

ORIGINAL RESEARCH

A study to assess the effect of intervention on awareness regarding Thalassemia of Higher Secondary School Teachers of Alipurduar District, West Bengal

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ABSTRACT

Introduction- Thalassemia is an inherited blood disorder, ranging from thalassemia major to minor. The disease is completely preventable if community awareness can be generated. The study was done to assess the awareness regarding thalassemia among the Higher Secondary School teachers and to find out the effect of a structured awareness materials on awareness of Higher secondary school teachers regarding Thalassemia. **Materials & Methods-** A community-based Intervention Study method was followed with a sample size of 110, using a structured interview schedule. After interview intervention was given as a form of structured awareness material and again knowledge regarding thalassemia was assessed after the post intervention. **Result-** Means of pre-intervention and post intervention knowledge score are respectively 25.62 and 37.17; mean difference of knowledge score is 11.55. While 66% respondent are below median knowledge score in preintervention, 44% are above or equal to the median score. There is significant difference in knowledge scores from the other studies which may be due different socio demographic status. **Conclusion-** after the intervention, comparison between pre-intervention and post-intervention total knowledge score shows significant increment in knowledge score. This study findings also show intervention with a structured awareness material can be effective for the high school teachers.

Keywords: Awareness, Thalassemia, Awareness Material, Knowledge

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INTRODUCTION

Thalassemia is a blood disorder, characterized by abnormal hemoglobin production, where there is increased destruction of Red blood cell (hemolysis). There are various severities of the disease from thalassemia major-the severe form in which the patient needs regular blood transfusions in order to survive, to thalassemia minor- an asymptomatic carrier state, with patients of thalassemia intermedia in between. This is an inherited (passed on to the children from parents) blood disorder, in which the inheritance is autosomal recessive, that is both parents must carry the defective gene to pass on thalassemia major to the child. ¹

Thalassemia major is the state in which body is not able to produce enough hemoglobin to meet out the requirement and thus becomes dependent on blood of

donor. People with a thalassemia mutation, only in one gene are known as carriers or are said to have thalassemia minor. Thalassemia minor results in no anemia or very slight anemia. People who are carriers do not require blood transfusion or iron therapy, unless proven to be iron deficient.² In Thalassemia's there is anemia, that is the hemoglobin in the blood is less than the normal level, this is due to the rapid breakdown of the red cells, a process called hemolysis. The patients of thalassemia major have severe anemia, which needs regular blood transfusions for treatment. ¹ β -Thalassemia, originally named Cooley's anemia initially was described by Dr. Cooley's in 1925 in Detroit as an inherited blood disease. Genetic disorders are disorders that can be passed from one generation to the next. They result from some disorders in gene or chromosome

structure. Genetic abnormalities can occur at the moment of ova and sperm fusion or even earlier, in the meiotic division phase of the gametes. Any alteration in the pattern of chromosomes results from abnormalities or 'mutations', on the chromosomes. Others may arise due to defects in the genes.³ It is genetic blood disorder which can be fatal if proper treatment is not received. It is characterized by partial or no production of alpha or beta global chains which form part of the structure of the hemoglobin in red blood cells. Regular blood transfusions allow patients with thalassemia to grow normally and be active. Unfortunately, transfusions result in deadly accumulation of iron in the heart and liver. If the excess iron is not removed, then the patients may suffer from a premature death due to iron overload. Nowadays, drugs designed to remove excess iron (iron chelators) have significantly changed the prognosis of thalassemia. Patients can grow and develop normally, with relatively normal heart and liver functions. Patients are living longer and having families of their own. Medical advances continue and promise to improve the life expectancy and quality of life further for those living with thalassemia.⁴ However, a cure remains to be found. The genetic cause of thalassemia was one of the first genes discovered in the 1970's, yet 30 years later, gene therapy still eludes thalassemia patients. Bone marrow transplantation is not only expensive, it is a very hectic process finding a matching bone marrow.⁵ Thalassemia is a global public health problem, with an estimated 900,000 babies with this disorder expected to be born during the next 20 years. The incidence of hemoglobin (Hb) E approaches 60% of population in many regions of south East Asia. The carrier rate for β Thalassemia major gene varies from 1 to 3 % in southern India to 3 to 15% in northern India.⁶ Globally, it is estimated that there are 270 million carriers with abnormal hemoglobin's and thalassemia's, of which 80 million are carriers of β -thalassemia. Recent surveys suggest that between 300,000 and 400,000 babies are born with a serious hemoglobin disorder each year (23,000 with β -thalassemia major) and that up to 90% of these births occur in low or middle-income countries.⁷ India is the thalassemia capital of the world with 40 million carriers and over 1,00,000 thalassemia majors under blood transfusion every month. Earlier studies have shown that an estimate of around 8,000 - 10,000 new births with major disease each year. ⁸ Haemoglobin E has prevalence of 3-10% an β -thalassemia of 3.5% in North Bengal and it is believed to be harboured mostly by Rajbanshis, who form majority of the local population in North Bengal. The only way thalassemia can be prevented is by preventing the birth of affected children.⁹ Proper identification of various haemoglobin variants including β -thalassemia trait can prevent occurrence of more serious disorders like thalassemia major in new-borns.⁷ for this definite need of awareness among the normal population³ so

that they can take the preventive measures to control thalassemia.

JUSTIFICATION

The patient depends on lifelong blood transfusion at every 3-4 weeks interval. Besides financial and emotional stress, regular arrangement of safe blood is the biggest challenge the family faces. Thalassemia is not curable through medicines, but totally preventable. It is therefore important that awareness about it prevention is created at mass level so that its occurrence can be prevented. There is a huge influence of teachers among the adolescent period, students follow the teacher as a guide, so if the teachers are having proper awareness about thalassemia, then broadly the teachers may also guide or aware their student about thalassemia, so that the students in future may practice the minimum preventive measures to control and prevention of thalassemia. So this study was done to assess the awareness of Higher Secondary School Teachers of Alipurduar District regarding thalassemia with the following research questions What is the perception of Higher Secondary School Teachers of Alipurduar District regarding thalassemia? What is the impact of a structured awareness material of Thalassemia on the higher secondary school teachers of Alipurduar district?

Based on the following hypothesis

H0 – There will be no increment of knowledge score after the intervention.

H1- There will be increased knowledge score after intervention

AIMS AND OBJECTIVES

The study is aiming to assess the effect of intervention on awareness regarding thalassemia among the higher secondary school teachers of Alipurduar district with following two objectives.

- To assess the awareness regarding thalassemia among the Higher Secondary School teachers of Alipurduar District.
- To find out the effect of a structured awareness materials on awareness of Higher secondary school teachers regarding Thalassemia.

MATERIALS AND METHODS

Study Type- A community-based Intervention Study method was followed to conduct the study.

Study Design- Longitudinal study using structured awareness material.

Study population- Higher secondary school teachers of Alipurduar district,

Inclusion criteria- Permanent school teachers who are teaching student in class 9-12 standard.

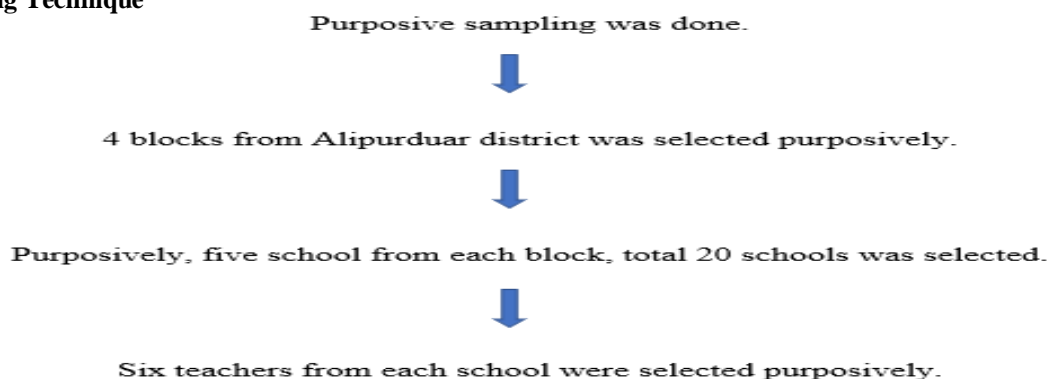
Exclusion criteria- Teacher who are working on deputation and those who are not willing.

Sample size- Sample size was calculated using the formula, $N = z^2 PQ/d^2$ (where P=50% (with assumption that 50% teachers are aware of thalassemia), Q= (1-P)

=50%, d= 10 (allowing 10% absolute precision), z value at 95% confidence level is 1.96 , $z^2=3.84$)
 So according to this formula the sample size is 96 assuming 20% non-response, final sample size 118.

To make it a round figure and ease of calculation a total of 120 teachers was taken.

Sampling Technique



Study Tools- Pre-structured, pre-tested interview schedule was used as the tools of the study.

Data collection procedure- Validated structured interview schedule was used to collect the data, which was conducted in the month of December and January. Data on socio demographic status and knowledge variables on thalassemia among the school teachers was collected by using structured schedule at 7 days interval (pre and postintervention). The pre-intervention knowledge was assessed using a pre structured pre tested interview schedule, and post intervention knowledge assessment was done on the

very same schedule, after discussion and providing structured awareness material to them.

Data analysis- Mean and standard deviation of knowledge score, paired T-test was done to check the statistical significance of the mean knowledge score. All the collected data was analyzed using statistical software (STATA/SE 12.0), after entry of the data in a master sheet using MS Excel. After cleaning of the data, a total of 110 sample population remained for data analysis.

The question of the schedule was subdivided as follows.

General Questions
1. Have you ever heard the term thalassemia?
2. What type of Disease is Thalassemia?
3. What type of disorder happens in Thalassemia?
4. How thalassemia is Transmitted?
5. Is there any role of consanguineous marriage in thalassemia?
6. How many types of thalassemia can happen?
7. Can the Thalassemia carriers donate blood to other patient?
Screening and Diagnosis
8. What is the diagnostic test for thalassemia?
9. Is there a clinical procedure to know if the pre-natal baby is Thalassemic or not?
10. Should Thalassemia minor parents go for thalassemia screening in fetal stage of the baby?
Prevention and Treatment
11. Is blood transmission mandatory in the thalassemia Traits
12. Do the thalassemia major patients need lifelong blood transfusion?
13. How Thalassemia Can be prevented?
14. What can happen if both the parents are thalassemic carrier/trait?
15. Will the baby always be thalassemic if either of the parents is carrier.
Complications
16. Can any complication occur after prolonged blood transfusion to the thalassemia patients?
17. What may be the complications?

Ethical issues- Vulnerable populations- There is no such population covered in the study.
Risks-No such risk is there.

Benefits-If the awareness material can generate and increase awareness regarding thalassemia, the teacher also can pass the awareness to their students, thus the

vulnerable adolescent students can be motivated to take necessary steps to prevent thalassemia in future.

Ethical clearance: -Ethical clearance was obtained from institutional Ethics committee of the Society for Health and Demographic Surveillance.

Confidentiality- Proper confidentiality has been maintained, data has been collected separately, and all documents have been kept anonymous. **Informed consent-** Written consent has been taken from each study participant after giving full information on how the study would be carried out and how the collected data would be handled to ensure confidentiality and privacy. **Study Variables-** Section 1- data was collected regarding socio-demographic status, which includes, age, sex, marital status, religion, caste, by a validated interview schedule. Section 2- Which includes knowledge about the term thalassemia, type of disease, transmission method, role of consanguineous marriage, carrier transmission, diagnostic procedure, transfusion needs, preventable nature, curability, want to know if carrying thalassaemic baby during pregnancy, risk of child of having the diseases depending on parent's genetic status.

Operational definitions

Thalassemia- Thalassemia is an inherited blood disorder in which the body makes an abnormal form of haemoglobin. If both of your parents are carriers of thalassemia, you have a greater chance of inheriting a more serious form of the disease. The three main forms of thalassemia are alpha thalassemia, beta thalassemia, and thalassemia minor.¹⁰ **Thalassemia trait-** People who have thalassemia trait (also called thalassemia minor) carry the genetic trait for thalassemia but do not usually experience any health problems except perhaps a mild anaemia.⁸ **Knowledge-**in the study knowledge means having adequate knowledge score depending on the response of the questionnaire. **Consanguineous marriage-** A union between two individuals who are related as second cousins.⁹ **Iron overload-** Iron overload or Hemochromatosis is a disease in which too much iron builds up in the body due to prolonged blood transfusion and it is toxic. In hemochromatosis, body absorbs more iron than you needed as no natural way to get rid of this extra iron. It stores it in body tissues, especially the liver, heart, and pancreas. The extra iron can damage the organs. Without treatment,

it can cause organ failure.¹⁰ **Hereditary Disease-**Genomics and family health history play a role in many diseases such as cancer and heart disease. These diseases are partly the result of how your genes interact with your behaviours, such as your diet and physical activity, and your environment. If you have a family health history of a disease, you are more likely to get that disease yourself, but you can take steps to prevent disease or find it early.¹¹

Communicable disease-Communicable, or infectious diseases, are caused by microorganisms such as bacteria, viruses, parasites and fungi that can be spread, directly or indirectly, from one person to another. Some are transmitted through bites from insects while others are caused by ingesting contaminated food or water.¹²

Non-communicable Disease- Noncommunicable diseases (NCDs), also known as chronic diseases, tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behaviours factors. The main types of NCDs are cardiovascular diseases (like heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes.¹⁵ **Bone marrow transplantation-** A stem cell or bone marrow transplant replaces damaged blood cells with healthy ones. It can be used to treat conditions affecting the blood cells, such as leukaemia and lymphoma. Stem cells are special cells produced by bone marrow (a spongy tissue found in the centre of some bones) that can turn into different types of blood cells.¹³ **Autosomal recessive-** Autosomal recessive is one of several ways that a trait, disorder, or disease can be passed down through families. An autosomal recessive disorder means two copies of an abnormal gene must be present in order for the disease or trait to develop.¹²

Pre-natal- Before birth; during or relating to pregnancy.¹⁶

Practical consideration

Field work- Schools was visited by travelling with motorcycle, Motorized Rickshaw, Rickshaw and bus.

Logistics- Printed predesigned structured questionnaire, printed informed consent form, ball pen, camera for photography etc. was carried during field visit.

RESULTS & ANALYSIS

Age Group	Frequency	Percent
26-30	9	8.2
31-35	42	38.2
36-40	32	29.1
41-45	9	8.2
46-50	2	1.8
51-55	10	9.1
56-60	6	5.4

Total	110	100
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Table 1 showing age group wise frequency and percentage of the total study population where. Age group 26-30 have (9, 8.2%), 31-35 have (42, 38.2%), 36-40 have (32, 29.1%), 41-45 Have (9, 8.2%), 46-50 have (2, 1.8%), 51-55 have (10, 9.1%), 56-60 have (6, 5.4%).

Sex	Freq	Percent
Male	60	54.55
Female	50	45.45

Table 2 showing 60 (54.55%) was male and 50 (45.55%) was female.

Variable	Freq.	Percent
Married	94	85.45
Unmarried	16	14.55

Table 3 showing among the study population (94, 85.45%) was and (16, 14.55%) was unmarried.

Religion	Freq.	Percent
Hindu	102	92.73
Muslim	4	3.64
Christian	3	2.73
Other	1	0.91

Table 4 showing the Frequency and percentage of study population according to their religious view. Where, Hindu (102, 92.75%), Muslim (4, 3.64%) Christian (3, 2.73) and other (1, 0.91 %).

Caste	Freq.	Percentage
General	57	51.82
Schedule Caste (SC)	34	30.91
Schedule Tribe (ST)	8	7.27
OBC	11	10

Table 5 showing among the study population 57 (51.82%) was from general caste frequency and percentage of caste where General (57,51.82%), Schedule caste (SC) (34, 30.91%), Schedule Tribe (8, 7.27%), OBC (11,10%)

Variable	Mean	Std. Dev.	Median	Min score	Max score
Preintervention knowledge score	25.62	4.12	26	17	37
Post intervention knowledge score	37.17	3.47	38	24	40

Table 6 shows that mean of knowledge score in pre-intervention and post intervention are respectively 25.62 and 37.17, SD 4.12 and 3.47 median 26 & 38, range 17 to 37 and 24-40.

Knowledge score	Frequency	Percentage
<Median	66	60
>=Median	44	40

Table 7 shows that 66% respondent showing less than median knowledge score in preintervention therefore greater than or equal median score respondent are 44%.

Knowledge score	Mean knowledge score	Mean difference	df	t value	Remarks
Pre-intervention	25.62	11.55	109	22.05	S**
Post-intervention	37.17				

Table 8 shows that mean knowledge score in pre-intervention and post-intervention is 25.62 & 37.17, mean difference is 11.55, the mean difference of knowledge is statistically significant at a level of 0.001 level of significance.

Knowledge area	Minimum knowledge score	Maximum knowledge score	Mean	Std. Dev.
General Questions	8	14	10.89	1.27
Screening and Diagnosis	3	6	4.23	0.99
Prevention & Treatment	5	9	7.18	1.04
Complication	1	10	3.32	2.43

Table 9. showing mean and standard deviation of 10.89 and 1.23 respectively for general questions and 4.23 and .099 respectively for screening and diagnosis.

Knowledge areas	Mean	Std. Dev.	Min	Max
General Questions	13.67	0.76	10	14
Screening and Diagnosis	5.80	0.50	4	6
Prevention & Treatment	8.85	1.07	6	10
Complication	8.82	2.20	1	10

Table 10. showing mean and standard deviation of 13.67 and 0.76 respectively for general questions and 5.80 and 0.50 respectively for screening and diagnosis.

Area	Mean	Mean diff	Std. Dev.	t value	df	Remarks
Post-intervention	13.67	2.78	0.76	20.69	109	Highly significant
Pre-intervention	10.89		1.27			

Table 10a. shows mean and standard deviation of 13.67 and 0.76 respectively for post intervention and 10.89 and 0.50 respectively for pre-intervention with a mean difference of 2.78 which is statistically significant.

Area	Mean	Mean diff	Std. Dev.	t value	df	Remarks
Post-intervention	5.80	1.57	0.50	t = 14.72	109	Highly Significant
Pre-intervention	4.23		0.99			

Table 10b. shows mean and standard deviation of 5.80 and 0.50 respectively for post intervention and 4.23 and 0.99 respectively for pre-intervention with a mean difference of 1.57, which is statistically significant.

Area	Mean	Mean diff	Std. Dev.	t value	df	Remarks
Post-intervention	8.85	1.67	1.07	11.72	109	Highly Significant
Pre-intervention	7.18		1.04			

Table 10c. shows mean and standard deviation 8.85 and 1.07 respectively for post intervention and 7.18 and 1.04 respectively for pre-intervention with a mean difference of 1.67, which is statistically significant.

Area	Mean	Mean diff	Std. Dev.	t value	df	Remarks
Post-intervention	8.89	5.57	2.2	16.57	109	Highly Significant
Pre-intervention	3.32		2.43			

Table 10d. shows mean and standard deviation 8.89 and 2.2 respectively for post intervention and 3.32 and 2.43 respectively for pre-intervention with a mean difference of 16.57, which is statistically significant.

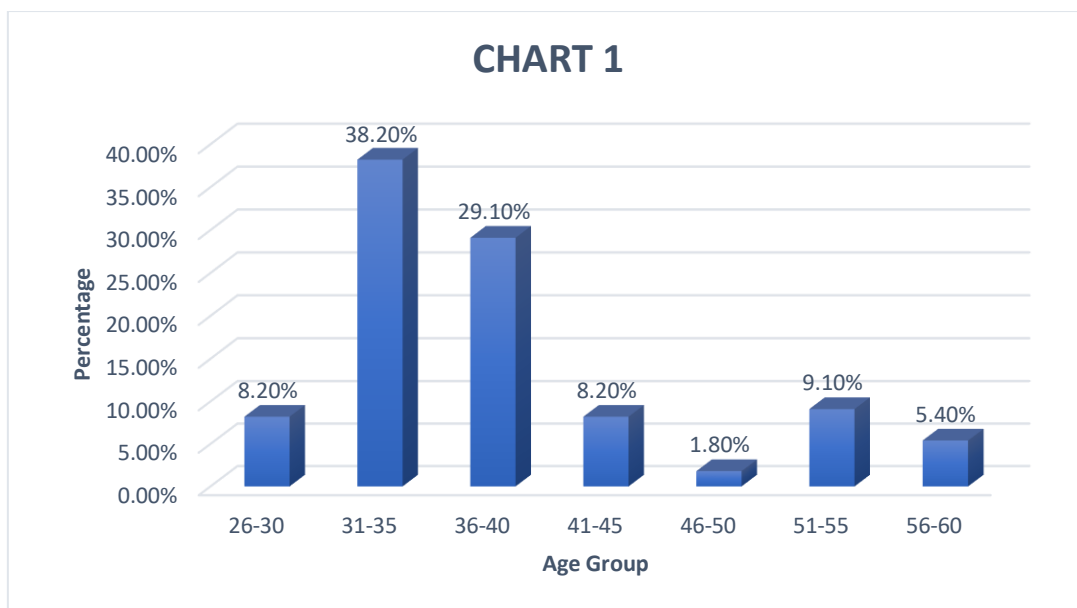


Table 1 & Chart 1. Shows 38.2% of study population belongs to age group 31-35 and 1.8% of population belongs to age-group 46-50.

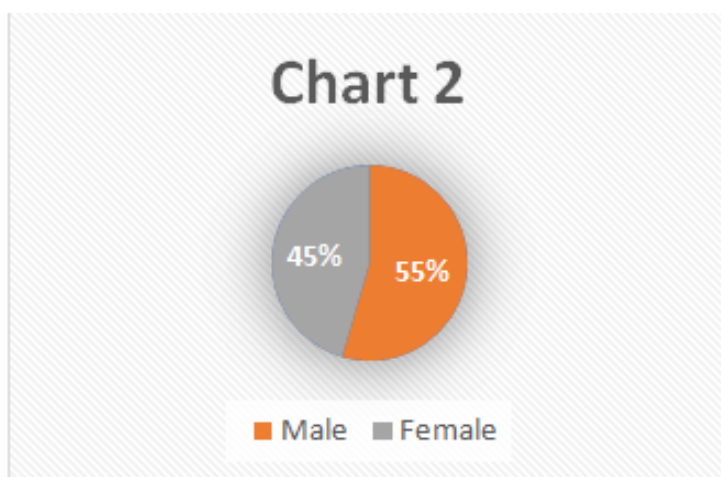


Table 2 and chart 2 shows 55% of the study population is male and 45% is female.

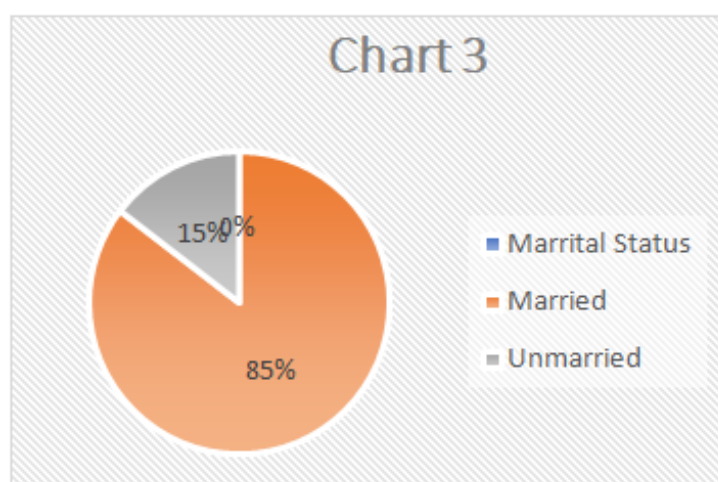


Table 3 and Chart 3 shows 85.45% of study population is Married and 14.55% of the study population is Unmarried.

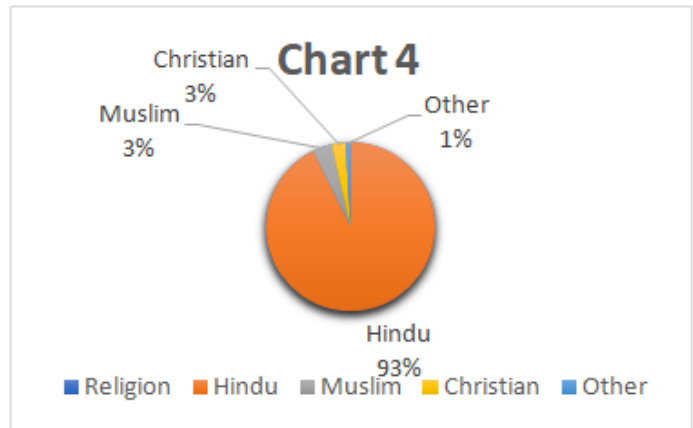


Table 4 and Chart 4 shows 92.75% of the population is Hindu and 2.73% of the study population is Muslim.

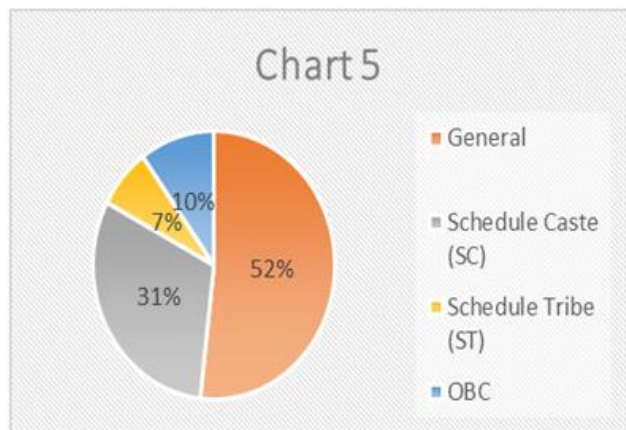


Table 5 and Chart 5 shows 82% of the study population is general and 7.27% belongs to (Schedule Tribe) ST category.

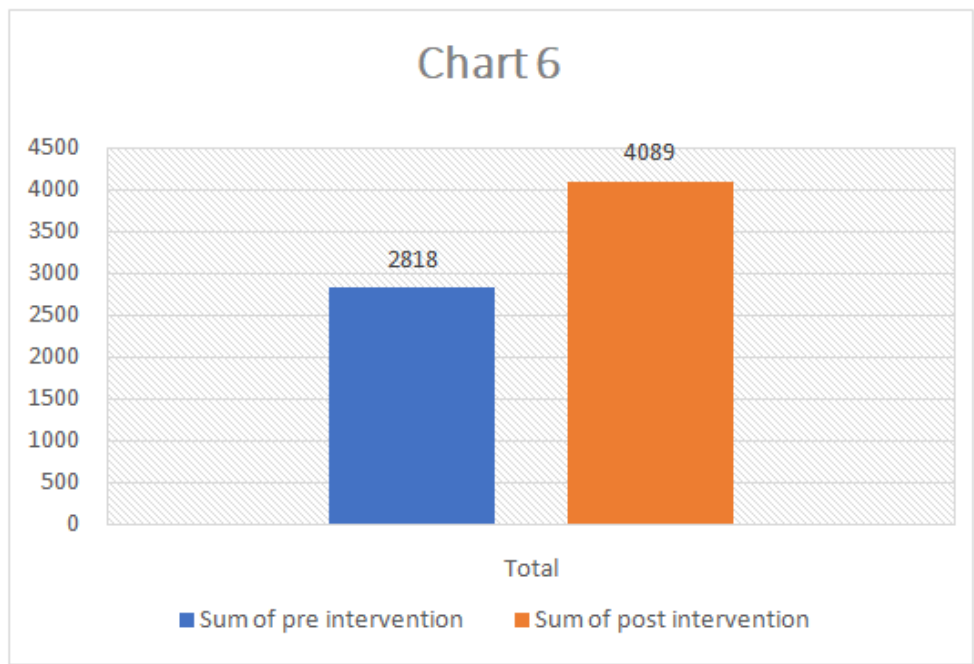


Chart 6. shows comparison between pre-intervention and post-intervention total knowledge score. Where Sum of pre-intervention knowledge score is 2818 and sum of post-intervention knowledge score is 4089, the finding is statistically significant.

Table No-6. shows that means of pre-intervention and post intervention knowledge score are respectively 25.62 and 37.17; SD 4.12 and 3.47; median 26 and 38, range 17-37 and 24-40.

DISCUSSION

Thalassemia is an inherited blood disorder, ranging from thalassemia major to minor. The disease is completely preventable if community awareness can be generated. Teachers being pillars of society may play a pivotal role in this regard. So, an interventional longitudinal study was conducted to assess the pre-existing knowledge regarding thalassemia among 110 high school teachers of Alipurduar Districts, West Bengal and if there is any increment in knowledge after supplementing with structured awareness material with the following research questions-

- What is the perception of Higher Secondary School Teachers of Alipurduar District regarding thalassemia?
- What is the impact of a structured awareness material of Thalassemia on the higher secondary school teachers of Alipurduar district?
- And with following two objectives.
- To assess the awareness regarding thalassemia among the Higher Secondary School teachers of Alipurduar District.
- To find out the effect of a structured awareness materials on awareness of Higher secondary school teachers regarding Thalassemia.

Table No-7. shows while 66% respondent are below median knowledge score in preintervention, 44% are above or equal to the median score. Where in a different study by Pujani M. et al shows 75.25% MBBS students had good knowledge about thalassemia,¹¹

There is significant difference in knowledge scores, which may be due to the MBBS student are gradually being introduced to medical related terms and disease conditions.

In another similar study by M Basu It has been seen that 57.94 % of the population have adequate knowledge regarding thalassemia among the outpatient department at a tertiary care hospital of Kolkata.¹²

In another study in South eastern Iran, results indicated that 14.7% students had good knowledge regarding thalassemia. The significant variation in knowledge regarding thalassemia due to the mean age group of the school students (16.9 ± 0.8 years)¹³

Table 8 shows that mean knowledge score in pre-intervention and post-intervention is 25.62 & 37.17, mean difference is 11.55, the mean difference of knowledge score is statistically significant. In a different study by Lulu Eva Rakhmilla et al., shows that average knowledge score of high school students after the intervention with video media was significantly increase (from mean 11.53, SD 1.968), mean 14.95, SD 1.463).¹⁴

The difference in result score can be due to video graphic intervention which can illustrate something that happens in real life that affects a person's motivation in understanding a material.

Table 9. showing mean and standard deviation of 10.89 and 1.27 respectively for general questions; 4.23 and 0.99 respectively for screening and diagnosis; 1.04 and 7.18 respectively for Prevention & Treatment; 3.32 and 2.43 respectively for Complications related questions in pre-intervention.

Table 10. showing mean and standard deviation of 13.67 and 0.76 respectively for general questions; 5.80 and 0.50 respectively for screening and diagnosis; 8.85 and 1.07 respectively for Prevention & Treatment; 8.82 and 2.20 respectively for Complication related questions in post-intervention.

Table 10a. shows t value 20.69 at df 109 between means of pre-intervention and post-intervention knowledge score for general questions; which is statistically significant.

Table 10b. shows mean difference of pre-intervention and post intervention knowledge score for Screening and Diagnosis questions which is statistically significant with a t value 14.72 at df 109.

Table 10c. shows pre-intervention and post intervention knowledge score difference for Prevention and Treatment questions. Where, t value 11.72 at df 109; which is statistically significant.

Table No-10d. shows difference between means of pre-intervention and post intervention knowledge score with t value 16.57 for Complications questions which is statistically significant at df 109.

SUMMARY

Thalassemia is an inherited blood disorder, ranging from thalassemia major to minor. The disease is completely preventable if community awareness can be generated. The study was done to assess the awareness regarding thalassemia among the Higher Secondary School teachers and to find out the effect of a structured awareness materials on awareness of Higher secondary school teachers regarding Thalassemia. Means of pre-intervention and post intervention knowledge score are respectively 25.62 and 37.17; mean difference of knowledge score is 11.55. While 66% respondent are below median knowledge score in preintervention, 44% are above or equal to the median score. There is significant difference in knowledge scores from the other studies which may be due different socio demographic status.

For general questions mean and standard deviation is 10.89 and 1.27 respectively in pre-intervention and 13.67 and 0.76 respectively in post-intervention. 4.23 and 0.99 respectively in pre-intervention and 5.80 and 0.50 respectively in post intervention for screening and diagnosis; 1.04 and 7.18 respectively in pre-intervention and 8.85 and 1.07 respectively for post intervention for Prevention & Treatment; 3.32 and 2.43 respectively in pre-intervention and 8.82 and 2.20 respectively in post-intervention for Complications related questions in pre-intervention.

CONCLUSION

High prevalence of Thalassemia in India as well as West Bengal, high costs of treatment of Thalassemia major patients as well as the social problems, the mental burden of families and lack of certain treatment make us assume it as the top health priority to be prevented. One of the basic prevention axes is concentration on public education, and the most important target group is adolescent students because they are in pre-marriage. The findings revealed that some basic awareness material can increase the knowledge regarding thalassemia among the high school teachers. Comparison between pre-intervention and post-intervention total knowledge score, depicts sum of pre-intervention knowledge score is 2818 and sum of post-intervention knowledge score is 4089. Moreover, this study finding also shows intervention with a structured awareness material can be effective for the high school teachers.

RECOMMENDATION

It has been seen from the present study that even teachers don't have adequate knowledge on thalassemia; and they need a high level of information regarding Thalassemia. This finding may be a representative of general population. However, further studies in large scale taking general population as target should be carried out to know the exact magnitude of awareness. In the present research applying the structured awareness material was significantly efficient in promotion of the teacher's knowledge toward Thalassemia. Health education on the knowledge and prevention of thalassemia needs to be implemented on a much broad scale. Awareness program should be spread in the community level, so that they can effectively participate in the program and be motivated for premarital screening of thalassemia.

LIMITATION

There were some limitations of this study

1. Shortage of time,
2. The study could not be performed in the general population.

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