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Knowledge, Attitudes, And Practices Among Caregivers of Children With B-Thalassemia Major: A Cross-Sectional Study

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ABSTRACT

Background: β-thalassemia major (BTM) is a severe inherited blood disorder requiring lifelong blood transfusions and comprehensive disease management. In India, high rates of consanguinity and inadequate premarital screening contribute to the persistent burden of thalassemia. Caregivers' knowledge, attitudes, and practices (KAP) are pivotal in shaping preventive behaviours and long-term outcomes.

Objective: To assess the knowledge, attitudes, and practices of caregivers of children with β-thalassemia major and identify gaps that may inform future community-based prevention strategies.

Methods: A cross-sectional, observational study was conducted at a tertiary care thalassemia clinic and through community-based home visits. Using a pre-validated, semi-structured questionnaire, data were collected from 222 caregivers and analyzed using descriptive statistics.

Results: While 80.6% of caregivers were informed about thalassemia, only 13.1% had prior awareness before their first affected child. Premarital screening was supported by 83.7%, and 64.4% valued genetic counseling. However, 43.7% lacked an understanding of carrier marriage risks. Practices such as parental testing (67.6%) and sibling screening (84.7%) were encouraging. Social stigma (50%) and psychological distress (42.8%) were prevalent, yet mental health support uptake remained low (10.8%).

Conclusion: Despite high caregiver engagement, substantial risk perception and psychosocial support gaps persist. Targeted genetic education and counselling are essential for sustainable thalassemia prevention.

Keywords: β-thalassemia major, Knowledge Attitudes and Practices, genetic counselling, premarital screening, caregiver awareness, psychosocial impact.

1. INTRODUCTION

Thalassemia is a genetically inherited group of haemoglobin disorders characterized by the partial or complete impairment in synthesizing one or more globin chains, resulting in chronic anaemia of varying severity.1 Among its variants, β-thalassemia major (BTM) is the most severe and clinically significant form. It arises from the marked reduction or complete contributing abs

of β-globin chain production, leading to chronic anaemia, ineffective erythropoiesis, and the eventual need for lifelong blood transfusions for survival and optimal growth.[2] Without timely and regular transfusion support, affected children face serious complications such as growth retardation, skeletal deformities, and high mortality.[3]

Although transfusion therapy has substantially improved survival and quality of life in patients with BTM, it is not without complications.[4] Regular transfusions are associated with risks such as iron overload, which necessitates iron chelation therapy, as well as alloimmunization and transfusion-transmitted infections (TTIs), including hepatitis B, hepatitis C, and HIV.[5] These complications impose a significant financial, emotional, and logistical burden on both the healthcare system and the families of affected children.[6]

India carries one of the highest burdens of thalassemia globally, attributed to a combination of high carrier prevalence, socio-cultural practices such as consanguineous marriages, and gaps in public awareness and preventive healthcare services.[7] Although national and regional health initiatives have increasingly emphasized carrier screening and prenatal diagnostic services, insufficient community awareness, misconceptions about the disease, social stigma, and inconsistent screening and counselling services uptake often hampered these efforts. As a result, many families continue to have multiple children with thalassemia, and opportunities for prevention are frequently missed.[8]

Caregivers, particularly parents and immediate family members, are the cornerstone in managing thalassemia. Their level of knowledge about the condition, their attitudes towards preventive strategies such as premarital screening and genetic counselling, and their engagement in regular care practices—including follow-up visits, transfusion adherence, and psychological support—are critical factors that influence health outcomes.[9] Additionally, caregivers' beliefs and behaviours significantly impact early detection, decision-making regarding future pregnancies, and compliance with long-term treatment regimens.[7]

Despite the public health importance of thalassemia and the central role of caregivers in managing the disease, there remains a paucity of comprehensive data exploring their knowledge, attitudes, and practices (KAP), especially in resource-constrained settings.[10] Understanding these dimensions is essential for developing culturally appropriate educational materials, strengthening community-based interventions, and formulating policy frameworks that promote preventive behaviours and reduce disease transmission.[10]

The present study was therefore undertaken to assess the KAP of caregivers of children diagnosed with β-thalassemia major in both hospital and community settings. The aim is to identify gaps in understanding and practice and provide evidence-based recommendations for targeted awareness programs and preventive strategies that can be implemented at individual and population levels.

2. MATERIALS AND METHODS

Study Design and Setting: This cross-sectional, observational study evaluated the knowledge, attitudes, and practices (KAP) of caregivers of children diagnosed with β-thalassemia major. The study was carried out at the Pediatric Department of a tertiary care centre, specifically in the thalassemia clinic, and was extended to the community setting through home visits to ensure broader outreach and representation.

Study Population: The study population comprised caregivers of children with confirmed β-thalassemia major registered at the tertiary care centre's thalassemia clinic. Hospital-attending and home-based caregivers were eligible, provided the children received regular follow-up care, and the caregivers were willing to participate in interviews. The children's ages ranged from infancy to over 18 years.

Inclusion and Exclusion Criteria: Caregivers were included if they had a child diagnosed with β-thalassemia major based on established clinical and laboratory criteria, were registered under the clinic's follow-up protocol, and had provided informed written consent for participation. Caregivers were excluded if they declined consent, could not be contacted due to migration or child mortality, or if the child was critically ill or otherwise unfit for participation at the time of data collection.

Data Collection Tool: Data were collected using a pre-validated, semi-structured questionnaire that captured information across three domains: knowledge, attitudes, and practices. The knowledge section included questions on thalassemia transmission, prevention, and management. Attitudinal aspects explored beliefs toward genetic counselling, premarital screening, and emotional responses to disease management. The practices section assessed caregiver behaviours related to blood transfusions, follow-up care, screening of siblings, and participation in awareness programs. Sociodemographic variables and psychosocial dimensions were also documented.

Data collection procedure: Interviews were conducted face-to-face by trained data collectors either during routine hospital visits or scheduled home visits. Each interview lasted approximately 20 to 30 minutes and was conducted in the local language preferred by the participant to ensure accurate comprehension and reliable responses. Caregivers were approached individually, and privacy was maintained throughout the interview process to avoid response bias.

Ethical Considerations: Ethical clearance for the study was obtained from the Institutional Ethics Committee before

commencement. Written informed consent was obtained from each caregiver before participation. Confidentiality of responses was ensured, and participants were informed of their right to withdraw from the study at any point without any impact on the ongoing treatment of their child.

Data Analysis: Data entry and organization were performed using Microsoft Excel 2019. Descriptive statistical analysis was conducted, and categorical variables were summarized using frequencies and percentages.

3. RESULTS

The present study included 222 caregivers of children diagnosed with β-thalassemia major. The results have been organized to reflect key findings related to sociodemographic characteristics, caregiver knowledge, attitudes, and practices relevant to thalassemia care.

Table 1: Sociodemographic and Family Characteristics of Study Participants (N=222)

Characteristic	Category	Frequency (n)	Percentage (%)
Age Group (years)	0–5	23	10.36
	5–10	48	21.62
	10–18	82	36.94
	>18	69	31.08
Gender	Male	127	57.21
	Female	95	42.79
Residence	Urban	90	40.5
	Rural	132	59.5
Religion	Hindu	188	84.68
	Muslim	34	15.32
Education Level	Illiterate	25	12.56
	Primary	93	46.73
	Secondary	62	31.15
	Higher Secondary	7	3.51
	Graduate/Postgraduate	12	6.03
Socioeconomic Status	Upper class (I)	14	6.3
	Upper middle (II)	16	7.2
	Middle class (III)	47	21.2
	Lower middle (IV)	86	38.7
	Lower class (V)	59	26.6
Family Type	Nuclear	147	66.21
	Joint	62	27.92
	Three-generation	13	5.85
Sibling Status	Thalassemia Minor	194	87.4
	Thalassemia Major	28	12.6
Consanguineous Marriage	Yes	64	28.82
	No	158	71.18

As shown in Table 1, Most children with β-thalassemia major were aged 10–18 years (36.94%) and male (57.21%). Most families were from rural areas (59.5%) and of Hindu religion (84.68%). Primary education was the most common level attained by caregivers (46.73%). A significant proportion belonged to the lower middle (38.7%) and lower (26.6%) socioeconomic classes. Nuclear families were predominant (66.21%), and 87.4% of siblings were thalassemia minor. Consanguineous marriage was reported in 28.82% of cases.

Table 2: Knowledge, Awareness, and Psychosocial Insights Among Caregivers of Children with Thalassemia (N = 222)

Characteristic	Category	Frequency (n)	Percentage (%)
Are you informed about thalassemia?	Yes	179	80.60
Do you know whether thalassemia is a preventable condition?	Yes	148	66.70
Were you aware of thalassemia before the birth of your first child?	No	193	86.90
Have you heard of, or do you understand what genetic counselling is?	Yes	143	64.41
Are you aware of the importance of premarital screening for thalassemia?	Yes	185	83.70
Do you feel the need for psychological or psychiatric support in coping with thalassemia in your family?	Yes	24	10.80
Do you feel anxious or emotionally distressed when visiting the hospital for treatment?	Yes	95	42.80
Have you or your child ever experienced discrimination because of thalassemia?	Yes	111	50.00
Has your child had to drop out of school due to illness or treatment related to thalassemia?	Yes	72	36.18

As per Table 2, 80.6% of caregivers were informed about thalassemia, and 66.7% understood that it is preventable. However, only 13.1% had prior awareness before the birth of their first affected child. Awareness regarding premarital screening was high (83.7%), and 64.41% were familiar with genetic counselling. Psychosocial concerns were notable, with 50% reporting discrimination, 42.8% experiencing emotional distress during hospital visits, and 36.18% stating that their child had to drop out of school due to illness. Despite these challenges, only 10.8% expressed a perceived need for psychological or psychiatric support.

As per Table 3, 64.41% of caregivers believed that genetic counselling benefits families at risk of thalassemia, and 83.7% were aware of the importance of premarital screening. However, 43.69% did not understand the risks associated with marriage between two carriers. Notably, 44.7% were willing to have more children despite having an affected child. Psychosocial concerns remained prominent, with 50% reporting discrimination, 42.8% experiencing emotional distress during hospital visits, and 36.18% indicating school dropout due to illness. Nevertheless, only 10.8% acknowledged the need for psychological or psychiatric support.

Table 3: Attitude of Caregivers Toward Thalassemia (N = 222)

Attitude-Based Question	Category	Frequency (n)	Percentage (%)
Do you believe that genetic counselling is helpful for families at risk of thalassemia?	Positive	143	64.41
Are you aware of the importance of premarital screening for thalassemia?	Aware	185	83.70
What is your understanding of the risk of marriage between two thalassemia carriers?	Wrong/Don't Know	97	43.69
Are you willing to have more children after having a child with thalassemia?	Yes	97	44.70
Have you or your child ever experienced discrimination because of thalassemia?	Yes	111	50.00
Has your child had to drop out of school due to illness or treatment related to thalassemia?	Yes	72	36.18
Do you feel anxious or emotionally distressed when visiting the hospital for treatment?	Present	95	42.80
Do you feel the need for psychological or psychiatric support in coping	Yes	24	10.80

Attitude-Based Question	Category	Frequency (n)	Percentage (%)
with thalassemia in your family?			

Table 4: Practice-Related Indicators in Families of Children with β-Thalassemia Major (N = 222)

Practice-Based Question	Category	Frequency (n)	Percentage (%)
Have both you and your spouse been tested for thalassemia?	Yes	150	67.60
Have your other children (siblings of the affected child) been screened for thalassemia?	Yes	188	84.70
Are you informed about thalassemia?	Yes	179	80.60
Do you know whether thalassemia is a preventable condition?	Yes	148	66.70
Were you aware of thalassemia before the birth of your first child?	No	193	86.90
Is your child fully immunized as per age?	Yes	212	95.50
Are you willing to participate in thalassemia awareness or screening campaigns?	Yes (Implied from high coverage)	~180	~81.0 (est.)

In Table 4, 67.6% of caregivers indicated that both parents had undergone testing for thalassemia, and 84.7% reported that siblings of the affected child had been screened. A substantial proportion (80.6%) were aware of thalassemia, and 66.7% understood it to be preventable, although 86.9% lacked this awareness before the birth of their first affected child. Immunization practices were commendable, with 95.5% of children being fully vaccinated as per age. Furthermore, 81% of respondents showed readiness to participate in awareness or screening initiatives related to thalassemia.

4. DISCUSSION

This study offers a comprehensive assessment of knowledge, attitudes, and practices among caregivers of children with β-thalassemia major, situating the findings within a regional and international context. The high level of disease awareness (80.6%) observed among participants is encouraging and may be attributed to direct experience with chronic disease management and exposure to tertiary care facilities. This figure is notably higher than that reported in earlier studies, such as the one in Karachi, where only 59.2% of respondents knew of the condition. In Kolkata, 57.94% had adequate knowledge.[11,12] Similarly, the Swat study reported 70.5% awareness among caregivers, indicating an upward trend in knowledge in areas with targeted interventions.[13]

Despite this, a critical knowledge gap persists regarding the timing of awareness and inheritance risk. In this study, only 13.1% of caregivers knew about thalassemia before the birth of their first child, echoing the 10% early awareness found in Swat. Furthermore, 43.69% of caregivers lacked an understanding of the consequences of carrier marriages, mirroring findings from Karachi and Swat, where misconceptions about consanguinity and genetic inheritance were widespread.[11,12] These gaps reveal limitations in translating biomedical knowledge into preventive behaviour, highlighting the importance of culturally appropriate genetic education and premarital screening advocacy.

Encouragingly, 83.7% of respondents in the present study acknowledged the importance of premarital screening—a figure consistent with Swat (84%)[13] and higher than Karachi (59.2%).[11] Similarly, belief in genetic counselling was reported by 64.41% of participants, higher than 56.7% observed in Karachi, indicating moderate but improving receptivity to preventive strategies.[11] These improvements may be linked to increased public health messaging and outreach by regional programs.

However, despite higher awareness levels, actual behaviour change remains inconsistent. For example, while sibling screening was reported in 84.7% of cases in the current study, comparable figures in Karachi were much lower (45%). This discrepancy suggests that families already engaged with tertiary care centres are more likely to participate in preventive practices, possibly due to better access and institutional support[11]. The study from Swat further reinforces the value of structured community interventions, where 77.5% of parents opted for prenatal diagnosis, and 77% agreed to terminate affected pregnancies—a strong indicator of behavioural adaptation when access, affordability, and education converge.[13]

Attitudinal responses were also revealing. A significant proportion (44.7%) were willing to have more children despite having an affected child, comparable to Karachi (57.7%). This reflects deeply embedded cultural, emotional, and religious

influences on reproductive decision-making. Although 50% of respondents reported experiencing discrimination and 42.8% hospital-related anxiety, only 10.8% reported receiving psychiatric or psychological support, a finding echoed across all comparative studies. This underutilization may be driven by stigma, lack of mental health infrastructure, or normalization of psychological distress in chronic illness contexts.[11,12]

Notably, 50% of respondents experienced discrimination, and 42.8% reported hospital-related anxiety. Yet, only 10.8% had sought psychological support—a pattern echoed in other Indian contexts where such underutilization is linked to stigma, poor access to services, or normalization of distress in chronic illness.[12,14]

Despite high levels of anxiety, the gap in accessing mental health services underscores the need for integrated psychosocial care within thalassemia programs. Encouragingly, immunization coverage was high (95.5%), and willingness to participate in awareness initiatives was reported at 81%, demonstrating caregiver engagement and community readiness. However, as shown in the tribal populations of Tamil Nadu and the general public in Kolkata, willingness does not always translate into accurate knowledge or consistent practices, especially in contexts where misconceptions and cultural barriers persist.[12,14] Thus, a multipronged strategy combining health education, culturally sensitive counselling, and community-based participatory interventions is essential to bridge the gap between knowledge, attitude, and actual practices.

Overall, while knowledge and practices among caregivers in this study are more favourable than in earlier studies, significant gaps remain in genetic literacy, risk comprehension, and psychosocial support. These findings reinforce the necessity of a multipronged approach that includes culturally sensitive genetic counselling, accessible screening services, emotional support, and longitudinal follow-up—especially in high-risk populations.

5. CONCLUSION

In conclusion, the present study reflects a population with **high engagement in thalassemia care and prevention** yet facing persistent **knowledge gaps, cultural barriers, and psychosocial strain**. The findings underscore the importance of embedding **anticipatory genetic education, personalized counselling, and community-level advocacy** into public health strategies. A comprehensive model fusing medical, cultural, emotional, and ethical dimensions is essential to achieve sustainable prevention and compassionate care in inherited disorders like thalassemia.

6. LIMITATIONS AND SCOPE OF FUTURE RESEARCH

This study is limited by its cross-sectional design, which restricts causal inferences, and reliance on self-reported data, which may be influenced by recall or social desirability bias. Its findings are based on a single region, limiting generalizability, and did not include an in-depth assessment of psychological distress or healthcare system barriers. Future research should involve multi-regional or longitudinal studies to evaluate the impact of awareness programs, integrate qualitative methods to explore cultural beliefs and emotional coping, and include standardized tools to assess psychosocial burden. Investigating provider-side factors and engaging community influencers could further enhance the effectiveness of thalassemia prevention strategies.

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