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Knowledge, attitude, practices among parents of β thalassemia children regarding thalassemia

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Abstract
Introduction: Thalassemia is a hereditary hemglobinopathy and a chronic disorder requiring lifelong blood transfusions, investigations and medications; creating an emotional and financial burden on the family.
Materials and Methods: After taking consent from parents/caregivers of β thalassemic children, a pre designed structured questionnaire was provided to one parent/caregiver per β thalassemic children.
Results: 48.4% (126/260) were aware that thalassemia is a genetic disorder, 47.3% (123/260) know that thalassemia traits can be detected antenatally, 66. 1% (172/260) have awareness about need of blood transfusions. 74.6% (194/260) were worried about children's education and also they are getting emotional distress about child future. 94.2% were taking their child to hospitals for regular blood transfusion, 90.3% were taking regular medications.
Conclusion: Age, Education, Socioeconomic status were significant predictors in relation to practices of caregivers. Government agencies should take initiative activities like awareness campaigns, premarital counselling, prenatal diagnosis, and regular counselling sessions in their vernacular language.

Keywords: Knowledge, attitude, practice, thalassemia

1. Introduction
Thalassemia occurs due to production of abnormal Haemoglobin either by absence or reducing synthesis of globin chain. It is a genetic disorder, categorized as alpha and beta thalassemia depending upon the globin chain involvement; which can cause mild to severe anaemia [1].
Depending on number of beta globin genes missing, beta thalassemia is classified as major, intermedia and minor [2]. Beta thalassemia major is an auto recessive disorder, caused by mutations in HBB gene on chromosome 11 and also an aggressive condition may present with severe symptoms and need regular transfusions, investigations, medications.
The estimated incidence of beta thalassemia is about 1 in 100,000 globally [3]. It is listed under "rare disease" as it was estimated that every year, approximately 20 deaths worldwide. Every year, 7% of the world's population are carriers and 4, 00,000 babies are born with the trait [4].
Diagnosis of beta thalassemia is usually delayed because of fetal haemoglobin presence until six months of life. Thalassemia can be suspected clinically based on features such as pallor, fatigue etc., Beta thalassemia major may require repeated blood transfusions, which causes iron over load and also create negative impact on the organs function. To treat iron overload, they may require repeated chelation therapy and investigations; iron overload can be due to blood transfusions and enhanced iron absorption by gastrointestinal tract [1, 5].
The purpose of the present study was to assess the gap in knowledge, attitude and practices among parents/caregivers of β-thalassemia children.

2. Materials and Methods
A cross sectional, descriptive and hospital based study conducted from January 2018 to July 2019 in a pediatric unit of Government Medical College/Hospital of Anantapuram district of Andhra Pradesh. A total of 260 parents/caregivers of β thalassemic children were included in this study. Informed consent was obtained from all the participants before their participation in this study. After taking consent from parents/caregivers of β thalassemic children, a pre

designed structured questionnaire was provided to one parent/caregiver per β thalassemic children. Only one caregiver per β thalassemic children was advised to answer the questionnaire for convenience of study.

This questionnaire includes: questions related to Knowledge, Attitude and practices of thalassemia along with general details pertaining to age, sex, education, income, and place of residency. This questionnaire was drawn up in English followed by a translation in the local language. Score more than or equal to 4 was considered under satisfactory knowledge regarding the disease.

Scores of Knowledge, Attitude, Practices of individual participant were entered in excel sheet. Results were analyzed.

2.1 Statistical Analysis

Qualitative Descriptive analysis of these parameters was expressed in the form of numbers and percentages. P value and Odds ratio of comparative parameters was calculated at 95% CI by using graph pad soft ware. The p value <0.05 was considered as significant statistically**.**

3. Results

The mean age of study population was 28.62±7.12. Majority of the population were in the age group of 21-30 years i.e., 62.6%. Male and female caregivers of β thalassemic children in this study were almost same. 33.8% of caregivers were father, 40% were mother and remaining 20.7% were grandparents. 50.7% were having either bachelor or masters degree. Socioeconomic status was assessed by Kuppuswamy's scale, out of 260 parents, 148 (56.9%) were upper lower class, 56 (21.5%) were lower middle class.

Table 1: Demographic characteristics of study population

Demographic characteristics	No. of patients (n=260)	Percentage (%)
Age in years		
21-30	163	62.6
31-40	66	25.3
≥41	31	11.9
Sex		
Male	124	47.6
Female	136	52.3
Caregiver		
Father	88	33.8
Mother	104	40
Grand parents	54	20.7
Education		
Primary	50	19.2
Secondary	78	30
Academic	132	50.7
Socioeconomic status		
I	0	0
II	12	4.6
III	56	21.5
IV	148	56.9
V	44	16.9

On assessment of knowledge about thalassemia, 48.4% (126/260) were aware that thalassemia is a genetic disorder, 47.3% (123/260) know that thalassemia traits can be detected antenatally, 56.5% (147/260) believe that thalassemia occurs due to consanguineous marriages, 66.1% (172/260) have awareness about need of blood transfusions, 43.07% (112/260) were up to date about need of regular investigations, 58.4% (152/260) were well known about purpose of taking regular medications, 59.6% (155/260) were clearly know about side effects of both blood transfusion and chelation therapy, 51.9% (135/260) have knowledge about optional vaccines.

On assessment of attitude, 43.07% (112/160) won't feel as a financial burden, 71.5% (186/260) didn't consider their children as a burden, but 74.6% (194/260) were worried about children's education and also they are getting emotional distress about child future, 43.07% didn't disclose about their child's condition to family and society. Among those who are planning for next pregnancy 66.1% (172/260) were wishing to undergo antenatal tests related to thalassemia and 65.3% of them were willing to undergo MTP if it is confirmed as a thalassemic child.

On assessment of practices, 94.2% were taking their child to hospitals for regular blood transfusion, 90.3% were taking regular medications, 66.1% were undergoing required investigations regularly, 66.1% were haven't provided optional vaccines to their child, 31.5% persons had undergone antenatal investigations in their next pregnancy, all the study population (100%) were encouraging their child to lead a normal life.

At 95% CI, p value was calculated and analysed for age, sex, education and socioeconomic status (SES). In relation Knowledge score, education of caregivers has shown statistical significance (p value – 0.006). In relation to Attitude score, education and age dependent factors have shown statistical significance of 0.0351 and 0.0308 respectively. In relation to practices, statistical significant factors are education, age and SES.

Table 2: Assessing statistical correlation of few parameters

Parameter	Knowledge			Attitude			Practices		
	OR	CI	P	OR	CI	P	OR	CI	P
Education									
≤secondary vs Academic	2.00	1.21-3.28	0.006	0.57	0.34-0.96	0.0351	0.28	0.15-0.52	<0.0001
Age in years									
≤30 vs >30	1.28	0.77-2.13	0.332	0.55	0.32-0.94	0.0308	0.25	0.12-0.50	0.0001
Sex									
Male vs Female	1.52	0.93-2.48	0.09	1.01	0.61-1.68	0.94	1.22	0.69-2.14	0.4801
Socioeconomic status									
II-III vs IV-V	1.11	0.64-1.94	0.695	1.35	0.77-2.38	0.2902	3.75	2.05-6.85	<0.0001

4. Discussion

Thalassemia is a hereditary hemglobinopathy and a chronic disorder requiring lifelong blood transfusions, investigations and medications; creating an emotional and financial burden on the family. It can be detected during antenatal period by chronic villus sampling, amniocentesis, fetal blood testing depending on gestational age.

Prevention of thalassemia is a most important aspect to reduce the burden on society, for these social scientists, doctors and counsellors should play a major role in prevention. Usually at government hospital of tertiary level in all states are often over-crowded and the staff are over-burdened to offer repeated counselling and sustained motivation to parents of children suffering from thalassemia, even though this is a tough situation, doctors and counsellors should focus on serve to people from simple infections to long lasting chronic illnesses. Government should take initiation to give enough support in providing counsellors for such aggressive disorders [6].

In the present study, the mean age of study population was 28.62±7.12 years. 47.6% were males and 52.3% were females. 33.8% of caregivers were father, 40% were mother and remaining 20.7% were grandparents. 19.2% were having primary education, 30% were secondary, and 50.7% were having academic degrees.

Saima Ali *et al*. [7] documented out of 200 patients, 76 (38%) were accompanied by mother and 124(62%) were accompanied by their father. 61% don't have formal education, 28% were completed matric, 9% were having bachelor degree, 2% were Masters. Amit Saxena *et al*. [8] noted male preponderance with males of 62.5% and females of 37.5%. A study by Goyal JP *et al*. [9] and Bashwati Bandyopadhyay *et al.* [6] showed male preponderance similar to present study. In similar to our study, a study conducted in Pakistan by Fehmina A *et al*. [10] showed slight female preponderance.

In our study, 48.4% (126/260) were aware that thalassemia is a genetic disorder, which is similar to Amit Saxena *et al*. [8] (47.5%), Ishaq F *et al*. [11] (44.6%), Maheen *et al*. [12] (55.2%). Few studies have observed misconceptions about the cause of thalassemia including sexually transmitted, food transmitted, due to destiny, patient contact transmission etc. [12, 13].

In our study, 47.3% (123/260) know that thalassemia traits can be detected antenatally. This is in concordance with study done by Inamdar *et al*. [14] reported 45%. Ishaq F *et al*. [11] Aamir shahzad *et al*. [15] reported higher percentage as 76.5% and 89%. Aamir Shahzad *et al*. [15] did a multicentric study in Pakistan on 410 thalassemic children selected from various thalassemia centres. Noted 89% had knowledge about premarital screening, 86.1% were opposed to intermarriages of carrier and 57% believed that if carrier got married then prenatal diagnosis or Chorionic villus sampling test is necessary. On assessing practices, about 76.8% of the couples were screened and 42.2% had an experience of Chorionic villus sampling among which 20% abortions were reported. Overall 82% parents had received genetic counselling.

According to the present study, 66.1% (172/260) have awareness about need of blood transfusions, 43.07% (112/260) were up to date about need of regular investigations 58.4% (152/260) were well known about purpose of taking regular medications, 51. 9% (135/260) have knowledge about optional vaccines. Saima Ali *et al*. [7] observed 100% of parents had knowledge on repeated blood transfusions and investigations required like HBV, HIV. Amit Saxena *et al* .[8] 62.5% were aware of regular blood transfusion, 23% parents were aware of the regular medications taken by their children, 42.5% parents had adequate knowledge of the optional vaccines to be taken. Inamdar *et al*. [14] reported 77.1% knew that regular blood transfusion and regular medication needed.

Bijit Biswas *et al*. [16] did a study on Knowledge of the 328 caregivers of thalassemic children and observed only 47.6% knew about genetic etiology of the disease, while only 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively. Regarding treatment of the disease, 75.9% knew that both blood transfusion and iron chelation are the treatment of thalassemia, while only 19.2% and 2.7% of them had knowledge regarding splenectomy and bone marrow transplantation, respectively.

Singh G *et al*. [17] conducted on different communities of Patiala, Punjab. They observed that Knowledge regarding the treatment options available was found more in parents from Bania, Khatri and Kamboj communities. 51% of the parents knew that this disease is manageable, 77% of parents knew that blood transfusion is needed for growth of the child and to maintain hemoglobin levels and 61% of the parents knew the role of ferritin levels. 60% of the parents knew role of chelation therapy, 43% knew the option of deferiprone.

43.07% (112/160) won't feel as a financial burden, 71.5% (186/260) didn't consider their children as a burden, but 74.6% (194/260) were worried about children's education and also they are getting emotional distress about child future as per this study.

Sharma S *et al*,. [18] focused a study on quality of life among children and their caregivers, observed an emotional stress

and poor health among caregivers of thalassemic children than the control group. In similar, Ismail A *et al*. [19] from Malaysia stated that the quality of life of thalassemia patients is indeed much lower than the quality of life of healthy controls regardless of age, gender and ethnicity. Mallik S *et al*. [20] reported that 70% of the families had to spend up to 20% of their yearly income for treatment of thalassemia. 72% of parents did not consider their child as a burden emotionally but almost 65% were burdened financially.

Saima Ali *et al*. [7] did a multicentric study from June 2011 to December 2011 at Pakistan stated that 68 (34%) parents already knew that they have a positive family history of thalassemia, but among them 85.2% were not screened. 74% had knowledge about prenatal screening, but none of the couple opted for it.

Amit Saxena *et al*. [8] stated that 90% parents followed a good practice of getting their child for regular blood transfusion and 92.5% gave them regular medicines, 31 parents would periodically get their child investigated but 65% of parents lacked in giving optional vaccines to the child, 60% agreed to undergo MTP while only 45% knew about the antenatal detection.

Bijit Biswas *et al*. [16] assessed knowledge score of caregivers of thalassemic children. 52.7% had satisfactory knowledge regarding the disease. In multivariable model, caregivers educational level (adjusted odds ratio, AOR-3.13 [1.87–5.25]), working status (AOR-2.18 [1.23–3.86]), place of residence (AOR-2.05 [1.19–3.52]), and socioeconomic class (AOR-2.11 [1.25–3.58]) were significant predictors of their knowledge.

AS per this study, in relation Knowledge score, education of caregivers has shown statistical significance (p value – 0.006). In relation to Attitude score, education and age dependent factors have shown statistical significance of 0.0351 and 0.0308 respectively. In relation to practices, statistical significant factors are education, age and SES.

Few KAP studies on thalassemia patients had reported level of education, occupation, and age as the major determinant of the patients' knowledge about their disease [21-23].

Masumi Basu *et al*. [24] stated that about 57.94% of the study population had adequate knowledge; 83.88% had positive attitude and only 14.02% had good practice about thalassemia.

5. Conclusion

Thalassemia is a major public health problem which is a chronic illness causing burden on families and large financial cost to health services. In this study, majority of the parents/caregivers followed good practices and more than fifty percent of them had positive attitude and enough knowledge about thalassemia. Age, Education, Socioeconomic status were significant predictors in relation to practices of caregivers. Knowledge on thalassemia to be increased in this community, by community based programmers.

Prevention is the only option to reduce this disease burden. As thalassemia affected families have adequate knowledge about thalassemia when compared to general public, State and Central government agencies should take initiative activities like awareness campaigns, premarital counselling, prenatal diagnosis, and regular counselling sessions in their vernacular language.

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