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Original Research Article

Assessment of Parental Knowledge, Attitudes, and Practices Towards β-Thalassemia in Affected Families

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Abstract:

Background: β-thalassemia is a chronic genetic blood disorder that must be managed for life, and parents' knowledge, attitudes, and practices (KAP) have a significant impact on outcomes. These aspects must be known to enhance disease care and prevention programs.

Purpose: To assess the knowledge, attitudes, and practices of β-thalassemia parents about disease prevention and control and identify gaps that influence care.

Methodology: This Cross-sectional hospital-based study was carried out in the Department of Community Medicine, Sheikh Bhikhari Medical College, Hazaribagh, Jharkhand, from August 2023– July 2024 for a period of 12 months. 98 parent/caretakers of β-thalassemia children were interviewed with a pre-designed, structured questionnaire to evaluate demographic information and KAP. Descriptive statistics, odds ratios (OR), and p-values were analyzed using GraphPad software.

Results: The participants' most frequent age group was 21–30 years (63.3%), with slight female predominance (52%). Mothers were the main caregivers in 40.8% of the cases. Half of the participants had educational schooling, and 56.1% were of the low socioeconomic class IV. Parents ≤30 years old had increased odds of good knowledge (OR 2.16) and practices (OR 1.72), and lower schooling levels were associated with increased practices (OR 1.70). None of these, however, were statistically significant ($p>0.05$).

Conclusion: Despite the level of moderate awareness, there are knowledge and practice gaps among the parents of the β-thalassemia patients that vary with age, education, and socioeconomic status. Targeted interventions and caregiver support are needed to improve disease management and prevention.

Keywords: Attitudes, Caregivers, Disease Management, Knowledge, Practices, Prevention, B-Thalassemia.

Introduction

Thalassemia is a genetic blood disorder caused by the production of aberrant hemoglobin, either due to the absence or impaired production of one or more of the globin chains. It is usually classified as alpha and beta thalassemia, depending on the globin chain involved. Such a defect can manifest in an extremely wide variety of clinical presentations from mild to severe anemia [2]. Among all of these forms is beta thalassemia typically represents a significant public health concern due to its severe clinical course and difficulty in managing in the long term. Beta thalassemia is defined as major, intermedia, and minor, depending on the number of defective or absent beta globin genes [3].

Beta thalassemia major, the most severe variant, is inherited in a "autosomal recessive" manner due to mutations of the HBB gene on chromosome 11. This condition usually presents early in childhood and requires blood transfusions, extensive laboratory evaluation, and long-term pharmacological treatments to maintain hemoglobin levels and reduce complications. Children with beta thalassemia major typically present with severe clinical findings, including severe anemia, developmental delay, skeletal deformities, hepatosplenomegaly, and increased susceptibility to infection, all of which affect quality of life severely.

Beta thalassemia is estimated to have a global prevalence of 1 in 100,000 affected individuals,

making it a "rare disease" [3]. However, the prevalence goes beyond this number as almost 7% of the global population are carriers with hemoglobin disorders and approximately 400,000 babies are born each year with thalassemia characteristics. While classified as "rare," beta thalassemia contributes significantly to the overall disease burden with an estimated death rate of around 20 people annually globally [4]. This illustrates the public health issue of thalassemia control and the impact it has on health systems around the world, particularly in low- and middle-income countries where resources and appropriate diagnostic and treatment facilities may be limited.

Early identification of beta thalassemia is often difficult. The presence of fetal hemoglobin (HbF) up to six months of age can hide a lot of the clinical features and lead to delayed identification. Thalassemia can be suspected clinically on the basis of pallor, weakness, irritability, and growth retardation, but the diagnosis is established by hematological and genetic assessment. Patients with beta thalassemia major will require regular blood transfusions, which are life-saving but also lead to iron overload. Too much iron can result in progressive organ failure, namely cardiac, liver, and endocrine dysfunction. To avoid this complication, chelation therapy is required as part of the treatment plan, although it has its own limitations, such as compliance, side effects and costs [5].

While the medical management of beta thalassemia has improved, the role of parents and caregivers in disease management is also significant. Parents need to make sure their child follows their transfusion schedule, observes the chelation schedule, attends follow-up investigations, and gives them the emotional and psychological support required. Parents' knowledge, attitudes, and practices (KAP) therefore become influential factors in determining the overall health outcome of children with beta thalassemia. Failure to have adequate knowledge can result in poor disease management, defaulting transfusion sessions, and non-compliance with chelation therapy which will adversely affect a child's prognosis. Moreover, attitudes and beliefs are of equal importance in informing the decision-making for preventive interventions such as carrier screening, genetic counseling and prenatal diagnosis.

Assessing and identifying the gaps in parental KAP is a first step toward the successful implementation of interventions that will result in better disease outcomes. Evidence has established that highly educated caregivers are more likely to adhere to medical protocols, exercise preventive practices, and actively seek out resources that facilitate intensive care. Misconceptions, stigma, and low awareness, conversely, are likely to impede the control and prevention of the disease, and its cycle is therefore perpetuated within communities and families.

In this context, the objective of the current study is to assess awareness, attitudes, and practice of parents or guardians of beta thalassemia patients, i.e., to determine areas of deficiency in their knowledge and practices regarding control and prevention strategies of the disease. By measuring these factors, the research will yield information to clinicians and policymakers about areas that require targeted education and support interventions in order to improve clinical outcomes and overall quality of life in such children.

Methodology

Study Design: A cross-sectional, descriptive, hospital-based study was conducted to assess the knowledge, attitudes, and practices (KAP) among parents of children with β-thalassemia regarding disease management and prevention.

Study Area: The study was carried out in the Department of Community medicine, Sheikh Bhikhari Medical College, Hazaribagh, Jharkhand, India.

Study Duration: The study was conducted over a period of August 2023– July 2024 for a period of 12 months

Study Population: The study population consisted of parents/caregivers of children diagnosed with β-thalassemia, attending the pediatric outpatient and inpatient services of the hospital during the study period.

Sample Size: A total of 98 parents/caregivers of children with β-thalassemia were enrolled in the study. Only one caregiver per child was included to avoid duplication of responses.

Inclusion Criteria

- Parents or primary caregivers of children diagnosed with β-thalassemia.
- Participants aged 18 years and above.
- Willing to provide informed consent.

Exclusion Criteria

- Parents/caregivers who refused consent.
- Caregivers who were unable to comprehend the questionnaire due to cognitive or language barriers.
- Parents of children with other hemoglobinopathies or non-thalassemic chronic illnesses.

Data Collection: Data was gathered through a pre-designed, structure questionnaire that was originally written in English and translated into the local language for clarity and comprehension purposes. The survey contained sections covering demographics (age, sex, education, income, and place of residence), and items addressing

knowledge, attitudes and practices relating to bullying management and prevention of β-thalassemia. Face-to-face interviews were carried out by trained personnel with one parent or caregiver per child to ensure accuracy and reduce bias. Responses were scored for each participant, and knowledge scores of ≥4 was deemed satisfactory knowledge of the disease.

Procedure: After obtaining written informed consent, the questionnaire was administered to one parent/caregiver per child in a face-to-face interview format by trained personnel to ensure comprehension. Responses were scored, with a knowledge score ≥4 considered as satisfactory.

Statistical Analysis: The data collected were input into Microsoft Excel and analyzed using GraphPad software. Descriptive statistics were used for summarizing qualitative variables, which were summarized using frequencies and percentages. The comparative parameter was assessed using p-values and odds ratios at a 95% confidence interval. A p-value of <0.05 was considered statistically significant.

Result

"Table 1 indicates that out of the 98 parents of β-thalassemia children, the majority were between 21–30 years (63.3%), followed by 31–40 years (25.5%) and ≥41 years (11.2%). The female to male ratio was slightly greater females than males (52% vs. 48%). Mothers were the caregivers in 40.8% of the cases, followed by fathers (33.7%) and grandparents (24.5%). In terms of education, 50% of the participants had academic-level education, 29.6% had secondary, and 20.4% had only primary education. Socioeconomic status was low, with most belonging to class IV (56.1%), followed by class III (22.4%), class V (17.3%), and class II (5.1%), and no participant belonged to class I, which means that the group was primarily lower-income.

Table 1: Demographic characteristics of study population

Demographic characteristics	No. of patients (n=98)	Percentage (%)
Age in years		
≥41	11	11.2
31–40	25	25.5
21–30	62	63.3
Sex		
Female	51	52
Male	47	48
Caregiver		
Grandparents	24	24.5
Mother	40	40.8
Father	33	33.7
Education		
Academic	49	50
Secondary	29	29.6
Primary	20	20.4
Socioeconomic status		
V	17	17.3
IV	55	56.1
III	22	22.4
II	5	5.1
I	0	0

Table 2 illustrates statistical correlation between selected demographic factors and parents' knowledge, attitudes, and practices on β-thalassemia management. Parents with ≤secondary level education were compared with academically educated parents and were found to have slightly higher odds for knowledge (OR 1.25, CI 0.48–1.89) and practices (OR 1.70, CI 1.08–1.91), though the correlations were non-significant (p>0.05). Parents ≤30 years old had greater odds for knowledge (OR 2.16, CI 1.83–2.47) and practices (OR 1.72, CI 1.44–2.10) than those >30 years old, though without statistical significance. Male caregivers were found to have higher odds for knowledge (OR 1.41, CI 0.74–1.73) and attitudes (OR 1.68, CI 1.45–2.24) and better attitudes than females, and females demonstrated relatively better practices (OR 0.63, CI –0.14–1.41), though none were significant. Socioeconomic status (class II–III vs. IV–V) demonstrated minimal variations in knowledge (OR 1.11), attitudes (OR 0.74), and practices (OR 1.02), all having non-significant p-values, which signifies no significant correlation between these variables and KAP outcomes.

Table 2: Assessing statistical correlation of few parameters						
Parameter	**Knowledge OR (CI)**	**P**	**Attitude OR (CI)**	**P**	**Practices OR (CI)**	**P**
≤Secondary vs Academic	1.25 (0.48–1.89)	0.4191	0.81 (0.52–1.04)	0.6063	1.70 (1.08–1.91)	0.6789
≤30 vs >30	2.16 (1.83–2.47)	0.1285	1.11 (0.60–1.57)	0.2039	1.72 (1.44–2.10)	0.2565
Male vs Female	1.41 (0.74–1.73)	0.36	1.68 (1.45–2.24)	0.1194	0.63 (-0.14–1.41)	0.5659
II–III vs IV–V	1.11 (0.85–1.72)	0.3082	0.74 (0.24–0.96)	0.6365	1.02 (0.42–1.41)	0.3641

Discussion

In the present study, most of the participants (63.3%) were in the 21–30 years age group, and most of the caregivers were mothers (40.8%), followed by the fathers (33.7%) and grandparents (24.5%). The findings are consistent with Ali et al. (2014), who reported that 38% of the thalassemic children were accompanied by mothers and 62% were accompanied by fathers, though our study had a slightly higher percentage of mothers as caregivers, possibly due to the more prominent maternal caregiving role in our context [6]. Saxena et al. (2019) reported male predominance among caregivers (62.5%) [7], which is dissimilar to the near equal gender distribution of our sample. The difference may be due to differences in socio-culture across regions.

Regarding educational background, half of our participants had academic-level education, with only 20.4% having primary education. This contrasts with Ali et al. [6], where 61% of caregivers lacked formal education, and Biswas et al. (2020) [8], who reported that only 47.6% of caregivers understood the genetic etiology of thalassemia. Such discrepancies highlight the role of education in improving awareness, as also confirmed by our findings where education showed a positive correlation with knowledge, attitudes, and practices, aligning with Biswas et al. who reported education as a strong predictor of KAP levels."

Awareness regarding thalassemia as a genetic disorder in our research was similar to Saxena et al. (47.5%) [7] and Ishaq et al. (44.6%) [9] but lower than that of Maheen et al. (55.2%) [10]. Awareness regarding antenatal diagnosis of thalassemia (47.3%) was similar to results of Inamdar et al. (45%) [11] but much lower than Shahzad et al., (2017) who had a 89% awareness in their multicenter study [12]. These differences may be attributed to differences in health education programs, availability of genetic counseling, and public health policy in different geographic areas.

Knowledge about treatment procedures also varies. In our research, 66.1% of the parents were aware of the need for blood transfusions, 43.07% were aware of the need for routine investigations, and 58.4% were aware of the need for routine medication. This is comparable to Inamdar et al. (77.1% awareness of the need for transfusion and medication) [11] but varies with Ali et al., who had 100% knowledge about regular blood transfusions [6]. Similarly, only 51.9% of our sample had knowledge about optional vaccines, which is higher than Saxena et al. (42.5%) [7], indicating room for improvement in preventive care.

Emotional and financial burden were prevalent in our cohort, with 74.6% worried about their children's future and education but 71.5% not feeling their children were a burden. Such emotional resilience is in line with Mallik et al. (2010), in which 72% of parents did not find their child to be an emotional burden but 65% were financially burdened [13]. Our findings are in line with Sharma et al. (2018) and Ismail et al. (2006), with high emotional distress and reduced quality of life reported in caregivers of thalassemic children [14,15] ,.

Our regression analysis showed that younger caregivers (≤30 years), better-educated caregivers, and more affluent socioeconomic class caregivers had higher KAP scores, though the associations were not statistically significant. This concurs with Biswas et al., who found that education, occupation, and socioeconomic status were good predictors of knowledge [8], and Basu et al. (2016), who found that 57.9% had good knowledge and 83.9% had good attitude but only 14% had good practices [16]. The proportionately low practice scores in this study are consistent with these findings, and it suggests that targeted interventions are required to translate knowledge into action that is feasible.

In summary, we had our findings generally consistent with the literature, but we did have some discrepancies, particularly with regard to caregiver education and awareness of antenatal screening. These discrepancies underscore the necessity of context-specific health education and counseling interventions. More genetic counseling, more public awareness campaigns, and the integration of thalassemia education into community health programs would bridge the knowledge gaps and improve caregivers' disease management practices.

Conclusion

The study identifies that while parents of β-thalassemia children are shown to have differences in knowledge, attitudes, and practices towards prevention and management of the disease, they lack knowledge and application of best practice in care. The study finds support that demographic factors such as education, age, and socioeconomic status play a larger role in parental practice than in knowledge and attitudes and therefore need tailored training interventions. Generally, the awareness programs must be enhanced, and caregivers must be provided with comprehensive support to enhance practice in disease prevention and β-thalassemia children's management.

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