

A STUDY ON KNOWLEDGE, ATTITUDE AND PRACTICE ABOUT THALASSEMIA AMONG GENERAL POPULATION IN OUTPATIENT DEPARTMENT AT A TERTIARY CARE HOSPITAL OF KOLKATA

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ABSTRACT

Background & Objectives: BETA – thalassemia is the most common single gene disorder in India. A WHO update on b-thalassemia in India indicated a carrier frequency of 3–4%, which gave the current national population between 35.6 and 47.5 million carriers of the disorder nationwide. This study was conducted to assess the knowledge, attitudes and practice about thalassemia among general population.

Methods: A descriptive cross sectional study carried out in a tertiary teaching hospital in Kolkata, India from April 2014 to June 2014 among 428 study population using a pre designed pre-tested structured schedule by face-to-face exit interview method. All statistical analyses were conducted using Statistical Package for Social Sciences (SPSS 22.0).

Results: About 57.94% of the study population had adequate knowledge; 83.88% had positive attitude and only 14.02% had good practice about thalassaemia. The significant contributing factors of thalassemia knowledge and attitude were age (middle age), gender (male), residence (urban), marital status (married), education level (bachelor degree), occupation (students & service holders), and Per Capita Monthly Income (high SE scale).

Interpretation & conclusions: General public don't have adequate knowledge on thalassemia; their attitude was good but practice was very poor; and they need a high level of information.

Key words: Thalassemia, Knowledge, Attitude, Practice.

INTRODUCTION

Thalassaemia is the commonest monogenic disorder in the world that result from absence of or decreased globin chain production.¹ A person can get thalassemia trait or disease by inheriting the genes from their parents.² The two main types of thalassemia are alpha and beta : Individuals with alpha thalassemia don't produce enough alpha globin chains causing excess beta globin chains; those with beta thalassemia don't produce enough beta globin chains, causing excess alpha chains. The common signs and symptoms of thalassaemic diseases include pale skin, retarded growth & puberty, anaemia, enlarged spleen, and increased susceptibility to infections.³ High prevalence of Beta-Thalassaemia is present in Mediterranean, Middle-East, Transcaucasus, Central Asia, Indian subcontinent, and Far East⁴. The highest incidences are seen in Cyprus (14%), Sardinia (12%), and South East Asia⁵.

Globally annual affected conceptions with major thalassaemias are about 56,000 (β and α thalassaemias are 42409 & 13 466 respectively) including 30, 000 who need regular transfusions and 5500 who die perinatally due to thalassaemia major. Worldwide estimated annual births with β thalassaemias are 40,618; about 25,511 are transfusion dependant; annual number starting transfusion are 2989 (11.7%); 22,522 die annually because not transfused. About 97630 known patients are currently living with regular transfusions; 37,866 (39%) obtain iron-chelation therapy and 3000 die annually in their teens or early 20s due to iron overload.⁶

BETA – thalassemia is the most common single gene disorder in India.⁷ About 10% of the world thalassaemia children are born in India every year.⁸ A 1989 WHO Working Group estimated 3.9% carrier frequency for b-thalassemia in India.⁹ A WHO update on b-thalassemia in India indicated a similar carrier frequency of 3–4%, which gave the current national population between 35.6 and 47.5 million carriers of the disorder nationwide^{10,11}. Certain communities in India like Sindhis, Gujratis, Punjabis, and Bengalis, are more affected with beta thalassemia, the incidence vary from 1 to 17%¹².

Problem of Haemoglobinopathy in India was first described by Professor J.B. Chatterjee who initiated thalassaemia diagnosis and research work in West Bengal¹³; in 1959 he described that the incidence of HbE and Beta thalassaemia trait in West Bengal was 3.9 % and 3.7% respectively.¹⁴ In a screening study in West Bengal in collaboration with ICMR (multicentric Jai Vigyan Mission project on thalassaemia control; 2000 to 2005) it was found that carrier rate of β thalassaemia and HbE is around 5.1 % and 4% respectively. In a recent study, the carrier rate in rural West Bengal is shown to be around 16.23% in general population.¹⁵

Thalassaemia can be controlled by preventive health services. Education about the risks of conceiving a child with thalassaemia combined with family planning services is an effective approach to inform the behaviours of those at risk. Laboratory blood tests can diagnose the status of thalassaemia in a person. Screening and genetic counselling are associated with numerous benefits, including

decreased number of thalassaemic newborns.¹⁶ With this background this study was conducted to assess the knowledge, attitude and practices about thalassemia among general population.

MATERIALS AND METHODS

Study type and study setting: This was an institution based observational descriptive study, cross sectional in design, carried out in a tertiary teaching hospital in West Bengal, India during the 3 months period from April 2014 to June 2014. **Study population** was patients attended general OPD of IPGME&R/SSKM hospital on the month of May 2014. **Inclusion criteria** were aged 18 and above, both sexes, not seriously ill, gave informed written consent to participate in the study. **Exclusion criteria** were aged below 18 years, seriously ill, not gave informed written consent.

Sample size has been estimated using EPI Info version 6.0 computer program. With a type-1 error of 5% ($\alpha=0.05$) and 95% level of significance, it was estimated that 460 study population would be required in order for the study to detect a 50% difference in odds ratio (OR) at a power level equals 90%.¹⁷ Therefore the target has been set to reach 460 participants in order to achieve the objective of the study.

Sampling technique: Selection of the study population was done by simple random sampling among population attending general OPD during the study period.

Study tool was a pre designed pre tested structured KAP schedule which was designed by a research team, including an expert physician involved in counselling for many years, an expert professor of community medicine and a haematologist with history of practice in thalassemia ward. Based on available literature on KAP on thalassemia, the schedule was developed with items that would not contravene our socio cultural teaching. Close-ended questions, in a checklist format, were designed to investigate people's knowledge towards thalassemia while open-ended questions were designed to explore people's opinion towards the reasons for their answer selection. The schedule was composed of three main parts- the first part-socio-demographic data (7 items - age, gender, marital status, residence, educational level, occupation & Per Capita Monthly Income/PCMI); the second part was concerned about participant's knowledge (15 items with a total score of 15) and the third part consisted of their attitude & practices. The attitude and practice was assessed using 8 statements.

The schedule was piloted among 30 randomly selected participants attended the same setting to assess its clarity, reliability & validity. After some minor modifications the questionnaire was re-evaluated by the same panel of experts. The content and construct validity of the schedule was

confirmed by a research team and as well as well as the reliability of the schedule was controlled by the test-retest method & inter-rater reliability were high ($\kappa=0.81$). The participants who were included in the pilot study were not included in the whole study sample.

Study variables: Socio demographic variables(age, gender, residence, marital status, educational level, occupation, PCMI); **knowledge** (hereditary nature, transmitted by blood, role of consanguineous marriage, types, meaning of carrier, symptoms of diseased & carrier, diagnosed by blood test, lifelong blood transfusion, necessity of PMCS, preventable nature, curability, places for treatment, chance of thalassaemic child if both parents are carrier/one parent is carrier); **attitude** (prefers consanguineous marriage, like to marry a thalassaemia patient/carrier, want to know if carrying thalassaemic baby during pregnancy, whether thalassaemia carriers should go for children, like to donate blood for thalassaemia patients, importance of PMCS, importance of MTP, importance of public training about thalassaemia); **practices** (consanguineous marriage within family, PMCS done among family members, married to a carrier person, having major/minor thalassaemia within family, donated blood for thalassaemia patients, pre-marital counselling done, prenatal testing for thalassaemia child among family members, MTP done after positive result).

Data collection procedure: The purpose of the study as well as methodology was explained in details. Candidates who agreed to participate in the study were asked to sign a consent form and were provided with contacts of the investigators for any further inquiries. Then data collection was done by face-to-face exit interview method. At last, any questions they had were answered. They were ensured about their anonymity and confidentiality. Only those who positively responded to the first question: 'Have you ever heard of thalassaemia?' were eligible to answer the subsequent questions.

DATA ANALYSIS

Correlation of some variables were studied using Chi square test. The odds ratios (OR) and 95% confidence intervals (CI) were calculated. A p value of <0.05 was interpreted as significant. All statistical analyses were conducted using Statistical Package for Social Sciences (SPSS 22.0).

Operational definitions:

1. Illiterate – A person can be considered illiterate if he/she cannot read and write with understanding in any language should be above 7 years of age.¹⁸
2. Socio economic classification: As per Modified B.G.Prasad Scale 2013¹⁹

3. Consanguineous marriage: A union between two individuals who are related as second cousins or closer, with the inbreeding coefficient (F) equal or higher than 0.0156 where (F) represents a measure of the proportion of loci at which the offspring of a consanguineous union is expected to inherit identical gene copies from both parents.²⁰
4. Carrier of thalassemia: People who have thalassemia trait (thalassemia minor) carry the genetic trait for thalassemia but do not usually experience any health problems except a mild anemia. A person may have either alpha thalassemia trait or beta thalassemia trait, depending upon which form of beta protein is lacking.²¹
5. Diagnosis of Thalassemia : Doctors diagnose thalassemias using blood tests, including a complete blood count (CBC) and HPCL (High Performance Liquid Chromatography) or automated capillary electrophoresis tests.²²
6. Pre Marital Carrier Screening (PMCS): A premarital test in which couples that are going to get married are tested for genetic, infectious and blood transmitted diseases to prevent any risk of transmitting any disease to their children.²³
7. Pre marriage counseling: Educational and supportive advice rendered to people planning marriage by a clergy member skilled in counseling, a therapy professional, or some other properly skilled individual. Premarital counseling might take the shape of guidance and responses to queries covering a wide array of issues.²⁴
8. Pre natal diagnosis (PND) : It is a screening test for pregnant women done when there is a chance that the baby could be affected, mother is offered counselling to discuss whether she want to have a test for the unborn baby. This test finds out whether the unborn baby actually has thalassaemia - and which type.²⁵

RESULTS

A total of 460 persons were approached and 432 (93.91%) consented to participate in the study; about 4 schedule were excluded from the study due to incomplete responses. A total of 428 study population were therefore included in the analysis.

Regarding the socio demographic characteristics of the study population, it was seen that out of total 428 study population, 347 (81.07%) were males; mean age was 45.4 years (ranging from 18 to 78 years) & median was 45 years; 68.22% were from rural area; 73.60% were married; their level of education ranged between illiterate to postgraduate; 32.24% completed their bachelor degree; 77.57% of them were employee while 13.32% were still students; 36.45% belonged to class II followed by

class III (31.31%) as per Modified B.G. Prasad Scale 2013.

Table 1 demonstrated the Knowledge, Attitude and Practice (KAP) scores about thalassemia among the study population. Concerning knowledge, the mean score of knowledge was 8.62 \pm 0.3. For each question, a correct response was given a score of one, and an incorrect was scored as zero, total possible score was 0-15, with higher scores indicating better knowledge. Study population with scores of 9(60%) and above were considered as having "adequate knowledge" and scores below 60% were interpreted as "inadequate knowledge". About 248 (57.94%) participants had adequate and 180 (42.06%) had inadequate knowledge about thalassaemia. Similarly, the attitude was assessed using 8 questions, (negative and positive attitude if the correct questions score were less than 50% and more than or equal to 50% correct scores). About 83.88% and 16.12% of the study population had positive and negative attitude respectively. The mean score of attitude and practice were 6 \pm 2.83 and 4 \pm 76 respectively (score \pm standard error) respectively. Also the practices were assessed using 8 questions, (bad and good practices if the correct questions score were less than 50% and more than or equal to 50% respectively). Only 14.02% had good practices and rest 85.98% had bad practices.

Table 2 demonstrated indicators of knowledge of the study population towards thalassemia and main source of knowledge. About 60.05% of them knew that thalassemia is a hereditary disorder .The unknown part of information consisted mainly of curability (48.36%) and probability of having thalassemia child due to marriage between a healthy person & a carrier (27.57%) and between two carriers (45.09%). The three most frequently cited sources of information about thalassaemia were health care providers (37.38%), electronic media (31.77%) and friends & relatives (29.21%).

Table 3 revealed indicators of attitude and practice among participants towards thalassemia. Overall only 07.94% of the participants preferred consanguineous marriage. About 80.14% had positive attitude regarding marrying a thalassemia carrier .Their response were supportive of PND (92.06%). About 99.06% of the participants viewed that premarital screening for thalassaemia carrier is necessary. Only 57.48% were of the opinion that couples who are thalassaemia carriers should have children. About 81.31% believed that it is better to terminate pregnancy than to let the child suffer after he/she is born.

Regarding practice, 4.44% of the study population had consanguineous marriage within their family; only 2.80% had history of marrying a thalassemia carrier and 13.32% done PMCS for thalassemia. About 12.38% participants had pre

marriage counselling and 4.9% had PND during pregnancy.

Results of association between socio demographic characteristics and knowledge & attitude obtained from logistic regression modelling (**Table 4**). The six significant contributing factors of thalassemia knowledge were gender (male), residence (urban), marital status (married), education level (higher secondary & above), occupation (students & service holders), and PCMI (high socio economic scale). Similarly the six significant contributing factors of thalassemia attitude were age (18-38

years), gender (male), residence (urban), education (secondary & above), occupation (students & service holders), and PCMI (upper socio economic scale).

Results of association between socio demographic characteristics and knowledge & attitude were obtained from logistic regression modelling (**Table 5**). The significant contributing factors of thalassemia knowledge and attitude were age (middle age), gender (male), residence (urban), marital status (married), education level (bachelor degree), occupation (students & service holders), and PCMI (high SE scale).

Table 1: Knowledge, Attitude and Practice scores of thalassemia among study population (N=428)

Knowledge (15 items)	Number (n)	Percentage (%)
Adequate (score ≥ 9 or 60%)	248	57.94
Inadequate (score < 9 or 60%)	180	42.06
Attitude (8 items)	Number (n)	Percentage (%)
Positive (score ≥ 4)	359	83.88
Negative (score < 4)	69	16.12
Practice (8 items)		
Good (score ≥ 4)	60	14.02
Bad (score < 8)	368	85.98
Total	428	100

Table 2: Distribution of the study population according to knowledge about Thalassaemia and sources of information (N=428)

Information sought	Number of (n) correct response	Percentage (%)
Hereditary (genetic) nature of thalassaemia	257	60.05
Transmission by blood	289	67.52
Positive role of consanguineous marriage	228	53.27
Different types of thalassemia	36	08.41
Aware of carrier status of thalassaemia	225	52.57
Thalassemia carriers have no symptoms & look normal	48	11.21
Symptoms of thalassemia disease	85	19.86
Diagnosis of disease & carrier by blood test	353	82.48
Preventable nature of thalassemia	296	69.16
Usefulness of premarital carrier screening (PMCS)	272	63.55
Complete cure is not possible	207	48.36
Usual place of treatment (Government hospitals)	252	58.88
Requirement of blood transfusion throughout life	285	66.59
Marriage between a healthy person and a carrier lead to a major thalassaemic child (no)	118	27.57
Marriage between two carrier lead to a major thalassaemic child (yes)	193	45.09
Sources of information about thalassemia (Multiple response)		
Health Care Professionals	160	37.38
Electronic Media	136	31.77
Print Media	82	19.16
Friends and Relatives	125	29.21
Seminars and Lectures	29	06.77
Periodical notes (monthly magazines)	08	01.87

Table 3: Distribution of the study population according to attitude and practice about Thalassemia (N=428)

Information sought	Number (n)	Percentage (%)
Attitudes about thalassaemia		
Prefer consanguineous marriage	34	07.94
Like to marry a thalassaemic carrier	343	80.14
Want to know if carrying thalassaemic baby during pregnancy (PND)	394	92.06
Whether thalassaemia carriers should go for children	246	57.48
Like to donate blood for thalassaemia patients	423	98.83
Importance of blood test for thalassaemia (PMCS) before marriage	424	99.06
Want MTP if pre-natal diagnosis revealed thalassaemic child	348	81.31
Importance of public training about thalassaemia	387	90.42
Practices about thalassaemia		
Consanguineous marriage within family	19	04.44
PMCS done for thalassaemia among family members	57	13.32
Marrying a carrier person among family members	12	02.80
Having major/minor thalassaemia patient within family	05	01.17
Donated blood for thalassaemia patients	111	25.93
Pre marriage counselling done among family members	53	12.38
Prenatal testing for thalassaemia child done	21	04.90
MTP done in the family after knowing positive result of prenatal diagnosis	10	2.33

Table 4: Association between knowledge & attitude towards thalassemia with socio-demographic variables (N=428)

Variables	Knowledge				Attitude		
	Adequate N =248	Inadequate N =180	Total N =428	Chi square; p value	Positive N=359	Negative N=69	Chi square; p value
Age							
18-38	142(56.13)	111(43.87)	253(59.11)	1.72; 0.42	221(87.35)	32(12.65)	6.53; 0.03
38-58	93(62.00)	57(38.00)	150(35.05)				
58-78	13(52.00)	12(48.00)	25 (05.84)				
Gender							
Male	214(61.67)	133(38.33)	347(81.07)	10.45; 0.001	297(85.59)	50(14.41)	3.98; 0.04
Female	34(41.98)	47(58.02)	81(18.93)				
Residence							
Urban	105(77.21)	31(22.79)	136 (31.78)	30.35; 0.000	122(89.71)	14(10.29)	5.01; 0.02
Rural	143(48.98)	149(51.02)	292 (68.22)				
Marital status							
Married	194(60.82)	125(39.18)	319(73.60)	4.23; 0.04	269(84.33)	50(15.67)	3.76; 0.05
Single	54(49.54)	55(50.46)	109(24.53)				
Education							
Illiterate	12(42.86)	16(57.14)	28(06.54)	18.50;0.001	13(46.43)	15(53.57)	40.20;0.000
Primary	28(41.18)	40(58.82)	68 (15.89)				
Secondary	56(54.37)	47(45.63)	103(24.07)				
Higher secondary	57(62.64)	34(37.36)	91(21.26)				
Graduate &above	95(68.84)	43(31.16)	138(32.24)				
Occupation							
Unskilled labourers	54(43.20)	71(56.80)	125(29.21)	33.50; 0.000	105(84.00)	20(16.00)	31.70; 0.000
Skilled labourers	23(53.49)	20(46.51)	43 (10.04)				
Service	87(71.90)	34(28.10)	121(28.28)				
Business	23(53.49)	20 (46.51)	43 (10.04)				
Housewives	17(43.59)	22(56.41)	39 (09.11)				
Students	44(77.20)	13(22.80)	57 (13.32)				
Per capita monthly income (PCMI)* Modified B.G. Prasad Scale 2013							
Class I	31(75.61)	10(24.39)	41(09.58)	13.40; 0.01	37(90.24)	04(09.76)	57.30; 0.000
Class II	95 (60.90)	61 (39.10)	156(36.45)				
Class III	79 (58.96)	55 (41.04)	134(31.31)				
Class IV	20 (46.51)	23 (53.49)	43(10.05)				
Class V	23 (42.59)	31 (57.41)	54(12.61)				

Table 5: Univariate analysis of Socio- Demographic factors on Thalassemia knowledge and attitude (N=428)

Factors	Knowledge			Attitude		
	Adequate (N=248)	Inadequate (N=180)	Odds Ratio (95% CI)	Positive (N=359)	Negative (N=69)	Odds Ratio (95% CI)
Age (median age<45years)	182(57.23)	136(42.77)	0.89(0.56-1.42)	271(86.58)	42(13.42)	1.98(1.11-3.51)
Gender (male)	214(61.67)	133(38.33)	2.22(1.33-3.74)	297(85.59)	50(14.41)	1.82(0.96-3.42)
Residence(urban)	105(77.21)	31(22.79)	3.52(2.17-5.75)	122(89.71)	14(10.29)	2.02(1.04-3.97)
Marital status(married)	194(60.82)	125(39.18)	1.58(0.99-2.50)	269(84.33)	50(15.67)	0.48(0.21-1.06)
Education(higher secondary & above)	152(66.38)	77(33.62)	2.11(1.40-3.19)	206(89.96)	23(10.04)	2.69(1.51-4.80)
Socio-economic class(I&II)	126(63.96)	71(36.04)	1.58(1.05-2.38)	180(91.37)	17(8.63)	3.07(1.65-5.76)

DISCUSSION

In the present study more than half (57.94%) participants had adequate knowledge about thalassaemia which was corroborative with the finding by Pausri at Srinagarind hospital.²⁶ However it was far higher than study by Seyam et al at Guilan university²⁷ and Moghaddan et al at Iran²⁸ where only 12.17% and 14.7% respectively had adequate knowledge about the disorder. Unlike the study from Myanmar by Han et al²⁹, rural Bengal by Srivastava et al³⁰ and Lahore by Ishaq et al³¹ where 28%, 22.27% and 44.6% respectively knew that thalassemia is a genetic disorder; our study revealed that about 60.05% had correct knowledge about the inherited nature of the disease. About 67.52% of this study population recognized that thalassemia is a blood disorder, which was almost similar as shown by Srivastava et al.³⁰

In response to the question about different types of thalassemia, only 08.41% of the present study population answered correctly which was also in line with study by Srivastava et al.³⁰ Almost one fifth of the study participants knew correctly about some symptoms of thalassemia disease. This finding was nearly similar to finding of another previous studies conducted at Thailand (27%)²⁶ and Bengal(20.88%).³⁰ Almost half of the study population were aware about carrier status of thalassemia but only one fifth knew about symptoms of it. However in rural Bengal study the rate was only 21.62% & 10.07% respectively.³⁰

Regarding the diagnosis of the disease and carrier by blood test, 82.48% people had correct knowledge; whereas in Thailand study only 45.6% and in Lahore study only 33% had correct information.^{26,31} Two third of the study population of this study knew that blood transfusion is the treatment of the disease; this finding was contradictory to finding Bahrain study where only one third (33.9%) knew it.³² About 63.55% agreed that premarital screening can prevent thalassemia which was similar to studies by Ishaq et al.³¹ and Hajeri et al.³² About 45.09% knew that both parents have to be carriers of beta thalassemia to have an

affected child; almost similar to result of the study by Hajeri et al at Bahrain (40.5%).³²

The significant contributing factors of thalassemia knowledge were male gender, married individuals, urban residence, higher education level, students & service holders and higher income. However in Iran study²⁸ and Bahrain study³², females showed better knowledge of thalassemia than males. In Bahrain study³² university students, professionals, married individuals had better knowledge of thalassemia like our study. Also in Srinagarind hospital study significant contributing factors of thalassemia knowledge were education level and family income.²⁶

However a study in Pakistan revealed that even educated respondents were ill-informed about thalassaemia.³³ In Iran study²⁸ urban population had more knowledge towards thalassemia which was corroborative with the finding of the present study. In this study, no relationship was found between thalassemia knowledge and age group whereas in Bahrain study, respondents aged 60 and above and those falling in the 40-49 years age group gave more correct answers compared to the rest of age groups.³² In the present study, commonest source of information about thalassemia was from health care professionals; similar to result of study by Pausri²⁶ and Ishaq³¹.

ATTITUDE

In the present study, 83.88% had positive attitude towards thalassemia which was corroborative with the findings by Pausri et al²⁶, Moghaddam et al²⁸ and Srivastava et al.³⁰ In our study, majority (80.14%) were willing to marry a carrier. However in Bengal study very few had the attitude to marry a thalassemia carrier.³⁰ Majority of our study population (90.42%) agreed with the need of public training about thalassemia which was nearly similar to study by Pausri et al.²⁶ and Seyam et al (92.33%).²⁷ Positive attitude was more among females than males and among more educated than less educated in our study and in Iran study.²⁸ About 92.06% of participants had the attitude to have prenatal diagnosis of thalassemia; which was in line with the finding of Thailand²⁶ and Myanmar.²⁹

About 81.31% agreed that they will terminate pregnancy if they were definitely carrying a

thalassemic child and that it is better to terminate pregnancy than to let the child suffer after he/she is born which was corroborative to Thailand study (88%)²⁶, Myanmar study (70%)²⁹ and Lahore study (86.1%).³¹

PRACTICE

Only 4.44% of our study participants had consanguineous marriage in their family whereas it was as high as 81.7% at Lahore.³¹ We recognized some **limitations** in our study: First of all, there was little relevant literatures available regarding thalassemia among population of West Bengal. Also because of the small sample size the results obtained may not truly reflect awareness of Thalassemia in the population. Moreover there is a possibility that some of the responses to certain questions being inaccurate

CONCLUSIONS AND RECOMMENDATIONS

It was seen from our study that general public don't have adequate knowledge on thalassemia; their attitude was good but practice was very poor; and they need a high level of information. Health education on the knowledge and prevention of thalassemia needs to be implemented on a much larger scale. Awareness program with community participation will be effective as people witness the seriousness of the disease in their day-to-day life.

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