VER
Vascular & Endovascular Review

A pre-experimental study to assess the effectiveness of Information Booklet on knowledge regarding care of thalassemia children among parents in selected hospitals of Pune city

Dr. Bhagyshree Jogdeo[1]*, Mr. Jitesh Dorkar[2]

[1]Principal, Bharati Vidyapeeth College of Nursing, Pune.
[2]M.Sc. Nursing, Bharati Vidyapeeth College of Nursing, Pune.

***Corresponding Author**
Dr. Bhagyshree Jogdeo

ABSTRACT

Introduction: One of the most predominant genetic disorders in the world is thalassaemia. A decrease in haemoglobin synthesis is the hallmark of this inborn haemolytic anaemia, also known as Mediterranean anaemia or Cooley's anaemia. It causes haemolysis, fruitless erythropoiesis, and defective haemoglobinization of red blood cells, which results in hypochromic microcytic anaemia.

Aims of the Study: To assess the effectiveness of Information Booklet on knowledge regarding care of thalassemia children among parents in selected hospitals of Pune city.

Methodology: In the present study, the researcher adopted a quantitative approach and employed a pre-experimental one-group pre-test post-test design. The study was conducted on a sample of 100 participants, selected using a non-probability purposive sampling technique. Data were collected using a demographic profile tool. An intervention in the form of an informational booklet on the care of children with thalassemia was provided to the participants. Data analysis was primarily carried out using descriptive statistical methods to evaluate the effectiveness of the intervention.

Results: Most parents were aged 26–45 years and had one child with thalassemia. Nearly half were employed full-time, and 42% had a high school education. Most rated their child's health as very good or excellent. Pre-test scores showed poor to average knowledge (mean = 10.3), with gaps in fatigue management, folic acid use, and iron monitoring. Post-test scores improved significantly (mean = 14.6, $p = 0.00001$), confirming the intervention's effectiveness. Most participants had average or good knowledge post-intervention. No significant correlation was found between demographic factors and knowledge levels.

Conclusion: In conclusion, the study showed that the information booklet effectively improved parental knowledge on thalassemia care, with a significant increase in post-test scores (mean 14.6). This highlights the importance of educational interventions in enhancing disease management. However, further education on specific areas like fatigue management and blood clot prevention is needed for more comprehensive care.

KEYWORDS: Thalassemia, parental knowledge, information booklet, educational intervention, self-care practices, knowledge improvement, disease management.

How to Cite: Dr. Bhagyshree Jogdeo, Mr. Jitesh Dorkar, (2025) A pre-experimental study to assess the effectiveness of Information Booklet on knowledge regarding care of thalassemia children among parents in selected hospitals of Pune city, Vascular and Endovascular Review, Vol.8, No.6s, 418-424.

INTRODUCTION

The term "thalassaemia" describes a class of hereditary blood conditions that interfere with the normal synthesis of haemoglobin, Red blood cells include a protein that contains iron and transports oxygen throughout the body. This genetic disorder causes decreased or faulty haemoglobin production and is inherited from parents to their offspring. Thalassaemia patients may therefore suffer from moderate to severe anaemia in different proportions. Fatigue, bone abnormalities, liver and spleen enlargement (hepatosplenomegaly), and severe red blood cell breakdown (haemolytic anaemia) are typical symptoms. Regular blood transfusions, hormone therapy for growth, haematopoietic stem cell transplantation, gene-based medicines, and stimulation of foetal haemoglobin (HbF) production are common management options for thalassaemia.

Between 2010 and 2015, the overall prevalence of thalassemia rose from 33.5 to 37.1 per 100,000 individuals. In contrast, the incidence rate declined significantly during the same period—from 72.4 to 34.6 per 100,000 live births. Among the various forms of thalassemia, β-thalassemia major (β-TM) accounted for the majority, comprising approximately 73.9% of all cases. Around two-thirds (66%) of the affected individuals were younger than 15 years. Notably, 78.8% of patients were born to consanguineous parents, and 55.9% of them experienced at least one associated complication.

As stated by WHO Thalassemia's age-standardized prevalence rate (ASPR) was 18.28 per 100,000 individuals worldwide in 2021. From 1990, this represents a drop of 0.18 per 100,000. In tropical and subtropical areas, particularly those where malaria has been or is endemic, thalassaemia is more prevalent. The WHO estimates that 3–4% of Indians are carriers of β-thalassemia

on average. The frequency, however, differs by region and is higher in some localities. There were 1,310 thalassaemia cases globally in 2021, which is a reduction of 0.18 cases per 100,000 people (95% UI: -0.22 to -0.14) between 1990 and 2021. According to research, the government and healthcare professionals need to pay more attention to educating the public and starting a thalassaemia awareness campaign.

NEED OF THE STUDY

Approximately 7% of people worldwide suffer from a haemoglobin disease, with thalassaemia being more common in countries with low or middle incomes. It is one of the most prevalent chronic and hereditary blood disorders. Each year, about 200,000 children are born with homozygous thalassemia, while nearly 240 million people are heterozygous carriers of β-thalassemia. Approximately 2.7 per 1,000 pregnancies are affected, and 1.1% of couples worldwide face a risk of having a child with a haemoglobin-related disorder."

"In India, sickle cell diseases and beta thalassaemia represent a substantial health burden. According to the 2011 Census of India, the average prevalence of β thalassaemia carriers is 3–4%, or 35–45 million carriers, among our 1.21 billion people, who are multi-ethnic, culturally and linguistically varied, and comprise around 8% of tribal communities. Studies were out in 2013 among the Sindhis of Nagpur, Maharashtra, revealed that 16.81% of them possessed the β-thalassemia trait. The prevalence is significantly greater for a number of ethnic groups (4–17%). The Thalassaemia Society of Maharashtra was able to help 70 individuals from Pune and western Maharashtra with their disability certificate applications. There are around 600 to 800 persons with thalassaemia major in Pune.

Thalassemia is a hereditary blood disorder, and parental awareness is vital for early detection, screening, and prevention through informed family planning. Educating parents helps ensure proper daily care, including managing diet, medications, and transfusions, while enabling early recognition of complications like iron overload or infections. Understanding the genetic nature of thalassemia may also encourage parents to seek genetic counselling, especially in high-risk groups. Identifying knowledge gaps allows for tailored educational interventions, aiding early diagnosis and effective care. Research assessing parental understanding is essential to reduce the disease burden and improve the quality of life for affected families.

MATERIALS AND METHODS

The researcher employed a quantitative approach using a pre-experimental one-group pre-test post-test design. Data were collected from selected hospitals in Pune City, with a sample size of 100 determined in consultation with the research guide. Participants were selected through purposive sampling. An informational booklet covering key topics—medication management, dietary needs, symptom identification, and lifestyle tips for improved health—was used as the intervention. For content validity, the tool was reviewed by experts from the Medical-Surgical and Pediatric Departments. Reliability of the tool will be assessed using the test-retest method with Karl Pearson's formula. Descriptive statistics, including mean, median, standard deviation, and mean percentage, will be used to analyze pre- and post-test knowledge scores. Chi-square analysis will be conducted to explore associations between knowledge scores and selected demographic variables.

RESULTS

SECTION - I Demographic Profile of participants

Table no.1 Demographic variables n=100

Demographic Variables	f	%
1. Parent's Age Range:		
a. 18-25 years	26	26
b. 26-35 years	27	27
c. 36-45 years	32	32
d. Above 45 years	15	15
2. Number of Children with Thalassemia:		
a. 1	72	72
b. 2	28	28
c. More than 3	0	0
3. Employment Status of Parent:		
a. Employed full-time	49	49
b. Employed part-time	19	19
c. Self-employed	23	23
d. Unemployed	0	0
e. Homemaker	9	9
4. Highest Level of Education Attained by Parent:		

a. Less than high school	20	20
b. High school diploma/GED	42	42
c. Some college/Associate degree	23	23
d. Bachelor's degree	8	8
e. Master's degree	7	7
f. Doctoral/Professional degree	0	0
5. Parent's Perception of Child's Health:		
a. Excellent	26	26
b. Very good	47	47
c. Good	27	27
d. Fair	0	0
e. Poor	0	0

The majority of parents (59%) were aged between 26–45 years, with 26% aged 18–25 years and 15% above 45 years. Most parents (72%) had one child with thalassemia, while 28% had two affected children. Regarding employment, nearly half (49%) were employed full-time, 23% self-employed, 19% part-time employed, and 9% homemakers; none reported being unemployed. In terms of education, 42% held a high school diploma, 23% had some college education, and 20% had less than high school education. Only a small percentage had a bachelor's (8%) or master's degree (7%), with no doctoral qualifications. Most parents rated their child's health positively, with 47% reporting "very good," 26% "excellent," and 27% "good," indicating a generally optimistic view of their child's well-being.

SECTION II

Section II a: Finding related to assess the Knowledge level of parents regarding care of children with thalassemia before intervention.

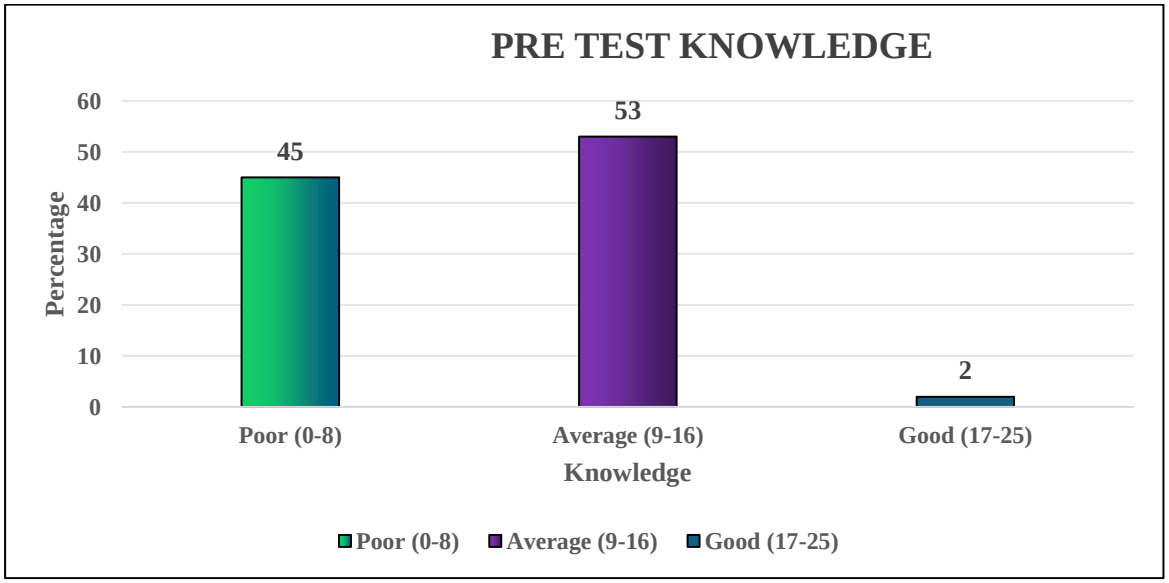

Figure 1: Pre-test knowledge regarding care of children with thalassemia.

The bar graph illustrates the distribution of participants' knowledge levels regarding thalassemia care before the intervention. A majority, 53%, demonstrated average knowledge (scores 9–16), while 45% had poor knowledge (scores 0–8). Only 2% of participants achieved a good knowledge level (scores 17–25). This indicates that prior to the educational intervention, most participants had limited understanding of thalassemia care, with a clear need for improved awareness and education to elevate knowledge from poor or average to good levels.

Table No.2 - Related to pre-test self-structured questionnaire.

Sr.No	Questions	Frequency	Percentage
1	What is the primary cause of thalassemia in children?	67	67
2	Which of the following is a characteristic feature of thalassemia?	51	51
3	Which of the following is NOT a recommended dietary practice for children with thalassemia?	70	70

4	What is the primary goal of care for children with thalassemia?	45	45
5	Which of the following is a recommended care practice for children with thalassemia to prevent infections?	61	61
6	How can children with thalassemia ensure proper hydration as part of care?	54	54
7	What should children with thalassemia do to minimize the risk of bone fractures as part of care?	48	48
8	Which of the following dietary recommendations is important for children with thalassemia as part of care?	40	40
9	How can children with thalassemia manage fatigue as part of care?	29	29
10	What role does physical activity play in care for children with thalassemia?	36	36
11	How can children with thalassemia protect themselves from excessive sun exposure as part of care?	37	37
12	What should children with thalassemia do to manage stress effectively as part of care?	61	61
13	Which of the following is NOT a recommended care practice for children with thalassemia?	41	41
14	Which of the following activities should be avoided by children with thalassemia?	30	30
15	What is the recommended frequency for monitoring iron levels in children with thalassemia?	22	22
16	What is the most effective way to prevent infections in children with thalassemia?	48	48
17	Which of the following statements is true regarding folic acid supplementation in children with thalassemia?	14	14
18	How can parents support the emotional well-being of children with thalassemia?	36	36
19	Which of the following factors can exacerbate symptoms in children with thalassemia?	31	31
20	How can parents help their child cope with fatigue caused by thalassemia?	16	16
21	What should parents do if their child with thalassemia experiences dizziness or fainting spells?	39	39
22	Which of the following vaccines is recommended for children with thalassemia?	42	42
23	How can parents help their child manage stress associated with thalassemia?	43	43
24	What is the recommended approach for preventing blood clots in children with thalassemia?	33	33
25	How can parents ensure proper medication management for their child with thalassemia?	36	36

The pre-test revealed varied knowledge among participants about thalassemia. While 70% correctly identified dietary practices to avoid and 67% knew its primary cause, knowledge was lower for managing fatigue (16%), iron monitoring (22%), and folic acid use (14%). Moderate awareness was seen in stress management and emotional support (36–43%). These gaps highlight the need for focused educational interventions to enhance understanding of key care practices, nutrition, and support for children with thalassemia, ultimately improving their health outcomes and quality of life.

Section IIb: Finding related to assess the Knowledge level of parents regarding care of children with thalassemia after intervention.

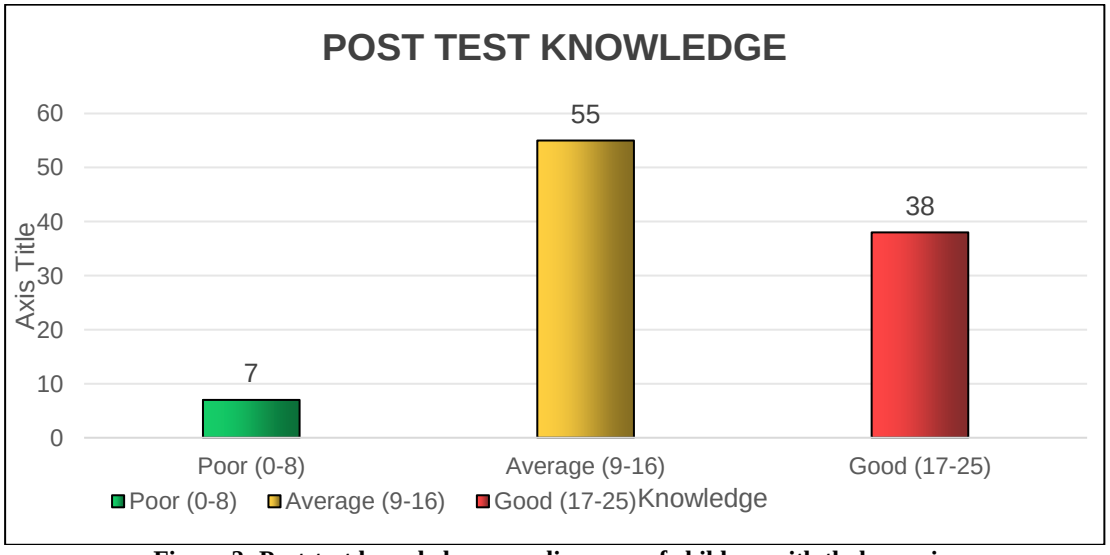

Figure 2: Post-test knowledge regarding care of children with thalassemia.

The above figure shows a significant improvement in participants' knowledge after the educational intervention. A majority, 55%, achieved average knowledge (scores 9–16), while 38% reached a good level of knowledge (scores 17–25), compared to only 2% in the pre-test. Only 7% remained in the poor knowledge category (scores 0–8), indicating a marked decrease. These results suggest that the intervention effectively enhanced participants' understanding of thalassemia care, with a substantial shift from poor to average and good knowledge levels.

Table No.3- Related to post-test self-structured questionnaire.

Sr.No	Questions	Frequency	Percentage
1	What is the primary cause of thalassemia in children?	71	71
2	Which of the following is a characteristic feature of thalassemia?	52	52
3	Which of the following is NOT a recommended dietary practice for children with thalassemia?	72	72
4	What is the primary goal of care for children with thalassemia?	51	51
5	Which of the following is a recommended care practice for children with thalassemia to prevent infections?	68	68
6	How can children with thalassemia ensure proper hydration as part of care?	60	60
7	What should children with thalassemia do to minimize the risk of bone fractures as part of care?	53	53
8	Which of the following dietary recommendations is important for children with thalassemia as part of care?	48	48
9	How can children with thalassemia manage fatigue as part of care?	38	38
10	What role does physical activity play in care for children with thalassemia?	49	49
11	How can children with thalassemia protect themselves from excessive sun exposure as part of care?	49	49
12	What should children with thalassemia do to manage stress effectively as part of care?	71	71
13	Which of the following is NOT a recommended care practice for children with thalassemia?	60	60
14	Which of the following activities should be avoided by children with thalassemia?	49	49
15	What is the recommended frequency for monitoring iron levels in children with thalassemia?	44	44
16	What is the most effective way to prevent infections in children with thalassemia?	65	65
17	Which of the following statements is true regarding folic acid supplementation in children with thalassemia?	50	50
18	How can parents support the emotional well-being of children with thalassemia?	69	69
19	Which of the following factors can exacerbate symptoms in children with thalassemia?	56	56
20	How can parents help their child cope with fatigue caused by thalassemia?	52	52
21	What should parents do if their child with thalassemia experiences dizziness or fainting spells?	70	70
22	Which of the following vaccines is recommended for children with thalassemia?	67	67
23	How can parents help their child manage stress associated with thalassemia?	68	68
24	What is the recommended approach for preventing blood clots in children with thalassemia?	59	59
25	How can parents ensure proper medication management for their child with thalassemia?	65	65

The post-test responses indicate a noticeable improvement in participants' knowledge across various aspects of thalassemia care. High awareness was observed for dietary practices to avoid (72%), the primary cause of thalassemia (71%), and stress management (71%). Additionally, participants showed strong understanding in infection prevention (68–65%), emotional support (69%), and medication management (65%). Moderate knowledge levels were noted for hydration (60%), bone health (53%), and fatigue management (38–52%). Awareness regarding iron monitoring (44%) and folic acid supplementation (50%) also improved compared to pre-test results but still indicated room for further education. Overall, the post-test results suggest that the educational intervention effectively enhanced knowledge, especially in critical care areas, leading to better preparedness among parents for managing thalassemia in children. Targeted efforts may still be needed in areas like fatigue management and iron monitoring to ensure comprehensive understanding.

SECTION III

Section III: Finding related to effectiveness of pre-test and post-test knowledge regarding care practices for children with thalassemia.

Table No.4: Effectiveness of pre-test and post-test knowledge regarding care practices for children with thalassemia.

Effectiveness	Mean	SD	DF	T test calculated value	P value	Remark
Pre test	10.3	2.89	99	13.74	0.00001	Significant
Post test	14.6	3.59	99			

The comparison of pre-test and post-test scores shows a significant improvement in knowledge regarding care practices for children with thalassemia after the educational intervention. The mean pre-test score was 10.3 (SD = 2.89), which increased to 14.6 (SD = 3.59) in the post-test. The calculated *t* value of 13.74 with a *p* value of 0.00001 indicates that this improvement is statistically significant. This demonstrates that the educational intervention was highly effective in enhancing participants' knowledge about thalassemia care.

SECTION IV: Finding related to association of level of knowledge with selected demographic variables.

The chi-square analysis revealed no statistically significant association between demographic variables and post-test knowledge levels regarding thalassemia care, as all *p* values were above 0.05. Parent's age ($p = 0.113$), number of children with thalassemia ($p = 0.993$), employment status ($p = 0.128$), education level ($p = 0.199$), and perception of the child's health ($p = 0.985$) did not show any meaningful correlation with knowledge outcomes. This indicates that the educational intervention was effective across all demographic groups, with improvements in knowledge observed irrespective of the participants' age, employment, education, or perception of their child's health status.

DISCUSSION

The effect of a self-instructional section (SIM) on improving parental knowledge of Thalassaemia care was assessed in the study "Assessment of the Efficiency of Self-Instructional Module upon Understanding With regard to Home Care Management of Thalassaemia Children between Parents within A.V.B.R. Hospital, Wardha" by Padmane E et al. (December 2021). The findings demonstrated a notable increase in knowledge following the session. Despite these improvements, areas like managing fatigue and preventing bone fractures still posed challenges for some parents, as indicated by lower post-test scores in these topics. The study also found no significant influence of demographic variables (age, education, employment status) on the effectiveness of the SIM, suggesting that the intervention was universally effective across different parent groups.

The present study, titled "A Pre-Experimental Research to Assess the Efficiency of an Information Booklet on Knowledge Regarding the Care of Children with Thalassemia Among Parents in Selected Hospitals of Pune City," demonstrated that the booklet was effective in increasing parental awareness about key areas such as the primary cause of thalassemia, recommended dietary practices, and infection prevention. However, knowledge gaps remained in more complex areas like fatigue management and the role of folic acid supplementation. In comparison, a study by Padmane E. and Patiye S. evaluated the effectiveness of a Self-Instructional Module (SIM), which offered a detailed, self-paced, and interactive learning experience. The SIM enabled deeper engagement with content, leading to better knowledge retention, especially in stress management, hydration, and infection prevention. Its comprehensive design covered a wider range of care practices, making it more effective in areas requiring thorough understanding. Despite the differences in intervention methods, both studies highlighted persistent gaps in managing fatigue and bone fractures, indicating a need for more focused and targeted educational strategies in these areas.

CONCLUSION

The study titled "A Pre-Experimental Study to Evaluate the Effectiveness of an Information Booklet on Knowledge Regarding the Care of Children with Thalassemia Among Parents in Selected Hospitals of Pune City" demonstrated that an information booklet can significantly enhance parents' understanding of thalassemia care. The intervention led to improved knowledge about the primary cause of thalassemia, appropriate dietary practices, infection prevention, and the importance of regular health monitoring. Parents who initially had limited awareness showed substantial improvement in their ability to manage their child's condition effectively at home.

However, the study also revealed persistent knowledge gaps in complex areas such as fatigue management, early recognition of complications, and aspects of long-term treatment, indicating that more in-depth educational approaches may be necessary. While the statistical analysis confirmed the effectiveness of the booklet with significant gains in post-test scores, it also suggested that the booklet alone may not provide comprehensive education. Supplementary strategies like follow-up sessions, interactive learning modules, or additional materials may be required to reinforce learning. In conclusion, the study highlights the value of information booklets as cost-effective tools for improving parental knowledge, leading to better disease management and health outcomes. Future research should focus on developing more comprehensive interventions to address remaining gaps and ensure holistic support for families.

DECLARATION BY AUTHORS:

Ethical Approval: The study was approved by the institutional ethics committee of Bharati Vidyapeeth College of Nursing, Pune. The study participants were briefed about the purpose and nature of the study and written informed consent was obtained before data collection.

Acknowledgement: The authors thank all research participants, government health authorities, and community health representatives in their respective areas.

Source of Funding: There is no funding Source for this study.

Conflict of Interest: The authors declare no conflict of interest.

REFERENCES

1. Beta Thalassemia (for Parents) | Nemours KidsHealth. (n.d.). Retrieved August 28, 2024, from https://kidshealth.org/en/parents/beta-thalassemia.html.
2. https://www.google.com/search?q=prevalence+rate+of+thalessimia+in+nation+according+to+WHO.
3. https://www.google.com/search?q=prevalence+rate+of+thalessimia+in+india+according+to+WHO
4. https://www.google.com/search?q=prevalence+rate+of+thalessimia+in+pune+according+to+WHO.
5. Naz, Sehrish & Jan, Anayat & Khan, Shabnam. (2022). Assesment of Thalassemic Children' Parents Knowledge Regarding Thalassemia. Journal of Farkhanda Institute of Nursing And Public Health (JFINPH). 2. 41-45. 10.37762/jfinph.31.
6. Thalassemia in Kids | Symptoms & Care | Children's Minnesota. (n.d.). Retrieved August 28, 2024, from https://www.childrensmn.org/services/care-specialties-departments/cancer-blood-disorders/conditions-and-services/blood-disorders-services/hemoglobinopathy-sickle-cell/thalassemia/
7. Tuo, Y., Li, Y., Li, Y., Ma, J., Yang, X., Wu, S., Jin, J., & He, Z. (2024). Global, regional, and national burden of thalassemia, 1990–2021: a systematic analysis for the global burden of disease study 2021. EClinicalMedicine, 72, 102619. https://doi.org/10.1016/J.ECLINM.2024.102619/ATTACHMENT/A47F6E8D-F6E7-4EEC-86B8-5C3229C9D6E8/MMC26.DOCX.
8. Taher, A. T., Musallam, K. M., & Cappellini, M. D. (2021). β-Thalassemias. New England Journal of Medicine, 384(8), 727–743. https://doi.org/10.1056/NEJMRA2021838.
9. Basu M. A study on knowledge, attitude and practice about thalassemia among general population in out patient department at a tertiary care hospital of Kolkata. J Prev Med Holistic Health. 2015;1(1):5-12. 6.
10. Padmane E, Patiye S, Patel A, Pawar P, Lohave (Taksande) A. Assessment of the effectiveness of self-instructional module on knowledge regarding home care management of thalassemia children among the parents in A.v.b.r. hospital, Wardha. J Pharm Res Int [Internet]. 2021;271–81. Available from: https://journaljpri.com/index.php/JPRI/article/view/4520
11. Verma R, Kumari R, Verma N, Charan A. Effectiveness of an information booklet regarding home based management on knowledge of caregivers of children with thalassemia. Int J Contemp Pediatr [Internet]. 2020;7(12):2339. Available from: https://www.ijpediatrics.com/index.php/ijcp/article/view/3788