Knowledge, Attitude and Practice of Prevention of Thalassaemia of the Parents of Children with Thalassaemia attending in a Tertiary Care Hospital in Bangladesh

F BEGUM[a], MF SHIRIN[b], MA SAYED[c], LS SHARMIN[d], MB UDDIN[e]

Abstract:

Introduction: Inherited disorder of Hemoglobin is widely distributed throughout the world. Among them, Thalassaemia is a common disorder with widespread geographical distribution.

Objectives: The objective of the study was to determine the level of knowledge, attitude and practice of thalassaemia prevention among parents of children with Thalassaemia.

Methodology: This was a descriptive cross sectional study. This study was conducted in inpatient and outpatient department of paediatrics, Rajshahi Medical College Hospital over a period of July 2020 to June 2021. 45 parents of children with thalassaemia were purposively selected as study subjects. Informed written consent were obtained from the parents before enrollment in the study. Data were collected on variables of interest. All the findings were recorded and analyzed. Statistical analysis were done using statistical package for social science (SPSS) software version 21.

Result: Total 45 parents of children with thalassaemia were enrolled in the study. Among the informants, 73.3% (total 33) were mother and 26.6% (total 12) were father. 77.7% (total 35) children were from rural areas and 22.22% (total 10) were from urban areas. All the study population received knowledge about thalassaemia from the physicians. Knowledge of the parents about the disease, its treatment options and methods of its prevention were assessed by likert scale questionnaire. 22.22% parents had adequate knowledge , 64.44% had average knowledge and 13.33% had inadequate knowledge about the disease. 60% parents had adequate knowledge 31.11% had average knowledge and 8.89% had inadequate knowledge about prevention of thalassaemia. Attitude of all the parents (100%) were positive.

Conclusion: Most of the parents have adequate knowledge and positive attitude for thalassaemia prevention and they can serve as resource for spreading awareness about thalassaemia in community

Key words: Thalassaemia, Attitude, Methods of prevention.

(J Bangladesh Coll Phys Surg 2024; 42: 6-11)

DOI: https://doi.org/10.3329/jbcps.v42i1.70623

a. Dr. Fardoushi Begum, Medical Officer, Outpatient Department (Paediatrics), Rajshahi Medical College & Hospital, Rajshahi.

b. Dr. Mst. Farhana Shirin, Assistant Registrar, Department of Paediatrics, Rajshahi Medical College & Hospital, Rajshahi.

c. Dr. Md. Abu Sayed, Registrar, Department of Surgery, Rajshahi Medical College & Hospital, Rajshahi.

d. Dr. Laila Shamima Sharmin, Assistant Professor, Department of Paediatrics, Rajshahi Medical College & Hospital, Rajshahi.

e. Prof. Md. Belal Uddin, Professor and Head, Department of Paediatrics, Rajshahi Medical College & Hospital, Rajshahi.

Address of Correspondence: Dr.Fardoushi Begum, 362/1; Terokhadia Poschimpara, post: Cantonment, post code 6202, Rajshahi Phone: 01757826094,
Email: drfardoushi@gmail.com

Received: 7 Oct., 2022 **Accepted:** 18 Sept., 2023

Introduction:

Hereditary disorder of Hemoglobin is widely distributed throughout the world. Among them, thalassaemia is a common disorder with widespread geographical distribution. No population is completely free from the condition[1].

World Health Organization, in an estimate, shows that 7% of world population are a carrier of hereditary hemoglobin disorder. About 300000 to 500000 children with hemoglobin disorder are born every year with a majority in developing countries[2]. Hemoglobin disorder is a very significant problem in Bangladesh[3]. The mainstay of treatment of thalassaemia is regular blood transfusion, Iron chelation and periodic monitoring for

development of complications[4]. But iron chelators are expensive and there is lack of thalassaemia care centers and inadequate access to different treatment modalities. There is also knowledge gap and misperceptions about thalassaemia among general population[5].

These all together put the children with thalassaemia in a vulnerable condition and leads to increase mortality and morbidity in them. So, prevention of thalassaemia is of prime importance. Srilanka started 'safe marriage' strategies for prevention of thalassaaemia for last 15 years, but it failed to reduce the number of affected birth[6]. Maldives adopted free carrier screening for thalassaemia for more than 20 years. But lack of awareness caused rise in thalassaemia cases again[7]. So primary prevention by creating awareness among population, carrier screening, easy access to prenatal diagnosis and genetic counseling all together may contribute in thalassaemia reduction effectively. Inclusion of health education in academic curriculum may create awareness in future generation and increase in carrier detection. But dissemination of knowledge at societal level is a must for prevention of thalassaemia as school children may loose the message by the time they marry[8].

Hemoglobin disorders provide a model of population screening for inherited disorder and offer a unique opportunity to develop and plan methods and concepts for the future of genetic screening. Thalassaemias are being increasingly prioritized for health care planning in Bangladesh. The Ministry of health has published a draft version of management guideline for thalassaemia[9]. Government are making policies for provision of easy access to clinical management and creating awareness in public. The present study was conducted with an aim to assess knowledge, attitude and practice of methods of prevention among parents of children with thalassaemia. It will help to detect knowledge gap and area of emphasis to prevent thalassaemia like educational program, genetic counseling and creating mass awareness, thus will contribute to accelerate government steps.

Materials & Methods:

This descriptive cross sectional study was carried out in paediatric wards and outpatient department of paediatrics, Rajshahi Medical College Hospital over a period of July 2020 to June 2021. Study subjects were purposively selected 45 parents of children with thalassemia attending in paediatric wards and outpatient department. Approval from the ethical review committee of Rajshahi Medical College were taken prior to the study. Informed written consent were obtained from the parents before enrollment in the study. Parents were interviewed using a Likert scale responses to assess the knowledge and attitude about different aspects of Thalassaemia. We used content and face validity to determine the validity of the questionnaire. It was determined by evaluation by one paediatricians and one professor of department of Community Medicine. Questionnaire was introduced in Bengali to the respondents by the investigator. Data were collected on variables of interest in a structured data sheet. All the findings were recorded and analyzed. Statistical analysis were done using statistical package for social science (SPSS) software version 21. Quantitative data were presented as Mean ±SD and qualitative data were presented as frequency and percentage.

Results:

Total 45 parents of children with thalassaemia were enrolled in the study. Among the informants, 73.3% (total 33) were mother and 26.6% (total 12) were father. Total 35 (77.77%) children were from rural areas and total 10 (22.22%) were from urban areas. Level of education of the parents ranged from illiterate to higher secondary level. 6.6% (total 3) parent were illiterate, 48.88% (total 22) completed primary level education, 33.33% (total 15) received secondary school education and 11.11% (total 5) completed higher secondary education. In 100% cases, source of information were physician who attended during hospital admission. Knowledge of the parents about the disease, its treatment options and methods of it prevention were assessed by likert scale questionnaire.

We assessed knowledge about disease, treatment options and methods of prevention of thalassaemia using 3 point questionnaire. For each question highest score were 3 and lowest were 1. Study participants who gave more than 80% and 50% correct answer were considered as having adequate knowledge and average knowledge respectively. Attitude was assessed by 4 point questionnaire with 50% correct answer were considered as positive attitude. The parents willingness to practice different methods of prevention were also assessed. The response is shown in following graphs.

Most of the parents were familiar with that children with Thalassaemia are anemic, the disease runs in the family

and it is a disorder affecting blood cell. But they have less idea that it is a chromosomal disorder and it is not a contagious disease.

Figure 2 shows that majority of the parents knows about iron level, fate of untreated of thalassaemia, need for iron rich food restriction and treatment options of thalassaemia.

Most of the parents accepted the need for limiting family size. They are well informed about outcome of marriage between two carriers, problems of consanguineous marriage and risk of recurrence in future pregnancy. But they are less informed about methods of prenatal diagnosis and where it is available.

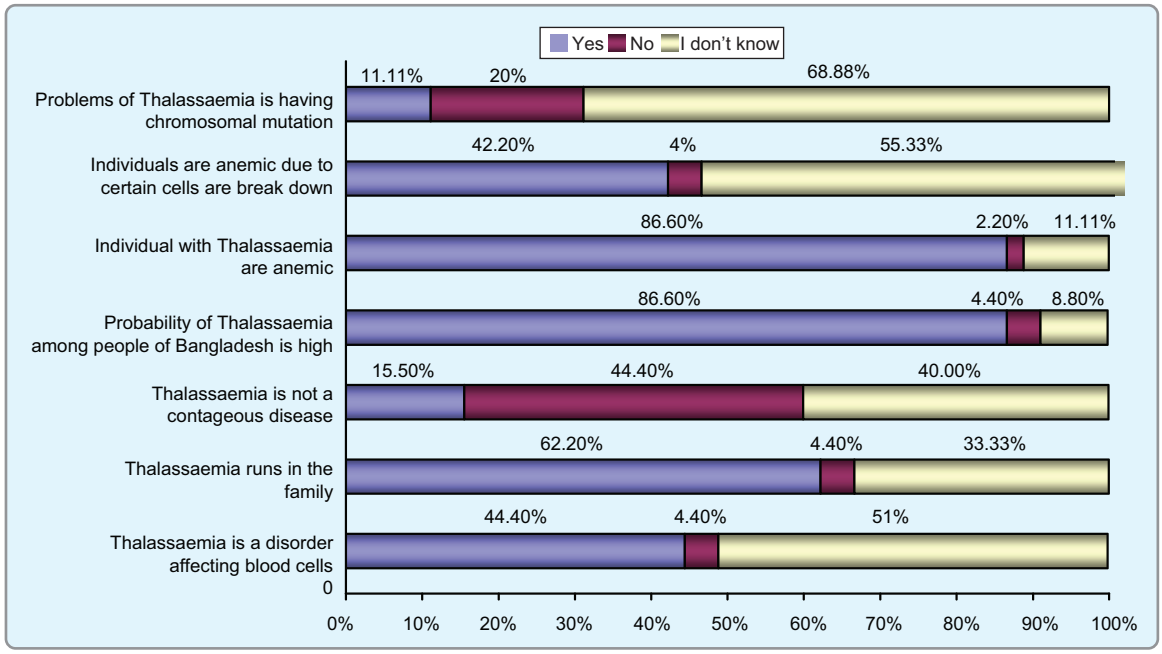

Fig.-1: *Responses of parents regarding questions about Thalassaemia*

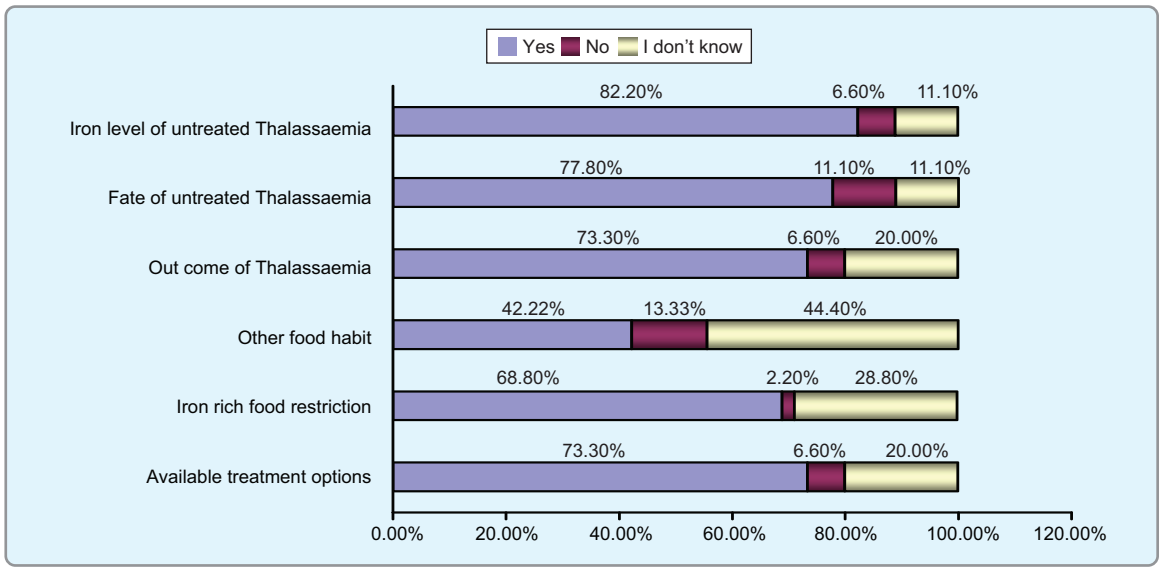

Fig.-2: *Responses about treatment & outcome of Thalassaemia*

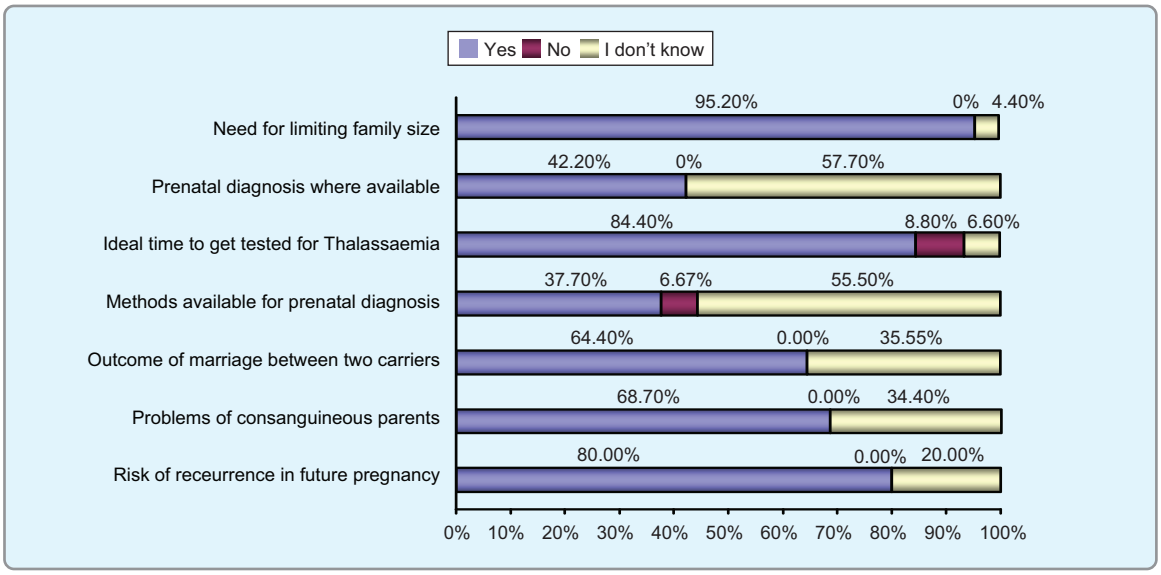

Fig.-3: *Knowledge about methods of prevention*

Assessment of attitude towards different aspects of thalassaemia revealed that most of the parents (84.4%, total 38) willing to disseminate what they have learnt in their life and wanted to participate in thalassaemia prevention program (80%, total 36). About half of the parents (51.11%, total 23) thoughts that disclosure of trait status will affect the prognosis of getting married. Majority of the parents (68.9%, total 31) were indecisive about termination of affected fetus and 17.77% (total 8) totally disagreed. Most of the parents strongly believed that carriers should not marry each other and carrier couples should have children only after antenatal diagnosis (Table I).

Table II showed that 10% parents had adequate knowledge and most of the parents had average knowledge about Thalassaemia disease.

Table III showed that majority of the parents had adequate knowledge about treatment options of thalassaemia.

Table IV showed more than half of the parents had adequate knowledge about different methods of prevention of thalassaemia.

Attitude of all the parents (100%) were positive (mean score 34±2.89) and all were willing to practice different methods of prevention of thalassaemia in their life (mean score 9.62±0.74).

Table I

Attitude of parents about different aspects of Thalassaemia

Different domains	Strongly agree	Agree	Disagree	Indecisive
Willing to disseminate what they have learnt	84.4(38)	15.6(7)	0	0
Willing to participate in prevention program	80(36)	20(9)	0	0
Want to donate blood	86.6(39)	11.11(5)	2.2(1)	0
Want to screen oneself for carrier status	82.2(37)	15.5(7)	0	2.22(1)
Disclosure of trait status affects the prognosis of getting married	51.1(23)	40(18)	8.8(4)	0
Compulsory screening before marriage	75.5(34)	20(9)	0	4.4(2)
Termination of pregnancy of affected fetus	6.6(3)	6.6(3)	17.7(8)	68.8(31)
Carrier couple should have children after antenatal diagnosis	82.2(37)	8.8(4)	4.4(2)	4.4(2)
Carriers should not marry each other	80(36)	11.1(5)	6.6(3)	2.2(1)

(n=45)

Table-II

Knowledge about disease among parents

Knowledge	Frequency	Percentage	Mean score
Adequate	10	22.22	
Average	29	64.44	14.2±3
Inadequate	6	13.33	

Table III

Knowledge about treatment options

Knowledge	Frequency	Percentage	Mean score
Adequate	29	64.44	
Average	12	26.67	14.9±2.88
Inadequate	4	8.89	

Table IV

Knowledge about methods of prevention

Knowledge	Frequency	Percentage	Mean score
Adequate	27	60	
Average	14	31.11	23.33±7.23
Inadequate	4	8.89	

Discussion:

The present study gave an overview about the current knowledge of the study population.

The role of carrier detection and genetic counseling in preventing thalassaemia is well established. Prevention has been successfully practiced in some countries. The result of three year voluntary screening program and prenatal diagnosis for the prevention of halassaemia in Sardinia were encouraging[10]. So more focus on prevention of thalassaemia than cure should be adopted.

In the present study, majority of parents had adequate knowledge about the treatment options and methods of prevention and most of them had average understanding of the disease. In the study conducted by Singh L et al, showed that 95.83% parents and 31.86% relatives had adequate knowledge about thalassaemia. They concluded that parent had better knowledge about different aspects of thalassaemia than relatives[11]. In another study conducted at Gujarat in India, awareness about thalassaemia were found to be inadequate among parents[12].

In this study, physicians were the source of information for the parents. In another study, parents received information mostly from physician but there were several other sources like paramedics, electronic media, print media, seminars, internet and from relatives[13]. Several other studies also showed a positive impact of social educational program in increasing the knowledge of parents about the disease[14,15]. Steps can be taken for dissemination of knowledge about thalassaemia by using print and electronic media, inclusion of the disease in curriculum of secondary education, health education by health care workers, social workers etc in our country. Creating awareness will bring large number of population under self screening, increase in carrier detection and prevention of marriage between carrier couples thus will reduce the number of affected infants. Study shows, antenatal screening, availability of prenatal diagnostic methods and termination of affected fetus can greatly reduce the burden of chromosomal disorder[16].

In this study, all of the parents possessed positive attitude and they were willing to practice different methods of prevention of thalassaemia in their family. But regarding the question of termination of pregnancy with thalassaemia major fetus, most of the parents (68.8%) were indecisive and 17.77% parents totally disagreed. Their religious beliefs makes therapeutic abortion difficult. But Ahmed et al concluded in their study that attitude of Pakistani women living in UK towards prenatal diagnosis and therapeutic abortion were influenced by multiple factors. Therefore religion should not be taken as sole cause for their attitude towards termination of pregnancy[17].

Community participation should be an integral part of health system to make the carrier screening of thalassaemia successful and reducing the recurrence risk in family. Counseling about risk of recurrence and need for limiting family size is of paramount importance and affected families are greatly benefited from this. In Mediterranean area, optimal care for every patient has been achieved through carrier screening and genetic counseling[18]. Population based interventions for prevention of genetic disease has a great potential specially in low resource country [19]. Iran had adopted a national screening program for thalassaemia which consisted of screening at primary care level and genetic counseling since 1996. The result was very much encouraging with 70% reduction of birth of affected infants[20].

Thalassaemia prevention program should be started from the parents of the children With thalassaemia as

they are the worst sufferer of the disease consequences. As they already knows the burden of raising an affected child, creating awareness among them may contribute to disseminate the knowledge at societal level. All of our study participants were willing to spread what they have learnt in their life to other. They want to take part in Government programs for creating social awareness about thalassaemia. Government can utilize these population resource to create awareness among general people, students and prospective couples. They can share knowledge about outcome of marriage between carriers, consanguineous parents, explain the need for limiting family size, need for antenatal testing of carrier couples when they plan pregnancy. In this way they can help to reduce the burden of thalassaemia in society.

Conclusion:

The present study revealed that most of the parents had adequate knowledge and positive attitude for thalassaemia prevention and they can serve as resource for spreading awareness about thalassaemia in community. Research should be emphasized on methods of prevention of genetic disease like thalassaemia. Creating family awareness and carrier detection should be a part of primary health care and have to be implemented as national strategy for control of genetic disease. It will greatly reduce the economic burden of family for health services and affected individual will have a possibility of raising a healthy child.

References:

1. Firkin F, Chesterman C, Pennington D, Rush B. Disorders of hemoglobin structure and synthesis, De Gruchy's clinical hematology in medical practice. 5th ed. Oxford: Oxford Blackwell Science; 1996.
2. World Health Organization. Management of hemoglobin disorders: report of a joint WHO-TIF meeting, Nicosia, Cyprus, 16-18 November 2007.
3. Khan WA. Thalassemia in Bangladesh. Dhaka Shishu (Children) Hospital Journal. 1999; 15:42-44.
4. Janet L. Kwiatkowski .Hemoglobinopathies in Lanzkowsky P. Manual of Paediatric Hematology and Oncology,6th ed .London. Elsevier Academic press,2005:186-87.
5. Hossain M S, Hasan M M, Raheem E, Islam M S. Mosabbir A A, Petrou M, Telfer P,. Siddiqee M.H. Lack of knowledge and misperceptions about thalassaemia among college students in Bangladesh: a cross-sectional baseline study. Orphanet Journal of Rare Diseases. 2020;15:54.
6. Amarasinghe N, Amarasena A, Thabrew A, Wearawatte P, Premawardhena A, Malik F, Abusaeed M, Wickramasinghe C. Redesigning New Policy Options for Thalassemia Prevention in SriLanka.Thalass:Rep.2022,12:135-142.
7. Waheed F. Thalassaemia prevention in Maldives: Effectiveness of Primary, Secondary and Tertiary Prevention Interventions. Doctoral Thesis, The University of Western Australia, CCraeley, W A, Australia, 2015.
8. Rishmitha, Badagabettu S, Archana M V, Vani Lakshmi R, J omon C U. Awareness on thalassaemia and opinion of carrier screening among young women from selected undergraduate colleges of udupi district. Clinical Epidemiology and Global Health. 2022;14:100978.
9. DGHS: Draft Guidelines for the Management of Thalassemia in Bangladesh. In. Dhaka, Bangladesh: Directorate General of Health Services (DGHS); 2018. https://dghs.gov.bd/images/docs/Notice/Notice_10_10_2018_6.pdf.
10. Cao A, Furbetta M, Galanello R, Melis MA, Angius A, Ximenes A, et al. Prevention of homozygous beta thalassaemia by carrier screening and prenatal diagnosis in Sardinia. American journal of human genetics.1981Jul;33(4):592-605.
11. Singh L, Wade M, Agrawal M. Awareness about Thalassemia and feasibility of cascade screening in families of Thalassemia major patients. Int J C ontemp Pediatr 2019;6:xxx-xx.
12. Goyal JP, Hapani PT, G agiya H. Awareness among parents of children with Thalassemia major from Western India. Int J Med Sci Public Health 2015;4:1356-1359.
13. Fouzia Ishaq, Hasnain Abid, Farkhanda Kokab, Adil Akhtar and Shahid Mahmood. Awareness Among Parents of Thalassemia Major Patients Regarding Prenatal Diagnosis and Premarital Screening. Journal of the College of Physicians and Surgeons Pakistan 2012; 22(4): 218-221.
14. Dehkordi AH, Heydernejad MS. Enhancement of parents' awareness about Thalassemia disorder through two educational programs. Pak J Med Sci 2008; 24:283-6.
15. Paholpak S, Jetsrisuparb A, Wiangnon S, Sangsahachat D, Padtawaro LO. Result of video-education on "genetic transmission in thalassemia" thalassemic patients and their parents. J Med Assoc Thai 2006; 89:1909-14.
16. Moorthie S et al (2018) Estimating the birth prevalence and pregnancy outcomes of congenital malformations worldwide. J Community Genet. https://doi.org/10.1007/s12687-018-0384-2
17. Ahmed S, Green JM, Hewison J. Attitudes towards prenatal diagnosis and termination of pregnancy for thalassemia in pregnant Pakistani women in the north of England. Prenat Diagn 2006; 26:248-57.
18. Angastiniotis M, Modell B, Englezos P, Boulyjenkov. Prevention and control of haemoglobinopathies. Bull WHO 1995;73375-86.
19. Christianson AL, Modell B. Medical genetics in developing countries. Ann Rev Genomics Hum Genet 2004;5:219-65.24.Alwan A, Modell B. Recommendation for introducing genetic services in developing countries. Nature Rev Genet 2003;4:61-8.
20. Karimi M, Jamalian N, Yarmohammadi H, Askarnejad A, Afrasiabi A, Hashemi A. Premarital screening for thalassemia in Southern Iran: options for improving the program. J Med Screen 2007;14:62-66.