

## A Mixed-method Study on Coping Mechanism among Caregivers of Thalassemia patients Attending A Tertiary Care Hospital in West Bengal, India

Shaswati Biswas<sup>1</sup>, Madhumita Bhattacharyya<sup>2</sup>, Monalisha Sahu<sup>3</sup>, Rivu Basu<sup>4</sup>, Bobby Paul<sup>5</sup>

<sup>1</sup>Postgraduate Doctor, <sup>4</sup>Assistant Professor, <sup>5</sup>Professor and Head, Department of Preventive and Social Medicine, All India Institute of Hygiene and Public Health, Kolkata, India

<sup>2</sup>Professor, Department of Maternal and Child Health, All India Institute of Hygiene and Public Health, Kolkata, India

<sup>3</sup>Associate Professor and Head, Department of Occupational Health, All India Institute of Hygiene and Public Health, Kolkata, India

**Correspondence:** Dr. Shaswati Biswas, Email: biswashaswati95@gmail.com

### Abstract:

**Introduction:** Thalassemia is a severe chronic anaemia. Caregivers face many stresses to provide the best possible medical care for their children. They develop a variety of coping mechanism. **Objectives:** To determine coping mechanism among caregivers of thalassemia patients and its associated factors; To explore challenges faced by caregivers of thalassemia patients. **Methods:** Institutional based observational study with convergent parallel mixed method study design was conducted in tertiary care hospital at OPD of Haematology Department in Kolkata, India. Total of 130 caregivers were selected through systematic random sampling for the quantitative strand who were interviewed using pre-tested questionnaire and the Coping Health Inventory for Parents-45 (CHIP). Additionally, seven in-depth interviews were conducted for the qualitative strand. Data were analysed using MS Excel 2019, SPSS v25, and QDA Miner Lite v3.0.2 with coding and thematic analysis after data saturation. **Results:** Among the caregivers 55 (42.3%) and 75 (57.7%) were mothers and fathers respectively with median age of 34 years. The median total score of the CHIP was 75, where 49% caregivers had adequate and 51% had inadequate coping skills. There was significant association between inadequate coping with poor social support ( $p=0.045$ ) and frequent blood transfusion interval ( $p=0.020$ ). The qualitative strand of this mixed-methods study identified five major themes—health problems, self-negligence, financial issues, familial issues and spiritual beliefs. **Conclusion:** Nearly half of the caregivers exhibited inadequate coping due to poor social support and shorter intervals between blood transfusions. Comprehensive support systems are crucial to improve their coping and overall quality of life.

**Keywords:** Coping Mechanism, Caregivers, Convergent-Parallel, Mixed Method study, Thalassemia,

### Introduction:

Thalassemia is one of the common autosomal recessive inherited blood disorders, characterized by genetic defect in production of alpha or beta globin chains. Thalassemia major is the homozygous form of

deficiency of beta globin chain synthesis which results in a severe transfusion dependent anaemia that becomes apparent in first six months of age. This is one of the major public health problem in Mediterranean, the Middle East, Indian subcontinent and the Southeast Asia.<sup>[1]</sup> In India, prevalence of  $\alpha$ -Thalassemia 3-4%.

Quick Response Code	Access this article online	How to cite this article :
	Website : www.healthlinejournal.org	Biswas S, Bhattacharyya M, Sahu M, Basu R, Paul B. A Mixed-method Study on Coping Mechanism among Caregivers of Thalassemia patients Attending A Tertiary Care Hospital in West Bengal, India. Healthline. 2025;16 (4): 261-268
	DOI : 10.51957/Healthline_726_2025	

Received : 14-06-2025

Accepted : 14-11-2025

Published : 31-12-2025

Every year, 10000-15000 babies are born with Thalassemia. India alone contributes to approximately 25% of the global  $\hat{a}$ -thalassemia burden.<sup>[2]</sup> In West Bengal, every 10th person is a thalassemia carrier and more commonly found among Muslim, scheduled caste, and scheduled tribe populations.<sup>[3,4]</sup>

Caregiver is an individual who provide care and support to someone who is unable to fully care for themselves due to distress, illness, age, disability or other challenges.<sup>[5]</sup> In the case of chronic diseases like thalassemia, they face many challenges in providing quality care to their children. By definition, caregiver burden refers to a high level of stress or strain one experiences while caring for another person (usually a family member) with some illness. For example, a person caring for someone with a chronic disease like thalassemia may experience stressors such as financial strain, physical strain, their mental health, relationship with the care receiver, and social support. Cost of treatment of the disease and its complications impose a significant burden on the clients of thalassemia. It also imposes a significant burden on their caregivers too and the society at a large. Coping strategies are a set of cognitive and behavioural efforts that are applied so as to interpret and correct a stressful situation and leads to the alleviation of suffering from it.<sup>[5]</sup>

Today, with the use of new drugs and timely treatment, life expectancy of these patients has increased but with repeated blood transfusion, long-term use of drugs the general health, mental health and quality of life of these patients and their families have been deteriorated. The greatest stress is on parents as thalassemia cause a high level of psychological pressure on them. Depression and stress are also common among them.<sup>[6]</sup> Poor adaptability to stress usually induce psychosocial problems and marginalization along with negative attitude toward the child's illness. Parenting of children with chronic disease requires coping with stressors, such as administering medication, helping child to manage their pain, frequent hospital visits, and helping the child to cope with negative feelings. Therefore they develop a variety of coping strategies in response to the stress.<sup>[7]</sup>

Parental coping strategies like maintaining social support, self-esteem, and psychosocial stability are associated with improvements in child physical as well as mental health<sup>[8]</sup>. There are many studies related to quality of life among caregivers of thalassaemic patients, but studies related to coping styles of parents of thalassaemic children are limited in West Bengal. So this study will help to find their coping styles and to identify the factors associated with it. Objective of the study is to determine the coping mechanism and the associated factors among caregivers of thalassemia patients and also to explore the difficulties faced by them.

#### Methods:

An institutional based cross sectional study with convergent parallel mixed method study design was conducted in a tertiary hospital in the Haematology OPD in Kolkata, West Bengal, India from March 2024 to August 2024.

**Operational definition:** Primary caregiver is the person who takes principal responsibility for providing regular care and support to someone who cannot fully care for themselves due to age, illness, disability, or other conditions.

**Sampling and data collection:** Primary caregivers of diagnosed thalassemia patients with at least one blood transfusion in the last one year attending the tertiary care hospital were included in the study; whereas those other than primary caregivers, study participants who did not give informed written consent and who were critically ill, were excluded.

Using Cochran's formula;  $N = Z^2 pq/d^2$ , sample size was calculated for the quantitative strand, where N= Sample size, Z= 1.96, p=57% (prevalence; considering, a previous study done in Bangalore where coping mechanism was found to be effective in 57% of the study participants)<sup>[7]</sup>, q= 43% and d=9% (absolute error), taking 10% non-response rate, total sample size calculated was 130.

The study participants were selected by systematic random sampling technique from OPD of Haematology department of Institution of Haematology and Transfusion Medicine, Kolkata. Almost 50-60

thalassemia patients come every Monday in the OPD, and data collection was done for two months, so total patients came around 400, so we calculated sampling interval of 3 (total patients/sample size). Then using a random number generator we selected a random starting point and choose every 3<sup>rd</sup> patient until target was reached, each day 16-17 patients were selected this way. The data collection tools included a demographic questionnaire and the Coping Health Inventory for Parents (CHIP).<sup>[15]</sup> Interviewer administered questionnaire was used for face-to-face interviewing the study participants, where dependent variables was Coping mechanism among the caregivers of thalassemia effected children and independent variables included socio-demographic characteristics, socio-economic factors, Oslo social support scale-3<sup>[16]</sup> and clinico-therapeutic factors (age at diagnosis, blood transfusion frequency and spleen status).

Collected data were compiled using MS Excel 2019 and tabulated accordingly. Software like IBM Statistical Package for the Social Sciences (SPSS) statistics (version 25) was used for analysis for quantitative data. Descriptive statistics, univariate and multivariable logistic regression were performed. Coping Health Inventory for Parents (CHIP) is interpreted in terms of median value.

For qualitative strand, an agreement on data saturation was reached with the participation of 7 individuals. After 5 interviews, data saturation was reached with no further theme was obtained. However, two more interviews were conducted to confirm the absence of new theme. These study participants were selected using purposive sampling technique and interviewed using In-Depth Interview (IDI) guide to explore the challenges faced by them. Qualitative Data Analysis (QDA) Miner Lite (version 3.0.2) software was used for analysis for qualitative data, where codes, categories and theme were generated.

Results from both the strands were compared and interpreted in the discussion section. This study was approved by the Institutional Ethics Committee.

## **Result:**

### **Quantitative results**

#### **Socio-demographic characteristics**

Among 130 study participants, nearly 39.2% belonged to age group of 30-40 years (median age: 34 years, IQR (25,75), 75 (57.7%) were fathers and 55 (42.3%) were mothers. Majority followed Hindu religion (96, 73.8%) followed by Muslim (33, 25.4%), resided in urban area (116, 89.2%), lived in nuclear family (96, 73.8%) and had more than equal to 4 family members (128, 98.5%). Most of them were currently married (117, 90%). More than one-fourths of the study participants had completed primary level of education (38, 29.2%), fathers were engaged in semi-skilled work (15, 27.3%) and mothers were homemakers (43, 57.3). More than half of the participants belong to middle class (42, 32.3%) and lower middle class (37, 28.5%) as per B.G. Prasad's Scale updated for the year 2024<sup>[17]</sup> and three-fourth had loss of their daily wages due to treatment. About 51.3% had history of substance abuse. Three-fourth of the participants had total one or two child; 90% (117) had at least one thalassemia major diagnosed child and nearly three-fifth of them had their first-born child thalassemia major effected; 59.2% (77) had female child and 40.8% (53) had male child. More than three-fifth (84, 64.5%) of them had their child diagnosed before their first birthday and require blood transfusion at less than 30 days interval (86, 66.2%). Only 3.8% of them had children with splenectomy done while all of their children received anti-chelating. Less than one-tenth (6.2%) had child suffering from TTIs, of which 75% and 25% were HBsAg- and anti-HIV-positive, respectively (Table 2).

#### **Social support**

One-tenth (12, 9.2%) of the study participants had poor social support, rest had moderate to poor social support according to Oslo social support scale-3 (Table 1).

**Table 1. Sociodemographic details of the study participants (N=130)**

Variables	Number (%)
<b>Relation with the affected child</b>	
Mother	55 (42.3)
Father	75 (57.7)
<b>Age (in completed years)</b>	
≤20	1 (0.8)
21-30	44 (33.8)
31-40	51 (39.2)
41-50	25 (19.2)
≥51	9 (6.9)
<b>Marital status</b>	
Currently married	117 (90)
Widow/separated	13 (10)
<b>Religion</b>	
Hindu	96 (73.8)
Muslim	33 (25.4)
Christian	1 (0.8)
<b>Area of residence</b>	
Rural	14 (10.8)
Urban	116 (89.2)
<b>Type of family</b>	
Nuclear	96 (73.8)
Joint	34 (26.2)
<b>Number of family members</b>	
≤4	2 (1.5)
>4	128 (98.5)
<b>Highest level of education</b>	
Illiterate	19 (14.6)
No formal education, but literate	15 (11.5)
Primary	38 (29.2)
Middle school	14 (10.7)
Secondary	16 (12.4)
Senior secondary	17 (13.1)
Graduate	11 (8.5)
<b>Occupation</b>	
Housewife	43 (33.1)
Farmer	8 (6.2)
Office staff	3 (2.3)
Self employed	15 (11.5)
Semi professional	2 (1.5)
Semi-skilled	19 (14.6)

Skilled labour	7 (5.4)
Unskilled labour	33 (25.4)
<b>Per capita income</b>	
I (Upper class)	3 (2.3)
II (Upper middle class)	34 (26.2)
III (Middle class)	42 (32.3)
IV (Lower middle class)	37 (28.5)
V (Lower class)	14 (10.8)
<b>Loss of wages</b>	
Yes	99 (76.2)
No	31 (23.8)
<b>Substance abuse</b>	
Absent	61 (46.9)
Present in any form	69 (53.1)
<b>Social support</b>	
Strong support	90 (69.2)
Moderate support	28 (21.5)
Poor support	12 (9.2)

**Table 2. Characteristics of the Thalassemia children (N=130)**

Variables	Number (%)
<b>Total number of children of the caregivers</b>	
≤2	100 (76.9)
>2	30 (23.1)
<b>Number of thalassemia affected child</b>	
1	117 (90.0)
>1	13 (10.0)
<b>Gender of the affected child</b>	
Female	77 (59.2)
Male	53 (40.8)
<b>Age at thalassemia diagnosis</b>	
≤1 year	84 (64.5)
>1 year	46 (35.5)
<b>Blood transfusion interval</b>	
≤30 days	86 (66.2)
>30 days	44 (33.8)
<b>Splenectomy of child</b>	
Yes	5 (3.8)
No	125 (96.2)
<b>Transfusion transmitted disease</b>	
HBsAg 5	3 (3.8)
Anti-HIV positive	3 (2.4)
None	122 (93.8)

**Table 3. Distribution of CHIP item subscale according to median and IOR**

Subscales of CHIP	Median	IQR
1. Maintaining family integration, cooperation, and an optimistic definition of the situation	29	25-32
2. Maintaining social support, self-esteem and psychological stability	30	26-33
3. Understanding the medical situation through communication with other parents and consultation with medical staff	12	Oct-14
<b>Total coping of CHIP</b>	<b>75</b>	<b>67-84</b>

**Table 4. Common Coping Behaviours Expressed by the Parents (N=130)**

Subscale	Most helpful		Not helpful	
	Items	Number (%)	Items	Number (%)
Maintaining family integration, cooperation, and an optimistic definition of the situation	Being sure prescribed medical treatments for child (ren) are carried out at home on a daily basis	84 (64.6)	Eating	101 (77.7)
Maintaining social support, self-esteem and psychological stability	Believing in God	85 (65.4)	Sleeping	118 (90.8)
Understanding the medical situation through communication with other parents and consultation with medical staff	Taking good care of all the medical equipment at home	84 (64.6)	Allowing myself to get angry	123 (94.6)

**Coping Health Inventory for Parents**

As demonstrated (Table 3), the median total score of the CHIP was 75, where 49% caregivers had adequate and 51% had inadequate coping skills. There are 3 subscale “Maintaining family integration, cooperation, and an optimistic definition of the situation”, “Maintaining social support, self-esteem and psychological stability” and “Understanding the medical situation through communication with other parents and consultation with medical staff” with median value of 29, 30 and 12 respectively.

Table 4 indicates the most helpful coping behaviours by caregivers for each subscale. For the subscale “Family integration, cooperation, and optimism,” the items of “Being sure prescribed medical treatments for child (ren) are carried out at home on a daily basis” extremely helpful for 64.6% of the caregivers. For “Social support, self-esteem, and mental

stability,” 65.4% found “Believing in god” extremely helpful. In addition, considering the “Medical communication and consultation” subscale, 64.6% found chose “Taking good care of all the medical equipment at home”.

As Table 4 shows, the least performed behaviours in the subscale “Family integration, cooperation, and optimism” was “Eating” (77.7%). Concerning the “Social support, self-esteem, and mental stability” subscale, the least expressed statements included “Sleeping” (90.8%). In addition, the least common coping behaviours in the subscale “Medical communication and consultation” were found to be “I let myself get angry” (94.6%).

Table 5 shows, univariate and multivariable logistic regression. There is significant association between coping and relation with child, age, marital status, type of family, number of family members, social support,

**Table 5. Association between independent variables and inadequate coping mechanism by univariate and multivariate logistic regression (N=130)**

Variables	UOR (95%)	p-value	AOR (95%)	p-value
<b>Relation with children</b>				
Father (ref)				
Mother	0.314 (0.2-0.7)	0.002	1.551 (0.4-5.5)	0.499
<b>Age category</b>				
≤34 years (ref)				
>34 years	2.917 (1.4-5.9)	0.003	0.294 (0.6-4.2)	0.294
<b>Marital status</b>				
Currently married (ref)				
Separated	0.275 (0.7-1.1)	0.059	0.304 (0.6-1.6)	0.167
<b>Type of family</b>				
Joint (ref)				
Nuclear	0.424 (0.2-1.0)	0.038	0.4450 (0.1-1.4)	0.165
<b>Number of family members</b>				
≤5 (ref)				
>5	4.415 (1.7-11.3)	0.002	1.867 (0.5-6.8)	0.343
<b>Substance abuse</b>				
Absent (ref)				
Present	2.109 (1.1-4.3)	0.037	1.567 (0.5-5.2)	0.466
<b>Oslo social support</b>				
Poor (ref)				
Good	4.941 (2.2-11.4)	0	3.047 (1.0-9.1)	0.045
<b>Age at thalassemia diagnosis</b>				
≤1 year (ref)				
>1 years	2.882 (1.4-6.0)	0.005	1.190 (0.4-3.4)	0.747
<b>Blood transfusion frequency</b>				
≤30 days (ref)				
>30 days	0.230 (0.1-0.6)	0.001	3.8 (1.2-11.7)	0.02

substance abuse, age at thalassemia diagnosis and frequency of blood transfusion interval ( $p < 0.05$ ). In the final multivariable logistic regression model (Table 5), child requiring blood transfusion at >30 days interval had 3.8 odds of adequate coping [AOR: 3.809 (1.2–11.9)] and caregiver with good social support adequately coped than those with poor support [AOR: 3.047 (1.0–9.1)]. Independent variables were explaining 37.1% variability.

### Qualitative results

Study participants were interviewed ( $n=7$ ) to explore the challenges faced by them. There were 3 father and 4 mother participants. Median age was 38 years belonging to lower middle and middle class as per Updated B.G. Prasad scale for 2024. The broad theme, i.e., difficulties faced by the caregivers of thalassemia diagnosed patients, was classified into 5 categories: a) health problems, b) self-negligence, c) familial conflicts, d) financial issues and e) lack of access to healthcare resources (Table 6).

**Table 6. Thematic analysis of In-Depth Interviews of study participants showing the challenges faced by them (N=7)**

Themes	Categories	Quotable quotes
Health problems	Physical distress	“our health deteriorated. Sometimes I felt tired” (participant 1, 50 years, Female)”The day I come becomes very stressful” (participant 3, 41 years, Female) “previously I used to feel very tired” (participants 6, 27 years, Female)
	Psychological distress	“his father is very worried about him” (participant 7, 45 years, Female) “When I first came to know, I was devastated” (participant 5, 38 years, Male) “I was so mentally broken just thinking about the cost of treatment” (participant 4, 38 years, Male) If I don’t get blood, I worry more” (participant 2, 34 years, Male)
Self-negligence	Ignorant about selfcare	“no time to think about ourselves” (participant 6)
	Restless life	“ I have to visit every fifteen days” (participant 3) “if we don’t get blood, we have to rush” (participant 2)
Financial issues	Travel expenses	“We come from far away; travel costs a lot” (participant 7) “Day by day the cost of transportation is increasing so much that a lot of money is being spent” (participant 1)
	Medicine expenses	“medicines are not always available, many a times medicines have to be bought from outside” (participant 2) “a lot of money goes into medicines” (participant 4)
	Loss of wage	“I can’t go to work on the day I come” (participant 7) “if I don’t go to work, I don’t get pay for that day” (participant 4) “I work as labour, if I don’t work, the owner won’t pay” (participant 6) “what will we eat, if I don’t go to work” (participant 2)
	Patient care	“sick child at home so there are expenses” (participant 2) “he has many food restrictions, so have to take proper care” (participant 3)
Familial issues	Unstable family	“his father is drunk all time” (participant 6) “He would come back drunk and beat me” (participant 3) “He left me and got married elsewhere after she was diagnosed with thalassemia” (participant 3)
	Conflict within family relatives	“There are many relatives who avoid us a bit” (participant 2) “No relatives can be found when needed” (participant 2) “When we will die, I don’t know who will take care of him” (participant 7) “His brothers do not take proper care of him” (participant 2)
Spiritual beliefs	Spirituality	“we have left everthing in the name of Allah. Allah will do everything” (participant 2) “Allah has given it, so we have to bear with this, can’t leave the kid alone” (participant 3) “ I left everything to God” (participant 5)
Shortage of patient care equipment	Shortage of blood supply	“during unavailability of blood, it becomes very difficult” (participant 1) “they don’t even write so that we can bring blood with a donor” (participant 6) “sometimes we face problem due to lack of donor” (participant 4) “it is always possible for us to find a donor with matched blood group” (participant 5) “ until and unless they write refer from here, it is hard to get blood transfusion from other hospitals” (participant 3)
	Shortage of medicine supply	“medicines are not available all the time” (participant 1)
	Shortage of drug and blood	“medicines are not always available” (participant 5) “it was hard to find blood sometimes” (participant 7)

**Discussion:**

In the present study, 42.3% of the study participants are father and rest 57.7% are mothers with median age of 34 years. Majority (73.8%) of them live in nuclear family. 29.2% of them have primary level of education with 4.5 median years of schooling. Most of them (89.2%) reside in urban area and 90% are currently married. 27.3% of the fathers are engaged in semi-skilled work and 57.3% of the mothers are homemakers. 32.3% of the study participants belong to middle class followed by lower middle class 28.5% as per Updated B.G Prasad scale 2024 with mean per capita income of Rs 3749.9. 76.9% of the study participants are having less than or equal to 2 children with 90% having only one thalassemia affected child and 59.2% of them are having affected girl child. About 64.5% of them had their child diagnosed before their first birthday and 66.2% require blood transfusion at less than 30 days interval. These socio-demographic characteristics are in line with existing literature<sup>[7]</sup>. Majority (69.2%) are having poor social support.

CHIP-45 have 3 subscale “family integration, cooperation”, “maintaining social support, self-esteem and psychological stability” and “understanding medical situation” whose median scores are 29, 30 and 12 respectively. Overall 65% of the study participants found “Believing in God” is an extremely helpful way for coping up, which is in accordance with previous studies<sup>[10]</sup>. About 64.6% of the parents ensured children received appropriate care at home on a daily basis and 63.8% valued trusting medical professionals. Also trusting spouse were seen as extremely helpful coping strategies among 51.5%. This shows importance of importance of social support and family integrity for good coping.

The present study showed several challenges faced by the caregivers like health problem, psychological issues, self-negligence, financial and family issues, shortage of blood supply, bed and drugs, similar to a study.<sup>[12-14]</sup> It suggests the need for a bi-directional exploration of interactions among individual, familial and community.

**Conclusion:**

Caregivers of thalassemia children face significant psychosocial, financial, and health-related challenges that affect their coping abilities. Good social support and frequent transfusion needs were independent predictors of better coping, explaining about 37% of variability. Interventions should focus on strengthening social support systems and reducing treatment-related burdens to enhance caregiver resilience.

**Acknowledgement:** We would like to extend our acknowledgment and gratitude to the Director and Professor of the Institution of Haematology and

Transfusion Medicine, Kolkata and Principal sir of Medical College, Kolkata to grant permission to conduct the study.

**Declaration**

Funding: Nil

Conflict of Interest: Nil

**References:**

1. Biswas B, Naskar NN, Basu K, Dasgupta A, Basu R, Paul B. An Epidemiological Study of the Quality of Life of Children With Beta-Thalassemia Major ( $\beta$ -TM) and Its Correlates in Kolkata, West Bengal, India. *Cureus*. 15 (3):e36888.
2. Ministry of Health and Family Welfare. (2016). Prevention and control of hemoglobinopathies in India: Thalassemias, sickle cell disease, and other variant hemoglobins – Guidelines on hemoglobinopathies 2016. Government of India
3. Hossain MS, Raheem E, Sultana TA, Ferdous S, Nahar N, Islam S, et al. Thalassemias in South Asia: clinical lessons learnt from Bangladesh. *Orphanet J Rare Dis*. 2017 May 18;12 (1):93.
4. Colah R, Italia K, Gorakshakar A: Burden of thalassemia in India: the road map for control. *Pediatr Hematol Oncol J*. 2017, 2:79-84. 10.1016/j.phoj.2017.10.002
5. Gothwal VK, Bharani S, Reddy SP. Measuring Coping in Parents of Children with Disabilities: A Rasch Model Approach. *PLoS ONE*. 2015 Mar 2;10 (3):e0118189.
6. Sahu S, Agrawal A, Shrivastava J, Tonk S. Psychiatric disorders and caregiver burden in children with transfusion dependent  $\beta$ -thalassaemia and their caregivers. *World J Clin Pediatr*. 2023 Jun 9;12 (3):125–32.
7. Saldanha SJ. Stress and coping among parents of children having thalassemia. *Int J Sci Res*. 2013;4 (7).
8. Salehi S, Morovati S. Coping behaviors in families with children suffering from thalassemia major and evaluating the implementation effect of nursing intervention on these behaviors *Int J Med Res Health Sci*. 2016;5:58–63
9. Snezana C, Vucic V, Mihaljevic O, Djordjevic J, Colovic S, Radovanovic S, et al. Social support score in patients with malignant diseases—with sociodemographic and medical characteristics. *Front Psychol*. 2023 Jun 1;14:1160020.
10. Kermansaravi F, Najafi F, Rigi S. Coping Behaviors in Parents of Children with Thalassemia major. *Med - Surg Nurs J [Internet]*. 2018 [cited 2024 Jan 28];7 (1). Available from: <https://brieflands.com/articles/msnj-81173#abstract>
11. Yazdi K. Psychosocial, social and financial problems with coping strategies among families with thalassemic patients. *J Gorgan Univ Med Sci*. 2007;9 (2):71–5.
12. Nabavian M, Cheraghif F, Shamsaei F, Tapak L, Tamadoni A. A Qualitative Study Exploring the Experiences of Mothers Caring for Their Children with Thalassemia in Iran. *Ethiop J Health Sci [Internet]*. 2021 Nov 1 [cited 2024 Jan 25];31 (6). Available from: <https://www.ajol.info/index.php/ejhs/article/view/219382>
13. Padhy, P. & Kumar, N. Understanding resilience in chronically ill children: Parental perspectives on strengths, difficulties and fostering resilience in children with thalassemia major *IJHW*. 2017 Oct 26;8(7):588-593
14. McCubbin, H.I., McCubbin, M.A., Patterson, J.M., Cauble, A.E., Wilson, L.R. & Warwick, W. (1983). CHIP-Coping Health Inventory for Parents: An Assessment of Parental Coping Patterns in the Care of the Chronically Ill Child. *Journal of Marriage and the Family*, 45 (2), 359-370. doi: 10.2307/351514.
15. Oslo Social Support Scale (OSSS-3) – EMERGE [Internet]. [cited 2024 Dec 20]. Available from: [https://emerge.ucsd.edu/r\\_1mq2f0ksb7qyidj/](https://emerge.ucsd.edu/r_1mq2f0ksb7qyidj/)
16. National Family Health Survey (NFHS-5), 2019-21, India Report. Ministry of health and Family Welfare, Government of India. 2022.
17. Javalkar SR, H. S, B. Davalagi S, G. S. V. Socio economic status assessment in India: history and updates for 2024. *Int J Community Med Public Health*. 2024 Feb. 29;11(3):1369-77. doi:10.18203/2394-6040.ijcmph20240648.