion:** Study concludes; More significant improvement of knowledge of parents and care givers observed in different aspects regarding thalassemia disease like about general awareness, symptoms, disease transmission, screening and diagnosis and healthy living and treatment. Overall, the study emphasizes the value of education as a tool for enhancing health literacy and promoting proactive health behaviours among parents of children with beta thalassemia. By continuing to invest in and develop such educational initiatives, we can significantly improve the quality of life for affected families and contribute to better disease management and prevention strategies.

**Keywords:** Educational intervention, Thalassemia.

**DOI:** 10.25258/ijcpr.18.1.19

This is an Open Access article that uses a funding model which does not charge readers or their institutions for access and distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0>) and the Budapest Open Access Initiative (<http://www.budapestopenaccessinitiative.org/read>), which permit unrestricted use, distribution, and reproduction in any medium, provided original work is properly credited.

**Introduction**

The most prevalent inherited condition worldwide, thalassaemia is a significant public health concern. It is distinguished by a flaw in the genes that produce haemoglobin. Alpha and beta chains make up the protein known as haemoglobin. Beta-thalassemia, which results in aberrant red blood cell

development and ultimately anaemia, happens when a genetic defect stops beta chains from forming<sup>1</sup>.

The most dangerous type of beta-thalassemia (homozygous condition) is still thalassaemia major.

Affected infants are healthy at birth because beta-globin synthesis is not necessary throughout foetal life in the early postnatal period. Reduced activity, progressive pallor (anaemia), abdominal fullness, growth retardation, hepato-splenomegaly, and changes in bone structure are common symptoms in the second part of infancy [2].

The babies do not grow and may experience diarrhoea, fever, and feeding issues. Heart failure caused by severe thalassaemia might result in early death (between 20 and 30 years) [3]. Because thalassaemia necessitates a lifetime of blood transfusions and chelating medications, it presents a burden for patients, their families, and the healthcare system. Iron chelation therapy, which removes iron from the body, helps improve the prognosis for patients with beta-thalassaemia major, who require a lifelong regimen of frequent blood transfusions every three to four weeks. The majority of thalassaemia cases are found in Malaysia, South China, and India. In the Mediterranean, Southeast Asia, and India, beta-thalassaemia mutations are widely distributed [4]. The most prevalent genetic hemoglobinopathy in the world is thalassaemia. Heterozygous (carriers) individuals with beta-thalassaemia make up 1.5% of the global population. The overall prevalence of the beta-thalassaemia trait is 2.78%, with state-specific variations ranging from 1.48% to 3.64%. In southern Odisha, the prevalence is 11%. [5].

A thalassaemia child's quality of life can be greatly enhanced by regular blood transfusions, chelation therapy, infection prevention, growth monitoring, immunisation, and diet. Children with severe anaemia need longer hospital stays and additional medicine, which can increase mental anguish and financial strain on the affected family. A better life for children with thalassaemia will result from the easy methods of identifying anaemia symptoms early, using chelation agents on a regular basis, regularly checking growth, and solving any other issues.

In clinical practice, children with thalassaemia frequently visit hospitals for blood transfusions when their haemoglobin levels are extremely low or when they exhibit signs of severe anaemia and associated consequences. Therefore, parents can be informed about the significance of timely blood transfusions, preventive iron chelation therapy, and personal care and cleanliness in order to reduce difficulties by identifying the symptoms of anaemia early and transfusing at the appropriate time.

The difficulty of treating beta thalassaemia emphasises how crucial thorough patient and family education is. Because they are in charge of monitoring treatment compliance, seeing early warning indicators of problems, and coordinating care with medical professionals, parents and other

carers are essential to the management of the illness.

The nature of the illness, the significance of consistent monitoring and treatment compliance, and methods for controlling iron excess are all common topics of parent education. Additionally, because living with a chronic illness may be difficult for both the kid and their family, parents need advice on how to support their child's emotional and psychological well-being [6]. Mothers and parents of children with thalassaemia major do not have a maternal educational study (KAP). In order to validate or adjust our screening program, we sought to determine the parameters impacting awareness of beta thalassaemia.

### Materials & Methods

This prospective quasi-experimental study was conducted in the department of paediatrics, MKCG, MCH, Berhampur from the period of October 2022 to September 2024.

Study population included parents or care givers of thalassaemia children of age group 6 month to 14 year.

**Study Design:** A hospital based Prospective Quasi-experimental Pre- Post-test design to evaluate the Effectiveness of an educational intervention.

**Study Setting:** Department of Pediatrics, MKCG Medical College & Hospital, Berhampur, Ganjam

**Study Period:** October 2022- September 2024

**Source of Data:** Beta-thalassaemia Children of age 6 month to 14 years with their parents (care giver) presented to MKCG Medical College & Hospital for regular blood transfusion.

**Sample size:** According to prevalence of thalassaemia from various literature and south odisha study, sample size calculated with 11% prevalence as per formula. A total of 147 cases was enrolled.

**Inclusion Criteria:** Parents (caregivers) of thalassaemia children of age group of 6month- 14 years

**Exclusion Criteria:** Parents who refused to participate in the study

Before taking as sample, all the parents and care givers of thalassaemia children were taken in to account for knowledge, attitude and practice study. Written informed consent was taken from the parents on a pre structured proforma. Approval by institutional ethical committee was taken prior to the start of the study.

Basic data of patients including name, age, gender, socioeconomic status, residence, etc were taken into account Knowledge, attitude, practice of

parents of thalassemia children assessed and recorded in a tabular format using predesigned questionnaire. 3 month after giving education, the parents called by for data collection regarding

change in their knowledge, attitude and practice in management of beta- thalassemia

### Result

**Table 1: Distribution of Beta-Thalassemia Patient According To Age Group.**

Age Group	Number(n)	%
1-5yr	38	25.9
>6-10yr	73	49.7
>10yr	36	24.5
Total	147	100.0

The participants in the study were divided into three age groups.

25.9%, and those aged over 10 years, comprising 24.5%.

The largest group was individuals aged 6-10 years, accounting for 49.7% of the participants. This was followed by the 1-5 years age group, representing

This distribution indicates a focus on younger age demographics, which may be relevant for studies involving early childhood development or health.

**Table 2: Assessment of Knowledge of Parents Regarding Beta Thalassemia before Educational Intervention. (N=147) (Mc.Nemar's Test)**

Questionnaire	Before educational intervention		3 month after educational intervention		p-value
	Yes		yes		
	n	(%)	n	(%)	
1. Do you know about thalassemia disease?	122	83.0	141	95.9	<0.01
2. Do you know about symptoms of thalassemia?	109	74.1	139	94.6	<0.01
3. Do you think cousin marriage play a role in transmission of disease?	66	44.9	144	98.0	0.12
4. Do you think both parents should get screened for thalassemia before marriage?	61	41.5	139	94.6	0.01
5. Do you have knowledge about pre-natal diagnosis of thalassemia?	51	34.7	120	81.6	<0.01
6. Can you tell how thalassemia transferred within family?	66	44.9	144	98.0	0.11
7. If yes can it be transferred by inter family marriage?	36	24.5	88	59.9	<.01
8. Do you think thalassemia patient can lead a healthy life?	62	42.2	117	79.6	<0.01
9. Do you know how thalassemia can be diagnosed?	129	87.8	138	93.9	<0.01
10. Do you think thalassemia can diagnosed through blood test?	110	74.8	135	91.8	0.06
11. Do you have knowledge about pre-marital screening?	59	40.1	135	91.8	0.03
12. Do you have knowledge about iron overload and its consequence?	117	79.6	129	87.8	<0.01
13. Do you know about the treatment of thalassemia?	88	59.9	123	83.7	<0.01
14. If yes do you think blood transfusion is the only treatment for thalassemia?	66	44.9	121	82.3	0.887
15. Do you think there should more awareness program regarding thalassemia?	132	89.8	142	96.6	<0.01

### Knowledge Assessment

1. **General Awareness:** There was a significant

increase in participants' awareness about thalassemia, with 83.0% knowing about the disease before the intervention, rising to

- 95.9% afterward ( $p < 0.01$ ).
- Symptoms and Transmission:** Knowledge of thalassemia symptoms improved from 74.1% to 94.6% ( $p < 0.01$ ). Awareness about cousin marriage as a transmission factor jumped from 44.9% to 98.0%, though this change was not statistically significant ( $p = 0.12$ ).
  - Screening and Diagnosis:** The importance of parental screening before marriage saw a substantial increase in awareness from 41.5% to 94.6% ( $p = 0.01$ ), and knowledge about prenatal diagnosis improved from 34.7% to 81.6% ( $p < 0.01$ ).
  - Healthy Living and Treatment:** Understanding that thalassemia patients can lead healthy lives increased from 42.2% to 79.6% ( $p < 0.01$ ). Knowledge about diagnosis methods, such as blood tests, improved significantly, with awareness about pre-marital screening rising from 40.1% to 91.8% ( $p = 0.03$ ).
  - Treatment Options:** Awareness of thalassemia treatment options rose from 59.9% to 83.7% ( $p < 0.01$ ).

**Table 3: Assessment of Parental Attitude towards Thalassemia before and after 3month Of Educational Intervention. (Mc.Nemar's Test)**

Questionnaire	Before educational intervention		3 month after educational intervention		p-value
	yes		yes		
	n	%	n	%	
1. Do you believe beta-thalassemia is caused because of sin committed by parents?	20	13.6	4	2.7	<0.01
2. Do you think beta-thalassemia is caused because of defect in mother?	69	46.9	24	16.3	<0.01
3. Do you think beta-thalassemia is caused because of defect in father?	26	17.7	10	6.8	<0.01
4. Do you believe the beta-thalassemia child makes the family life miserable?	92	62.6	61	41.5	<0.01
5. Do you think family is unlucky where the beta-thalassemic child is born?	100	68.0	56	38.1	<0.01
6. Is it better to die than to live with a deadly disease like beta-thalassemia?	35	23.8	23	15.8	<0.01
7. Do you feel discomfort from the neighbor having beta-thalassemia?	7	4.8	4	2.7	<0.01
8. Do you feel discomfort living with a person suffering from beta- thalassemia?	3	2.0	1	0.7	0.02
9. Do you feel discomfort establishing a marriage relation where someone is suffering from beta-thalassemia?	129	87.8	114	77.6	<0.01
10. Do you feel discomfort accepting a life partner who is beta-thalassemia minor carrier?	122	83.0	103	70.1	<0.01
11. Can a thalassemia patient survive without treatment?	35	23.8	124	84.4	0.01
12. Can it be spread by eating, playing and sleeping with a thalassemia child?	17	11.6	4	2.7	<0.01

#### Attitude Assessment

- Misconceptions and Stigma:** There was a significant reduction in misconceptions, such as thalassemia being a punishment for parental sins, dropping from 13.6% to 2.7% ( $p < 0.01$ ).
- Family Impact:** Attitudes about the impact of thalassemia on family life improved, with fewer participants (41.5% from 62.6%) believing it makes family life miserable ( $p < 0.01$ ).
- Social Acceptance:** Discomfort with having a thalassemic neighbor decreased from 4.8% to 2.7% ( $p < 0.01$ ), and willingness to accept a life partner with thalassemia also increased.
- Survival and Transmission:** Beliefs about survival without treatment changed significantly, with an understanding that treatment is necessary improving from 23.8% to 84.4% ( $p = 0.01$ ).

**Table 4: Assessment Of Parental Practice Regarding Beta – Thalassemia Before and 3month After Educational Intervention. (Mc.Nemar's Test)**

Questionnaire	Before educational intervention		3 month after educational intervention		p-value
	yes		yes		
	n	%	n	%	
1. Have you tested for beta-thalassemia?	99	67.3	135	91.8	<0.01
2. Would you like to go for beta-thalassemia test	135	91.8	144	98.0	<0.01
3. Would you like to go for a genetic test with your fiancé before marriage for beta-thalassemia?	114	77.6	130	88.4	<0.01
4. Would you like to adopt for prenatal diagnosis procedure if you and your spouse are beta-thalassemia minor/carriers?	82	55.8	141	95.9	0.01
5. Would you like to like to abort a baby when it would be diagnosed with beta-thalassemia major?	123	83.7	135	91.8	<0.01
6. Would you like to share knowledge about beta-thalassemia with others?	81	55.1	123	83.7	<0.01
7. Do you think balanced diet can be helpful in management of thalassemia?	95	64.6	114	77.6	<0.01
8. Do you think a proper hygiene practice at home can help in managing thalassemia patient?	89	60.5	123	83.7	<0.01
9. Do you think timely blood transfusion can help your thalassemic child?	117	79.6	133	90.5	<0.01

**Practice Assessment**

- Screening and Testing:** Participation in beta-thalassemia testing increased from 67.3% to 91.8% ( $p < 0.01$ ). The desire for prenatal genetic testing before marriage rose significantly from 77.6% to 88.4% ( $p < 0.01$ ).
- Knowledge Sharing:** The willingness to share knowledge about thalassemia with others increased from 55.1% to 83.7% ( $p < 0.01$ ).

- Management Practices:** Belief in the efficacy of balanced diets and hygiene in managing thalassemia increased significantly. Timely blood transfusions were recognized as beneficial, with positive responses rising from 79.6% to 90.5% ( $p < 0.01$ ).

**Mean Hemoglobin Levels:** The mean hemoglobin level improved significantly from  $6.34 \pm 1.14$  g/dl to  $7.51 \pm 1.37$  g/dl after the intervention ( $p = 0.01$ ).

**Table 5: T-Test and Chi-Square Test for Pre-Transfusion Hemoglobin before and After Educational Intervention**

Hb before intervention (Mean $\pm$ S.D)	Hb after intervention (Mean $\pm$ S.D)	Mean difference	95% CI	p-value paired-t test
6.34 $\pm$ 1.14	7.51 $\pm$ 1.37	-1.26	-1.51 / - 0.99	0.01

The proportion of participants with hemoglobin levels below 5 g/dl decreased from 10.9% to 5.4% ( $p < 0.01$ ). Those with levels between 5-7 g/dl decreased from 57.8% to 27.2%, and levels above 7 g/dl increased from 31.3% to 67.3%, indicating a significant improvement in overall hemoglobin status ( $p < 0.01$ ).

**Table 6:**

Pre transfusion Hb(g/dl)	Number of cases (n) before intervention (%)	Number of cases (n) after intervention (%)	Chi-square p-value
<5	16 (10.9%)	8 (5.4%)	<0.01
5-7	85 (57.8%)	40 (27.2%)	
>7	46 (31.3%)	99 (67.3%)	

**Table 7: Distribution of Thalassemia Patients According To Consanguineous Marriage History**

Consanguineous marriage	n	%
Yes	39	26.5
No	108	73.5
Total	147	100

The data revealed that 26.5% of participants were from families with a history of consanguineous marriages, while 73.5% were not. This information is important for understanding genetic risk factors and inheritance patterns in the study population.

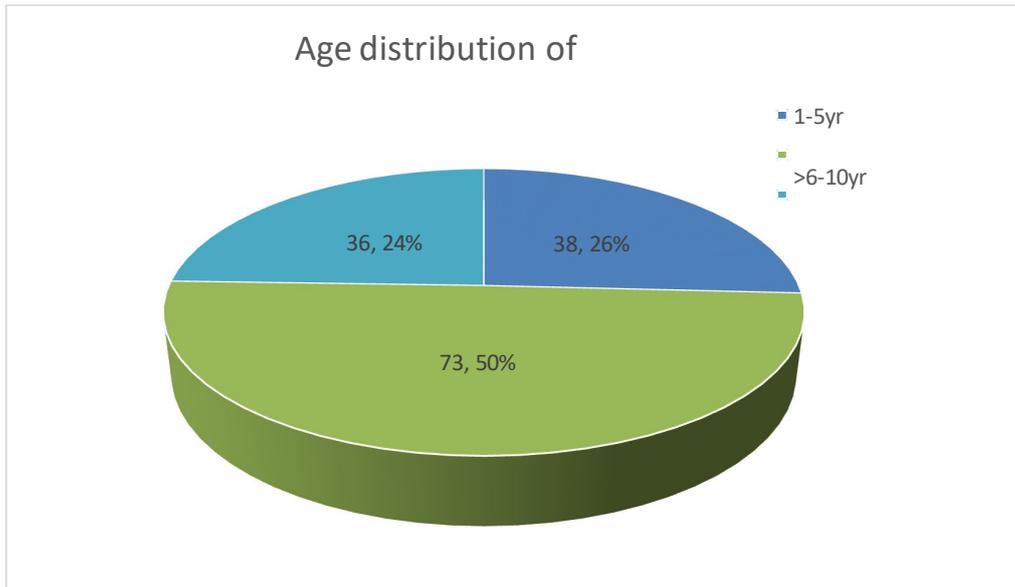


Figure 1: Age distribution of participants

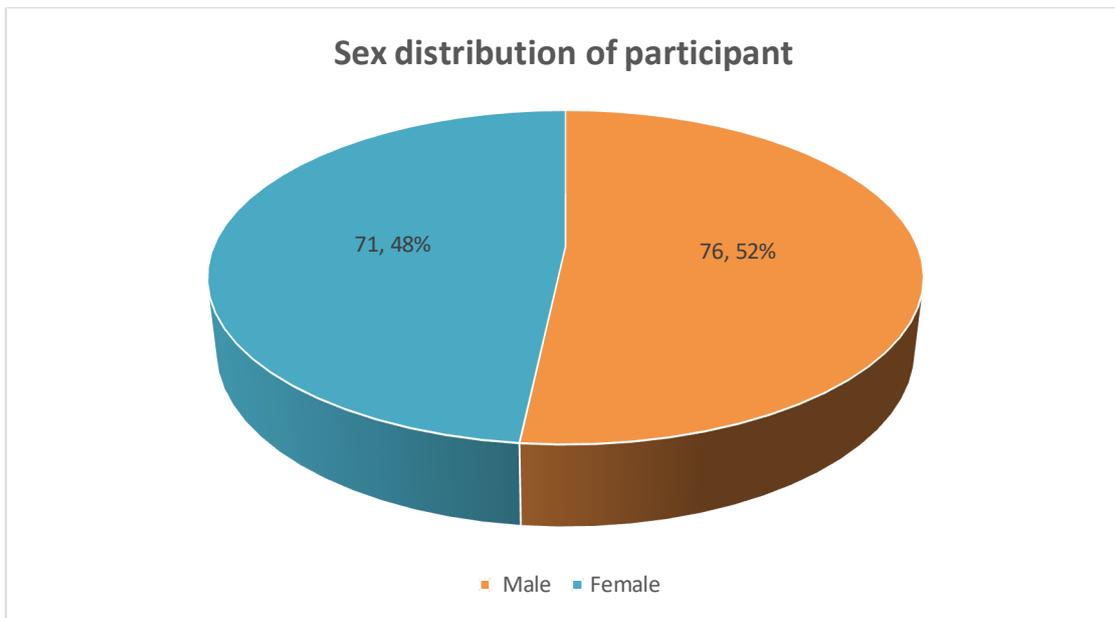


Figure 2: Sex distribution of participant

**Discussion**

The majority of participants in our study were between the ages of 6 and 10 (49.7% of the sample), followed by those between the ages of 1 and 5 (25.9%) and over the age of 10 (24.5%). This distribution suggests an emphasis on younger age groups, which is pertinent to research on the health or development of young children. With 51.7% of people being men and 48.3% being women, the gender distribution was comparatively equal. Although the age and gender distribution of the

participants was not included in the majority of the studies, we believe that this information is crucial because it provides us with a better understanding of the baseline and the standards we are evaluating, giving the impact of these characteristics on the research outcomes sufficient weight.

However, research on parental KAP in children, such as Masood et al. (2003), found that children's mean age was 8.25 years with a standard deviation of 2.82, which is compatible with our study since around half of the participants were between the

ages of 6 and 10. The gender distribution is fairly balanced between males and females, according to studies that have focused on parental KAP, such as Ahmed et al. (2020), Alam et al. (2022), and Bazpour et al. (2019).

In contrast, Shahzad et al. (2017) reported that most of the families (69%) had young parents and came from rural areas. Although the age distribution of children was not the objective of Shahzad's study, the concentration on younger parents points to a similar demographic focus on younger thalassaemia-affected families. Our participants' socioeconomic backgrounds varied, with the upper-middle class making up the largest group (39.5%), followed by the lower class (36.1%), upper-low (12.2%), higher (8.8%), and lower-middle (3.4%). This variability sheds light on how socioeconomic factors may affect health intervention knowledge, attitudes, and practices.

In contrast, Barua et al. (2021) discovered that the majority of participants (54.3%) were from rural backgrounds, indicating that these families may have distinct socioeconomic difficulties than the research group. Similar to this, Pv and Pujari (2020) found that the majority of participants belonged to Class III and IV (Middle and higher middle), and that this had a substantial impact on carer practices, suggesting that families' management of thalassaemia can be influenced by economic circumstances. It is also easy to compare our study results with existing evidence because Alam et al. (2022) and Kalra et al. (2019) showed that the middle income group had a higher socioeconomic distribution (82% and 50%, respectively).

The disparity in socioeconomic position between our study and others draws attention to possible variations in access to education and healthcare resources, which may have an effect on how well treatments work. According to Shahzad et al. (2017), metropolitan inhabitants showed more awareness because they had better access to healthcare and educational resources.

This suggests that our participants from higher socioeconomic backgrounds may have more opportunity to obtain information and services. According to our research, 42.9% of participants' parents had completed secondary school, compared to 57.1% who had only completed primary school. This degree of education indicates a comparatively rudimentary understanding, which may have an impact on health literacy and the choices made about medical interventions and treatments.

In Contrast, Barua et al. (2021) reported that 51.5% of fathers and 48.6% of mothers had completed secondary school, whereas 20% of moms had never gone to school. These findings

highlight the parents' significantly lower educational position compared to our study. Another interventional study by Bazpour et al. revealed that up to 40% of parents had only completed high school. Additionally, a greater percentage of parents (76%) had less than a high school education, according to Kalra et al. Conversely, 48.4% of parents were aware that thalassaemia is a genetic condition, according to Pv and Pujari (2020), suggesting a knowledge gap that corresponds with lesser educational attainment.

The need of customising educational interventions to address the requirements of various groups is shown by the lower educational levels in our study and others. Shahzad et al. (2017), for example, discovered that frequent trips to thalassaemia clinics enhanced parents' comprehension of the illness, highlighting the need of ongoing education in improving practices and knowledge. 29.3% of participants in our study came from metropolitan areas, whereas 70.7% lived in rural areas. The effectiveness of health interventions may be impacted by the difficulties rural populations may encounter in obtaining healthcare services and instructional materials, as this distribution illustrates. In a similar vein, Barua et al. (2021) found that the majority of their participants (54.3%) came from rural areas and had comparable difficulties getting access to healthcare. In line with our findings and highlighting the need of addressing healthcare inequities in rural areas, Shahzad et al. (2017) similarly reported a high number of rural families (69%). Comparable distribution was also observed in other studies with a higher incidence of rural populations, such as Ahmed et al. and Alam et al.

A common difficulty in controlling thalassaemia in rural regions is highlighted by the constancy of rural residence across studies. Targeted interventions are necessary to guarantee that these people receive sufficient assistance and resources due to the limited access to healthcare facilities and educational opportunities in remote areas.

According to our research, the age of onset for beta thalassaemia was most frequently recorded at 7 months (32%), with notable cases discovered at 6 months (21.8%) and 8 months (24.5%). According to this distribution, the majority of cases are found between the ages of 6 and 8 months, highlighting the importance of early detection and treatment. The significance of early diagnosis and care is a recurring topic in the literature, even though other research did not particularly address the age of onset. Early detection enables prompt treatment of the illness, lowering complications and enhancing the health of impacted kids.

The increase in the practice of timely blood transfusions and adherence to chelation therapy

was also notable in our study. Similar findings were reported by Kalra et al. (2019), where education led to improved adherence to treatment protocols. However, Shukr et al. (2011) highlighted challenges in maintaining consistent adherence due to socio-economic barriers, suggesting that education alone may not be sufficient to overcome all obstacles.

### Conclusion

According to the study's findings, parents and carers' understanding of thalassaemia disease has significantly improved in a number of areas, including general awareness, symptoms, disease transmission, screening and diagnosis, and healthy living and treatment. The study also reveals a notable shift in mothers' and carers' attitudes about thalassaemia with regard to misconceptions, social stigma, the impact of the disease on family, and societal acceptance. Similarly, my research demonstrates that parental practices for thalassaemia screening and testing, sharing information about the condition, and maintaining a healthy diet and cleanliness have significantly improved.

Overall, the study highlights the importance of education as a means of improving health literacy and encouraging parents of children with beta thalassaemia to adopt proactive health habits. We can greatly enhance the quality of life for impacted families and support improved disease management and preventative techniques by continuing to fund and create such educational programs.

### Reference

1. Ali, S, Sabih, F, Jehan, S, Anwar, M, & Javed, S (2012). Psychological distress and coping strategies among parents of beta-thalassaemia major patients, international proceedings of chemical, Biologic and Environmental Engineering;27;124-128
2. Mannoor, K, H (2019). Role of Xmn1 polymorphism in HbF induction in HbE/ $\beta$  and  $\beta$ -thalassaemia patients. Bangladesh Medical Research Council Bulletin, 133-142
3. DeBaun, M.R, Glauser, T.A, Siegel, M, Borders, J & Lee, B. (2011). Noninvasive central nervous system imaging in sickle cell anemia. a preliminary study comprising transcranial, Doppler to magnetic resonance angiography. American journal of pediatric haematology/oncology 17,29-33
4. Piel, F B. (2016). The present and Future Global Burden of the Inherited Disorders Hemoglobin. Hematology/ Oncology Clinics, 663-680.
5. Sahu, Pramita MD, Purohit, Prasanta PhD, Mantri Santwana PhD, Tudu, Ramray MD, Nayak, Jayanti MD, Agrawalla, Sunil Kumar MD, Behera, Samira kumar MD; Patri, Manoj kumar MD, Karmee, Nivedita MD, Tripathy, Diptimayee MD, Mishara, Bharati MD, Debi Prasad MD; Porto Biomedical Journal; January/February 2021-volume 6-issue 1-p e126.
6. Kargar Nm, Borhani F, Dortaj Re, Sabzevari S. The Effect of Family-Centered Empowerment Model On The Mothers' knowledge and Attitudes About Thalassaemia Disorder.
7. Mariani D, Muffidah AS, Rosdiana I. The Family Psychoeducation to Improve Parents' Coping Strategies in Caring for Thalassaemia Children. Poltekita: Jurnal Ilmu Kesehatan. 2023 Nov 1;17(3):598-604.
8. Sadek EH, Elsayh KI, Mohammed FZ, Mohamed NT, Faheem SS. Effect of an educational program on self-efficacy of adolescents with thalassaemia major. Assiut Scientific Nursing Journal. 2020 Sep 1;8(22):72-85.
9. Biabani A, Kermansaravi F, Navidian A. The effect of group education on adaptive behaviors and caregiver burden in mothers of children with thalassaemia major: a trial clinical study. Medical-Surgical Nursing Journal. 2020 Feb 29;9(1).
10. Ishaq F, Hasnain Abid FK, Akhtar A, Mahmood S. Awareness among parents of  $\beta\beta$ -Thalassaemia major patients, regarding prenatal diagnosis and premarital screening. Journal of the College of Physicians and Surgeons Pakistan. 2012;22(4):218-.
11. Sananreangsak S, Lapvongwatana P, Virutsetazin K, Vatanasomboon P, Gaylord N. Predictors of family management behavior for children with thalassaemia. Southeast Asian Journal of Tropical Medicine and Public Health. 2012 Jan 1;43(1):160.
12. Mohammed YA, Abdalla AI. Effect of Health Coaching Intervention on Mothers' Performance and Quality of Life of their Children with Beta Thalassaemia. Assiut Scientific Nursing Journal. 2022 Jul 1;10(31):43-56.
13. Dayasiri K, Mudiyanse R. Effectiveness of training parents of beta thalassaemia patients in improving medical student-patient communication: a developing country-perspective. Sri Lanka Journal of Child Health. 2020 Dec 5;49(4):369-74.
14. Al Nasiri YS. Parent Educational Intervention Program (PEIP) for improving Parental Knowledge, Self-Efficacy, & Parent Perception of Health-Related Quality of Life in Children with Sickle Cell Disease Using Smartphone Technology. University of California, Los Angeles; 2018.
15. Borhani F, Najafi MK, Rabori ED, Sabzevari

- S. The effect of family-centered empowerment model on quality of life of school-aged children with thalassemia major. Iranian journal of nursing and midwifery research. 2011;16(4):292.
16. Saxena A, Sharif M, Siddiqui S, Singh S. Knowledge, practice and experiences of parents with a thalassaemic child. Int J Contemp Pediatr. 2017 Sep;4(5):1630-3.
  17. Sadek EH, Elsayh KI, Mohammed FZ, Mohamed NT, Faheem SS. Effect of an Educational Program on Self-efficacy of Adolescents with Thalassemia Major. Journal of Research and Health. 2015 Jun 10;5(2):211-9.
  19. Khresheh SM, Brair SL. Knowledge and practices among Mothers about Care of their children with Beta Thalassemia Major: A descriptive Study. Egyptian Journal of Health Care. 2020 Sep 1;11(3):1-2.
  20. Begum F, Shirin MF, Sayed MA, Sharmin LS, Uddin MB. Knowledge, Attitude and Practice of Prevention of Thalassaemia of the Parents of Children with Thalassaemia attending in a Tertiary Care Hospital in Bangladesh. Journal of Bangladesh College of Physicians and Surgeons. 2024 Jan 10;42(1):6-11.
  21. Hossain MS, Mahbub Hasan M, Petrou M, Telfer P, Mosabbir AA. The parental perspective of thalassaemia in Bangladesh: lack of knowledge, regret, and barriers. Orphanet journal of rare diseases. 2021 Dec; 16:1-0.
  22. Cheng K, Fucharoen S, Sanchaisuriya K, Fucharoen G, Sanchaisuriya P, Jetsrisuparb A. Effect of health education on severe thalassemia prevention and control in communities in Cambodia. Archives of Public Health. 2018 Dec; 76:1-8.
  23. Rujito L, Pusparini I, Lestari DW, Mulyanto J. Educational intervention to improve knowledge and attitudes about thalassemia premarital screening surveys among Muslim societies: A pilot study in Indonesia. Jurnal Keperawatan Soedirman. 2023 Mar 9;18(1):30-6.
  24. Karimzaei T, Masoudi Q, Shahrakipour M, Navidiyan A, Jamalzae AA, Bamri AZ. Knowledge, attitude and practice of carrier thalassemia marriage volunteer in prevention of major thalassemia. Global journal of health science. 2015 Sep;7(5):364.
  25. Ghafoor MB, Leghari MS, Mustafa G, Naveed S. Level of awareness about thalassemia among parents of thalassaemic children. Journal of Rawalpindi Medical College. 2016 Sep 30;20(3).