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Original Research Article

Thalassemia-an untoward situation among the pregnant women in North Bengal district, West Bengal, India

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ABSTRACT

Background: Thalassemia, an inherited hemoglobin disorder, affects approximately 7% of the global population. In India, thalassemia prevalence ranges from 3-4%, with significant variation among different communities and regions. This study aims to document the prevalence of thalassemia carriers among pregnant women in the Dakshin Dinajpur district of West Bengal, India.
Methods: A cross-sectional study was conducted from January 2023 to November 2023. Pregnant women were screened for thalassemia at Block Primary Health Centers, and samples were analyzed at the Thalassemia Control Unit in Balurghat district hospital using High-Performance Liquid Chromatography (HPLC). Results were recorded in Thalamon software and analyzed for carrier rates and demographic correlations.
Results: Out of 12,767 pregnant women tested, 29.6% (3,790) were identified as thalassemia carriers. The highest carrier rate was in Kushm and block (45.3%), while the lowest was in Banshihari block (22.9%). Hemoglobin E(Hb-E) carriers constituted 66% of carriers, followed by hemoglobin E disease (21%) and beta thalassemia carriers (9.6%). Significant correlations were found between carrier status and caste, with beta thalassemia being more prevalent among the Scheduled Tribes.
Conclusions: The study highlights a high prevalence of thalassemia carriers among pregnant women in Dakshin Dinajpur, particularly Hb-E carriers. Genetic counselling and early screening are crucial to managing and reducing the transmission of thalassemia traits. The findings underscore the need for increased awareness and preventive measures, especially in high-risk communities. Further studies are recommended to develop strategies for reducing maternal complications and preventing carrier transmission.

Keywords: Pregnant women, Thalassemia carriers, Human rabies

INTRODUCTION

It is estimated that 7% of the global population is affected by inherited hemoglobin disorders, with 300,000 to 500,000 infants born annually with symptomatic hemoglobin disorders1. Inherited hemoglobin disorders are categorized into two main types: (a) sickle cell disease, which accounts for approximately 70% of cases, and (b) thalassemia.[1]

In India, the prevalence of thalassemia is 3-4%, and it is present across the entire country.[2,3] However, higher numbers of cases are found in certain communities, including (i) Sindhis, (ii) Punjabis, (iii) Bengalis, (iv) Gujaratis, (v) Maharas, (vi) Kolis, (vii) Saraswatis, (viii) Lohanas, and (ix) Gours.[3,4] Hemoglobin S disease is highly prevalent among the tribal populations of Southern, Western, and Central states of India, reaching up to 48% in some communities.[5] In contrast, Eastern

India, including states such as West Bengal, Bihar, and Uttar Pradesh, exhibits lower frequencies of Hemoglobin S disease.[6] Hemoglobin E (Hb E) disease is predominant in the Northern and Eastern regions of India, with Hb E carriers accounting for 5-50% of the population, mostly found among Scheduled Tribes, Scheduled Castes, and other backward caste populations.[7]

Genetic disorders related to haemoglobinopathies are emerging as a significant public health problem 8. To identify thalassemia traits, a screening program for all pregnant women during the antenatal period was introduced in India in 2016. This initiative was aimed to implement preventive measures.[6]

The objective of this study is to document the prevalence of thalassemia carriers among pregnant women in the northern district of West Bengal, India.

METHODS

A cross-sectional study was conducted in Dakshin Dinajpur district of West Bengal, India, between January 2023 to November' 2023. Dakshin Dinajpur is one of the North Bengal districts, with a total population of 1,676,276 (2021), an 82.36% literacy rate, and 86% of the population living in rural areas. The district has two municipalities and eight development blocks.[9]

Data collection

All pregnant women were advised to undergo thalassemia screening tests. Blood samples were collected from the willing pregnant women and then placed it in EDTA vials at the Block Primary Health Center (BPHC) by laboratory technicians. A data collection form was completely filled up by the technicians before blood sample collection. After collection, the samples were transferred to the "Thalassemia Control Unit" (TCU) at Balurghat district hospital, maintaining the cold chain for thalassemia screening. The TCU is located at the district hospital in Balurghat and operates every day except Sundays and government holidays.

High-Performance Liquid Chromatography (HPLC)

Following proper processing, the blood samples were tested for thalassemia using a High-Performance Liquid Chromatography (HPLC) machine. The thalassemia reports categorized the presence of abnormal hemoglobin, fetal hemoglobin, any abnormal globin chain structure, and the presence of anemia in the blood into the following categories: (i) Normal, (ii) Beta thalassemia carrier, (iii) Hemoglobin (Hb) D carrier and Hb D disease, (iv) Hb E carrier and Hb E disease, (v) Hb E beta thalassemia, (vi) Hb E disease and double heterozygote, (vii) Hb S carrier, (viii) Hb S beta thalassemia, and (ix) Hereditary Persistence of Fetal Hemoglobin (HPFH) trait.[10,11]

All test results, whether positive or negative, were entered into the Thalamon software. Reports (normal, disease, or carrier) were sent to the respective BPHCs from where the samples were collected and were handed over to the clients with proper counseling.

Data analysis

After thalassemia test was done, all information were collected in data collection format were entered into the Thalamon software. Data were downloaded in Excel format from the Thalamon software. Information were analyzed in graphs, rates, frequencies, and proportions. Relationships with different parameters were assessed using Python programming language.

RESULTS

A total of 12,767 pregnant women were tested for thalassemia in the Dakshin Dinajpur district etween January to November 2023 at the Thalassemia Control Unit (TCU), district hospital, Balurghat, Dakshin Dinajpur. The thalassemia test reports were categorized as either normal or thalassemia carriers. The highest number of blood samples came from Kumarganj block, represented 22% (2,811/12,767) of the total, followed by Balurghat block and municipality with 21.8% (2,789/12,767). The lowest number of samples was from Banshihari block, accounting for 6.8% (875/12,767). In contrast, the carrier detection rate was highest in Kushmand block at 45.3% (654/1,442), followed by Tapan and Kumarganj blocks at 32.5% (482/1,479) and 30.8% (867/2,811), respectively. The lowest carrier detection rate was in Banshihari block at 22.9% (201/875). The overall carrier detection rate in the district was 29.6% (3,790/12,767) Table 1.

Table 1: Distribution of thalasaemia carriers among the pregnant women in blocks and municipality, Dakshine Dinajpur; West Bengal, India.

Block and municipality	Number tested	Thalas-aemia carrier	%
Banshihari	875	201	22.97
Harirampur	890	210	23.60
Hili	764	189	24.74
Balurghat and Municipality	2789	727	26.07
Gangarampur and municipality	1717	460	26.79
Kumarganj	2811	867	30.84
Tapan	1479	482	32.59
Kushmandi	1442	654	45.35
District total	12767	3790	29.69

Types of thalassemia carriers

Approximately 66% (2,483/3,790) of the identified carriers were hemoglobin E (Hb-E) carriers, the highest

proportion in this study, followed by hemoglobin E disease (Hb-E disease) at 21.0% (797/3,790) and beta thalassemia carriers at 9.6% (365/3,790). Over 90% of the carriers fell into these three categories: (a) hemoglobin E (Hb-E carrier), (b) hemoglobin E disease (Hb-E disease), and (c) beta thalassemia carrier (Table 2).

Table 2: Distribution of thalasaemia carriers among pregnant women detected in different caste, Dakshin Dinajpur district, West Bengal India.

Carriers detected	General caste	Muslim	Schedule caste	Schedule Tribe	Total
Beta thelasaemia carrier	153	51	15	146	365
Haemoglobin D carrier	10	5	1	1	17
Haemoglobin E carrier	1074	868	510	31	2483
Haemoglobin E disease	457	108	230	2	797
Haemoglobin E and haemoglobin S double heterozygote	4	4	0	0	8
Haemoglobin E betathalasaemia	8	7	3	0	18
Haemoglobin S carrier and haemoglobin S disease	29	23	16	19	87
Haemoglobin S betathalasaemia	5	1	1	1	8
Hereditary Persistence of Fetal Haemoglobin (HPFH) trait	4	0	2	1	7
Total	1744	1067	778	201	3790
% tested carrier	46	28	20	5	100

The study revealed that 46% (1,744/3,790) of carriers were detected among the general caste, while only 5% (201/3,790) were detected among the scheduled tribe population. However, 40% (146/365) of beta thalassemia carriers were found in the scheduled tribe population. Notably, 72.6% (146/201) of the total carriers in the scheduled tribe population were beta thalassemia carriers. Among the Muslim community, 81.3% (868/1,067) of hemoglobin E (Hb-E) carriers were detected, followed by 65.5% (510/778) among the Scheduled Caste, and 61.5% (1,074/1,744) among general caste pregnant women (Table 2).

Distribution carriers by age group

About 17% (2,150/12,767) of the pregnant women were below 19 years of age, with a carrier detection rate of 28.3% (608/2,150). The highest carrier detection rate was 43.2% (315/730) among those over 35 years, followed by 29.1% (1,124/3,859) in the 26-35 years age group, and 28.9% (1,743/6,028) in the 20-25 years age group. However, among the total carriers detected, 46.0% (1,743/3,790) were in the 20-35 years age group, and the lowest carrier detection rate was 8.3% (315/3,790) in those over 35 years (Table 3).

Table 3: Age wise distribution of pregnant women tested for thalasaemia and detected carriers' Dakshine Dinajpur district, West Bengal; India.

Age in group (years)	Total tested	Carrier detected	%
14-19	2150	608	28.3
19-25	6028	1743	28.9
25-35	3859	1124	29.1
> 35	730	315	43.2
Total	12767	3790	29.7

Table 4: The co-relation of haemoglobinopathies among religion and caste, of the study population, Dakshin Dinajpur district, West Bengal; India.

Indicator	Variables			P value
	Hindu	Muslim	Total	
Total haemoglobinopathies				
Normal	6371	2606	8977	
Disease/carrier	2723	1067	3790	0.32
Total	9094	3673	12767	
Beta thalasaemia carrier	Hindu	Muslim	Total	
Normal	6371	2606	8977	0.000

Continued.

Indicator	Variables			P value
Betathalasaemia carrier	314	51	365	
Total	6685	2657	9342	
Caste related				
Total haemoglobinopathies	General caste (GC)	Other caste	Total	
Normal	3693	2678	6371	
Disease/carrier	1744	979	2723	0.000
Total	5437	3657	9094	
Schedule Tribe (ST)	ST	Others	Total	
Normal	1894	7083	8977	
Beta thelasaemia carrier	146	168	314	0.00
Total	2040	7251	9291	
Haemoglobin E disease (Hb E)	Hindu	Muslim	Total	
Normal	6371	2606	8977	
Hb E disease/carrier	2304	976	3280	0.45
Total	8675	3582	12257	
Hb E among castes	General	SC/ST	Total	
Normal	3693	2678	6371	
Hb E disease/carrier	1531	773	2304	0.000
Total	5224	3451	8675	

Schedule caste (SC), Schedule Tribe (ST), General Caste (GC). p<0.05 is significant

Statistical analysis

There was no significant relationship between overall carrier detection (hemoglobinopathies) and religion (Hindu and Muslim) (p=0.32). However, Beta thalassemia carrier cases showed a significant positive relationship with Hindus compared to Muslims (p=0.000). Hemoglobinopathies were significantly more common in the general caste compared to other castes combined (p=0.000). Beta thalassemia carriers were significantly associated with the Scheduled Caste compared to other castes (p=0.000). There was no significant relationship between Hindus and Muslims for Hemoglobin E disease (p=0.45). Hemoglobin E disease and carrier status were significantly more common in the general caste compared to the Scheduled Caste (p=0.000) (Table 4). Hemoglobin E disease and carrier status were significantly more common in the general caste compared to the Scheduled Caste (p=0.000) (Table 4).

DISCUSSION

Thalassemia carriers among pregnant women were detected across the Dakshin Dinajpur district, West Bengal, India, in significant proportions.

The district comprises eight development blocks and two municipalities. The overall carrier detection rate among pregnant women in the district was 29.6%. In contrast, the prevalence of hemoglobinopathy in Southeast Asia is 4.13%, with 90% of these cases being Beta thalassemia and 4.3% alpha thalassemia.[12]

Our study showed that the Beta thalassemia carrier (trait) rate was 9.6%, and the Hemoglobin E carrier rate was 65%. A study at Medical College Kolkata in 2018 found that the Hemoglobin E (Hb-E) carrier rate was 54% and the Beta thalassemia trait rate was 34%.[13] These findings indicate that while the Hemoglobin E carrier rate is higher in our study, the Beta thalassemia trait rate is lower. The prevalence of Beta thalassemia carriers in India varies from 1% to 17% in different regions.[14]

Once any type of thalassemia is identified, the antenatal mother is treated as high-risk. Several studies have indicated that the outcome for thalassemia carriers during pregnancy may be uneventful, but some have noted problematic outcomes such as severe gestational anemia or pregnancy-induced hypertension.[15,16] During maternal death review in the district (2022-2023), it was revealed that 5/26 ante natal and post natal mother died. They had thalasemia carrier also.

These findings underscored the importance of preventing the transmission of the carrier trait. Proper counseling should be given to individuals of premarital age and antenatal mothers. The Government of India has engaged counselors at Adolescent Friendly Health Clinics (Annesha Clinics) to advise clients on thalassemia and other health issues. All pregnant women are encouraged to undergo thalassemia testing to identify their status, allowing for appropriate management. Primary screening of pregnant women for thalassemia has been found to be acceptable.[17]

Thalassemia carrier status in pregnant women is a multidisciplinary problem. It not only affects the health of the pregnant mother but also poses a risk of transmission to the baby. The prevalence of thalassemia carriers is highest in the Dakshin Dinajpur district. Maternal complications and deaths have occurred due to thalassemia carrier status. Approximately 86% of

pregnant women were found anemia (haemoglobin less than11 gm%). There were severe anemia (haemoglobin <7 gm%) was also noted during pregnancy in the district. There were notable differences in carrier prevalence among different races and religions. To reduce pregnancy-related complications, it is crucial to screen for thalassemia early in pregnancy and provide genetic counseling to the parents. Additionally, iron ferritin levels should be estimated before administering iron tablets to enhance hemoglobin levels. Raising awareness among higher secondary students about thalassemia will be helpful in reducing carrier transmission. Further studies on thalassemia in pregnancy may contribute to preventing carrier transmission and reducing maternal complications in the future.

This study has few limitations. There were only 11 months data were collected for analysis. Moreover, all pregnant women were not undergone thalasaemia carrier test. Though there is guideline for the test.

CONCLUSION

Thalasaemia carriers among pregnant women may complicate the pregnancy. Thalassemia carriers are predominant in North Bengal district of West Bengal; India. Early screening and awareness generation among the people may reduce the carrier in future. Further study in-depth is required to manage the pregnant women having thalassemia carriers.

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