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Research Article

Scarcity of Awareness and Level of Misconception about Thalassemia around the Population of Kolkata and Neighbouring Places- A Preliminary Study

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Abstract:

Thalassemia is a genetic disorder caused by the inheritance of mutated and abnormal genes involved in the production of hemoglobin from the parents. Thalassemia is most seen in Mediterranean region, Middle East, South-East Asia, Africa, and Indian subcontinent. It is also known as The Mediterranean Disease. The study aims to focus on the awareness of thalassemia among the population of Kolkata, emphasizing on college and university going students. A questionnaire-based survey was conducted among 55 willing participants in a 6-week tenure, from June to July 2022. The study used data visualization method and descriptive statistics for understanding the level of awareness, perception about thalassemia among the participants. The mean knowledge percentage was 25.43% which was analyzed by calculating the points obtained by the participants allotted to each question, the point range was 2–22 in which only 6 i.e., 10.9% of people had an excellent knowledge of the disease. The points acquired ranged from 8–22 i.e., 4 to 11 questions, more than half of the participants (60%, 33) believe there is a cure for thalassemia and almost 44% (24) participants believe screening of thalassemia can be done only by blood tests. This work focuses on the scarcity of information and degree of misconception about thalassemia. It calls for an urgent, routine need of thalassemia awareness program in the population.

Keywords: Thalassemia, genetic disorder, blood, hemoglobin, South-East Asia.

Introduction

Thalassemia is the commonest genetic disease of blood across the globe. Hemoglobin production is either totally or partially retarded based on the severity and types of the disorder[3, 10]. People suffering from thalassemia are unable to produce enough hemoglobin in the body which results in severe anemia[1,15]. The causes of thalassemia are the inheritance of abnormal and mutated genes involved in the production of hemoglobin from the parents. If one of the parents is a carrier of thalassemia, there is a chance that the child may become a carrier of the disease as well, although the child will not have any symptoms. But in case both the parent is a carrier there is a 50% probability of the child born to be a thalassemia patient. Thalassemia is widespread throughout the South-East Asia, Mediterranean region, the Middle East, Africa and the Indian[2,13] subcontinent. There are two main types of thalassemia namely Alpha Thalassemia and Beta Thalassemia[3,10]. Four alpha-globin and two beta-globin protein chains form hemoglobin and the severity of both the types depends on how many of four genes for alpha and two genes for beta globin chains are faulty or mutated. In case of Alpha Thalassemia, with one mutated gene patient has no symptoms And is a thalassemia carrier, this condition is known as alpha thalassemia minima. With two mutated gene patients have mild anemia, and this condition is known as alpha thalassemia minor. Furthermore, with three mutated genes patient has hemoglobin H disease, which is a type of chronic anemia and life-long blood transfusions are needed. Moreover, with four mutated genes a serious condition prevails where the fetus is affected i.e., fluid gets accumulated in several parts of the fetus body. This is the most severe form of alpha thalassemia and is known as Hydrops Fetalis. On the other hand, in beta thalassemia there is a lack of oxygen in many parts of the body is seen because of low hemoglobin levels. Among all the different types of thalassemia major Cooley's Anemia is the most crucial one. Its clinical presentation occurs within 6 to 24 months of birth. Infants affected with Cooley's Anemia fail to grow and become gradually pale having more dreadful consequences[1].

Background of the study

Despite the overwhelming progress of medical sciences Thalassemia continues to be one of the principal challenges across the global periphery. India is not an exception either.

Predominantly, lack of knowledge, authentic information about the disorder are the chief attributes towards it. Various misconceptions regarding this disease are seen in the society which needs to be eradicated with the factual terms of the disease. Previous studies showed inadequate and superficial knowledge about thalassemia. Complications regarding the disease is varying among population, henceforth, awareness about the disease can bring down the incidence rates to a considerable extent.

Objective

To assess awareness about thalassemia among the population of Kolkata, West Bengal, India emphasizing on college and university going students.

Materials and Method

This is a questionnaire-based study which was circulated among the willing participants that is 55 individuals in the form of google form in an online mode of circulation. The study used data visualization method and descriptive statistics[4] for understanding the level of awareness among the participants. These participants are from four different age group that is 16 – 20, 20 – 24, 24 – 28 & 28 and above. The questions asked were simple so that even a layman can understand what it means and can answer according to his/her knowledge which will provide a relevant data for this survey.

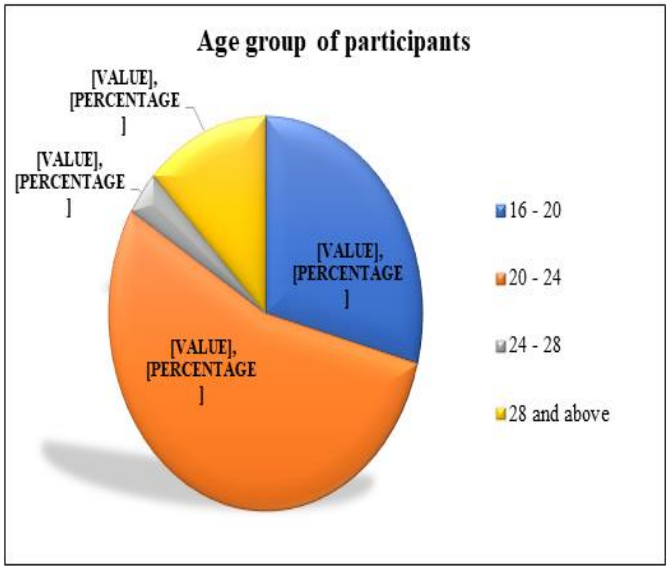


Fig-1: Age wise distribution of the participants

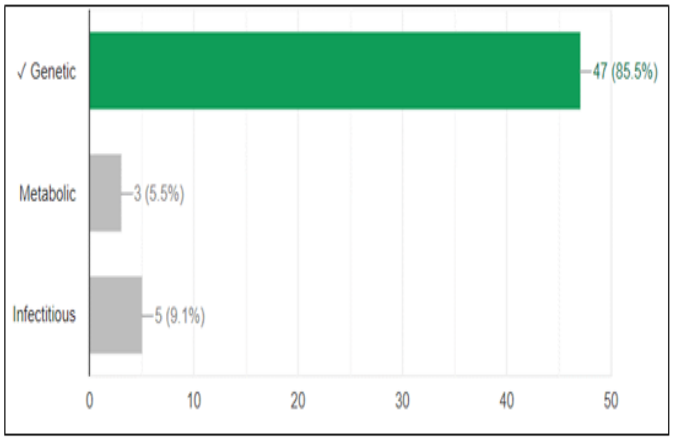
Results / Discussion

The degree of distribution of a disease is intimately associated with the knowledge, legitimacy of information and extent of conception about the disease among the members of a population. This work was performed among the population of Kolkata, West Bengal, India focusing on the level of awareness about thalassemia among college and university going students. The sample size was 55 as the study was for a limited time of 6 weeks. In this tenure questionnaires were prepared, circulated them among the known and unknown individuals of different age groups. Based on the collected data following statistics were learned:

Table 1: Frequency and Percentage of Age group and Education level of the study participants (N = 55)

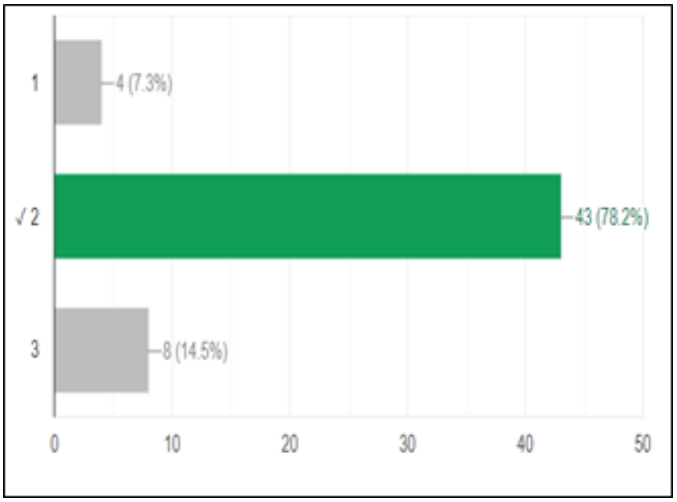
Variable	Frequency	Percentage (%)
Age group in years		
16 – 20	16	29.1
20 – 24	30	54.5
24 – 28	2	3.6
28 and above	7	12.7
Education Level		
High School	10	18.18
Senior Secondary	6	10.9
Undergraduate	30	54.54
Postgraduate	3	5.45
Working Professionals	4	7.27

Table 2: Knowledge base of thalassemia across the participants



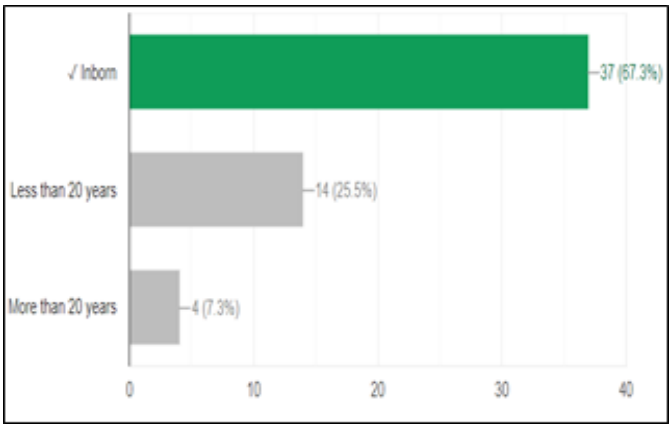
There are 47 correct responses (85.5%) out of the 55 participants and among the participants 5 of them believe it is an infectious disease. This is very surprising to see as students are all from school, college or even universities.

Table 3: Response of participants about the types of thalassemia



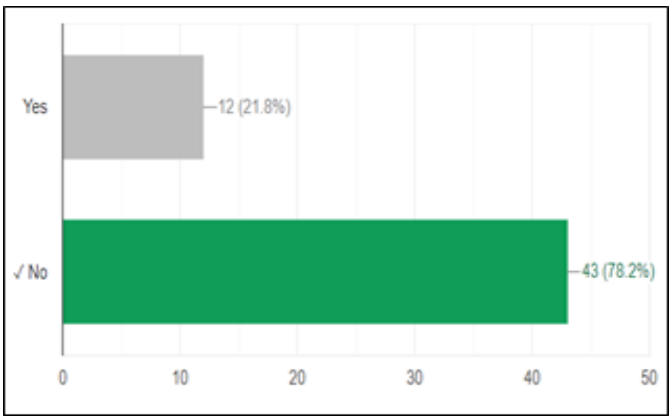
78.2% of the participants i.e., 43 out of 55 know that two types of thalassemia exist. Most of them have given the correct answer. Indeed, it is good to know that majority of the participants are aware of this fact.

Table 4: Response of participants about the epidemiology of thalassemia



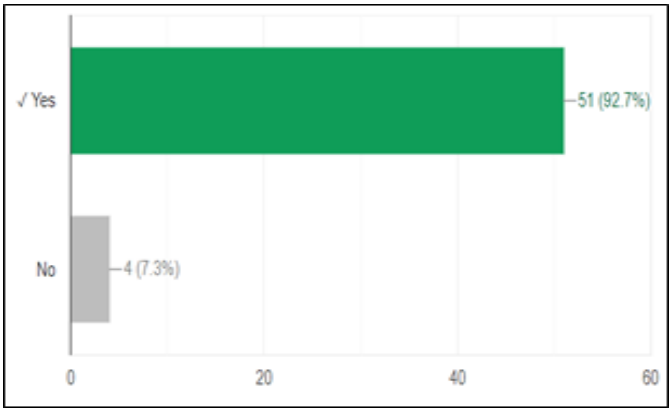
Thalassemia is a genetic disease, so it is obvious for it to be an inborn disease. 67.3% have given a correct answer but 14 out of 55 i.e., 25.5% of them believe it happens at a young age after birth which shows the relative scarcity of information about thalassemia.

Table 5: Response of participants about the cure of thalassemia



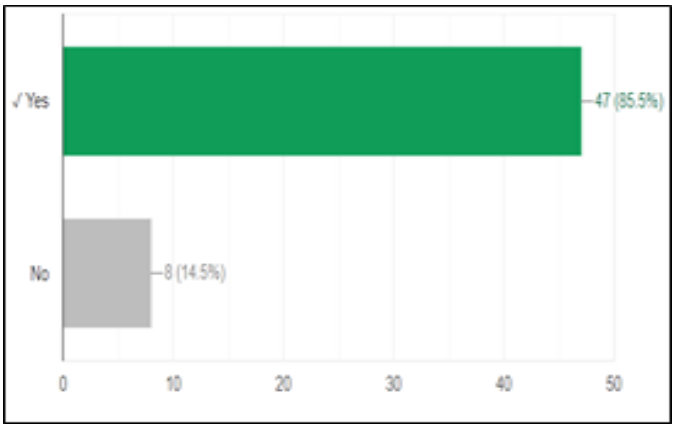
Out of the total number of participants 78.2% i.e., 43 got this point right but 21.8% still got this wrong which is a quite substantial number even in this short survey.

Table 6: Response of participants about the carrier status of thalassemia



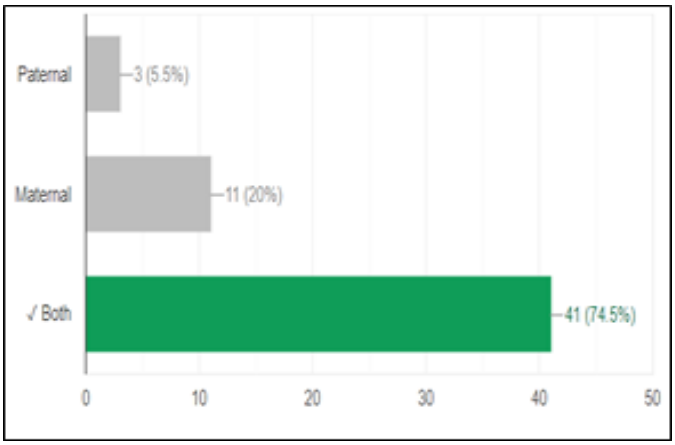
It is good to see among 55 participants 92.7% i.e., 51 of them gave a correct answer and seem to know about the carrier status of thalassemia and only 4 individuals (7.3%) got it wrong.

Table 7: Response of participants on mortality due to thalassemia



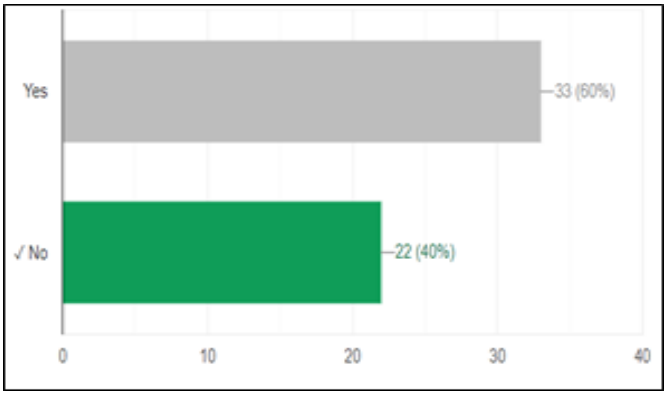
47 out of 55 participants (85.5%) got it right and 14.5% of them got it wrong who believe that people cannot die from thalassemia.

Table 8: Response of participants about the mode of inheritance of thalassemia



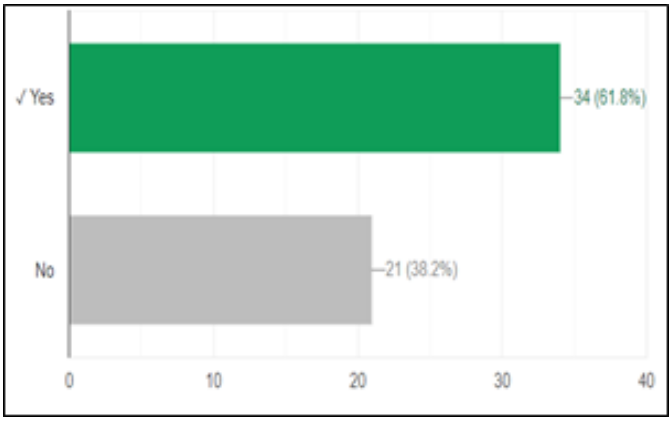
41 out of 55 participants i.e., 74.5% of them replied in the correct manner and 20% (11) of the participants believe it is maternal, while rest 5.5% believe it is paternal.

Table 9: Response of participants on cure of thalassemia



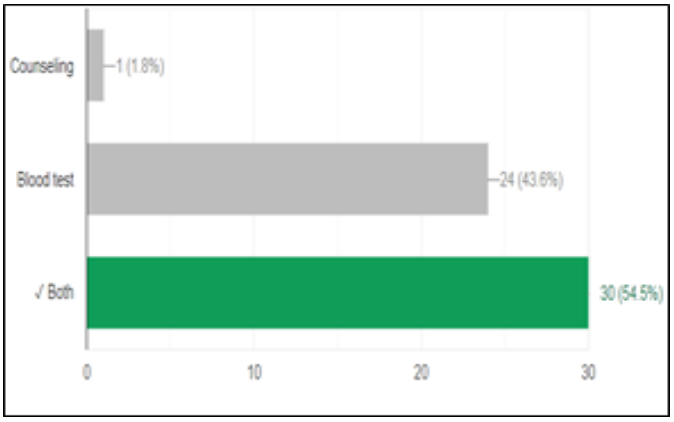
Even though, there is a treatment for thalassemia, it is not curable. Only 22 out of 55 participants got it right (40%) and 60% of them believe it is curable. This depicts that the awareness regarding this point is very less among the population.

Table 10: Response of participants about the thalassemia prevention



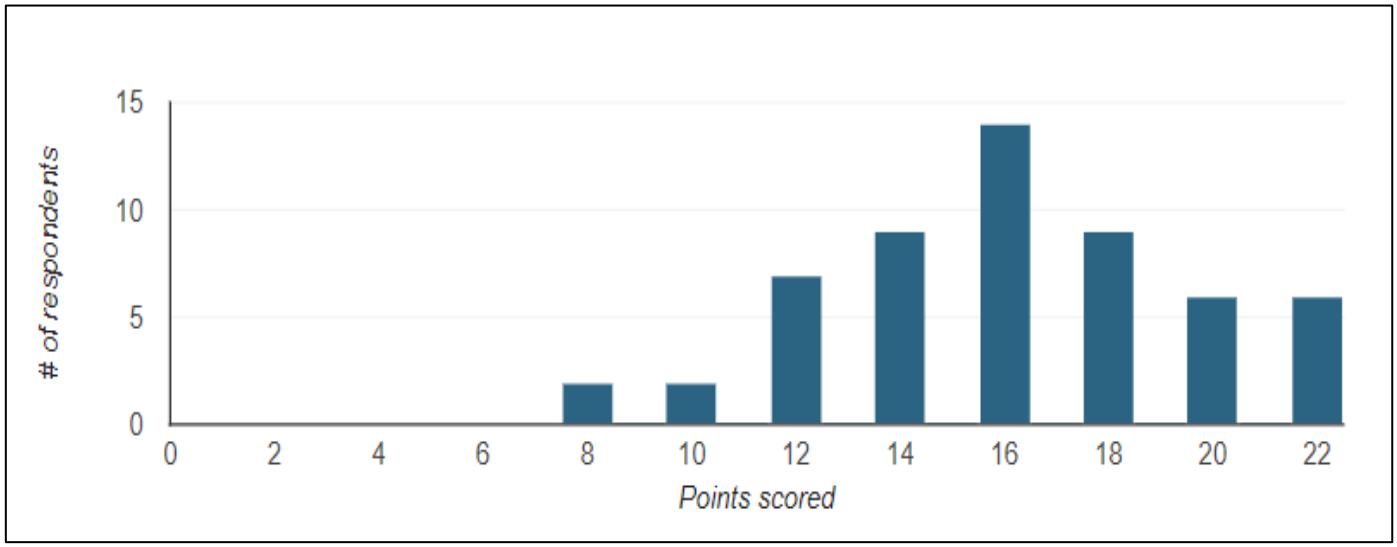
Regarding prevention, 34 participants out of 55 i.e., only 61.8% know it exists and 38.2% are still unaware of this fact.

Table 11: Response of participants about thalassemia counseling



Only 54.5% are aware of the fact how screening for thalassemia is done. Only 1 of the entire participating members knows about counselling and 43.6% are unaware of counselling and got it wrong.

Table 12: Discussion based on responses of the participants (score-wise)



For each question asked in the google form 2 points were allotted to check the range of awareness depending on the points scored by the participants. 14 (25.45%) participants have average knowledge about thalassemia and have scored 16 points each. Only 6 (10.9%) have excellent knowledge about thalassemia and have scored 22 out of 22 points. As clear in the graph above 6 (10.9%) people have scored 20, 9 (16.36%) people have scored 18 each and again 9 (16.36%) scored 14 points each out of 22, 7 (12.72%) people scored 12 points out of 22, 2 (3.64%) people scored 10 points and 2 (3.64%) people scored 8 points each out of 22 making a total of 55 participants. According to this survey the amount of knowledge people have is average if examined per question but in general the level of awareness is very poor among the people.

In a similar study regarding awareness among the university students about thalassemia[5,11,12] has concluded that the students from a science background have substantial knowledge and are more (28.6%) aware about the disease compared to the students of arts and humanities, commerce.

One of the recent studies was carried out to check the knowledge, attitude, and practice about thalassemia among general population in Outpatient Department at a Hospital of Kolkata the author stated that the public don't have adequate knowledge on thalassemia, whereas their attitude was good, but practice was below par, and they need a high level of legitimate information[6]. On the same note, another study reveals the public knowledge regarding thalassemia was found to be poor among general population[7]. Overall, in all the above articles including this survey concludes the level of awareness is low be it in rural or urban population.

Conclusion

It was seen in this study that there is an inadequate knowledge of awareness about thalassemia hovering across the community. Perhaps this might be a reason that the participants neither studied about this disease properly nor they experienced being close to the patients or their family members who suffer and know about this disease. The mass media is a great source of encouraging and making more programs such as dramas, talk shows, movies, etc., which are very favorable and easily reachable to almost all the general population of a country to help increasing the awareness by showing real patients who suffer from thalassemia. This study highlights the prevalence of various myths and a low level of knowledge regarding thalassemia and this calls for an urgent

need of thalassemia awareness programme[4,8]. Also, screening tests for thalassemia should become compulsory for every student so that, at least they know and show interest in learning about this type or similar blood disorders[9]. Furthermore, the study findings reveal how the present youth i.e., the study individuals who are college and university going students are unaware about a lot of facts about thalassemia even though digital platforms are plenty at their disposal. However, the number of data included in this work is still low to say the least. Therefore, further studies should be performed on a regular basis to come up with more detailed data in line with the conclusion.

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