RESEARCH PAPER

Impact of parent empowerment programme on the Caregiver burden and Resilience among parents of children with thalassemia

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Abstract:

Introduction: Thalassemia major is a chronic hereditary condition requiring lifelong blood transfusions and continuous medical care, placing a substantial burden on parents who act as primary caregivers. Caregiver burden often leads to physical, emotional, and social strain, while resilience helps caregivers adapt effectively to these challenges. Parent empowerment programmes have emerged as potential interventions to enhance coping abilities, reduce burden, and improve resilience among caregivers. However, limited evidence exists regarding their effectiveness among parents of children with thalassemia major. **Materials and Methods**: A quantitative pre-experimental one-group pretest–posttest design was adopted. The study was conducted in thalassemia day care centres in Raigad and Thane districts, Maharashtra. A total of 244 parents (122 mothers and 122 fathers) of children with thalassemia major were selected using purposive sampling. Data were collected using a sociodemographic questionnaire, the Zarit Burden Interview Scale, and the Connor–Davidson Resilience Scale. Following the pretest, a structured parent empowerment programme of 2 hours was administered. Posttests were conducted at one month and four months after the intervention. Data were analyzed using descriptive and inferential statistics. **Results and Discussion**: The findings revealed a significant reduction in caregiver burden among both mothers and fathers following the intervention ($p<0.05$). The mean burden scores decreased progressively from pretest to posttest 2. Similarly, resilience scores showed a significant increase after the programme ($p<0.05$). The intervention was effective in shifting caregivers from moderate–severe burden to mild–moderate levels. However, no significant correlation was found between caregiver burden and resilience. **Recommendation:** The study recommends implementation of parent empowerment programmes in thalassemia care settings to support caregivers. Multicentric studies are suggested for broader generalization. Establishment of nurse-led counselling services and strengthening healthcare policies to reduce financial burden are also recommended.

Key words: Thalassemia, Parents, Parent Empowerment Programme, Care giver burden, Resilience

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Introduction

Thalassemia major is a severe hereditary blood disorder characterized by defective synthesis of beta-globin chains, resulting in chronic hemolytic anemia and the need for lifelong blood transfusions. It remains a major public health concern, particularly in developing countries like India, where the prevalence of carriers is high. Advances in medical management, including regular transfusion therapy and iron chelation, have improved survival rates; however, these treatments require continuous care and impose a long-term burden on families[1].

Children with thalassemia major require repeated hospital visits, lifelong treatment, and continuous monitoring for complications such as iron overload and organ damage. In most cases, parents assume the role of primary caregivers and are responsible for meeting the physical, emotional, and medical needs of the child. This sustained caregiving responsibility significantly affects various dimensions of caregivers' lives, including their physical health, psychological well-being, social functioning, and financial stability[2].

Caregiver burden refers to the multidimensional strain experienced by individuals providing care to chronically ill patients. Parents of children with thalassemia major often experience high levels of stress, anxiety, and emotional exhaustion due to the chronic nature of the disease and the complexity of its management. Evidence suggests that caregivers frequently report reduced quality of life, psychological distress, and challenges in maintaining social and occupational roles[3]. Furthermore, the uncertainty surrounding the disease prognosis and the lifelong dependency on treatment contribute to increased caregiver burden[4].

In contrast, resilience is the ability of individuals to adapt positively in the face of adversity. Among caregivers, resilience plays a vital role in coping with stress and sustaining the caregiving role effectively. Factors such as social support, coping strategies, knowledge about the disease, and access to healthcare services are known to enhance resilience and reduce perceived burden[5].

Recent approaches in caregiving research emphasize the importance of parent empowerment programmes, which aim to equip caregivers with knowledge, skills, and psychological support to manage their child's condition effectively. Such programmes focus on improving caregivers' competence, confidence, and coping abilities, thereby reducing caregiver burden and enhancing resilience. Empowerment-based interventions have shown promising outcomes in improving psychological well-being and caregiving capacity among parents of children with chronic illnesses[6].

Despite the growing recognition of empowerment strategies, there is limited evidence assessing the combined impact of parent empowerment programmes on both caregiver burden and resilience among parents of children with thalassemia major, particularly in the Indian context. Understanding the effectiveness of such interventions is crucial for developing structured support systems for caregivers.

Therefore, the present study aims to evaluate the impact of a parent empowerment programme on caregiver burden and resilience among parents of children with thalassemia major. The findings of this study may contribute to the development of evidence-based interventions to support caregivers, enhance their well-being, and improve the overall quality of care provided to affected children. The Objectives of the Study is to compare the Caregiver burden of parents of children with thalassemia before and after the implementation of Parent empowerment program and to compare the Resilience of parents of children with thalassemia before and after the implementation of Parent empowerment program.

Methodology: The study adopted a Quantitative approach with Pre experimental design (One group Pretest Post test design) among 120 parents (Father & Mother) and children attending Thalassemia Day care centres and diagnosed with Thalasemia and who met the inclusion criteria. The inclusion criteria set up for the study is Parents of children with thalassemia major without other hemoglobinopathies, biological parents (Mother & Father) of child with thalassemia. The research study proposal was presented before Ethics Committee for Research on Human Subjects (ECRHS) at MGM Institute of health Sciences, Kamothe, Navi Mumbai. It was approved by the committee, approval letter MGMIHS/RES.02/2022/42. Necessary permissions were sought from the Hospital director and Thalassemia Day care center in charges for data collection .An information sheet explaining their involvement in the study was given to each participant, and it was translated into Hindi and Marathi. Each participant received personalized explanations and clarifications about the process and length of their participation. In both Hindi and Marathi, written informed consent was requested from each parent and Participants were made aware that they could leave the study at any time or choose not to participate. The tools used for data collection was Sociodemographic proforma , Zarit burden Interview Scale and Connor Davidson Resilience Scale (CD-RISC).Data collection was planned when the children come for blood transfusion once in every month. One month prior to the data collection, the researcher requested all the mothers and fathers to accompany the child as both the parents were required for the data collection. Informed consent was taken from the parents. Pretest was taken prior to the parent empowerment programme. Parent Empowerment Programme was given to the parents for a duration of 2 hours. The session was based on the importance of life style modifications, techniques to build resilience and methods to reduce the care giver burden in parents. The AV aids used for this session are PPT and Leaflets. The post test 1 was taken one month after the Parent empowerment programme and the Post test 2 was taken four months after the programme.

Results :

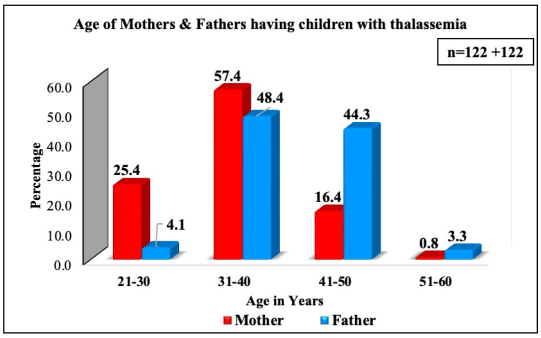

Figure.1: Distribution of age of parents having children with thalassemia

Majority of the mothers (57.4%) and fathers (48.4%) of children with thalassemia were in the age group between 31-40 years. The age group of 24.4% of mothers and 4.1% of fathers were between 21-30 years. 16.4% of mothers and 44.3% of fathers were in the age group between 41-50 years. Only 0.8% of mothers and 3.3% of fathers were in the age group between 51-60 years.(Fig 1)

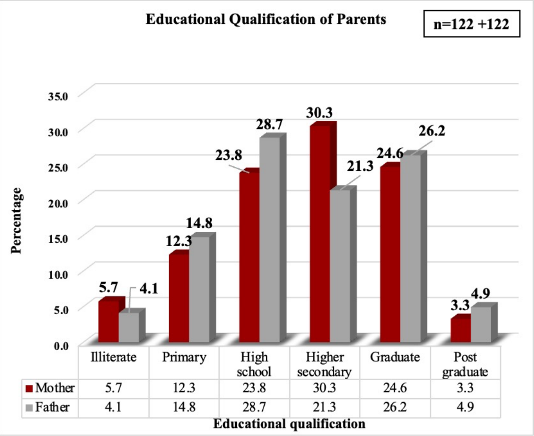

Figure.2 Educational qualification of parents having children with thalassemia

The educational qualification of most of the mothers (30.3%) were higher secondary, whereas most of the fathers (28.7%) had high school education. 12.3% of mothers and 14.8% of fathers had Primary education. 23.8% of mothers had high school education and 21.3% of fathers had higher secondary education. The mothers and fathers who have completed graduation were 24.6% and 26.2% respectively. Negligible proportion of mothers (3.3%) and fathers (4.9%) have completed Post graduation.(Fig 2)

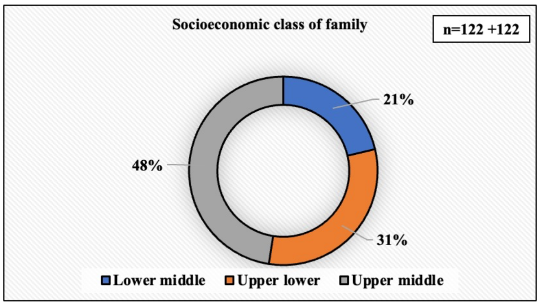

Figure.3: Socioeconomic class of parents having children with thalassemia

Majority of the family belongs to Upper middle class. 31% of parents belongs to Upper lower class and 21% belongs to Lower middle class.(Fig 3)

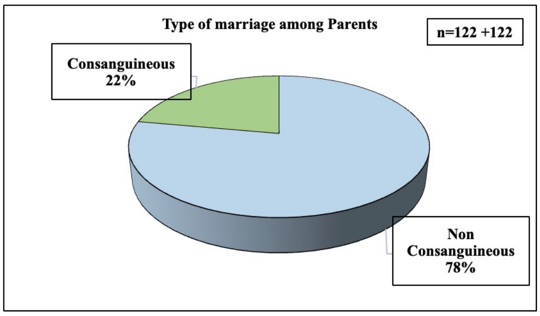

Figure.4: Type of marriage among parents of children with thalassemia

Majority (78%) of the parents had non-consanguineous marriage and 22% of them had Consanguineous marriage.(fig 4)

Table 1: Demographic variables of Parents

N= 122

Variables	f	(%)
Parents screened for thalassemia	98	80.3
Any family member diagnosed with thalassemia	26	21.3
How many children do you have?		
1	44	36.1
2	55	45.1
3	23	18.9
Number of children who have thalassemia minor		
0	93	76.2

1	27	22.1
2	2	1.6
Number of children who have Thalassemia Intermedia		
0	114	93.4
1	8	6.6
Number of children who have thalassemia minor		
1	112	91.8
2	10	8.2

80.3% of the parents have done thalassemia screening, but 19.7% of them have not undergone screening. Majority (43.4%) of the parents don't know whether any of their family members are diagnosed with thalassemia. 45.1% of the parents had two children, 36.1% had one child and 18.9% of the parents had three children. Majority (93.4%) of the parents had no children with thalassemia minor/trait. However, 22.1% of the parents had one child with thalassemia minor and 1.6% of them had two children with thalassemia minor. Only 6.6 % of the parents had one child with thalassemia intermedia. 99.8% of the parents had one child diagnosed with thalassemia, where as 8.2% of them had two children with thalassemia major. (Table1)

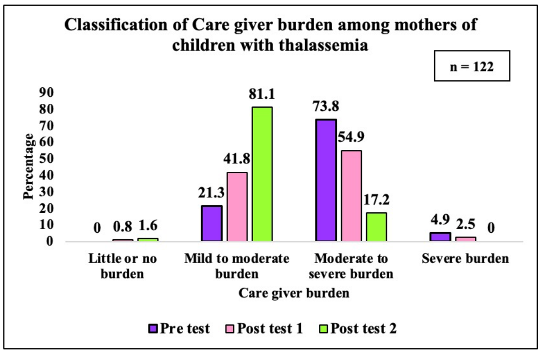

Figure 5: Classification of care giver burden among mothers of children with thalassemia before and after Parent Empowerment Programme

The Fig 5 illustrates that in the pre-test, a majority (73.8%) of mothers indicated moderate to severe burden, which subsequently decreased to 54.9% in post-test 1. In post-test 2, 81.1% of mothers exhibited mild to moderate caregiver burden. Only 17.2% of mothers experienced moderate to severe burden in Post Test 2.

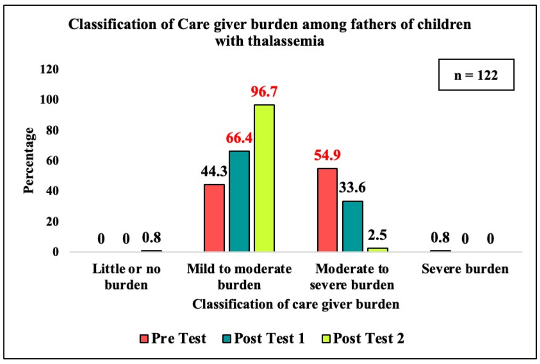

Figure 6 Classification of care giver burden among fathers of children with thalassemia before and after Parent Empowerment Programme

The Fig 6 indicates that in the pre-test, the majority (54.9%) of fathers experienced moderate to severe burden. Conversely, in post-test 1 (66.4%) and post-test 2 (96.7%), the majority exhibited mild to moderate burden.

Table 2 Comparison of care giver burden among mothers of children with thalassemia before and after PEP.

n=122

Care giver burden	Mean & SD	Mean difference	t value	'p' value	Significance at 0.05
Pre test-Post test 1	47.050 ± 9.317	4.828	23.018	0.001	S
Post test 1-Post test 2	42.220 ± 8.52	7.238	27.97	0.001	S
Pre test-Post test 2	34.980 ± 6.95	12.06	34.73	0.001	S

Table 2 shows that there is a significant difference is seen in the care giver burden of mothers before and after the parent empowerment programme, as the 'p' value is below the 0.05 level.

Table 3: Comparison of care giver burden among fathers of children with thalassemia before and after PEP.

n=122

Care giver burden	Mean & SD	Mean difference	t value	‘p’ value	Significance at 0.05
Pre test-Post test 1	42.080 ± 7.37	4.869	19.76	0.001	S
Post test 1-Post test 2	37.210 ± 6.26	4.492	23.69	0.001	S
Pre test-Post test 2	32.720 ± 4.96	9.361	27.88	0.001	S

Table 3 depicts that there is a significant difference is seen in the care giver burden of fathers before and after the parent empowerment programme, as the 'p' value is below the 0.05 level.

Table 4 Association of care giver burden among mothers of children with thalassemia with selected demographic variables of parents.

n=122

Characteristics		**Caregiver Burden Mother**			**Chi square (χ^2)**	**‘p’ value**	**Significance at 0.05**
		Mild to moderate burden	Moderate to severe burden	Severe Burden			
Social class	Lower middle	7	18	1	2.349	0.672	NS
	Upper lower	6	31	1			
	Upper middle	13	41	4			
Education of Mother	Graduate	7	21	2	9.936	0.446	NS
	High school	5	24	0			
	Higher secondary	9	26	2			
	Illiterate	0	6	1			
	Post graduation	1	2	1			
	Primary	4	11	0			
Education of Father	Graduate	7	24	1	12.840	0.233	NS
	High school	8	26	1			
	Higher secondary	6	19	1			
	Illiterate	0	5	0			
	Post graduation	1	3	2			

	Primary	4	13	1

NS- Non-Significant

Table 4 illustrates that for all demographic variables, the p-value was more than 0.05, hence no statistically significant association with care giver burden of mothers and selected demographic variables of parents.

Table 5- Association of care giver burden among fathers of children with thalassemia with selected demographic variables of parents. n=122

Characteristics		Caregiver Burden father			Chi square (χ^2)	'p' value	Significance at 0.05
		Mild to moderate burden	Moderate to severe burden	Severe Burden			
Social class	Lower middle	10	16	0	1.977	0.740	NS
	Upper lower	19	19	0			
	Upper middle	25	32	1			
Education of Mother	Graduate	13	16	1	7.664	0.662	NS
	High school	15	14	0			
	Higher secondary	15	22	0			
	Illiterate	3	4	0			
	Post graduation	0	4	0			
	Primary	8	7	0			

Contd…

Characteristics		**Caregiver Burden father** Mild to moderate burden	Moderate to severe burden	Severe Burden	**Chi square (χ^2)**	**'p' value**	**Significance at 0.05**
Education of Father	Graduate	9	23	0	26.557	0.003	S
	High school	19	16	0			
	Higher secondary	12	14	0			
	Illiterate	2	3	0			
	Post graduation	4	1	1			
	Primary	8	10	0			

NS- Non significant

Table 5 illustrates the association between care giver burden in fathers of children with thalassemia and specific demographic variables of the parents, including social class and the educational qualifications of both mothers and fathers. The chi-square test was used to determine the association between care giver burden of fathers and specific demographic variables of parents. For all demographic variables except education of father, the p-value was more than 0.05, hence no statistically significant association with care giver burden of fathers and selected demographic variables of parents. As the 'p' value of father's education is <0.05, there is a significant association exists between the care giver burden of father and the education of father.

Table 6: Comparison of Resilience among mothers of children with thalassemia before and after Parent Empowerment Programme.

n=122

Resilience	**Mean & SD**	**Mean difference**	**t value**	**'p' value**	**Significance at 0.05**
Pre test-Post test 1	54.340 ± 15.74	6.664	20.53	0.001	S
Post test1-Post test 2	61.000 ± 13.39	9.844	26.87	0.001	S
Pre test -Post test 2	70.840 ± 10.36	16.5	27.5	0.001	S

S- Significant

Table 6 compares the resilience among mothers of children with thalassemia prior to and subsequent to the Parent Empowerment Programme. The paired t-test has been used to compare the mean resilience scores of mothers. A significant difference is seen in the resilience before and after the parent empowerment programme, as the 'p' value is below the 0.05 level. Therefore, the H_{02} is rejected.

Table 7 Comparison of Resilience among fathers of children with thalassemia before and after Parent Empowerment Programme.

n=122

Resilience	**Mean & SD**	**Mean difference**	**t value**	**‘p’ value**	**Significance at 0.05**
Pre test-Post test 1	51.600 ± 12.93	8.91	23.36	0.001	S
Post test1-Post test 2	60.510 ± 11.27	8.352	22.09	0.001	S
Pre test -Post test 2	68.860 ± 9.46	17.26	32.41	0.001	S

S- Significant

Table 7 compares the resilience among fathers of children with thalassemia prior to and subsequent to the Parent Empowerment Programme. The paired t-test has been used to compare the mean resilience scores of fathers. A significant difference is seen in the resilience of fathers before and after the parent empowerment programme, as the 'p' value is below the 0.05 level. Therefore, the H_{02} is not supported.

Table 8- Correlation between Resilience and Care giver burden among mothers before and after Parent Empowerment Programme

n=122

Assessment	**Mean ± SD Resilience score**	**Mean ± SD Care giver burden score**	**Pearson correlation (r)**	**‘p’ value**	**Significance at 0.05 level**
Pre test	54.340 ± 15.74	47.050 ± 9.317	.063	.488	NS
Post test 1	61.000 ± 13.39	42.220 ± 8.52	.111	.223	NS
Post test 2	70.840 ± 10.36	34.980 ± 6.95	.080	.381	NS

Since the ‘p’ value is more than 0.05 in pre test, post test 1 and post test 2, there is no statistically significant correlation between resilience and care giver burden among mothers of children with thalassemia before and after Parent Empowerment Programme.

Table 9- Correlation between Resilience and Care giver burden among fathers before and after Parent Empowerment Programme

n=122

Assessment	**Mean ± SD Resilience score**	**Mean ± SD Care giver burden score**	**Pearson correlation (r)**	**‘p’ value**	**Significance at 0.05 level**
Pre test	51.600 ± 12.93	42.080 ± 7.37	-.151	.098	NS
Post test 1	60.510 ± 11.27	37.210 ± 6.26	-.076	.407	NS
Post test 2	68.860 ± 9.46	32.720 ± 4.96	-.058	.522	NS

Since the ‘p’ value is more than 0.05 in pre test, post test 1 and post test 2, there is no statistically significant correlation between resilience and care giver burden among fathers of children with thalassemia before and after Parent Empowerment Programme.

Table 10: Association of Resilience of mothers with selected demographic variables of children n=122

Demographic Variables		Resilience Mother		Chi square (χ^2)	‘p’ value	Significance at 0.05
		Poor Resilience	Good Resilience			
Social class	Lower middle	13	13	17.72	0.001	S
	Upper lower	32	6			
	Upper middle	24	34			
Education of Mother	Graduate	11	19	27.78	0.001	S
	High school	24	5			
	Higher secondary	14	23			
	Illiterate	6	1			
	Post graduation	1	3			
	Primary	13	2			
Education of Father	Graduate	11	21	19.49	0.002	S
	High school	24	11			
	Higher secondary	11	15			
	Illiterate	4	1			
	Post graduation	3	3			
	Primary	16	2			

The aforementioned table displays that Since the ‘p’ value is less than 0.05, it is found that there is a significant association exists between the resilience of mothers with the demographic variables like social class, education of mothers and fathers.

Table 11: Association of Resilience of fathers with selected demographic variables of children n=122

Demographic variables	Resilience Father

		Poor resilience	Good resilience	Chi square (χ^2)	'p' value	Significance at 5%
Social class	Lower middle	16	10	4.024	0.134	NS
	Upper lower	22	16			
	Upper middle	24	34			
Education of Mother	Graduate	9	21	10.12	0.721	NS
	High school	19	10			
	Higher secondary	21	16			
	Illiterate	2	5			
	Post graduation	2	2			
	Primary	9	6			
Education of Father	Graduate	15	17	6.024	0.304	NS
	High school	23	12			
	Higher secondary	10	16			
	Illiterate	2	3			
	Post graduation	2	4			
	Primary	10	8			

The table 11 displays that Since the 'p' value is more than 0.05, it is found that there is no significant association exists between the resilience of fathers with the demographic variables like social class, education of mothers and fathers.

Discussion

In the current study, during pre-test, a majority (73.8%) of mothers indicated moderate to severe burden, which subsequently decreased to 54.9% in post-test 1. In post-test 2, 81.1% of mothers exhibited mild to moderate caregiver burden. Only 17.2% of mothers experienced moderate to severe burden in Post Test 2. In the pre-test, the majority (54.9%) of fathers experienced moderate to severe burden. Conversely, in post-test 1 (66.4%) and post-test 2 (96.7%), the majority exhibited mild to moderate burden. A similar findings from an Indian study reported that majority of the care givers of children with thalassemia had mild to moderate burden (53%). The mean burden score in the present study is 47.050 ± 9.3 where as in the supporting study is 44.64 ± 3.4. In the current study, the care giver burden reduced to mild burden at the end of parent empowerment programme[7]. Another study also has similar finding stating that 50.7% of parents with thalassemia have mild care giver burden[8].

A significant difference is seen in the care giver burden of mothers before and after the parent empowerment programme, as the 'p' value is below the 0.05 level. The mean scores of care giver burden in Pre test, Post test 1 and in Post test 2 are 47.050 ± 9.317, 42.220 ± 8.52 and 34.980 ±

6.95 respectively. A similar study was found in a clinical trial on the effect of group training on the care giver burden among mothers of children with thalassemia. The mean care giver burden scores of mothers in pre test and post test are 55.57 ± 12.05 and 41.28 ± 7.01 respectively. There was a significant difference in the care giver burden score among experimental group and control group with 'p' value <0.001. Interventional programmes are effective for alleviating the care giver burden of parents having children with thalassemia[9].

In the current study, the mean resilience scores of mothers of children with thalassemia in pretest, posttest 1 and in posttest 2 are 54.340 ± 15.74, 61.000 ± 13.39 and 70.840 ± 10.36 respectively. In a study conducted by Bygi N et al. found that the mean resilience scores of mothers having adolescents with resilience is 58.53 ± 13.62[10]. In the current study, the mean resilience scores of fathers of children with thalassemia in pretest, posttest 1 and in posttest 2 are 51.600 ± 12.93, 60.510 ± 11.27 and 68.860 ± 9.46 respectively. An cross sectional study conducted in Iran was to assess the resilience in parents of children with cancer. The finding concludes that the mean scores of resilience in mothers and fathers are 63.8 ± 14.69 and 69.47 ± 13.83 respectively. There was association found between the resilience of the parents with the financial status of the family[11]. The same finding was seen in the current study in which there was a significant association found with resilience in mothers with the social class of the family ('p'<0.05).

Conclusion:

The Study recommends that a multicentre based study can be conducted to generalize the findings to large population. Speciality Specific advanced trained nurses can start nurse led clinics near to thalassemia day care centres for providing counselling sessions for parents and children with thalassemia. A qualitative study can add more insights into the various psychosocial concerns of the parents. Government policies should be formulated on raising funds for lessening the costs for thalassemia treatment. More number of private and public hospitals should initiate the treatment schemes for low-income patients with thalassemia.

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Author Contribution:

Dr.Anna Hima Thomas- Conceptualization, Methodology, Investigation, Formal analysis, Writing original draft.

Dr. Ponchitra Ramanathan- Methodology, Supervision, Formal Analysis, Reviewing & Editing the draft

Dr.Bageshree - Methodology, Supervision, Reviewing & Editing the draft

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