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Original Research Article

A Cross-Sectional Study Assessing Knowledge, Attitude and Practice (KAP) of Parents with B Thalassemia Children about Thalassemia

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Abstract

Aim: To assess the knowledge, attitude, and behaviours of parents with β thalassemia children about thalassemia.

Material and Methods: A cross-sectional study was conducted in the Department of Community Medicine, Darbhanga Medical College and Hospital, Laheriasarai, Darbhanga, Bihar, India from April 2018 to March 2019. We randomly selected 1,248 peoples (18–75 years old). However, selection of study area and respondents in this study were based on convenience sampling. Participants were selected from different places, such as public institutions, houses and local markets in order to capture them from various backgrounds in the community. Only the people who consented were included in this study. Furthermore, those who were <18 years of age were excluded from this study.

Results: Of the total respondents, only 47.4% (592/1,248) had heard of thalassemia. These 592 participants were considered for next questions. The urban residing participants (65.1%) who had heard of thalassemia were nearly twice as high as the participants (38.2%) who lived in semi-urban or rural settings. All of the socio-demographic characteristics except gender are significant (p<0.001) who heard the term thalassemia. Only 18.2% of participants have good knowledge on thalassemia. In the multivariable logistic regression model of potential predictors of knowledge on thalassemia, participants were more aware when they were in undergraduate (aOR: 23.445; 95% CI: 5.767–95.315) or they were graduate (aOR: 24.88; 95% CI: 6.238–99.232) and post-graduate (aOR: 33.18; 95% CI: 7.864–140.001). We found a significant association between overall knowledge on thalassemia and the education level of the respondents (p<0.001). However, 20–35 aged (189) and middle-income respondents (200) were more conscious about thalassemia, but there was no statistical significance found

Conclusion: Our study has specifically pointed out knowledge deficits regarding the genetics and pattern of inheritance of thalassemia major. Insights of the report depict that more concise and specially designed programs for disseminating awareness regarding thalassemia should spread across the country.

Keywords: Thalassaemic, Golovin, Cultural, Transplantations, Therapy

Introduction

B-thalassemia is an autosomal recessive single gene disorder characterized by defective production of haemoglobin and excessive destruction of Red Blood Cells. Haemoglobin is formed of four protein subunits, normally two α and two β. Genetic mutation in the gene encoding for β subunits of proteins, results in reduced or totally absent synthesis of β globin chain leading to the formation of abnormal haemoglobin or even to the absence of β haemoglobin. The defect causes an Abnormal development of Red Blood Cells and ultimately anaemia [1]. Mainstay of therapy of thalassemia major is transfusion therapy and management of its complications. Hyper transfusion remains the most accepted regimen in most parts of the world in which the haemoglobin level above a minimum of 10 g% is maintained [2]. Only definitive therapy available for thalassemia major which gives permanent cure is bone marrow transplantation, which is available at very few centres and cost is very high and is about 50,000 USD in developing countries [3]. It has been estimated that more than 1,00,000 people are born every year all over the world with thalassemia and 10,000 in India alone. Prevalence of thalassemia in

India is 3.3% in general population and 8-15% among certain communities and religions such as Sindhis, Punjabis, Khatris from North, Bengalis, Jains and Muslims. Prevalence of β thalassemia in Punjabis is 3.0-6.5%. Incidence in children of Punjabi origin was 7.6% in Delhi in 2010 [4] [5] [6]. The cultural and religious scenario in Muslims, Khatris and Punjabis migrated from Pakistan is such that consanguineous marriages are quite common. There is no concept of premarital screening of counselling of individuals with a family history of disease. The concept of termination of pregnancy is an ethical and religious issue in some communities [7]. Improvement of quality of patient care, reinforcement of medical education and enhanced efforts by clinical staff to provide practical knowledge to patients with thalassemia major should significantly improve patient's adherence to treatment [8-14]. The preventive measures have already been adopted successfully worldwide especially in Cyprus and Sardinia where the disease has almost been prevented. In the prevention of β thalassemia, social scientists and counselors have a major role to play. The Govt. teaching hospitals, inspite of tertiary level referral hospitals in states have to serve people from all socio economic strata and have to cater to all sorts of ailments, ranging from the simplest infections to highly complicated chronic illnesses. Thus they are often overcrowded and the staff is over-burdened to offer repeated counselling and sustained motivation to parents of children suffering from genetic disorders. On the other hand there are specialized Non Govt. Organizations (NGOs) that manage these disorders specifically and therefore, can devote more effort on the very important preventive counselling aspect of these disorders apart from therapeutic intervention [14-21]. The only way to prevent the disease and to reduce the morbidity and mortality is by educating the general population and best way is to improve the knowledge and awareness of parents of thalassaemic children about the disease, its prevention and treatment options available in our country

Material and Methods

A cross-sectional study was conducted in the Department of Community Medicine, Darbhanga Medical College and Hospital, Laheriasarai, Darbhanga, Bihar, India from April 2018 to March 2019. We randomly selected 1,248 peoples (18–75 years old). However, selection of study area and respondents in this study were based on convenience sampling. Participants were selected from different places, such as public institutions, houses and local markets in order to capture them from various backgrounds in the community. Only the people who consented were included in this study. Furthermore, those who were <18 years of age were excluded from this study. Data was collected via a structured questionnaire which was developed by this research team based on an extensive review of the literature [4, 9, 18, 19]. The study questionnaire was first developed in English and translated into Bengali after which translation accuracy was verified by an independent bilingual translator. Before conducting the actual data collection, the questionnaire was pilot tested in a community similar to the study population. The questionnaire was comprised of 26 questions, and divided into four sections which included: i) demographics (9 items), ii) knowledge towards this disease (12 items), iii) attitude (3 items), and iv) practice of thalassemia screening (2 items). The responses to knowledge questions (from Q11 to Q20) were categorized into three groups: (i) correct, which included the right answers, (ii) incorrect and (iii) do not know responses included as the wrong answers. A total knowledge score was calculated by summing the responses for participants who reported having heard of thalassemia. The total score ranged between 0 and 10. According to our criteria, participants' knowledge was considered good when the score was equal or more than 6. Cronbach's Alpha was used to assess the reliability coefficient which is a measure of the internal consistency of the questionnaire. The Cronbach's alpha coefficient for knowledge and attitude questions was 0.603 where the value 0.6–0.7 is considered acceptable [20]. Categorical variables were described using frequencies and percentages, and continuous variables were summarized using means and standard deviations. Socio-demographic characteristics (e.g. living place, gender, literacy status) had been considered as independent variables while ever heard of thalassemia or knowledge and attitude about thalassemia as outcome variables. Multivariable logistic regression models were generated to assess factors associated with knowledge of thalassemia. Adjusted odds ratios (aORs) and its 95% confidence intervals (CIs) were estimated. First, variables of interest were assessed using univariate analysis. Any factor that provided a univariate p-value ≤ 0.25 was entered into the multivariate analysis. The following variables were adjusted for in the models: age, gender, marital status, living place, literacy, occupation and socio-economic status. Collinearity was assessed using the variance inflation factor (VIF) to ensure a strong linear relationship among independent variables included in the model was not present. The goodness of fit of the model was checked using the Hosmer Lemeshow (H-L) test. P-values of <0.05 were considered significant. Data were analysed using IBM SPSS version 20 software.

Results

A total of 1,248 respondents participated in the study, out of which 699 (56%) were male and remaining 549 (44%) were females. Participants' ages ranged from 18–75 years with a mean of 37.99

± (13.42) years. Approximately half of the participants (59.9%) were unmarried. Sixty six percent of the participants were from Semi urban/ rural community (village) while rest participating in the study were from urban areas. Of the total respondents, 33.9% were students and majority of them (82.1%) belonged to middle class families (Table 1). About 15.7% of the participants reported a family history of genetic diseases

Table 1 Socio-demographic characteristics of respondents (n = 1,248).

Variables	n (%)
Gender	
Male	699 (56)
Female	549 (44)
Marital status	
Married	500 (40.1)
Unmarried	748 (59.9)
Age (years)	
18–19	39 (3.1)
20–35	615 (49.3)
36–50	382 (30.6)
51–75	212 (17)
Mean ± SD*	37.99 ± 13.42
Living place	
Urban	427 (34.2)
Semi-urban/rural	821 (65.8)
Literacy status	
Primary	380 (30.4)
Secondary	183 (14.7)
Intermediate	118 (9.5)
Undergraduate	348 (27.9)
Graduate	153 (12.3)
Post-graduate	66 (5.3)
Occupation	
Student	423 (33.9)
Housewife	272 (21.8)
Public sector	46 (3.7)
Private sector	139 (11.1)
Self-employed	280 (22.4)
Not employed	87 (7)
Socio economic status	
Low income (<15000 BDT/Month)	188 (15.1)
Middle income (15000 –<1,00,000 BDT/Month)	1024 (82.1)
High income (>1,00,000 BDT/Month)	36 (2.9)

Of the total respondents, only 47.4% (592/1,248) had heard of thalassemia. These 592 participants were considered for next questions. The urban residing participants (65.1%) who had heard of thalassemia were nearly twice as high as the participants (38.2%) who lived in semi-urban or rural settings. All of the socio-demographic characteristics except gender are significant (p<0.001) who heard the term thalassemia in Table 2.

Table 2 Demographic characteristics of participants and proportion who have heard of thalassemia (n = 1,248).

Variables	Have heard of thalassemia n (%)		Chi-square (χ2)	p value
	No	Yes		
Gender			0.255	0.613
Male	363 (51.9)	336 (48.1)		
Female	293 (53.4)	256 (46.6)		
Marital status			437.564	**<0.001**
Unmarried	82 (16.4)	418 (83.6)		
Married	574 (76.7)	174 (23.3)		
Living place			81.274	**<0.001**
Urban	149 (34.9)	278 (65.1)		
Semi Town/ rural	507 (61.8)	314 (38.2)		
Literacy status			549.592	**<0.001**
Primary	347 (91.3)	33 (8.7)		

Secondary	143 (78.1)	40 (21.9)		
Intermediate	61 (51.7)	57 (48.3)		
Undergraduate	47 (13.5)	301 (86.5)		
Graduate	40 (26.1)	113 (73.9)		
Post-graduate	18 (27.3)	48 (72.7)		
Employment status			517.713	**<0.001**
Student	50 (11.8)	373 (88.2)		
Housewife	227 (83.5)	45 (16.5)		
Public sector	18 (39.1)	28 (60.9)		
Private sector	62 (44.6)	77 (55.4)		
Self-employed	234 (83.6)	46 (16.4)		
Not employed	65 (74.7)	22 (25.3)		
Socio economic status			21.878	**<0.001**
Lower class	128 (68.1)	60 (31.9)		
Middle class	508 (49.6)	516 (50.4)		
Upper class	24 (55.6)	16 (44.4)		

Textbooks (45.3%) was cited as the most frequently mentioned source of information about thalassemia followed by family/friends (24.8%) and internet/social media (20.6%), respectively (S1 File). Of the participants who have heard of thalassemia, 0.8% (n = 05) had thalassemia major and 6.6% (n = 39) had family members or relatives with thalassemia major (Fig 1).

Table 3 shows the responses of participants to knowledge questions regarding thalassemia. The majority of the participants (79.1%) correctly answered that thalassemia is a hereditary disease. Only 32.8% of respondents knew that thalassemia was not a transfusion transmitted disease although half of the participants had no idea. Regarding risk factor of developing thalassemia major, 49.8% correctly identified consanguineous marriages as an important risk factor. Majority of them (69.3%) knew that marriage between two carriers can lead to a child with thalassemia major. However, 55.2% and 41.9% provide wrong answers when asked whether, the couple has a chance of having a child with thalassemia disease if one parent is a carrier and the thalassemia patients have low iron levels. Around half of the respondents (43.1%) thought that thalassemia is a completely curable disease and 72.5% knew that blood test is a diagnosis method to determine thalassemia.

Table 3: Knowledge about thalassemia among the participants who have heard regarding thalassemia (n = 592).

Items	Correct n (%)	Incorrect n (%)	Don't know n (%)
Thalassemia is a hereditary disease. (Yes)	468 (79.1)	92 (15.5)	32 (5.4)
Thalassemia could be transmitted through blood transfusion from a person with thalassemia. (No)	194 (32.8)	121 (20.4)	277 (46.8)
Consanguineous marriages (marriage between close relatives) have role in the incidence of thalassemia. (Yes)	295 (49.8)	81 (13.7)	216 (36.5)
Marriage between two carriers can lead to a child with thalassemia major. (Yes)	410 (69.3)	35 (5.9)	147 (24.8)
If one parent is a carrier, the couple has a chance of having a child with thalassemia disease. (No)	99 (16.7)	327 (55.2)	166 (28)
Thalassemia is related to any of the following diseases. (Leukaemia, heart problems)	192 (32.4)	104 (17.6)	296 (50.7)
Thalassemia can be identified by blood test. (Yes)	429 (72.5)	15 (2.5)	148 (25.1)
A person with thalassemia disease has low iron levels. (False)	65 (11)	248 (41.9)	279 (47.1)
Thalassemia is a curable disease. (No)	295 (49.8)	255 (43.1)	42 (7.1)
Thalassemia can be treated by (Blood Transfusion/ Iron Chelation Therapy/ Folic Acid Supplements/ Blood and Marrow Stem Cell Transplant)	392 (66.2)	-	200 (33.8)

Only 18.2% of participants have good knowledge on thalassemia. In the multivariable logistic regression model of potential predictors of knowledge on thalassemia, participants were more aware when they were in undergraduate (aOR: 23.445; 95% CI: 5.767–95.315) or they were graduate (aOR: 24.88; 95% CI: 6.238–99.232) and post-graduate (aOR: 33.18; 95% CI: 7.864–140.001). We found a significant association between overall knowledge on thalassemia and the education level of the

respondents (p<0.001). However, 20–35 aged (189) and middle income respondents (200) were more conscious about thalassemia, but there was no statistical significance found (Table 4).

Table 4: Univariate and multivariate analyses of factors associated with knowledge on thalassemia (n = 1,248).

Variables	Knowledge on thalassemia		Univariate		Multivariate	
	Poor n (%)	Good n (%)	OR (95% CI)	*p* value	OR (95% CI)	*p* value
Age						
18–19	30 (76.9)	9 (23.1)	Ref.	**<0.001**	Ref.	0.096
20–35	426 (69.3)	189 (30.7)	1.479 (0.689–3.176)		2.031 (0.91–4.532)	
36–50	359 (94)	23 (6)	0.214 (0.091–0.503)		2.732 (0.926–8.064)	
51–75	206 (97.2)	6 (2.8)	0.097 (0.032–0.292)		1.098 (0.298–4.051)	
Gender						
Male	565 (80.8)	134 (19.2)	Ref.	0.311	–	–
Female	456 (83.1)	93 (16.9)	0.86 (0.642–1.151)		–	–
Marital status						
Unmarried	318 (63.6)	182 (36.4)	Ref.	**<0.001**	Ref.	0.111
Married	703 (94)	45 (6)	8.941 (6.287–12.715)		0.588 (0.306–1.13)	
Living place						
Urban	305 (71.4)	122 (28.6)	Ref.	**<0.001**	Ref.	0.183
Semi-urban/rural	716 (87.2)	105 (12.8)	0.367 (0.273–0.492)		0.788 (0.556–1.118)	
Literacy status						
Primary	377 (99.2)	3 (0.7)	Ref.	**<0.001**	Ref.	**<0.001**
Secondary	175 (95.6)	8 (4.4)	0.016 (0.005–0.055)		5.198 (1.33–20.269)	
Intermediate	105 (89)	13 (11)	0.091 (0.038–0.291)		10.481 (2.667–41.179)	
Undergraduate	213 (61.2)	135 (38.8)	0.248 (0.115–0.535)		23.445 (5.767–95.315)	
Graduate	107 (69.9)	46 (30.1)	1.268 (0.727–2.209)		24.88 (6.238–99.232)	
Post-graduate	44 (66.7)	22 (33.3)	0.86 (0.464–1.594)		33.18 (7.864–140.001)	
Employment status						
Student	258 (61)	165 (39)	Ref.	**<0.001**	Ref.	0.192
Housewife	264 (97.1)	8 (2.9)	0.47 (0.023–0.098)		0.345 (0.126–0.947)	
Public sector	36 (78.3)	10 (21.7)	0.434 (0.21–0.899)		0.696 (0.262–1.848)	
Private sector	112 (80.6)	27 (19.4)	0.377 (0.237–0.599)		0.652 (0.325–1.305)	
Self-employed	271 (96.8)	9 (3.2)	0.052 (0.026–0.104)		0.362 (0.145–0.901)	
Not employed	79 (90.8)	8 (9.2)	0.158 (0.075–0.336)		0.479 (0.193–1.189)	
Socio economic status						
Low income	166 (88.3)	22 (11.7)	Ref.	**0.022**	Ref.	0.09
Middle income	824 (80.5)	200 (19.5)	1.831 (1.144–2.933)		0.524 (0.285–0.963)	
High income	31 (86.1)	5 (13.9)	1.217 (0.428–3.457)		0.375 (0.114–1.237)	

In response to the questionnaire, majority of the respondents who have heard of thalassemia showed positive attitudes towards thalassemia. About 68.2% respondents would prefer premarital screening of themselves or their family members to prevent thalassemia. The majority of the participants (85.3%) had given positive response about donating blood to thalassemia patients. Likewise, 96.1% agreed to spread the information about thalassemia in their community. Respondents were asked whether they had undergone thalassemia screening process, only 7.8% reported that they had been screened for thalassemia (Table 5).

Table 5 Participant's attitude and practice towards thalassemia (n = 592).

Items	Yes (n %)	No (n %)
Take any necessary steps to ensure blood testing for thalassemia before the marriage of you or your family members	404 (68.2)	188 (31.8)
Like to donate blood for thalassemia patients	505 (85.3)	87 (14.7)
Like to inform others about the potential danger of thalassemia	569 (96.1)	23 (3.9)
Ever performed a blood test for thalassemia detection	46 (7.8)	546 (92.2)

Our study results demonstrate that only 47.4% of the respondents had heard of thalassemia. As India lies in the thalassemia belt, the level of awareness is unexpectedly lower than the countries including Malaysia (76%), Greece (93%), Bahrain (65%) and

Italy (85%) [16, 18, 21, 22]. A previous study conducted with parents of children with thalassemia in india where 97% of respondents had never heard about the term, 'thalassemia' before the disease was diagnosed in their children [23]. The most worrisome finding in this study is that only 18.2% have adequate knowledge and the participants who declared to know about thalassemia, 20.4% believed that thalassemia is a transfusion transmitted disease. This result reflects a general lack of knowledge among the participants. More importantly, these participants may convey incorrect information to others who do not know about the disease.

The participants' knowledge of thalassemia as an inherited disorder was relatively better in this study. In contrast, a study conducted in Pakistan documented that only 40% were aware of the nature of disease [24]. However, an alarming finding of our study was that half of the respondents were unaware about the role of consanguineous marriages in the incidence of thalassemia major which was incongruous with a previous study in Pakistan [19]. About 69.3% had the correct knowledge that both parents have to be carriers of beta thalassemia to have an affected child. This percentage is more than the study findings conducted in Bangladesh and Pakistan [9, 25]. Half of the respondents had misconceptions that if one parent is a carrier, a child is born with thalassemia disease. These knowledge deficits may lead to stigmatization and have profound emotional effects on thalassemia carriers.

The findings from the present study showed, respondents' literacy status had a significant relationship with the level of knowledge on thalassemia. However, the study among participants in India reported that thalassemia knowledge was found to be significantly related to having higher education levels. These results were consistent with the study from Kolkata and Bahrain [2, 21]. This study result showed that other socio-demographic variables like age, gender, living place were not significantly associated with knowledge of thalassemia. In contrast to our result; gender, marital status, residence and higher income were also identified as significant contributing factors of thalassemia knowledge [2].

Textbooks were selected as the most common sources of information for those who had heard about thalassemia. Similar finding was reported in a previous study in Bangladesh [9]. From this study health professionals (family doctors, obstetricians, and genetic counsellors) contributed very little to spread awareness about thalassemia. About 24.8% of respondents reported family and friends as a source of information which was similar to the result of the study performed in Italy [22]. Some studies have already revealed that physicians can play a greater role in informing the public about thalassemia. In Sardinia, 70% of the target population was informed via physicians [26].

Despite the lack of knowledge, the participants who have heard of thalassemia showed positive attitudes towards the disease. Premarital screening and genetic counselling facilities will contribute to reduce the number of babies born with thalassemia [27]. However, about 68.2% of respondents in this study agreed to do premarital screening with a blood test before marriage which is less than Oman, where 92% participants responded that they will do the test in future [28,29]. A very positive finding of this study was that 85.3% were willing to donate blood to transfusion-dependent thalassemia patients. This study findings raise the hopes that future awareness programs could easily increase the number of blood donors and family members with thalassemia will be able to find blood donors. Merely 7.8% of the study population who heard about the disease got themselves screened for thalassemia. This finding was similar to the Indian study where 2% of the participants performed premarital testing [24]. Ignorance, fear of being stigmatized for positive results, and endangering future prospects of getting married are considered barriers to not perform any screening test.

Thalassemia is becoming a rising concern for public health in India. Based on our study, it could be recommended that public education about thalassemia should be emphasized for successful thalassemia prevention. It has already been proven in several countries worldwide that implementation of mandatory national premarital screening programs could drastically reduce the incidence of infants born with thalassemia major [16]. However, the Ministry of Health should provide adequate training to health workers so that they can give appropriate advice in an effort to bring about behavioural change among the public to discourage consanguineous marriages.

Conclusion

This study has identified major areas which need to be highlighted and emphasized in rural communities and public education for thalassemia screening and awareness campaigns in India. Our study has specifically pointed out knowledge deficits regarding the genetics and pattern of inheritance of thalassemia major. Insights of the report depict that more concise and specially designed programs for disseminating awareness regarding thalassemia should spread across the country.

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