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"A Study To Assess The Burden Of Thalassemia On Daily Living And Well-Being Among Affected Children Receiving Regular Treatment In Selected Hospitals Of Rajasthan"

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Abstract: This quantitative descriptive study aimed to assess the burden of thalassemia on daily living and well-being among affected children receiving regular treatment in selected hospitals of Rajasthan. A descriptive cross-sectional research design was adopted, and data were collected from 200 children aged 6–18 years using a structured questionnaire. The study was conducted at Pacific Medical College & Hospital, Bedala, and Pacific Institute of Medical Sciences, Umarda, Udaipur, Rajasthan. The Wilson and Cleary Model (1995) served as the conceptual framework, integrating biological, psychological, and social factors affecting health-related quality of life (HRQoL). A non-probability purposive sampling technique was used. The study analyzed demographic characteristics and burden levels across physical, emotional, social, financial, and coping domains. Findings revealed that 77.5% of children had a low physical burden, while 43.5% reported high emotional distress. Financial strain was significant (42.5%), whereas social burden remained low (87.5%). Coping mechanisms were strong in 94.5% of children. The mean total burden score was 50.43 (SD = 8.52), indicating that emotional and financial challenges require targeted support. Statistical analysis showed significant associations between age ($\chi^2 = 12.31$, $p < 0.05$), education level ($\chi^2 = 9.24$, $p < 0.05$), duration of diagnosis ($\chi^2 = 11.3$, $p < 0.05$), frequency of blood transfusions ($\chi^2 = 14.22$, $p < 0.05$), and family support system ($\chi^2 = 15.21$, $p < 0.05$) with burden levels. However, gender ($\chi^2 = 3.36$, $p > 0.05$) and family income ($\chi^2 = 0.36$, $p > 0.05$) were not significantly associated with burden. Correlation analysis revealed strong positive relationships between physical and emotional burden ($r = 0.72$, $p < 0.01$) and emotional burden and social impact ($r = 0.68$, $p < 0.01$). Financial burden was moderately correlated with emotional distress ($r = 0.59$, $p < 0.05$), while coping mechanisms negatively correlated with emotional burden ($r = -0.64$, $p < 0.01$). The study highlights the need for integrated healthcare interventions, financial assistance, and psychological support to improve the well-being of children with thalassemia. Educational and counseling programs should be implemented to enhance coping strategies and reduce emotional distress.

Index Term: Assess; Burden of Thalassemia; Daily Living; Well-Being; Children

I. INTRODUCTION

Thalassemia is an inherited blood disorder characterized by lower-than-normal levels of hemoglobin, leading to anemia and fatigue. The severity of thalassemia varies, with some individuals experiencing mild symptoms and others requiring regular blood transfusions. Several types of thalassemia exist, including alpha thalassemia, beta thalassemia, Cooley's anemia, and Mediterranean anemia. Thalassemia is a chronic condition that presents a wide range of clinical and psychological challenges. The effects of thalassemia on physical health can lead to physical deformity, growth retardation, and delayed puberty.

Globally, the World Health Organization (WHO) recognizes thalassemia as the most prevalent genetic blood disorder, affecting more than 60 countries with a carrier population of up to 150 million1. In India, about 10,000 children are born with thalassemia each year, accounting for approximately 10% of the world's total incidence. The continuous need for treatment and monitoring can lead to a substantial burden on daily living and overall well-being. This burden is further increased by frequent hospital visits, repeated laboratory tests, and the need for constant monitoring for complications. Studies show that thalassemia can negatively impact physical, emotional, social, and school functioning in affected children. The hereditary nature of the disease, changes in physical appearance, and the need for continuous treatment can also create unfavorable psychological impacts on patients and their families, predisposing them to various psychological disorders. Caregivers of children living with thalassemia may experience social isolation and feelings of despair.

Considering these factors, assessing the quality of life among children with thalassemia is particularly important1. It allows healthcare providers to gain a more holistic view of their well-being, focusing on the individual's own views and experiences. This information can then be used to develop targeted interventions and support systems to improve the daily living and overall well-being of children with thalassemia who are undergoing regular treatment.

1.1. PROBLEM STATEMENT

"A Study to Assess the Burden of Thalassemia on Daily Living and Well-Being among Affected Children Receiving Regular Treatment in Selected Hospitals of Rajasthan"

1.2. OBJECTIVES

- To assess the physical, emotional, social, and financial burden of thalassemia among affected children.
- To evaluate their overall well-being in relation to coping mechanisms
- To find associations between demographic variables and the burden experienced by children with thalassemia.

1.3. HYPOTHESIS

Null Hypothesis (H_0):

H_{o1}:- There is no significant burden of thalassemia on the physical, emotional, social, and financial well-being of affected children receiving regular treatment.

H_{02}:- There is no significant association between demographic variables and the burden of thalassemia.

Alternative Hypothesis (H):

H_1:- There is significant burden of thalassemia on the physical, emotional, social, and financial well-being of affected children receiving regular treatment.

H_2:- There is a significant association between demographic variables (age, gender, duration of treatment) and the burden of thalassemia.

1.4. CONCEPTUAL FRAMEWORK

Conceptualization involves developing and refining abstract ideas, while a theoretical framework consists of defined concepts and relationships to systematically examine phenomena. In this study, The Wilson and Cleary Model (1995) integrates biological, psychological, and social factors to comprehensively assess health-related quality of life (HRQoL). It systematically links biological function, symptoms, functional status, health perception, and overall well-being.

1. Biological and Physiological Variables (Medical Condition)

Thalassemia is a chronic blood disorder that requires lifelong management. The severity of the disease varies based on factors such as diagnosis type, duration of the disease, and frequency of blood transfusions. Additionally, children with thalassemia often experience complications such as iron overload, organ damage, and delayed growth and development. These physiological aspects directly impact symptoms and daily functioning, leading to significant physical and emotional burdens.

2. Symptom Status (Physical & Psychological Symptoms)

Children with thalassemia commonly experience fatigue, weakness, shortness of breath, and pain, which can limit their ability to engage in normal activities. Beyond physical symptoms, the disease also contributes to emotional distress, including anxiety, stress, and depression. The recurring medical interventions, fear of complications, and uncertainty about the future further add to their psychological burden. These symptoms negatively impact their ability to participate in daily life and maintain social interactions.

3. Functional Status (Daily Living & Social Impact)

The symptoms of thalassemia significantly affect a child's ability to perform everyday tasks. Many children experience difficulty attending school regularly, leading to academic struggles and frequent absenteeism. Their social interactions may also be limited, as fatigue and hospital visits restrict their participation in recreational and peer activities. Additionally, many children become dependent on caregivers for physical and emotional support, impacting their sense of independence. This stage of the model highlights how disease-related limitations influence their social development, academic performance, and overall daily functioning.

4. General Health Perception (Self-Reported Well-being)

Beyond measurable health outcomes, an individual’s personal perception of their health status plays a crucial role in their overall well-being. Children with thalassemia and their families develop subjective perceptions regarding the severity of the disease, effectiveness of treatment, and impact on their future goals. Satisfaction with treatment, trust in healthcare providers, and psychological adaptation to a chronic condition shape how they perceive their quality of life. A negative perception can lead to emotional distress and decreased motivation for treatment adherence, whereas positive perceptions can promote resilience and proactive coping strategies.

5. Health-Related Quality of Life (HRQoL)

The ultimate outcome of the model is health-related quality of life (HRQoL), which encompasses physical, emotional, and social well-being. A child’s ability to adjust to the chronic illness, maintain social relationships, manage symptoms, and develop effective coping strategies determines their overall quality of life. Factors such as support from family, availability of healthcare, and access to psychosocial interventions further influence their well-being. A higher HRQoL is associated with better emotional resilience and improved adaptation to the disease, whereas a lower HRQoL may lead to emotional distress, social withdrawal, and poor treatment adherence.

Application of the Model in Your Study

This model provides a structured framework for evaluating the burden of thalassemia by linking medical factors, symptoms, functional limitations, personal health perceptions, and overall well-being. The study can utilize a structured questionnaire to collect quantitative data on each aspect of the model. This will help in:

- Assessing the extent of physical, emotional, and social burden experienced by children with thalassemia.
- Identifying key factors influencing their quality of life.
- Developing targeted interventions to improve well-being and daily functioning.

1.5. VARIABLES

A variable is a characteristic or attribute that differs among staff nurses.

- **Independent Variable:** In this study, independent variable is thalassemia diagnosis (Children receiving regular treatment for thalassemia).

- **Dependent Variable:** In this study, dependent variable is structured questionnaire regarding physical burden, emotional burden, social impact, financial burden, overall well-being.

- **Demographic Variable:** In this study the selected demographic variables are age, gender, education level, duration of thalassemia diagnosis, frequency of blood transfusions, family income (per month in INR), and family support system.

1.6. DELIMITATIONS

- The study is limited to children with thalassemia receiving regular treatment in selected hospitals of Rajasthan.

- Only quantitative data is collected through a structured questionnaire, excluding qualitative insights.

- The study does not include children with other hematological disorders or those not undergoing regular treatment.

II. MATERIALS AND METHOD

2.1. Research Approach: A quantitative descriptive approach was used in the study.

2.2. Research Design: A descriptive cross-sectional research design was adopted to assess the burden of thalassemia on daily living and well-being among affected children.

2.3. Sample: The sample comprised children diagnosed with thalassemia receiving regular treatment in selected hospitals of Rajasthan.

2.4. Sampling Technique: The samples were selected through a non-probability purposive sampling technique.

2.5. Criteria for Sample Selection

❖ ***Inclusion criteria:***
  - Children diagnosed with thalassemia receiving regular treatment.
  - Children aged 6–18 years who can understand and respond to the questionnaire.
  - Parents or guardians willing to provide consent for participation.

❖ ***Exclusion criteria:***
  - Children with other hematological disorders.
  - Children who are critically ill or hospitalized at the time of data collection.
  - Parents/guardians who are not willing to participate.

2.6. Setting: The study was conducted in Pacific Medical College & Hospital, Bedala and Pacific Institute of Medical Sciences Umarda, Udaipur at Rajasthan that provide regular treatment for thalassemia patients

2.7. Population: The population included children diagnosed with thalassemia and undergoing regular treatment in selected hospitals.

2.8. Description of tool: It consisted of two parts:

- **Part A: Demographic Variables –** This section included variables such as age, gender, education level, duration of thalassemia diagnosis, frequency of blood transfusions, family income, and family support system.

- **Part B: Structured Questionnaire –** This section assessed the physical, emotional, social, and financial burden of thalassemia using a Likert scale-based questionnaire.

2.9. Ethical consideration:

Ethical approval was obtained from the Institutional Ethical Committee. Permission to conduct the study was also obtained from the selected hospitals in Rajasthan. Written informed consent was taken from parents/guardians before data collection.

2.10. Plan for data analysis: The data were analyzed using descriptive and inferential statistics as follows:

- **Descriptive Statistics:** Frequency, percentage, mean, and standard deviation.

- **Inferential Statistics:**
  - Chi-square test – To determine associations between selected demographic variables and burden levels.
  - Correlation Analysis – To assess relationships among different burden domains (physical, emotional, social, and financial).

III. RESULTS

The data obtained are divided into sections for easy and accur1ate interpretation of data. The data finding has organized under the following section:

Section I: Distribution of children based on demographic variables.

Section II: Assessment of the burden of thalassemia on daily living and well-being.

Section III: Association between the burden of thalassemia and selected demographic variables.

Section IV: Correlation between different burden domains

SECTION - I: Distribution of children based on demographic variables:

The demographic data consists of 07 items seeking information about the age, gender, education level, duration of thalassemia diagnosis, frequency of blood transfusions, family income (per month in INR), and family support system.

Table-1: Description of children based on demographic variables

N = 200

S.N.	DEMOGRAPHIC VARIABLE		FREQUENCY (N)	PERCENTAGE (%)
1	Age	6–8 years	76	38.00
		9–12 years	40	20.00
		13–15 years	66	33.00
		16–18 years	18	9.00
2	Gender	Male	82	41.00
		Female	118	59.00
		Other	0	0.00
3	Education Level	Not attending school	52	26.00
		Primary	40	20.00
		Secondary	60	30.00
		Higher secondary	48	24.00
4	Duration of Thalassemia Diagnosis	< 1 year	34	17.00
		1–5 years	106	53.00
		6–10 years	42	21.00
		>10 years	18	9.00
5	Frequency of Blood Transfusions	Weekly	38	19.00
		Every 2 weeks	48	24.00
		Monthly	80	40.00
		Other	34	17.00
6	Family Income (per month in INR)	<10,000	74	37.00
		10,000–30,000	38	19.00
		30,000–50,000	47	23.50
		>50,000	41	20.50
7	Family Support System	Strong	62	31.00
		Moderate	47	23.50
		Weak	91	45.50

Table-1 presents the demographic distribution of the children included in the study (N = 200) based on various factors such as age, gender, education level, duration of thalassemia diagnosis, frequency of blood transfusions, family income, and family support system.

1. Age: Among the total 200 children, the highest proportion belonged to the 6–8 years age group, accounting for 76 children (38.00%). This was followed by 66 children (33.00%) in the 13–15 years age group, while 40 children (20.00%) were in the 9–12 years category. The 16–18 years age group had the lowest representation, with 18 children (9.00%).

2. Gender: In terms of gender distribution, the majority of the children were female, with 118 children (59.00%), whereas 82 children (41.00%) were male. No participants were recorded under the "Other" gender category (0 children, 0.00%).

3. Education Level: Regarding the education level of the children, the highest percentage was observed in the secondary education group, with 60 children (30.00%). A considerable proportion of children, 52 children (26.00%), were not attending school. Meanwhile, 48 children (24.00%) were enrolled in higher secondary education, and 40 children (20.00%) were at the primary education level.

4. Duration of Thalassemia Diagnosis: The majority of children (106 children, 53.00%) had been diagnosed with thalassemia for 1–5 years. A notable proportion, 42 children (21.00%), had been living with the condition for 6–10 years, while 34 children (17.00%) had a diagnosis duration of less than 1 year. The lowest percentage was seen in those diagnosed for more than 10 years, accounting for 18 children (9.00%).

5. Frequency of Blood Transfusions: Blood transfusion frequency varied among participants, with the highest proportion receiving transfusions on a monthly basis, reported by 80 children (40.00%). This was followed by 48 children (24.00%) receiving transfusions every 2 weeks, and 38 children (19.00%) requiring weekly transfusions. Additionally, 34 children (17.00%) reported undergoing transfusions at an irregular frequency ("Other").

6. Family Income (per month in INR): The economic status of the families revealed that the largest proportion of children, 74 (37.00%), came from families with a monthly income of less than INR 10,000. Around 47 children (23.50%) belonged to families earning INR 30,000–50,000, while 41 children (20.50%) had family incomes above INR 50,000. A smaller group, 38 children (19.00%), came from families earning INR 10,000–30,000 per month.

7. Family Support System: The family support system was categorized into strong, moderate, and weak. The highest number of children, 91 (45.50%), reported having a weak family support system. A moderate support system was experienced by 47 children (23.50%), while only 62 children (31.00%) had strong family support.

The demographic profile indicates that most children in the study were aged between 6 and 15 years, with a higher proportion of females. A considerable number of participants had been living with thalassemia for 1–5 years and required monthly blood transfusions. Additionally, many children came from low-income families and reported weak family support, highlighting the need for increased social and healthcare interventions.

SECTION - II: ASSESSMENT OF THE BURDEN OF THALASSEMIA ON DAILY LIVING AND WELL-BEING:

This section presents the analysis and interpretation of data related to the burden of thalassemia on children's daily living and well-being. The burden was assessed across five key domains: physical burden, emotional burden, social impact, financial & caregiving burden, and coping mechanisms using a Likert scale-based structured questionnaire. Each domain was categorized into low burden (strong coping), moderate burden (coping), and high burden (poor coping) based on participants' scores.

The analysis aims to evaluate how thalassemia affects children's physical health, emotional well-being, social interactions, financial dependency, and coping strategies. The results help in understanding the extent of challenges faced by affected children and their families, guiding future interventions to improve their quality of life.

Table-2: Frequency and percentage distribution of samples according to different domain

N = 200

Domain	Score Range	Low Burden / Strong Coping	Moderate Burden / Coping	High Burden / Poor Coping
Physical Burden (6 items)	6–30	155 (77.5%)	45 (22.5%)	0 (0.0%)
Emotional Burden (5 items)	5–25	73 (36.5%)	40 (20.0%)	87 (43.5%)
Social Impact (6 items)	6–30	175 (87.5%)	25 (12.5%)	0 (0.0%)
Financial & Care giving Burden (3 items)	3–15	115 (57.5%)	68 (34.0%)	17 (8.5%)
Coping Mechanisms (4 items)	4–20	189 (94.5%)	10 (5.0%)	1 (0.5%)

Physical Burden: The findings show that 155 children (77.5%) reported a low physical burden, indicating that they were able to manage their symptoms effectively with medical treatment and support. A smaller proportion, 45 children (22.5%), experienced a moderate physical burden, meaning they faced occasional physical discomfort such as fatigue, weakness, or pain but could still perform their daily activities with

some difficulty. Notably, no children (0.0%) reported a high physical burden, suggesting that the medical management of thalassemia symptoms was relatively effective for this group.

Emotional Burden: Emotional distress was more prevalent among children with thalassemia. Only 73 children (36.5%) experienced a low emotional burden, indicating they had good emotional resilience and effective coping strategies. Meanwhile, 40 children (20.0%) had a moderate emotional burden, showing signs of occasional stress, anxiety, or sadness related to their condition. However, a significant proportion, 87 children (43.5%), reported a high emotional burden, suggesting that they frequently experienced feelings of distress, anxiety, or depression. These findings highlight the need for psychological support and counseling to help children cope with the emotional impact of their illness.

Social Impact: The majority of children, 175 (87.5%), had a low social burden, meaning they could participate in social activities, attend school, and interact with peers without major restrictions. A smaller group, 25 children (12.5%), experienced a moderate social burden, indicating that their condition occasionally affected their ability to engage in social interactions or school activities. Importantly, none of the children (0.0%) reported a high social burden, suggesting that social support systems were generally effective in helping them maintain social connections.

Financial & Caregiving Burden: The financial burden of managing thalassemia varied among families. A little more than half, 115 children (57.5%), reported a low financial and caregiving burden, indicating that their families could afford regular treatment and caregiving needs without significant difficulty. However, 68 children (34.0%) experienced a moderate financial burden, meaning that their families faced occasional financial strain due to treatment costs. A smaller group, 17 children (8.5%), reported a high financial burden, highlighting the economic difficulties faced by some families in affording ongoing medical care and support. These findings emphasize the importance of financial aid programs and healthcare subsidies for families struggling with the costs of managing thalassemia.

Coping Mechanisms: Coping strategies among children with thalassemia varied widely. The vast majority, 189 children (94.5%), demonstrated strong coping mechanisms, meaning they adapted well to their condition and managed stress effectively. A small proportion, 10 children (5.0%), had moderate coping abilities, indicating occasional struggles with managing their disease-related challenges. Only 1 child (0.5%) exhibited poor coping mechanisms, suggesting a need for psychological intervention and emotional support to help them better handle the impact of their illness.

The findings reveal that while most children manage the physical and social impact of thalassemia well, emotional distress and financial strain remain significant concerns. A considerable proportion of children (43.5%) experience high emotional burden, indicating a strong need for psychological counseling and mental health support. Additionally, financial difficulties affect 42.5% of families (moderate to high burden), suggesting the necessity of financial assistance programs to ease the economic impact of the disease. Overall, the study underscores the importance of a comprehensive support system that includes medical, psychological, social, and financial interventions to enhance the well-being of children with thalassemia and improve their overall quality of life.

Table-3: Interpretation Mean & SD of Different Burden Domains

Domain	Mean Score	Standard Deviation (SD)	Interpretation
Physical Burden (6 items, range: 6–30)	11.095	4.06	Moderate burden due to fatigue, weakness, and complications from treatment.
Emotional Burden (5 items, range: 5–25)	15.87	5.56	High emotional burden, indicating stress, anxiety, and psychological distress.
Social Impact (6 items, range: 6–30)	8.825	4.65	Mild social impact, suggesting some difficulties in school attendance and peer interactions.
Financial & Care giving Burden (3 items, range: 3–15)	7.01	2.92	Moderate financial burden, indicating significant costs related to treatment and caregiving challenges.
Coping Mechanisms (4 items, range: 4–20)	7.63	1.27	Moderate level of coping, indicating mixed responses in adapting to thalassemia-related challenges.
Total Burden Score	**50.43**	**8.52**	**Overall, children experience a considerable burden across multiple aspects of life.**

1. Physical Burden: The mean score of 11.095 (SD = 4.06) indicates a moderate physical burden among thalassemia-affected children. Common issues include fatigue, weakness, and complications due to frequent blood transfusions and iron overload. These physical limitations affect daily activities, mobility, and participation in school or play. Higher scores suggest greater distress, emphasizing the need for medical and supportive interventions.

2. Emotional Burden: With a mean score of 15.87 (SD = 5.56), emotional burden is significantly high among affected children. Constant hospital visits, painful treatments, and social stigma contribute to anxiety and distress. Many children feel fearful, emotionally exhausted, and dependent on caregivers. Higher emotional burden may lead to depression, withdrawal, and decreased psychological well-being.

3. Social Impact: The mean score of 8.825 (SD = 4.65) suggests a low to moderate social burden. Frequent medical visits and physical limitations cause school absenteeism and affect friendships. Some children feel isolated due to their condition, leading to reduced peer interactions. However, strong family and school support can help maintain social engagement and emotional stability.

4. Financial & Caregiving Burden: A mean score of 7.01 (SD = 2.92) reflects moderate financial stress on families. The high cost of blood transfusions, chelation therapy, and medical care adds to their economic burden. Parents also face job instability and emotional strain due to caregiving responsibilities. Financial aid and community support are essential to reduce stress and improve care.

5. Coping Mechanisms: With a mean score of 7.63 (SD = 1.27), coping abilities vary among children and families. Strong family support, counseling, and social engagement help in better adaptation. Lower coping scores indicate a need for psychological and emotional interventions. Encouraging resilience-building activities can enhance well-being and emotional strength.

The total burden score was 50.43 (SD = 8.52), indicating a considerable overall burden among thalassemia-affected children. This score reflects the cumulative impact of physical, emotional, social, and financial challenges faced during their treatment journey. The high burden suggests that children experience difficulties in daily living, requiring continuous medical, emotional, and social support. Addressing these burdens through comprehensive care strategies, psychological support, and financial assistance is essential to improving their quality of life.

SECTION III: ASSOCIATION BETWEEN THE BURDEN OF THALASSEMIA AND SELECTED DEMOGRAPHIC VARIABLES:

This section analyzes the association between the burden of thalassemia and selected demographic variables. Identifying these associations is crucial in understanding which factors significantly impact the physical, emotional, social, and financial burden faced by affected children. The analysis was performed using the chi-square (χ^2) test, a statistical method used to determine relationships between categorical variables. The demographic variables considered in this study included age, gender, education level, duration of thalassemia diagnosis, frequency of blood transfusions, family income, and family support system. The association was tested at a 5% level of significance ($p < 0.05$), meaning that if the calculated chi-square value exceeded the tabulated value, the association was considered significant (S), indicating a strong relationship between the variable and the burden of thalassemia. Conversely, if the chi-square value was lower than the tabulated value, the association was considered non-significant (NS), suggesting that the variable did not have a major impact on the burden experienced by these children.

Table-4: Association between the burden of thalassemia and selected demographic variables

N = 200

S. N.	Demographic Variable	df	Tabulated value (0.05 level)	Calculated Chi-square (χ2)	Inference
1	Age	3	7.815	12.31	S
2	Gender	2	5.991	3.36	NS
3	Education Level	3	7.815	9.24	S
4	Duration of Thalassemia Diagnosis	3	7.815	11.3	S
5	Frequency of Blood Transfusions	3	7.815	14.22	S
6	Family Income (per month in INR)	3	7.815	0.36	NS
7	Family Support System	2	5.991	15.21	S

S = Significant or NS = Non Significant

Table-4 examines the analysis revealed a significant association between age and the burden of thalassemia ($\chi^2 = 12.31$, $p < 0.05$). Older children often experience a greater burden due to increased awareness of their condition, social limitations, and the long-term impact of the disease. In contrast, younger children may struggle more with physical symptoms but may have lower psychological distress due to their limited understanding of the condition. This finding highlights the need for age-specific interventions to help children cope with their condition at different developmental stages. Gender, however, showed no significant association with the burden of thalassemia ($\chi^2 = 3.36$, $p > 0.05$). This indicates that both male and female children experience similar levels of physical, emotional, social, and financial burden. Since gender does not play a crucial role in influencing the burden of thalassemia, interventions should be designed to provide equal support to all affected children, regardless of gender. A significant association was observed between education level and the burden of thalassemia ($\chi^2 = 9.24$, $p < 0.05$). Children with higher education levels tend to experience greater emotional and social burdens due to increased awareness of their illness, potential academic disruptions, and difficulties in peer interactions. This emphasizes the importance of educational support programs, school-based interventions, and counseling services to help children manage their academic progress while dealing with their health condition. The study also found a significant association between the duration of thalassemia diagnosis and the burden of the disease ($\chi^2 = 11.3$, $p < 0.05$). Children diagnosed for a longer period often experience cumulative physical fatigue, emotional stress, and financial challenges due to continuous treatment. The long-term impact of chronic illness can lead to increased psychological distress and social isolation. This highlights the need for long-term psychological and social support programs to assist children and their families in coping with the prolonged nature of the disease. A strong significant association was found between the frequency of blood transfusions and the burden of thalassemia ($\chi^2 = 14.22$, $p < 0.05$). Children who require frequent blood transfusions tend to experience greater physical distress, increased dependence on medical care, and

disruption of daily life. Frequent hospital visits can also lead to school absenteeism and social withdrawal. This finding underscores the importance of medical advancements to reduce transfusion dependency and the need for alternative treatment strategies to improve the overall quality of life for these children. Interestingly, the analysis found no significant association between family income and the burden of thalassemia ($\chi^2 = 0.36$, $p > 0.05$). This suggests that children from different economic backgrounds experience a similar level of burden, regardless of financial status. However, financial constraints may still affect treatment accessibility and family stress levels, even if they were not statistically significant in this study. Therefore, financial assistance programs, community support, and government aid remain essential in reducing the economic burden on affected families. The study found a highly significant association between family support and the burden of thalassemia ($\chi^2 = 15.21$, $p < 0.05$). Children with strong family support systems experience lower emotional and social burdens, as they receive encouragement, caregiving assistance, and psychological reassurance from their families. In contrast, children who lack family support are more likely to suffer from emotional distress, social isolation, and difficulties in coping with their condition. This finding underscores the importance of family-centered interventions, parental counseling, and peer support programs to enhance resilience and improve the overall well-being of affected children.

SECTION IV: CORRELATION BETWEEN DIFFERENT BURDEN DOMAINS

This section analyzes the relationship between different burden domains (Physical, Emotional, Social, and Financial) using Pearson's Correlation Coefficient (r).

Table-5: Interpretation of Correlation Analysis

Burden Domains	Correlation (r-value)	Interpretation
Physical Burden vs. Emotional Burden	0.72	**Strong positive correlation** – Higher physical burden is associated with greater emotional distress.
Physical Burden vs. Social Impact	0.51	**Moderate positive correlation** – Physical difficulties impact social interactions and school attendance.
Emotional Burden vs. Social Impact	0.68	**Strong positive correlation** – Higher emotional distress leads to greater social withdrawal.
Financial Burden vs. Emotional Burden	0.59	**Moderate positive correlation** – Families struggling financially tend to have children with higher emotional distress.
Coping Mechanisms vs. Emotional Burden	-0.64	**Strong negative correlation** – Children with better coping mechanisms experience lower emotional distress.

Physical Burden and Emotional Burden ($r = 0.72$, $p < 0.01$)
A strong positive correlation indicates that children experiencing severe physical difficulties, such as fatigue and weakness, are more likely to suffer from emotional distress, including stress and anxiety. The continuous medical treatments and discomfort contribute to their psychological burden. This highlights the need for healthcare providers to integrate physical care with emotional support. Counseling services and stress management techniques can help reduce emotional distress in these children.

Physical Burden and Social Impact ($r = 0.51$, $p < 0.05$)
A moderate positive correlation suggests that children with higher physical burden face more difficulties in social participation, such as attending school and interacting with peers. Frequent hospital visits and physical limitations may lead to social isolation and a sense of exclusion. Schools and communities should implement support programs to encourage social inclusion and academic engagement. Providing flexible attendance policies and peer support systems can help children stay connected with their social environment.

Emotional Burden and Social Impact ($r = 0.68$, $p < 0.01$)
A strong positive correlation shows that children with higher emotional stress often isolate themselves socially, avoiding peer interactions and group activities. Anxiety, fear of judgment, or self-consciousness about their condition may lead to withdrawal from social settings. Psychosocial interventions, including peer counseling, group therapy, and school-based mental health programs, can help improve emotional well-

being and encourage social participation. Strengthening emotional resilience can reduce social isolation among affected children.

Financial Burden and Emotional Burden (r = 0.59, p < 0.05)
A moderate positive correlation indicates that families struggling with financial burden report higher emotional distress in their children. The high cost of regular blood transfusions, medications, and hospital visits creates economic strain, which may lead to stress and anxiety within the family. Providing financial aid, government assistance, and community-based support programs can ease the financial pressure and improve the overall emotional well-being of both children and their caregivers.

Coping Mechanisms and Emotional Burden (r = -0.64, p < 0.01)
A strong negative correlation suggests that children with better coping mechanisms experience lower emotional distress. Effective coping strategies, such as family support, counseling, and engagement in social activities, help children manage their condition with a more positive mindset. Encouraging children to develop resilience through psychological interventions, support groups, and stress management training can significantly reduce their emotional burden. Enhancing coping skills can lead to better adaptation and an improved quality of life.

Children experiencing higher physical burden tend to have greater emotional distress and social difficulties, highlighting the need for integrated healthcare and psychological support. Financial burden significantly impacts emotional well-being, emphasizing the importance of economic support for affected families. Additionally, children with strong coping mechanisms are better able to manage stress, suggesting that targeted interventions such as counseling and peer support programs can enhance their overall well-being. Addressing these correlations can help improve the quality of life for children with thalassemia.

IV. DISCUSSION

Thalassemia is a chronic blood disorder that significantly impacts children's daily lives, well-being, and overall quality of life. This study aimed to assess the burden of thalassemia across physical, emotional, social, financial, and coping domains among children receiving regular treatment in selected hospitals of Rajasthan. Using a descriptive cross-sectional research design, data were collected from 200 children aged 6–18 years through a structured questionnaire. The Wilson and Cleary Model (1995) was used to integrate biological, psychological, and social factors impacting health-related quality of life (HRQoL). The findings provide a detailed insight into the challenges faced by children with thalassemia and emphasize the need for holistic healthcare interventions.

The demographic characteristics of the study participants revealed that the majority (76, 38.00%) belonged to the 6–8 years age group, followed by 66 (33.00%) in the 13–15 years category, and 58 (29.00%) in the 16–18 years category. More females (118, 59.00%) than males (82, 41.00%) participated in the study. Educational background showed that 60 (30.00%) had secondary education, while 52 (26.00%) were not attending school, 45 (22.50%) had primary education, and 43 (21.50%) had higher secondary education. The duration of diagnosis varied among participants, with the highest proportion (106, 53.00%) diagnosed for 1–5 years, followed by 58 (29.00%) diagnosed for more than five years, and 36 (18.00%) diagnosed for less than a year. Blood transfusions were essential for these children, with 80 (40.00%) undergoing monthly transfusions, 62 (31.00%) requiring bi-weekly transfusions, 40 (20.00%) needing weekly transfusions, and 18 (9.00%) receiving transfusions every two months. Family income analysis indicated that 74 (37.00%) of the children belonged to families earning less than INR 10,000 per month, 69 (34.50%) had a family income between INR 10,000–20,000, and 57 (28.50%) came from families earning above INR 20,000. A considerable proportion (91, 45.50%) reported weak family support, 68 (34.00%) had moderate support, and 41 (20.50%) experienced strong family support.

The burden of thalassemia was analyzed across different domains. In terms of physical burden, the majority (155, 77.5%) reported a low burden, while 45 (22.5%) experienced a moderate burden. This suggests that regular medical interventions, including blood transfusions and iron chelation therapy, help manage the physical symptoms of thalassemia. However, children requiring frequent transfusions or those diagnosed for a longer duration reported increased physical distress. Emotional distress was significantly high, with 87 (43.5%) experiencing a high emotional burden, 40 (20.0%) reporting a moderate burden, and 73 (36.5%)

experiencing a low burden. Frequent hospital visits, lifelong dependency on treatment, and social limitations contributed to emotional instability. In terms of social impact, the majority (175, 87.5%) reported a low social burden, while 25 (12.5%) experienced a moderate burden, and none faced a high burden. Despite their condition, most children maintained social interactions; however, the correlation analysis revealed that children experiencing higher emotional distress tended to withdraw socially, emphasizing the need for counseling and peer support programs. Financial and caregiving burdens were also notable, with 85 (42.5%) reporting a moderate to high financial burden, 65 (32.5%) experiencing a low burden, and 50 (25.0%) stating no financial burden. The costs of blood transfusions, iron chelation therapy, and regular hospital visits placed economic stress on families, particularly those with lower monthly incomes. These findings highlight the need for financial aid and subsidized treatment programs to alleviate economic hardships. Coping mechanisms among participants were found to be strong, with 189 (94.5%) effectively managing their condition, 10 (5.0%) having moderate coping abilities, and only 1 (0.5%) struggling significantly. A negative correlation ($r = -0.64$, $p < 0.01$) was observed between coping mechanisms and emotional burden, indicating that children with better coping skills experienced lower distress levels.

Statistical analysis revealed significant associations between age ($\chi^2 = 12.31$, $p < 0.05$), education level ($\chi^2 = 9.24$, $p < 0.05$), duration of diagnosis ($\chi^2 = 11.3$, $p < 0.05$), frequency of blood transfusions ($\chi^2 = 14.22$, $p < 0.05$), and family support system ($\chi^2 = 15.21$, $p < 0.05$) with the burden of thalassemia. Older children experienced higher emotional distress and social withdrawal. Children with higher education levels were more aware of their condition, leading to an increased emotional burden. A longer duration of diagnosis correlated with higher physical and emotional burden, while children requiring frequent transfusions reported increased physical discomfort and emotional distress. Strong family support significantly reduced the burden, reinforcing the importance of family involvement in disease management. However, gender ($\chi^2 = 3.36$, $p > 0.05$) and family income ($\chi^2 = 0.36$, $p > 0.05$) were not significantly associated with burden levels, suggesting that both boys and girls, as well as children from different economic backgrounds, experience similar distress levels.

Correlation analysis further indicated that physical burden had a strong positive correlation with emotional burden ($r = 0.72$, $p < 0.01$), suggesting that children with severe physical symptoms were more emotionally distressed. Emotional burden was also strongly linked to social impact ($r = 0.68$, $p < 0.01$), indicating that children experiencing emotional distress were more likely to withdraw socially. A moderate correlation was found between financial burden and emotional distress ($r = 0.59$, $p < 0.05$), highlighting the economic strain on families. Physical burden also affected social participation ($r = 0.51$, $p < 0.05$), limiting school attendance and peer interactions. Notably, coping mechanisms showed a strong negative correlation with emotional burden ($r = -0.64$, $p < 0.01$), suggesting that children with better coping strategies experienced less distress.

The study findings highlight the need for comprehensive interventions to address the multifaceted burden of thalassemia. Psychological counseling should be integrated into treatment plans to support children experiencing high emotional distress. Family education programs should be implemented to improve caregiving skills and strengthen family support. Financial assistance programs should be expanded to alleviate the economic strain on families. Social support groups and peer interactions should be encouraged to reduce social isolation, and awareness campaigns should focus on early diagnosis and treatment adherence to minimize disease burden. These findings align with previous research, which has highlighted the significant emotional and financial burden faced by children with thalassemia and their families. Studies by Ali et al. (2021) and Das et al. (2022) have similarly reported that emotional distress and financial challenges are among the most significant burdens associated with thalassemia. Moreover, a study by Kumar et al. (2020) found that children with strong family support demonstrated better coping mechanisms, reinforcing the current study's findings. Additionally, the impact of frequent transfusions on physical distress was observed in a study by Sharma et al. (2019), where children requiring more frequent transfusions exhibited higher fatigue and physical burden. In conclusion, the study suggests that while physical and social burdens are relatively manageable, emotional and financial challenges remain significant for children with thalassemia. Strong coping mechanisms and family support play a crucial role in reducing distress levels. Healthcare providers should adopt a multidisciplinary approach that includes medical, psychological, social, and financial interventions to improve the overall well-being of children affected by thalassemia.

V. CONCLUSION

In conclusion, this study highlights the significant emotional and financial burden faced by children with thalassemia, despite manageable physical and social challenges. Emotional distress was strongly linked to physical symptoms and social withdrawal, while financial strain impacted families' well-being. Strong coping mechanisms and family support played a crucial role in reducing distress. Significant associations were found between burden levels and factors like age, education, duration of diagnosis, frequency of transfusions, and family support. Comprehensive interventions, including psychological counseling, financial assistance, and social support, are essential to improving the quality of life for children with thalassemia.

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