Journal of Community Genetics
https://doi.org/10.1007/s12687-021-00540-5

ORIGINAL ARTICLE

Investigating the reasons for marriage among couples with thalassemia minor, in Iran

Fatemeh Hasanshahi[1] · **Narges Khanjani**[1]

Received: 19 February 2021 / Accepted: 8 July 2021
© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Thalassemia is one of the most prevalent genetic disorders in Iran. The birth of a child with thalassemia major is associated with many problems for the family, and society. In the present study, the reasons for marriage among people with thalassemia minor in Iran, in spite of receiving medical advice against it, have been investigated. The present study was a qualitative content analysis conducted in 2019 with the participation of 12 couples (24 participants) with thalassemia minor living in Rafsanjan, Iran; and 2 counselors working with thalassemia patients. Data collection was conducted through in-depth interviews. All interviews were recorded and transcribed. The text was read several times, categorized and main themes were extracted according to content analysis methods. The present study shows that giving inadequate or inaccurate information to people, strong emotional attachment between couples, taking the test at the wrong time, family interference and family insistence on marriage, having seen cases with no problems, and specific thoughts and beliefs are the most important reasons for marriage among couples with thalassemia minor in Iran. According to the results of the present study, the importance of providing thorough and accurate information to the public, setting an appropriate time for counseling and screening which is not immediately before the marriage ceremony, and briefing more efficiently at the time of counseling can help prevent marriage among couples with thalassemia minor in Iran.

Keywords Thalassemia · Cause · Marriage · Iran

Plain English summary

Thalassemia is one of the most common genetic disorders in Iran and the birth of children with this disease imposes heavy costs on the family and society every year. However, despite screening and prevention programs, babies with thalassemia major are still born in Iran. The aim of this study was to investigate the causes of marriage among couples with thalassemia minor.

Twelve couples (24 participants) with thalassemia minor living in Rafsanjan, Iran; and 2 counselors working with thalassemia patients participated in this qualitative study. Data collection was conducted through in-depth interviews.

The result of this study shows that giving inadequate or inaccurate information to people, strong emotional attachment between couples, taking the test at the wrong time, family interference and their insistence on marriage, having seen cases with no problems, and specific thoughts and beliefs are the most important reasons for marriage among couples with thalassemia minor in Iran.

In conclusion, it seems like providing thorough and accurate information at the appropriate time can help prevent marriage among couples with thalassemia minor in Iran.

Introduction

Beta thalassemia major, in which the beta-globin chain is not produced normally, is one of the most prevalent genetic blood disorders in many societies (Ambroggio et al. 2016). Approximately 60,000 to 70,000 children are born with the disease in the world annually. This disease is more prevalent in the Mediterranean region, North Africa, and the tropics. Iran is also known as one of the countries affected by the disease, in which thalassemia is the most prevalent genetic disorder (Li 2017).

✉ Narges Khanjani
n_khanjani@kmu.ac.ir

[1] Neurology Research Center, Kerman University of Medical Sciences, Kerman, Iran

Published online: 27 July 2021

Taking care of people with the disease imposes high costs on the health care system in addition to negatively affecting the family and the society. About 25% of the country's blood reserves are spent on the treatment of thalassemia major patients annually. Due to the high costs of treatment and the economic, social, and psychological problems imposed on the families and the society, it is important to prevent the birth of children with thalassemia major, increase awareness about this disease, and discourage carrier couples from marrying with each other (Cao and Galanello 2010).

According to the genetic pattern of the disease, if marriages take place between beta thalassemia carriers, the incidence of thalassemia major in the community will increase significantly. The results of many studies have indicated that thalassemia can be controlled and prevented by screening, genetic counseling, and prenatal diagnosis. In many countries such as Italy (since 1943) and England (since 1973), screening and abortion programs have been implemented successfully. In Iran, more than a decade has passed since the implementation of the thalassemia screening and control program. However, many cases of major thalassemia are still being reported (Zeinalian et al. 2013; Tosto et al. 2009; Fucharoen and Winichagoon 2007; Rezabeigi Davarani et al. 2019a), and because the cost of treatment is high, many of these patients are treated by finances coming from charities.

According to the latest health guidelines in Iran, premarital counseling is mandatory, and if the fetus is diagnosed with the disease, abortion can be performed legally in medical centers after the approval of the treating physician. Abortion is optional and a large part of the cost of legal abortion is paid by the insurance companies. This kind of abortion, is performed to prevent the psychological and financial burden of the disease, and has been accepted by many people in the society (Mahdavi et al. 2020; Fallah et al. 2009). Emotional support such as pre-abortion counseling and guidance is provided to couples seeking abortion.

Because of the high rate of genetic and congenital abnormalities in Iran for reasons such as consanguineous marriages, there have been efforts to reduce the number of these infants and one way is to advise patients with thalassemia minor not to marry with each other. But, it is not compulsory and the couples have to make the final decision themselves (Mahdavi et al. 2020; Fallah et al. 2009; Ardakani et al. 2005).

In Iran, according to the World Health Organization, about 4% of the population (2–3 million people are carriers of the thalassemia gene (thalassemia minor), and more than 18 thousand cases of thalassemia major live in different provinces of the country. Thalassemia is a widespread disease in Iran; however, it is more prevalent on the coasts of the Caspian Sea (Gilan and Mazandaran provinces), the coasts of the Persian Gulf and the Oman Sea (Sistan and Baluchestan, Bushehr, Hormozgan, Khuzestan, Fars, and the south of Kerman, Isfahan, and Kohgiluyeh-va-Boyer-Ahmad provinces) (Khodaei et al. 2013). Kerman province, located in the southeast of Iran, is one of the regions in which thalassemia is highly prevalent (Rezabeigi Davarani et al. 2019b, 2020).

Major thalassemia is a genetic disorder developed through the marriage of carrier couples. If two carriers marry, there is a 25% probability that the fetus will have thalassemia major. Nowadays, people's information about thalassemia has increased due to various factors including premarital counseling, and mass media education. Increased awareness about this disease in the society has led to a reduction in the birth of infants with beta thalassemia major. However, despite all of the efforts, marriage among couples with thalassemia minor is still happening. Investigating, recognizing, and preventing factors related to marriage among people with thalassemia minor can help prevent the birth of infants with beta thalassemia major. In this qualitative study, the reasons for marriage among thalassemia minor patients living in Iran, despite receiving medical advice were investigated.

Methods

This was a qualitative content analysis study conducted in 2019. The participants were couples which both had thalassemia minor and lived in Rafsanjan. Participants were selected by purposeful sampling. There were a small number of couples whom both had thalassemia minor and all of them were invited to participate in this study. Two counselors working with thalassemia patients also participated in this study.

Ethics approval was obtained from the Ethics Committee of Kerman University of Medical Sciences (Ethics code: IR.KMU.REC.1399.127). Data collection was conducted through in-depth semi-structured interviews with the couple (one couple in each interview), and after inquiring oral consent. Open-ended questions were asked. The duration of each interview was between 45 and 60 min. Interviews were conducted at the health center that provided premarital counseling in Rafsanjan. All interviews were recorded. Data collection continued until data saturation. After the end of each interview, the participants' answers were analyzed qualitatively and categorized (Graneheim and Lundman 2004). Two counselors (who were physicians) were also privately interviewed. These counselors worked at these health centers and were involved in offering consultation to these couples.

The validity of the results of the present study was evaluated based on the four criteria of credibility, dependability, confirmability, and transferability according to Lincoln and Guba's criteria. In order to achieve credibility, member

checking was done and the interpretations and final report were shown to four participants and they commented on the validity of the results. Researchers also asked them about their opinion about the report. Participants' comments were reviewed and used to improve the results of the study (Graneheim and Lundman 2004). In the case of transferability, thick description was done, and the details of the research and its participants, from sampling to data collection and analysis, were described. Therefore, readers can compare their settings with the participants of this study. Regarding the dependability of the present study, external audit was used and the opinions of other academics were used to review and assess data collection, analysis, and final interpretations and conclusions (Graneheim and Lundman 2004; Hsieh and Shannon 2005; Green 2004). For confirmability, triangulation was done and in addition to the couples, counselors were interviewed. Also, all research steps taken from the start of a research project to the development and reporting of findings were done under supervision.

Results

A total of 12 couples (24 people) and 2 counselors were interviewed. The participants' demographic characteristics are presented in Table 1.

Data on the reasons for marriage in couples with thalassemia minor were categorized into 6 themes. In general, the reasons for marriage in these couples despite medical advice were as follows:

Inadequate or inaccurate information

The thalassemia minor patients who participated in this study claimed that, despite attending premarital counseling sessions, they did not have enough information about the severe consequences they would face, and only general information about the types of the disease and its treatment had been provided to them. Some participants were not happy with the information that had been provided and stated that information such as the painfulness of amniocentesis and the probability of abortion following amniocentesis, had not been presented in detail and seriously. Furthermore, they did not know that deciding to have an abortion could be very difficult, due to emotional conflicts.

> "We were told before marriage, but they did not mention what would happen. They didn't clarify the issue."
> "We thought that we would get better over time..."
> "We thought that this disease could be cured with a special diet. Our information was not enough."
> "I had to have an abortion after three months; I was so frustrated that I wanted to commit suicide."
> "Maybe if I had had enough information, I wouldn't have gotten married at all."

On the other hand, the counselors at the health center had other reasons for the ineffectiveness of these consultations and stated that most of the people who came for counseling did not pay much attention to the points presented in the meetings.

> "I have fully explained all the issues and problems that arise, and despite these recommendations, they still get married."
> "When we give a training class, some people fall asleep, some people play with their mobile phones, and only about 20 to 30 percent pay attention."
> "[Thalassemia] minor couples claim, after marriage, that they did not tell us anything and gave us inappropriate information, because they want to blame others … for their own actions."

The participants had various opinions on how information about the disease should be delivered to people. One main comment was that information about this disease and the ways to diagnose and prevent it, must be provided at an appropriate time and before the age of marriage, for example at high school. Moreover, they believed it's better to talk to the couples separately.

> "The disease should be introduced to students during middle and high school."
> "We need to know about this disease in advance."
> "They must counsel the couples separately and explain the issue. When they are together, they do not take it seriously and do not care about it. Personally, I won't let my daughter marry under these circumstances."

Moreover, one of the participants even recommended that school children should see children with thalassemia major, so that they would get more familiar with the condition:

Table 1 The participants' demographic characteristics

		Women	Men
Educational status	Illiterate	1	0
	5th grade (primary)	3	2
	Middle school	3	3
	High-School diploma	4	6
	Associate's degree	3	1
Age groups	Under 25 years	0	1
	25–35	5	5
	36–45	8	6
	Over 45 years	1	0

"High school students should visit children with thalassemia major to learn about their problems."

Some of the other suggestions were providing information about the disease, using mass media, newspapers, social networks, and producing documentaries and educational short films. Furthermore, using religious ceremonies and public tribunes for informing people were also suggested:

"Information about the disease can be provided in Ziyarat Ashura, Dua Kumayl, and Friday prayers [Shia muslim religious events]."

Based on the information provided by the participants about the premarital counseling they had received, it can be inferred that the information provided by some counselors before marriage, indirectly, gave them hope that if they got married and had a sick child, it would not be a significant problem and the problem could be solved. Some of the statements made by the participants have been mentioned below:

"We were told that both of us had thalassemia minor and we did not have any problem now and we could cancel the marriage, but if we got married and wanted to have a child, the fetus had to be tested before the eleventh week of pregnancy and we could have an abortion, if it had thalassemia major."

The majority of participants stated that they received most of the important information about this subject not during premarital counseling, but during pregnancy, abortion, and tests of fetal well-being. The majority of the participants pointed out that they were not aware of the reality and later suffered from various problems such as stress and anxiety due to this lack of information.

"If I could marry again, I would never do this, and I recommend that couples with thalassemia minor not get married; it is not worth the problems."
"Considering the difficulties, I had during pregnancy, I do not want my child to marry a person with thalassemia minor."

Strong emotional attachment between couples

A few couples admitted that they got married because they loved each other, although they knew that if they got married, they may have a child with thalassemia major, and they would face many problems. Some of the statements made by the participants are mentioned below:

"We loved each other; even if we would face problems with having a baby after marriage, and even if we wouldn't be able to have a baby, since we loved each other, we took our chances."

Moreover, it was pointed out that the blood test is performed at the time the emotional connection has already developed between young couples, and therefore, separation is difficult for them and their families.

"We took the test late. We were tested when we were in love. Our families did not agree, but our emotional attachment led to our marriage."

Furthermore, in several cases there were emotional connections between couples who were relatives and already knew each other and socialized with each other. This can strengthen these emotional relationships:

"We were cousins. We loved each other and separation was very difficult for us."

Taking the test at the wrong time

The majority of the participants claimed that the time of premarital testing and counseling is inappropriate and stated that after two persons got acquainted and their families made the arrangements for their marriage, it is too late to find out that they are carriers, and even if there is a possibility of giving birth to a child with thalassemia major, the marriage cannot be canceled in many cases.

"I wish we had been told we had thalassemia minor before the age of marriage and had had enough information about it and had not had these problems at the time of marriage."
"Information should be provided to people beforehand and the issue should be explained for lay people"

Family interference and insistence on marriage

Another point mentioned by the participants was interference of family members and their insistence on the marriage. In the current society of Iran, there are still traditional marriages that take place by the decision of family members, and sometimes these cases lead to excessive family interference, which leads to marriage, despite awareness of the problems.

"My father…wanted me to marry my cousin who had thalassemia [minor], and he said nothing could go wrong."

Having seen cases with no problems

Considering the fact that this disease is hereditary, in many cases the couples had seen similar marriages among their relatives. And in some cases, because their children did not have thalassemia major, the couple had thought that their situation would be similar and that the chance of giving birth

to a sick child was low, therefore, they had not taken this issue seriously.

> "… because my brother and his wife had this problem and none of their children had thalassemia major."
> "… because of personal experience, because my brother had thalassemia [minor] and had three healthy children."

Specific thoughts and beliefs

Participants also mentioned special viewpoints and beliefs that had led to their marriage. For instance, some of them thought that if they don't marry, people would talk behind their backs or stigmatize them as sick people.

Moreover, one of the participants stated that some people believe that whatever God wants will happen, as if they have no free will to make decisions.

> "In some parts of the country, people believe that testing is not necessary or according to old traditions, abortion must not be performed and we must be satisfied with what God gives us. People's awareness must be raised."

Discussion

Major thalassemia imposes a heavy financial and medical burden on the family and the community. Considering the rather high prevalence of the disease in Iran, currently thalassemia prevention programs are important and are specifically based on screening and premarital counseling (Seyam and Assemi 2010). These efforts for prevention of thalassemia major cases in Iran have been underway during the last two decades (Kosaryan et al. 2009). Many interventional programs have been carried out in Iran to increase awareness and reduce the prevalence of the disease in the community, but for reasons such as different tribal, cultural and social structures and misconceptions, these interventions have not been completely successful (Sargolzaie et al. 2018). The results of prevention programs in countries like Thailand, Italy, and Greece have shown that education, teaching parents and screening play an important role in these programs (Singha et al. 2021; Monni et al. 2018; Loukopoulos 2011). Although in Iran, marital counselors advise against and try to prevent marriages between people who are both carriers of beta-thalassaemia, this might not be an accepted goal in many western countries.

Training, screening, and counseling couples are the main strategies of the thalassemia major prevention program in Iran. Various strategies have been used for controlling thalassemia in different countries; for instance, in Italy, premarital tests and therapeutic abortion have been performed since 1943 (Silvestroni and Bianco 1975). Also, since the 1970s, genetic testing and counseling have been performed in Mediterranean countries, countries with high thalassemia birth rates, and countries such as Cyprus and Germany where the number of immigrants from these affected areas is high (Cao and Kan 2013).

Similar to the results of the current study, the results of a study conducted in Malaysia showed that people had little knowledge about thalassemia and highlighted the need for effective public education programs. Researchers also suggested that public education and promotional activities should be conducted according to local cultural and religious beliefs; and by performing suitable educational programs, with emphasis on identifying problems and increasing knowledge, societies can hope to improve health behaviors and prevent the occurrence of thalassemia major (Wong et al. 2011). Awareness programs for individuals and families using mass media have been included in the health agenda of many countries as a complement to the prevention of this disease (Kosaryan et al. 2009).

However, the high rate of marriage among thalassemia carrier couples in Iran indicates that many people do not take the issue seriously and still more information should be provided. For instance, studies have stated that only 15 to 20% of carrier couples in Khorasan Razavi (Khodaei et al. 2013), Golestan (Jaafari et al. 2006), Hormozgan (Sadaghiani and Faridi 2001), and the south of Kerman canceled their marriages (Kiani and Ghorbani Aliabadi 2019).

One of the reasons for not canceling the marriage is familial relationships. Consanguineous marriages can increase the incidence of congenital diseases such as major thalassemia (Karimzaei et al. 2015; Sarker et al. 2018; Kashfi et al. 2018). Cultural and racial factors and lack of knowledge regarding the adverse effects of consanguineous marriages are related to the high prevalence of consanguineous marriages in Iran.

Another issue raised in this study was the inappropriate time of informing people that they have thalassemia minor, which is shortly before marriage, when the couples and their families are fully prepared for the marriage, and in some cases, the emotional bonds have been strongly formed. Most participants recommended informing people about this disease sooner, for instance during high school, and through various means such as mass media, official lectures, and inclusion in school books.

Different studies have indicated that the best strategy to prevent the disease is to control and identify the carriers before marriage. However, carriers must be identified and screened at a younger age, and especially at the beginning of school, and information and education should be provided at the same time; because right now most couples receive premarital counseling when they have already made their final choice, their families have agreed, and

emotional attachments have been formed, which is the main obstacle for marriage cancelation (Silvestroni and Bianco 1975; Shaianmehr et al. 2016; Karami et al. 2017).

In general, paying attention to the concerns of couples with thalassemia minor can help health system policymakers make better decisions for decreasing thalassemia minor marriages. As far as we know, no qualitative study has been conducted before our study on the causes of these marriages, although there are some qualitative studies about mothers caring for their children with thalassemia (Sapountzi-Krepia et al. 2006; Prasomsuk et al. 2007).

This study had some limitations. As this was a qualitative study the results cannot be generalized. The reasons for marriage among thalassemia patients might be different in different world populations, but many of the reasons mentioned in this article might be true for other Iranian cities and other countries as well.

Conclusion

Factors such as insufficient knowledge and awareness, particularly in deprived and rural areas, the high percentage of consanguineous marriages, and inappropriate time for screening and counseling the carriers, are significant obstacles to the success of the thalassemia major prevention program. It is recommended that more timely and effective awareness and counseling programs be provided, in order to prevent the marriage of people with thalassemia minor with each other.

Acknowledgements The authors thank the couples and counselors who participated in this study.

Author contribution FH and NK conceived and drafted the manuscript. NK critically reviewed the manuscript. All authors read and approved the final manuscript.

Funding This study was supported by Grant No. 99000058 from Kerman University of Medical Sciences.

Data availability The datasets used and/or analyzed during the current study are available from the first author on reasonable request.

Declarations

Ethics approval and consent to participate Ethics approval was obtained from the Ethics Committee of Kerman University of Medical Sciences (Ethics code: IR.KMU.REC.1399.127).

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

References

Ambroggio S, Peris C, Picardo E, Mitidieri M, Minniti E, Benedetto C et al (2016) β-thalassemia patients and gynecological approach: review and clinical experience. Gynecol Endocrinol Taylor & Francis 32:171–176

Ardakani ZB, Akhondi MM, Sadeghi MR, Sadri-Ardekani H (2005) The necessity of a comprehensive study on abortion in Iran. J Reprod Infertil 6:299–320

Cao A, Galanello R (2010) Beta-thalassemia. Genet Med. Nature Publishing Group; 12:61

Cao A, Kan YW (2013) The prevention of thalassemia. Cold Spring Harb Perspect Med. Cold Spring Harbor Laboratory Press; 3:a011775

Fallah M, Samavat A, Zeinali S (2009) Iranian national program for the prevention of thalassemia and prenatal diagnosis: mandatory premarital screening and legal medical abortion. Prenat Diagnosis Publ Affil With Int Soc Prenat Diagnosis. Wiley Online Library 29:1285–1286

Fucharoen S, Winichagoon P (2007) Prevention and control of thalassemia in Asia. Asian Biomed J 1:1–6

Graneheim UH, Lundman B (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today Elsevier 24:105–112

Green B (2004) Personal construct psychology and content analysis. Pers Constr Theory Pract 1:82–91

Hsieh H-F, Shannon SE (2005) Three approaches to qualitative content analysis. Qual Health Res. SAGE publications Sage CA: Thousand Oaks; 15:1277–88

Jaafari F, Nodeh-Sharifi A, Zaeri F (2006) Effectiveness of thalassemia prevention program on couples knowledge and carriers and marriage couples opting in Gorgan city. Gorgan J Res Med Sci 8:68–72

Karami H, Jalali H, Mahdavi M, Mahdavi MR (2017) Identification of a neonate with thalassemia intermedia despite premarital screening program in Mazandaran Province (co-inheritance of Hb Knossos and IVS II-1 G> A Mutations). Res Mol Med. Research in Molecular Medicine; 5:34–6

Karimzaei T, Masoudi Q, Shahrakipour M, Navidiyan A, Jamalzae AA-Q, Bamri AZ (2015) Knowledge, attitude and practice of carrier thalassemia marriage volunteer in prevention of major thalassemia. Glob J Health Sci. Canadian Center of Science and Education; 7:364

Kashfi SM, Mohaghegh Sharifi E, Rakhshani T, Hosseini SS (2018) Tests for the prevention of thalassemia major in the couples referring to Behbahan Health Center, Iran during 2006–2016. J Human, Environ Heal Promot. Journal of Human, Environment and Health Promotion; 4:116–20

Khodaei GH, Farbod N, Zarif B, Nateghi S, Saeidi M (2013) Frequency of thalassemia in Iran and Khorasan Razavi. Int J Pediatr. Mashhad University of Medical Sciences; 1:45–50

Kiani A, Ghorbani Aliabadi E (2019) Investigating the causes of beta thalassemia after start of prevention program in Jiroft City during 2001–2015. J Jiroft Univ Med Sci. Journal of Jiroft University of Medical Sciences; 6:168–77

Kosaryan M, Vahidshahi K, Siami R, Nazari M, Karami H, Ehteshami S (2009) Knowledge, attitude, and practice of reproductive behavior in Iranian minor thalassemia couples. Saudi Med J 30:835–839

Li C-K. New trend in the epidemiology of thalassaemia. Best Pract Res Clin Obstet Gynaecol. Elsevier; 2017;39:16–26.

Loukopoulos D (2011) Haemoglobinopathies in Greece: prevention programme over the past 35 years. Indian J Med Res. Wolters Kluwer—Medknow Publications; 134:572.

Mahdavi SA, Jafari A, Azimi K, Dehghanizadeh N, Barzegar A (2020) Therapeutic abortion in Iran: an epidemiologic study of legal abortion in 2 years. BMC Res Notes Springer 13:1–6

Monni G, Peddes C, Iuculano A, Ibba RM (2018) From prenatal to preimplantation genetic diagnosis of β-thalassemia. Prevention model in 8748 cases: 40 years of single center experience. J Clin Med. Multidisciplinary Digital Publishing Institute; 7:35

Prasomsuk S, Jetsrisuparp A, Ratanasiri T, Ratanasiri A (2007) Lived experiences of mothers caring for children with thalassemia major in Thailand. J Spec Pediatr Nurs. Wiley Online Library; 12:13–23

Rezabeigi Davarani E, Khanjani N, Rezabeigi Davarani M, Daneshi S (2019) The effect of genetic counseling and health care in reducing the incidence of major beta-thalassemia in Kerman Country in 2017. 12th Conf Heal Sci Updat. Shahid Behesti University, Tehran, Iran

Rezabeigi Davarani E, Khanjani N, Rezabeigi Davarani M, Daneshi S (2019) The Incidence rate of Major Thalassemia and its etiology in Kerman, Iran; from 2012 until 2017. 12th Conf Heal Sci Updat. Shahid Behesti University, Tehran, Iran

Rezabeigi Davarani E, Mohseni Takaloo F, Vahidnia A, Daneshi S, Rezabeigi Davaranid M, Khanjani N et al (2020) Epidemiological investigation of a twenty-year major β-thalassemia surveillance in Kerman. Iran Arch Hyg Sci 9:265–274

Sadaghiani S, Faridi M (2001) Knowledge and attitude of couples about Thalassemia before marriage in Bandar Abbas. Hormozgan Med J 5:33–43

Sarker SK, Islam MT, Bhuyan GS, Sultana N, Begum MN, Al Mahmud-Un-Nabi M et al (2018) Impaired acylcarnitine profile in transfusion-dependent beta-thalassemia major patients in Bangladesh. J Adv Res. Elsevier 12:55–66

Shaianmehr M, Abassi M, Zareipour MA, Sadaghianifar A (2016) Premarital screening of beta thalassemia in Urmia county of northwest Iran during 2014: a short report. J RafsanjanUniv Med Sci 14:903–910

Sapountzi-Krepia D, Roupa Z, Gourni M, Mastorakou F, Vojiatzi E, Kouyioumtzi A, et al (2006) A qualitative study on the experiences of mothers caring for their children with thalassemia in Athens, Greece. J Pediatr Nurs. Elsevier; 21:142–52

Sargolzaie N, Montazer Zohour M, Ayubi E, Shahraki F (2018) Relationship between social determinants of health and the thalassemia prenatal diagnosis test in Zahedan, south eastern Iran. Hemoglobin. Taylor & Francis; 42:231–5

Seyam SH, Assemi A (2010) Study of the knowledge in Guilan University students about thalassemia. J Urmia Nurs Midwifery Fac 8:150–155

Silvestroni E, Bianco I (1975) Screening for microcytemia in Italy: analysis of data collected in the past 30 years. Am J Hum Genet. Elsevier; 27:198

Singha K, Fucharoen G, Fucharoen S (2021) δ-Hemoglobinopathies in Thailand: screening, molecular basis, genotype-phenotype interaction, and implication for prevention and control of thalassemia. Ann Hematol 100:1953–1963

Tosto F, Salvatore M, Falbo V, Floridia G, Censi F, Bombieri C, et al (2009) The Italian scheme of external quality assessment for β-thalassemia: genotyping and reporting results and testing strategies in a 5-year survey. Genet Test Mol Biomarkers. Mary Ann Liebert, Inc. 140 Huguenot Street, 3rd Floor New Rochelle, NY 10801 USA, 13:31–6

Wong LP, George E, Tan J-AMA (2011) A holistic approach to education programs in thalassemia for a multi-ethnic population: consideration of perspectives, attitudes, and perceived needs. J Community Genet. Springer; 2:71–9

Zeinalian M, Moafi AR, Fadayi-Nobari R (2013) A study to evaluate the results of pre-marital screening program for beta-thalassemia in Isfahan province, 1997–2010. Sci J Iran Blood Transfus Organ 10:20–30

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.