Public Perceptions and Attitudes of Bangladeshi Population towards Thalassemia Prevention: A Nationwide Study

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Abstract

Background: Thalassemia is one of the most common life-threatening yet preventable congenital hemoglobin disorders especially in South Asian regions like Bangladesh. It has become a rising public health concern for Bangladesh as 6-12% of the population are carriers and many of them are unaware of it. The purpose of the study is to inspect the knowledge and attitude towards thalassemia among the general people of Bangladesh.

Methods: A cross-sectional survey was conducted in eight administrative regions of Bangladesh between January and October of 2020. A self-administrative close-ended questionnaire was designed to collect information about thalassemia and socio-demographic characteristics. Pearson's chi-square ($\chi 2$) test and One-way ANOVA were performed to assess the association between the demographic variables with knowledge and practice regarding thalassemia. A p-value <0.05 was considered significant.

Results: Of the 1623 participants, only 44.7% (726/1623) had heard of thalassemia. The mean knowledge of thalassemia was scored 4.75 ± 2.05 out of a total possible score of 10. Half of the participants had no idea that thalassemia was not a transfusion transmitted disease. About 73.1% knew that blood tests are a diagnosis process to determine thalassemia. The urban residing participants had the highest (5.10 ± 1.99) and participants with primary education had the lowest (3.38 ± 1.37) mean score of knowledge. Participants' knowledge score varied significantly by marital status, living pace, literacy and occupation ($p< 0.05$). However, about 68.2% and 85.5% of the participants showed a positive attitude towards premarital screening of themselves or their family members and donating blood to thalassemia patients, respectively.

Conclusion: The study shows that there is a need to disseminate the information on thalassemia since the knowledge gap is huge among people. These findings will assist the implementation of significant steps such as educational programs, health counseling, premarital screening, campaigning, etc. to increase the awareness of thalassemia.

Introduction

Thalassemia is the most commonly inherited single-gene disorder globally that results from absence or decrease of globin chain production (1). Depending on the nature of the mutation, there are two types of thalassemia: alpha- (α-) thalassemia and beta- (β-) thalassemia (2, 3). High prevalence and the lack of cure make thalassemia as a global health concern (4). Globally an estimated 100 million people are carriers of beta-thalassemia, approximately 100,000 children are born and 50,000-100,000 children with thalassemia major die each year in low- and middle-income countries (5, 6). Thalassemia is highly prevalent in Southeast Asia, the Indian subcontinent, Mediterranean, middle Asia, Central Asia and West Africa (7). As a consequence of migration towards non-endemic regions, thalassemia is spreading in Europe and North America (8).

South Asia (India, Pakistan, Bangladesh and Sri Lanka) is a region with a high prevalence of hemoglobinopathy, representing 23% (approximately 1.56 billion) of the world's population (9). Bangladesh is situated in the South Asian region, with a population of over 160 million people. About 10–19 million people of this country (6–12% of the population) carry a thalassemia gene (10). According to World Health Organization (WHO) estimates, approximately 3% of the population (3.6 million) carries β-thalassemia and 4% (4.8 million) carries hemoglobin E (HbE) in Bangladesh (5, 11, 12). It is assumed that over 7000 children are born with thalassemia each year in Bangladesh (13). Furthermore, beta thalassemia or HbE has been found in 28% of assessed rural women in a recent study (14).

Allogeneic hematopoietic stem cell transplantation (alloHSCT) is currently the only curative therapy for thalassemia despite having limited access in the absence of suitable donors. However, most developing countries lack the necessary medical resources and skills to perform alloHSCT (15). Regular blood transfusions and iron chain treatment with

desferrioxamine is the standard management of thalassemia that begin in patients early in life and continue throughout their childhood, adolescence, and adult years (16). In addition, managing thalassemia patients and living with this condition financially and emotionally for a long time constitutes a heavy burden for patients and their families (17). Therefore, prevention is the best way to reduce the prevalence of this disorder. Different strategies were applied in different countries to reduce thalassemia. Increased awareness of general population, pre-marital screening and genetic counselling (PSGC) and prenatal diagnosis (PND), has led to almost total elimination of thalassemia in Cyprus and, to a considerable extent, in Greece, Italy and Sardinia (1, 18).

Although Bangladesh is in the world thalassemia belt, there is a lack of information about the epidemiology, clinical course, mortality, complications and treatment outcome of thalassemia. The general peoples of Bangladesh possess poor knowledge of the disease. This lack of awareness is influenced by region and population, including gender, marital status, education, employment, and socio-economic status (3). Furthermore, there is no national health insurance system or organized national program in Bangladesh to raise awareness, conduct career screenings or manage thalassemia patients (10).Therefore, this study aimed to assess public knowledge, perceptions and attitudes toward thalassemia and thalassemia screening practice.

Materials And Methods

Participants and study area

A cross-sectional study was conducted from January 2020 to October 2020 among randomly selected 1,623 peoples (16 - >50 years old) in eight divisional regions (Dhaka, Chittagong, Barisal, Khulna, Rajshahi, Rangpur, Mymensingh and Sylhet) of Bangladesh. We assumed a 50% prevalence of good knowledge and attitudes, with an error margin of 3% at a 95% level of confidence, the minimum number of respondents required to fulfil the objectives of this study was 1067 (19). 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, only those who were < 16 years of age and failed to respond to the questions were excluded.

Questionnaire Content

Data was collected via a self-administrative close-ended questionnaire which was developed by this research team based on an extensive review of the literature (4, 10, 20, 21). The study questionnaire was first developed in English and translated into Bengali after which translation accuracy was verified by an independent bilingual translator.

The questionnaire was comprised of 27 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 (3 items). The responses to knowledge questions (from Q11 to Q20) were categorized into three groups: (i) correct, which included the right answers, (ii) incorrect which included the wrong answers and (iii) do not know responses. 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 adequate when the score was equal or more than 6.

Data Analysis

Categorical variables were described using frequencies and percentages, and continuous variables were summarized using means and standard deviations. One-way ANOVA was performed to assess the association between the demographic variables (gender, literacy, marital status, living place, employment status and socio-economic status) and

knowledge of thalassemia among those who heard of the disease. Post-Hoc tests were conducted using Tukey's HSD. Pearson's chi-square ($\chi 2$) test was also used for testing the association between categorical variables. A p-value less than 0.05 was considered to be significant. Data were analyzed using IBM SPSS version 20 software.

Ethical Clearance

This study was conducted in accordance with the Declaration of Helsinki. The study was approved by the Dept. of Biotechnology and Genetic Engineering, Mawlana Bhashani Science and Technology University, Tangail-1902, Bangladesh ((Ref: MBSTU/BGE/Research project (87)/2009/103(A)). Informed verbal and written consent were taken from each participant before the start of the study. Those who were not willing to participate, were not given the questionnaires. Confidentiality of the respondents was maintained.

Results

Participant's characteristics

A total of 1623 respondents participated in the study, out of which 856 (52.7%) were male and remaining 767 (47.3%) were females. Participants' ages ranged from 16 - >50 years with a mean of 34.082 (± 12.44) years. Approximately half of the participants (47.9%) were unmarried. Sixty three percent of the participants were from Semi Town/ rural community (village) while rest participating in study were from urban areas. Of the total respondents, 43.2% were students and majority of them (82.9%) belonged to middle class families (Table 1). Approximately 16% of the participants reported a family history of genetic diseases (Fig. 1).

Of the total respondents, only 44.7% (726/1623) had heard of thalassemia (Table 1). These 726 participants were included in our study. The urban residing participants (60.9%) who had heard of thalassemia were nearly twice as high as the participants (35.3%) who lived in semi-urban or rural settings. Textbooks (47.4%) was cited as the most frequently mentioned source of information about thalassemia followed by family/friends (23.1%) and internet/ social media (20.8%), respectively (Supplementary file 1). Of the participants who have heard of thalassemia, 0.8% (n = 06) had thalassemia major and 6.9% (n = 50) had family members or relatives with thalassemia major (Fig. 1).

Table 1
Demographic characteristics of participants and proportion who have heard of thalassemia (n = 1623).

Variables	All participants N = 1623 n (%)	Have heard of thalassemia n (%)	
		Yes	No
Gender			
Male	856 (52.7)	400 (46.7)	456 (53.3)
Female	767 (47.3)	326 (42.5)	441 (57.5)
Age (year)			
<20 (16–19)	192 (11.8)	64 (33.3)	128 (66.7)
20–35	776 (47.8)	541 (69.7)	235 (30.3)
36–50	418 (25.8)	87 (20.8)	331 (79.2)
> 50	237 (14.6)	34 (14.3)	203 (85.7)
Mean ± SD*	**34.82 ± 12.44**		
Marital status			
Unmarried	777 (47.9)	544 (70)	233 (30)
Married	775 (47.8)	179 (23.1)	596 (76.9)
Separated/ Divorce/ Widow	71 (4.4)	3 (4.2)	68 (95.8)
Living place			
Urban	596 (36.7)	363 (60.9)	233 (39.1)
Semi Town/ rural	1027 (63.3)	363 (35.3)	664 (64.7)
Literacy status			
Primary	476 (29.3)	34 (7.1)	442 (92.9)
Secondary	267 (16.5)	50 (18.7)	217 (81.3)
Intermediate	147 (9.1)	65 (44.2)	82 (55.8)
Undergraduate	477 (29.4)	393 (82.4)	84 (17.6)
Graduate	187 (11.5)	135 (72.2)	52 (27.8)
Post Graduate	69 (4.3)	49 (71)	20 (29)
Employment status			
Student	701 (43.2)	502 (71.6)	199 (28.4)
Housewife	334 (20.6)	47 (14.1)	287 (85.9)
Public sector	46 (2.8)	28 (60.9)	18 (39.1)

*SD = Standard deviation

Variables	All participants N = 1623 n (%)	Have heard of thalassemia n (%)	
		Yes	No
Private sector	141 (8.7)	77 (54.6)	64 (45.4)
Self-employed	302 (18.6)	47 (15.6)	255 (84.4)
Not employed	99 (6.1)	25 (25.3)	74 (74.7)
Socio economic status			
Lower class	231 (14.2)	66 (28.6)	165 (71.4)
Middle class	1346 (82.9)	642 (47.7)	704 (52.3)
Higher class	46 (2.8)	18 (39.1)	28 (60.9)
*SD = Standard deviation			

Knowledge About Thalassemia

Table 2 shows the responses of participants to knowledge questions regarding thalassemia. Only 37.7% of participants who have heard thalassemia have adequate knowledge. The majority of the participants (79.5%) correctly answered that thalassemia is a hereditary disease. Only 32.1% 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, 49.7% correctly identified consanguineous marriages as an important risk factor. Majority of them (70.4%) knew that marriage between two carriers can lead to a child with thalassemia major. However, 55.4% and 44.2% 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 (50.1%) thought that thalassemia is a completely curable disease and 73.1% knew that blood test is a diagnosis process to determine thalassemia.

Table 3 represents the associations between the socio-demographic variables and knowledge of thalassemia among the respondents who have heard of thalassemia. The mean knowledge of thalassemia was scored 4.75 ± 2.05 out of a total possible score of 10. The urban residing participants had the highest (5.10 ± 1.99) and participants with primary education had the lowest (3.38 ± 1.37) mean score of knowledge. However, knowledge scores among the respondents varied significantly by marital status, living pace, literacy and occupation ($p < 0.05$).

Table 2: Knowledge about thalassemia among the participants who have

heard regarding thalassemia (n = 726).

Table 3
Associations between socio-demographic variables and knowledge of thalassemia (n = 726).

Items	Correct n (%)	Incorrect n (%)	Don't know n (%)
Thalassemia is a hereditary disease. (Yes)	577 (79.5)	108 (14.9)	41 (5.6)
Thalassemia could be transmitted through blood transfusion from a person with thalassemia. (No)	233 (32.1)	146 (20.1)	347 (47.8)
Consanguineous marriages (marriage between close relatives) have role in the incidence of thalassemia. (Yes)	361 (49.7)	93 (12.8)	272 (37.5)
Marriage between two carriers can lead to a child with thalassemia major. (Yes)	511 (70.4)	40 (5.5)	175 (24.1)
If one parent is a carrier, the couple has a chance of having a child with thalassemia disease. (No)	123 (16.9)	402 (55.4)	201 (27.7)
Thalassemia is related to any of the following diseases. (Leukemia, heart problems)	227 (31.2)	120 (16.6)	379 (52.2)
Thalassemia can be identified by blood test. (Yes)	531 (73.1)	18 (2.5)	177 (24.4)
A person with thalassemia disease has low iron levels. (False)	74 (10.2)	321 (44.2)	331 (45.6)
Thalassemia is a curable disease. (No)	364 (50.1)	313 (43.1)	49 (6.7)
Thalassemia can be treated by (Blood Transfusion/ Iron Chelation Therapy/ Folic Acid Supplements/ Blood and Marrow Stem Cell Transplant)	475 (65.4)	-	251 (34.6)

Variables	n	Mean ± SD	*p* value
Gender	400	4.70 ± 2.03	0.509
Male	326	4.80 ± 2.08	
Female			
Literacy status	34	3.38 ± 1.37	**< 0.001**
Primary	50	4.46 ± 1.54	
Secondary	65	4.11 ± 2.1	
Intermediate	393	4.99 ± 1.92	
Undergraduate	135	4.72 ± 2.33	
Graduate	49	4.96 ± 2.49	
Post-graduate			
Marital status	544	4.91 ± 2.04	**0.001**
Unmarried	179	4.27 ± 2.02	
Married	03	4.33 ± 1.16	
Separated/ Divorce/ Widow			
Living place	363	5.10 ± 1.99	**< 0.001**
Urban	363	4.39 ± 2.05	
Semi Town/ rural			
Employment status	502	4.95 ± 2.02	**< 0.001**
Student	47	3.81 ± 2.04	
Housewife	28	4.29 ± 2.8	
Public sector	77	4.71 ± 1.82	
Private sector	47	4.43 ± 1.54	
Self-employed	25	3.76 ± 2.54	
Not employed			
Socio-economic status	66	4.76 ± 1.68	0.985
Lower class	642	4.75 ± 2.08	
Middle class	18	4.67 ± 2.45	
Higher class			

Attitudes And Practice Towards Thalassemia

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 (85.5%) had given positive response about donating

blood to thalassemia patients. Likewise, 96.3% were agreed to spread the information about thalassemia in their community. The participants from Dhaka region showed more positive attitude than other regions of Bangladesh. Significant association was observed between agreement in opinion that prefer premarital screening and spread awareness about thalassemia with region ($p < 0.001$) (Table 4).

Respondents were asked whether they had undergone thalassemia screening process, only 7.7% reported that they had been screened for thalassemia. Among these, the majority of the participants (6.6%) were unmarried. No significant association ($p < 0.05$) was observed between the socio-demographic variables and the practice status (Table 5).

Table 4
Comparison of attitudes toward thalassemia among participants across the country (n = 726).

Proportion of agreement n (%)	***p* value**	**< 0.001**	**0.174**	**< 0.001**
	Rangpur	**64 (8.8)**	**71 (9.8)**	**80 (11)**
	Mymensingh	**56 (7.7)**	**63 (8.7)**	**75 (10.3)**
	Rajshahi	**63 (8.7)**	**82 (11.3)**	**93 (12.8)**
	Sylhet	**50 (6.9)**	**67 (9.2)**	**75 (10.3)**
	Khulna	**33 (4.5)**	**31 (4.3)**	**34 (4.7)**
	Chittagong	**28 (3.9)**	**29 (4)**	**33 (4.5)**
	Barisal	**31 (4.3)**	**59 (8.1)**	**67 (9.2)**
	Dhaka	**170 (23.4)**	**219 (30.2)**	**242 (33.3)**
	Positive	**495 (68.2)**	**621 (85.5)**	**699 (96.3)**
Questions		I would like to take necessary steps to ensure blood testing for thalassemia before the marriage of mine or my family members	I would like to donate my blood for thalassemia patients	I would like to inform others about the potential danger of thalassemia

Table 5
Associations between socio-demographic variables and performed a thalassemia detection test (n = 726).

Variables	Performed thalassemia screening			
	Positive n (%)	Negative n (%)	Chi-square (χ2)	*p* value
Gender	31 (4.3)	369 (50.8)	0.002	0.967
Male	25 (3.4)	301 (41.5)		
Female				
Marital status	48 (6.6)	496 (68.3)	3.839	0.147
Unmarried	8 (1.1)	171 (23.6)		
Married	0 (0)	3 (0.4)		
Separated/ Divorce/ Widow				
Living place	31 (4.3)	332 (45.7)	0.697	0.404
Urban	25 (3.4)	338 (46.6)		
Semi Town/ rural				
Literacy status	1 (0.1)	33 (4.5)	3.656	0.600
Primary	2 (0.3)	48 (6.6)		
Secondary	4 (0.6)	61 (8.4)		
Intermediate	36 (5)	357 (49.2)		
Undergraduate	9 (1.2)	126 (17.4)		
Graduate	4 (0.6)	45 (6.2)		
Post-graduate				
Employment status	40 (5.5)	462 (63.6)	2.488	0.778
Student	2 (0.3)	45 (6.2)		
Housewife	2 (0.3)	26 (3.6)		
Public sector	7 (1)	70 (9.6)		
Private sector	2 (0.3)	45 (6.2)		
Self-employed	3 (0.4)	22 (3)		
Not employed				

Discussion

This study was carried out to determine the public knowledge, attitude and screening practice of thalassemia in Bangladesh. Very few studies have investigated knowledge about thalassemia in different parts of Bangladesh, and in our knowledge, this is the first study conducted among the general peoples across the country. Our study helped to address the knowledge gaps related to thalassemia.

Our study results demonstrate that only 44.7% of the respondents had heard of thalassemia. As Bangladesh 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%) (17, 20, 22, 23). The most worrisome finding in this study is that of the participants who declared to know about thalassemia, only 37.7% have adequate knowledge and 32.1% 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 which was incongruous with a previous study in Pakistan (21). About 70.4% 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 (10, 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' marital, literacy and employment status had a significant relationship with the level of knowledge on thalassemia. However, the study among participants in Bangladesh reported that thalassemia knowledge was found to be significantly related to having higher education levels and being a student. These results were consistent with the study from Kolkata and Bahrain (2, 22).

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 (10). From this study health professionals (family doctors, obstetricians, and genetic counsellors) contributed very little to spread awareness about thalassemia. About 23% of respondents reported family and friends as a source of information which was similar to the result of the study performed in Italy (23). 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 counseling facilities will contribute to reduce the number of babies born with thalassemia (27). However, about 68% 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). A very positive finding of this study was that 85.5% 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 7.7% of the study population got themselves screened for thalassemia. This finding was similar with 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. In Bangladesh (and the South Asian region overall), marriage is synonymous with financial, emotional and physical security for many women (29).

Thalassemia is becoming a rising concern for public health in Bangladesh. 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 (17). In 2018, a writ petition was filed in the Bangladesh High Court to make pre-marital screening mandatory. Furthermore, the Minister for Health and Family Welfare also announced that "Bangladesh would be thalassemia free by 2028" (10). However, the Ministry of Health should provide adequate health workers and train them to give appropriate advice in an effort to bring about behavioral change among the public to discourage consanguineous marriages. Furthermore, like the polio

campaign, Thalassemia prevention programs should be planned and interventions should be made all over Bangladesh to get rid of thalassemia.

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 Bangladesh. The Ministry of Health, Bangladesh has announced an intention to start a national screening programme for thalassemia. Our study has specifically pointed out knowledge deficits regarding the genetics and pattern of inheritance of thalassemia. Insights of the report depict that more concise and specially designed programs for disseminating awareness regarding thalassemia should spread across the country.

Limitations

We recognized a few limitations in our study. Firstly, all data of this research were collected via face-to-face interviews; therefore, reporting bias due to socially desirable attitudes and behaviors might exist. Secondly, we faced some difficulties to translate the questionnaire from English to Bangla as some English words do not translate exactly into Bangla. Furthermore, a cross-sectional survey of this nature may capture only a snapshot of information about the respondents but cannot be generalized to other populations; the findings may change over time.

Declarations

Ethics approval and consent to participate

This research study was approved by the Department of Biotechnology and Genetic Engineering, Mawlana Bhashani Science and Technology University. Ethical approval Number:- 87/2009/103(A). All the participants provided their consent to participate in this research.

Consent for publication

Not applicable

Availability of data sets

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Competing Interest

The authors declare that they don’t have competing interests on this study.

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Author Contributions

Conceptualization and Methodology was performed by NE, IS, AKM, US, RBM and SA; Formal analysis and Data curation was performed by MMK, NE, MMI, NM and KC; Writing-original draft prepared by NE, MNB, DC, AKM, GB, KC, US and MSI; Writing-review and editing performed by GB, ON, SAA, KC,NE, AKM and MSI; Supervised by AKM, MSI and KC. All authors have read and agreed to submit the final version of the manuscript.

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Figures

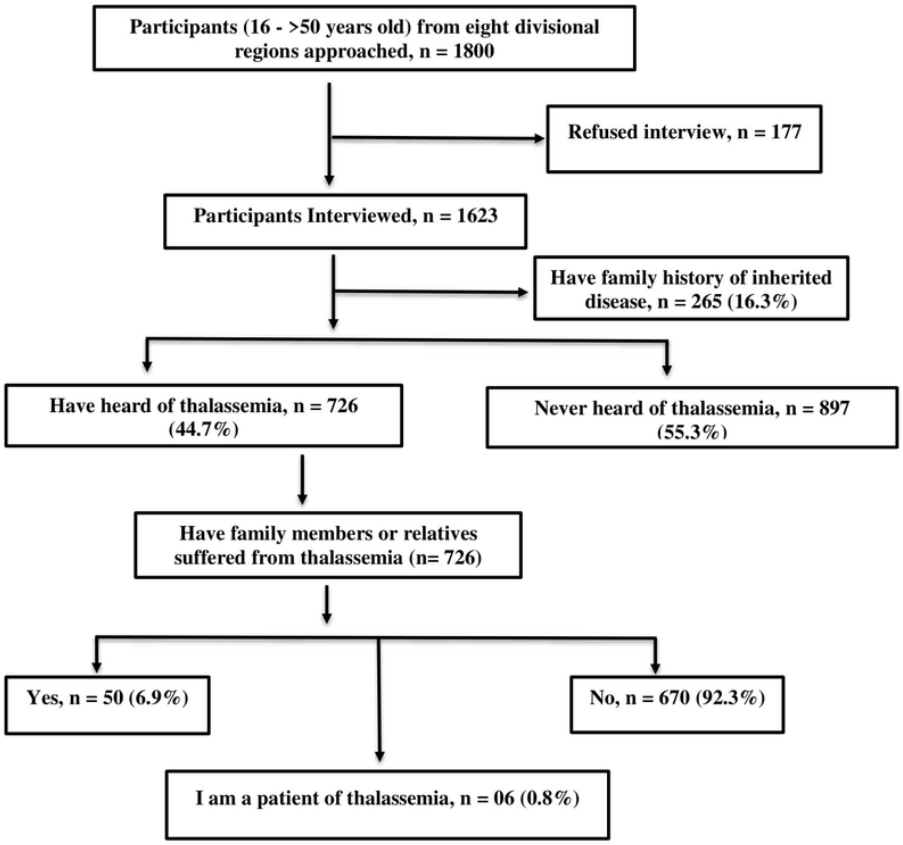

Figure 1

Participants' perceptions in thalassemia.

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