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Original Research Article

Quality of life and coping strategies among caregivers of children with thalassemia major in Southern Rajasthan

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ABSTRACT

Background: Thalassemia major (TM) is a chronic hereditary blood disorder requiring lifelong transfusions and chelation therapy, imposing a substantial physical, psychological, social, and financial burden on caregivers. Assessing caregivers' quality of life (QoL) and coping strategies is essential to understanding their adaptive functioning and identifying areas requiring psychosocial support. To evaluate the quality of life and coping strategies among caregivers of children with thalassemia major attending a tertiary care hospital in Southern Rajasthan.
Methods: A cross-sectional study among 140 caregivers of children with thalassemia major used a structured questionnaire with sociodemographic data, WHOQOL-BREF, and brief COPE. Data were analyzed using descriptive statistics, chi-square, and ANOVA, with $p<0.05$ as the significance level.
Results: Most caregivers were male (65.7%), rural residents (80.7%), and belonged to lower socioeconomic strata (70.7%). Emotional support (85.71%), religious coping (84.29%), and informational support (82.14%) were the most frequently adopted strategies. Social relationships showed the highest QoL scores (mean 10.46±2.22), while psychological health was the most affected domain (mean 16.61±3.62). Gender and education were significantly associated with QoL across multiple domains ($p<0.05$), whereas duration of illness and age showed no significant association.
Conclusion: Caregivers of children with thalassemia major experience considerable psychosocial strain, particularly affecting psychological and environmental well-being. Adaptive coping strategies, especially emotional and religious coping, appear to support resilience.

Keywords: Thalassemia major, Quality of life, Coping strategies

INTRODUCTION

Thalassemia major (TM) is a severe hereditary hemoglobinopathy characterized by defective hemoglobin synthesis, leading to chronic anemia, skeletal deformities, and growth retardation. Management requires lifelong, regular blood transfusions and iron chelation therapy, placing considerable physical, emotional, and financial burdens on affected families.[1] India is among the countries with the highest prevalence of thalassemia, with approximately 10,000 new cases diagnosed annually, making it a significant public health concern.[2] While clinical management of TM is crucial, the psychosocial impact on caregivers mostly parents is equally significant. They handle treatment adherence, frequent hospital visits, transfusion schedules, and the stress of an uncertain prognosis. These ongoing responsibilities often strain their physical health, mental well-being, and socioeconomic stability.[3]

Quality of life (QoL) in caregivers is shaped by multiple factors including treatment frequency, the child's clinical status, financial strain, and social support. Studies in India and neighbouring countries have consistently reported lower QoL scores among caregivers of children with TM compared to those caring for healthy children.[1,4]

Emotional health tends to be the most affected domain, with depression, anxiety, and chronic stress commonly reported.[5] Coping strategies employed by caregivers play a crucial role in moderating these effects. Positive coping mechanisms such as problem-focused coping, seeking social support, and positive reframing have been linked to better psychological outcomes and higher QoL.[5]

Conversely, maladaptive coping, such as denial or behavioural disengagement, can exacerbate stress and reduce resilience.[6] Cultural and religious coping approaches have also been documented, with evidence suggesting that positive religious coping can buffer psychological distress and enhance well-being.[7]

In the Indian context, socioeconomic disparities, healthcare accessibility, and lack of formal caregiver support systems compound the challenges faced by caregivers. Caregivers from rural or economically disadvantaged backgrounds often experience greater burdens due to travel costs, income loss, and limited health literacy.[8] Although research on caregiver QoL in thalassemia has grown in recent years, regional data from Rajasthan remain scarce. Given the cultural, socioeconomic, and healthcare delivery differences in this part of India, understanding caregiver experiences in Southern Rajasthan is critical to developing tailored interventions.

This study aims to assess the QoL and coping strategies among caregivers of children with TM in Southern Rajasthan. By identifying patterns and predictors of QoL, as well as the coping mechanisms most commonly adopted, this research can inform the design of psychosocial support programs, improve caregiver resilience, and ultimately enhance the continuity and quality of care for children with TM.

METHODS

This descriptive cross-sectional study was conducted at the Thalassemia Day Care Centre, Department of Paediatrics, Rabindranath Tagore (R. N. T.) Medical College and Associated Hospitals, Udaipur, Rajasthan, India. The study was conducted over a period of six months from January 2024 to June 2024. The study population consisted of primary caregivers who accompanied children aged 2 to 18 years for routine transfusion services. A consecutive sampling technique was used. All eligible caregivers of children with thalassemia major attending the Thalassemia Day Care Centre during the study period and fulfilling the inclusion criteria were enrolled until the required sample size of 140 caregivers was achieved.

Inclusion criteria

Inclusion criteria involved caregivers who had been providing continuous care for at least six months and were willing to give written informed consent.

Exclusion criteria

Caregivers with known psychiatric illness or those caring for children with additional chronic diseases were excluded.

A structured and validated questionnaire was administered through face-to-face interviews, covering socio-demographic data, WHOQOL-BREF for quality of life, and the Brief COPE inventory for coping strategies. Interviews were conducted in Hindi or the local language, with follow-up visits for unavailable participants. Data were entered in Excel and analyzed using statistical package for the social sciences (SPSS)-16. Descriptive statistics summarized the variables, while chi-square and one-way ANOVA tested associations. A 5% significance level ($p<0.05$) was used for all analyses.

RESULTS

Table 1 shows that most of the patients were females (51.4%), with the majority aged 11–15 years (43.6%) and a mean age of 9.95 years. About 74.3% had no family history of thalassemia. Most (67.9%) had illness duration <10 years, with a mean duration of 8.55 years, indicating early-childhood diagnosis and long-term disease burden.

Table 1: Frequency and percentage distribution of patient characteristics (n=140).

Variable	Category	Frequency (f)	Percentage (%)
Gender	Male	68	48.6
	Female	72	51.4
Family history	Both parents	21	15.0
	Sibling	15	10.7
	Nil	104	74.3
Age group (years)	0–5	36	25.7
	6–10	41	29.3
	11–15	61	43.6
	>15	2	1.4
	Mean±SD		9.95±5.27
Duration of illness (years)	<10	95	67.9
	10–20	43	30.7
	>20	2	1.4
	Mean±SD		8.55±5.10

Table 2 shows that caregivers were mainly male (65.7%), middle-aged (mean 37.49 years), and mostly married (95.7%). Fathers (62.1%) were the primary caregivers. A large proportion belonged to rural areas (80.7%) and lower socioeconomic status (70.7%). Most had no major illness (94.3%) and no substance use (87.1%). Table 3 shows that caregivers predominantly used positive coping such as emotional support, religion, and informational support (over 80% each). Maladaptive strategies like denial, substance use, and self-blame were least used. Overall, coping was more support-seeking and acceptance-based than avoidance-based.

Table 4 shows that most caregivers had good QoL in physical (73%), psychological (63%), social (93%), and environmental (63%) domains. Social QoL was strongest, while psychological health showed comparatively lower scores. Table 5 shows that significant differences in QoL were seen for gender, substance use, and education, affecting multiple domains. Duration of illness, age, and medical history showed no significant association. Table 6 shows that coping scores did not differ significantly across age, gender, religion, education, substance use, or illness duration. No demographic factor showed a significant association with coping.

Table 2: Frequency and percentage distribution of caregiver (n=140).

Variable	Category	Frequency (f)	Percentage (%)
Gender	Male	92	65.7
	Female	48	34.3
Age group (years)	<30	40	28.57
	31–40	46	32.85
	41–50	42	30.00
	≥51	12	8.57
	Mean±SD	–	37.49±9.73
Marital status	Married	134	95.7
	Single	2	1.4
	Widowed	4	2.9
Relationship to patient	Father	87	62.1
	Mother	42	30.0
	Others	11	7.9
Residence	Rural	113	80.7
	Urban	27	19.3
Religion	Hindu	128	91.4
	Muslim	12	8.6
Educational status	Illiterate	9	6.4
	Primary	25	17.9
	Middle school	44	31.4
	High school	26	18.6
	>Graduate	36	25.7
Socioeconomic status	Lower	99	70.7
	Middle	21	15.0
	Upper	20	14.3
History of medical illness	Thalassemia trait	3	2.1
	Hypertension	1	0.7
	Diabetes + hypertension	1	0.7
	Thyroid disorder	1	0.7
	Kidney stone	1	0.7
	Piles	1	0.7
	None	132	94.3
Substance use	Alcohol only	9	6.4
	Smoking only	2	1.4
	Tobacco chewing only	1	0.7
	Alcohol + smoking	2	1.4
	Alcohol + tobacco	3	2.1
	Other	1	0.7
	None	122	87.1

Table 3: Coping strategies ranked by mean score (n=140).

S. no.	Coping strategy	Frequency (percentage)	Mean±SD
1	Emotional support	120 (85.71)	2.94±0.68
2	Religion	118 (84.29)	2.94±0.87

Continued.

S. no.	Coping strategy	Frequency (percentage)	Mean±SD
3	Informational support	115 (82.14)	2.85±0.59
4	Acceptance	113 (80.71)	2.74±0.62
5	Planning	111 (79.29)	2.68±0.55
6	Active coping	107 (76.43)	2.65±0.51
7	Positive reframing	91 (65.71)	2.57±0.48
8	Behavioural disengagement	62 (44.29)	2.26±0.73
9	Self-distraction	49 (35.00)	2.17±0.44
10	Venting	40 (28.57)	1.85±0.56
11	Denial	36 (25.71)	1.78±0.64
12	Substance use	32 (22.86)	1.76±0.82
13	Self-blame	22 (15.71)	1.63±0.59
14	Humor	9 (6.43)	1.31±0.49

Table 4: Descriptive statistics of WHOQOL-BREF domain scores among caregivers of thalassemia patients (n=140).

S. no.	WHOQOL-BREF domain	Frequency (%) good QoL	Mean score	Standard deviation (SD)
1	Physical health	104 (73.24)	20.45	±3.66
2	Psychological health	90 (63.38)	16.61	±3.62
3	Social relationships	132 (92.96)	10.46	±2.22
4	Environmental domain	90 (63.38)	22.79	±5.72
5	Overall quality of life	94 (67.14)	70.31	±13.99

Table 5: Statistical comparison of QoL domains across caregiver characteristics.

Factors	Physical health (F, p)	Psychological (F, p)	Social Relationships (F, p)	Environmental (F, p)	Total QoL (F, p)	Significant domains
Duration of illness	0.129, 0.879	1.010, 0.367	0.842, 0.433	0.465, 0.629	0.573, 0.565	None
Relationship to patient	2.200, 0.140	3.793, 0.053	2.342, 0.128	3.651, 0.058	3.682, 0.057	Borderline (psych, env, total)
Substance use	1.933, 0.167	6.933, 0.009**	3.982, 0.048*	8.779, 0.004**	6.614, 0.011*	Psych, social, env, total
Gender	12.308, 0.001**	13.660, 0.000**	7.665, 0.006**	10.569, 0.001**	13.444, 0.000**	All domains
Education	2.853, 0.040*	4.415, 0.005**	2.366, 0.074	3.886, 0.011*	3.867, 0.011*	Physical, psych, env, total
Age category	0.710, 0.548	2.130, 0.099	0.492, 0.689	2.197, 0.091	1.543, 0.206	None
History of medical illness	0.019, 0.890	0.516, 0.474	0.079, 0.780	0.377, 0.540	0.183, 0.669	None

*p<0.05 (statistically significant); **p<0.01 (highly statistically significant); F=F-statistic from one-way ANOVA test; p=probability value

Table 6: Association between coping score by demographic variables of caregiver.

Variables	Group	Mean ± SD	F	P value
Duration of illness (years)	<10	64.22±5.04	0.137	0.873
	10–20	64.40±5.29		
	>20	62.50±2.12		
Family history	No	63.87±5.15	3.260	0.073
	Yes	65.79±4.52		
Caregiver age group (years)	<30	64.83±4.40	1.971	0.121
	31–40	62.78±4.87		
	41–50	65.10±5.53		

Continued.

Variables	Group	Mean ± SD	F	P value
	≥51	65.00±5.66		
Religion	Hindu	63.99±4.98	1.532	0.218
	Muslim	65.33±5.41		
Gender	Male	64.51±5.21	0.708	0.401
	Female	63.75±4.81		
Relation to patient	Father/mother	64.04±5.15	2.613	0.108
	Others	66.50±3.58		
Education	Illiterate	65.00±3.84	1.799	0.150
	Middle school	63.54±5.68		
	Graduate	66.15±4.15		
	High school/above	64.09±4.37		
Substance use history	No	64.27±5.05	0.015	0.901
	Yes	64.11±5.39		

DISCUSSION

Caregiving for children with thalassemia major imposes major emotional, psychological, social, and financial demands on families. Understanding how caregivers adapt, cope, and maintain their QoL is crucial for planning supportive interventions. This study assessed the WHOQOL-BREF domains and coping strategies among caregivers attending a tertiary care centre in Southern Rajasthan and compared the findings with existing evidence.

In our study, most children with thalassemia major belonged to the 11–15-year age group, which aligns with findings by Trehan et al and Jamali et al, who reported similar age patterns among thalassemia populations in India and Pakistan.[9,10] However, contrast to our study Jena et al found younger children (5–10 years) to be the largest group in their cohort, possibly due to earlier diagnosis programs in their region.[11]

The majority (74.3%) of children had no family history of thalassemia, consistent with Trehan et al and Khan et al who attributed this to limited premarital screening and underdiagnosis in previous generations.[9,12] In contrast to our study result a study conducted in Pakistani and stated that 96% of affected families reporting cousin-marriage history among parents of β-thalassemia major children, underscoring how genetic and cultural factors vary across regions.[13]

Although 74.3% of children in our study had no family history of thalassemia—a finding similar to Trehan et al and Khan et al who attributed this to limited premarital screening and underdiagnosis in earlier generations—several studies from high-prevalence regions such as Saudi Arabia and Egypt report much higher rates of positive family history (55–67.5%), largely due to widespread consanguinity, underscoring a sharp contrast with our findings.9,12–16Among caregivers, males were more represented (65.7%), and most belonged to rural backgrounds. This is in line with Angane et al and Bhandari et al who noted that rural fathers often assume primary responsibility for hospital visits in chronic childhood illnesses.[6,1] Conversely, Peter et al reported a predominance of mothers as caregivers, reflecting different cultural caregiving norms in their region.[17] These findings highlight the diverse caregiving dynamics across India.

In our study, emotional support, religious coping, informational support, acceptance, and planning were the most used strategies. These results support findings by Othman et al, who identified religion and acceptance as the predominant coping methods among thalassemia caregivers.[18] Similarly, Biswas et al highlighted active coping, planning, and acceptance as crucial adaptive strategies that help mitigate stress.[3] The strong reliance on religious coping aligns with Saba et al who emphasized the positive role of faith-based coping in improving psychological well-being.[7] In contrast, Matus et al found avoidance and denial to be frequently used among lower socioeconomic caregivers, indicating limited awareness and mental health access.[19]

The highest QoL in our study was observed in the social relationship's domain (92.96%), supporting Angane et al who found that caregivers often receive strong family and community support even when psychological distress is present.[6] However, Prasanna et al in 2021 reported low social domain scores due to stigma and social isolation in some communities, demonstrating that cultural acceptance plays a major role in social QoL. Regarding relationship to patient, in our study had slightly better QoL than non-parental caregivers, although differences were not statistically significant. Similar findings were reported by Alizadeh et al and Chandra et al who noted that parental caregivers often display stronger coping due to emotional attachment and sense of responsibility.[20,21]

Conversely, Biswas et al found that parents of thalassemia children often experience lower QoL due to cumulative emotional and financial strain, suggesting that the same emotional attachment that strengthens coping may also increase psychological burden. Regarding gender female caregivers in our study reported higher QoL scores across all domains.[3] This finding is supported by Hood et al and Bhandari et al who observed greater emotional resilience,

stronger social support, and adaptive coping among women caregivers in rural Indian settings.[22,1] Such patterns suggest that women may develop effective social and emotional coping strategies in caregiving roles, enhancing their overall quality of life. In contrast, Perveen et al found that male caregivers of thalassemia patients exhibited higher QoL and fewer mental health issues such as depression and anxiety, attributing this to reduced caregiving responsibilities and emotional burden.[23] Similarly, Fianza et al noted that female thalassemia patients reported greater psychological distress and poorer QoL, indicating gender-linked disparities in emotional resilience.[24]

Caregivers with higher education had significantly better QoL across multiple domains. This aligns with Amirah et al and Bhandari et al who reported that education enhances coping capacity, access to information, and resource utilization.[25,1] In contrast, Choi et al found no association between education and QoL, likely due to uniformly low socioeconomic status in their study sample.[26] Age and medical illness history did not significantly influence QoL in our study, similar to Amirah et al who observed minimal differences across age groups.[25]

Conversely, Lambert et al reported that older caregivers had lower QoL due to reduced physical capacity, suggesting that health variations within older age groups may explain the difference.[27]

Limitations

The present study has certain limitations. Being a cross-sectional study, causal relationships between caregiver characteristics, coping strategies, and quality of life could not be established. The study was conducted at a single tertiary care centre, which may limit the generalizability of the findings to caregivers in other regions or healthcare settings. Information on coping strategies and quality of life was self-reported and may therefore be subject to recall and social desirability bias. Despite these limitations, the study offers valuable regional data on caregiver well-being in thalassemia major.

CONCLUSION

The study shows that caregivers mainly use emotional and religious coping, yet psychological and environmental challenges remain. QoL is significantly influenced by education, gender, and substance use, while age, caregiver role, and illness duration have minimal impact. These findings highlight the need for interventions that support mental health, strengthen coping skills, provide family counselling, offer financial guidance, and screen for substance use to improve caregiver well-being and patient outcomes.

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