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Wishes, Choices and Experiences in Marriage and Reproduction of People with Genetic Diseases: An Example of People with Thalassemia Major in Iran

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Abstract

This study examines the choices and experiences in marriage and reproduction of people with a severe type of genetic blood disorder, thalassemia major, which is the target of a worldwide prevention program. Under this program, they are required to consider whether their partner-to-be is suitable for marriage in order to avoid having children with the same genetic traits, but the restrictive influence of the program on the marriage and reproductive choices of people with thalassemia major has not been thoroughly studied. Information was gathered through questionnaires, interviews, and participant observation in Isfahan. Several factors were considered, including social norms to reinforce ideal marriage, negative attitudes towards physical conditions, misinformation surrounding genetic characteristics and symptoms, familial opposition, inadequate genetic counseling, and exclusion by societal institutions. These can all be seen as disabling barriers preventing those with thalassemia major from fulfilling their marital and reproductive wishes.

Keywords: genetic disease; marriage rights; reproductive rights; Iran; thalassemia major

1. Introduction

1) Purpose of This Study

The development of genetic medicine and its clinical implementation are expected to enhance humankind's health and well-being. Technology based on genetic and genomic discoveries contributes to identifying the pathology of many diseases (Epstein 2006). Premarital carrier screening, prenatal diagnosis, and selective abortion of some genetic diseases have been widely practiced to avoid births with impairments. Thalassemia, one of the most common inherited blood diseases globally, is a well-known example of the application of genetic medicine by the introduction of prevention programs in many countries.

Thalassemia is an autosomal recessive inherited hemoglobin production disorder, which causes anemia. Patients are divided into different groups depending on the severity of their anemia. People with thalassemia minor, who are also called thalassemia carriers, do not require regular medication (hereafter referred to as carriers). People with thalassemia major (hereafter referred to as TM), which is described as a severe type of thalassemia or transfusion-dependent thalassemia, need life-long regular blood transfusions due to their severe anemia. It is explained that there is a one-in-four chance that every pregnancy may produce a baby with TM if a carrier of the thalassemia gene has a child with a carrier partner[1].

To prevent the birth of babies with TM, the combination of premarital carrier screening, prenatal diagnosis, and selective abortion has been implemented in some countries such as Cyprus and Iran, which have dramatically reduced newborn cases. Many studies have been conducted to discuss the ethical

[1] In reality, the variation of thalassemia genes is more diverse. There are people with thalassemia intermedia whose anemic symptoms are not as severe as TM, requiring less frequent or no blood transfusions.

dimension of the thalassemia prevention programs (e.g., Cowan 2008, Ghotbi and Tsukatani 2005, Strauss 2009).

However, these studies focus on the issues involved in carriers' choices and overlook the possible impact of the prevention programs on marriage and reproductive choices of people with TM, who could have been aborted but were not, and survive until now. It is because people with TM used to die before their reproductive age, and the possibility of marrying, having children, and leaving their genes to the next generation had not been envisioned until recently. Now however, marriage and reproduction have become viable options for many TMs.

In this paper, the personal experiences of marriage and reproductive choices of people with TM in Iran are examined as a descriptive study for further ethical discussion and the practical implications of social policy to control genetic diseases.

2) Genetic Health Policy for Low-Resourced Countries

Genetic medicine is "the science of human biological variation as it related to health and disease" (Epstein 2006). Its primary purpose is curing diseases or reducing suffering from illnesses (ibid.:434). Nevertheless, it has highlighted many ethical challenges in broader fields of society. The most frequently disputed ethical issue is whether genetic medicine could be used as eugenic measures or not because the inhumane eugenic policies of the Nazis are deeply embedded in people's minds.

Since the purpose of this paper is not to explore the linkage or discontinuities between eugenics in the early 20th century and modern genetic medicine, here only two different perspectives on prenatal testing and selective abortion will be introduced to clarify the discussion related to the thalassemia prevention program.

One is the standpoint of disability rights critique. Parens and Asch declare that selective abortion is ethically misleading because it is discriminatory, not only towards the impairments themselves but also toward the person with impairments. Furthermore, it does not accept the diversity of human nature, and it has negative influences on society and family (Parens and Asch 2000:13).

Parens and Asch classify the disability rights' critical viewpoints into three groups. One presumes that prenatal testing/diagnosis followed by abortion enhances the notion that disability is caused by an individual's impairments, not by discrimination existing in the wider society. The second implies that prenatal testing encourages parents to accept only those babies with their preferable traits, from which impairments, in most cases, are excluded. The third sees the parents as misinformed that having children with impairments will not allow them to enjoy ideal childrearing (ibid.:12-13).

There is another discussion on abortion of impaired fetuses in public health or medical management of low-income countries. Medical care for severe impairments is unaffordable for most people in underdeveloped countries (Alwan and Modell 2002:65). Therefore, WHO recommends utilizing genetic medicine for preventive purposes in counties with lower financial capabilities, simply because it is cheaper than providing costly medical treatments (ibid.:65).

Ballantyne stresses that discussions of disability rights critique, which primarily focus on the concepts of free choice, autonomy, and value of life with impairments, are for developed countries, but the most critical issue could be very different in less developed countries. It is not a matter of the value of life with impairments, but rather, a matter of family burden and the ethics of distribution of limited medical resources at a national level (Ballantyne et al. 2009).

Thus, people with particular impairments or diseases are somehow judged to be ineligible to receive a large allocation in terms of cost-benefit analysis because the treatments for them are too

expensive or the outcome of the treatment is so poor. In this situation, the WHO's policy emphasizes thalassemia prevention. The WHO's strategy places thalassemia as a "point of entry for genetics services" (Alwan and Modell 2002:65), based on reasons as follows.

Firstly, in the Middle East and Asia, in which there are fewer economically developed countries, the prevalence of thalassemia is high. Secondly, thalassemia is 'visible.' The cost of treatments is extremely high, but the patients often suffer or die young. These characteristics clearly show the patients' hardships and the country's financial difficulties in providing treatment. Thirdly, identifying the carrier status and prenatal diagnosis in the early gestation period is possible, which also makes prevention tactics visible (ibid.:65).

Some studies try to affirm the thalassemia prevention program's legitimacy by showing that religious authorities and community members approve it, and most carrier parents or even people with TM agree to follow it (e.g., Cowan 2009）. One of these studies was conducted in Iran, a survey of TM patients and their parents in Shiraz, asking their attitudes towards prenatal diagnosis and abortion. A high percentage of both parents (90.3%) and patients (98.4%) accept the prenatal diagnosis, but the attitudes towards abortion are a little different. 91.3% of the parents are in favor of terminating the pregnancy of affected fetuses, while 77.5% of the patients think it is right (Karimi et al. 2010).

Certainly, thalassemia patient organizations both at the international and local level support prenatal screening because the more people born with TM, the less allocation of the necessary blood and drugs each living person with TM can share (Cowan 2009:101). Therefore, it could be possible to conclude that the acceptability of 'selective abortion among parents and people with TM is very high' (Karimi et al. 2010:52). However, opinions towards the thalassemia prevention programs usually do not assume that the patients' marriage and pregnancy may result in having affected babies.

The discussion of the genetic health policy in low-resourced countries advocates, as disability rights critique warns, that the decisions for selective abortion are made on account of society's convenience or a mothers' benefit (Anstey 2008:236). More attention should be paid to the fact that the people who receive profits from abortions are different from those subject to intervention because the fetus will never be alive and never have a voice (ibid.:236). People with TM may experience the policy differently when considering their own marriage and reproduction since they will also transmit their thalassemia gene to their children.

3) Marriage and reproduction of people with TM

Marriage and reproduction among people with TM are relatively new issues since the life expectancy of people with TM in countries with a high prevalence of the condition has been prolonged only in recent decades (De Sanctis et al. 2019).

Currently, the majority of individuals with TM are reaching reproductive age, but there is little research on the social barriers they experience regarding marriage. Most studies have focused on the clinical management of fertility, pregnancy, and childbearing or on surveys of reproductive outcomes based on their medical records (e.g., Zafari and Kosaryan 2014). The importance of discussing the disabling social factors against the reproductive and sexual rights of people with TM has not been fully acknowledged (Bou-Fakhredin et al. 2020).

The social situation around the carriers, as well as their clinical presentations, thoroughly differ from those of people with TM. To avoid conceiving a baby with TM, carriers may have to reconsider their marriage and family planning if their partner is also found to be a carrier. However, carriers neither require

regular medical treatment nor is their carrier status apparent. They can enjoy lifestyles no different from those of people without the thalassemia trait.

In contrast, people with TM cannot produce normal hemoglobin in their bodies and present with severe anemia, requiring two to four blood transfusions per month throughout their lives. Repeated blood transfusions cause an accumulation of excessive iron in the body, leading to a number of serious complications. In the 1930s, a British pediatrician reported that most patients died before the age of 6. Nowadays the life expectancy of patients with TM has increased through the development of blood transfusion therapy, improvements in iron chelation (drugs to remove iron from the body), and advances in the treatment of complications (Cowan 2008:181-197).

The application of gene therapy has been examined, and bone marrow transplantation can be an effective treatment for TM. However, it is neither universal nor accessible to all patients, especially in less developed countries (Hussein et al. 2013). According to Cappellini et al. (2014), at present, in regions where regular transfusion therapy is available, the impairment itself is not fatal. Causes of death are complications stemming from treatment for TM. A person with TM may have various complications such as heart, liver, or kidney dysfunction, viral infections such as hepatitis C, decreased immunity or thrombosis due to the removal of an enlarged spleen, infertility, bone deformities of the face and head, short stature, osteoporosis, diabetes, cramps and pain in the limbs, and others. Some of these are life-threatening conditions but can be minimized with appropriate treatment and self-management, and many people with TM work and have active social lives.

Although the recent progress of their conditions, life with TM is captured in an ontological dilemma under the prevention program. On the one hand, people with TM cannot reject the legitimization from distribution ethics viewpoints since they cannot survive without regular blood transfusion and routine

medications, which are both expensive and limited medical resources. Additionally, the diagnostic/genetic identity of a person with TM is the credential necessary to gain public support for medical treatments and membership in patient rights movements led by patient organizations, as the discussion of "biological citizenship" portrays (Rose 2007). On the other hand, people with TM are defined as having the same genetic identity as those who should be prevented from being born and whose hereditary transmission through reproduction should be restricted.

The ethics of marriage and reproduction among people with genetic diseases should be discussed along with their particular conditions and specific experiences. A person with TM may choose a partner with TM, a carrier, or someone without the thalassemia gene (De Sanctis et al. 2019:235, Miri-Aliabad et al. 2016). Thalassemia takes on an autosomal recessive inheritance pattern. Therefore, if people with TM marry a partner without the thalassemia trait, all their children will be carriers, which is not a problem. However, if they choose to marry a person with TM, all their children will be born with TM.

Other genetic conditions lead to different experiences: cystic fibrosis (CF) is also an autosomal recessive inheritable disease with severe symptoms. CF inevitably affects male fertility, which causes challenging circumstances in marriage (Sawyer et al. 2009). Unlike a person with TM, it is not realistic for a person with CF to marry a partner with the same disease because people with CF should never meet as they carry bacteria within their lungs that could be harmful to each other (Cystic Fibrosis Trust 2021).

Huntington's disease has a late-onset, so by the time a person is diagnosed, s/he is likely to have already married and had children. Since it is a dominant form of inheritance, all those who inherit the gene will develop the disease, so the question is how to diagnose her/his children when the children have not yet developed the disease (Konrad 2005). In dwarfism, there are marriages between partners with the same traits in spite of the fact that their children may have “double dominance,” a condition with severe medical

complications and early death (Saxton 2006:108). The discussion of Deaf-Deaf marriage (Murray 2004) provides another perspective. Deaf people claim their rights to have Deaf children because they are not disabled but are a minority language group, enjoying their own communication method through sign languages (Lane 2005).

In 2014 and 2015, the author conducted a preliminary study on marriage and reproduction among people with TM in three Iranian cities. The results revealed that, in many cases, their health conditions deteriorated after disturbing events related to marriage and reproduction. Therefore, this paper tries to document how people with TM viewed themselves, their actual choices on marriage and reproduction, and what happened to them after taking actions within the particular conditions with TM in the context of Iran. This attempt has clear value for future ethical discussions of genetic programs or the sexual and reproductive rights of disabled people.

2. Research Process

Since there are limited studies accumulated in this field, it was essential to employ different methodologies as follows.

(1) A literature review and preliminary field research in order to understand the local situation were conducted from 2014 to 2015 in Tehran, Isfahan, and Shiraz. (2) Questionnaire research in the Thalassemia Center of the hospital in Isfahan, in which about 800 people with TM are registered for blood transfusions. 143 valid responses were collected in 2016 and 2017 from people with TM over 18 years old who agreed to participate in the questionnaire research. (3) Interviews with those who had completed the questionnaire. (4) Intermittent participant observation and ethnographical interviews with people with TM, their family members and friends, and health workers in the Thalassemia Center and activities of people

with TM in Isfahan, such as bus trips to Tehran for medical checkups, events on International Thalassemia Day, local meetings and wedding or birthday parties held by people with TM from 2014 to 2019. (5) Visits to international conferences, thalassemia centers, and thalassemia societies in England, Germany, Greece, UAE, Azerbaijan, Jordan, Turkey, and Thailand, which have either high thalassemia prevalence, thalassemia prevention programs, or active patient groups, directed towards understanding the particularity of the Iranian situation.

Persian is not the author's native language, though she is reasonably proficient. Therefore, the following process was adopted in the preparation of research questionnaires and interviews. Firstly, based on the insights obtained in research methods of (1), (4), and (5), the author's draft of the questionnaire in Persian was examined by the members of the Isfahan Thalassemia Society, two nurses in the Thalassemia Center, and members of Isfahan University of Medical Sciences. The revised version of the questionnaire was printed and distributed to the people with TM who came to the Thalassemia Center for a regular blood transfusion. Interviews were conducted by the author simultaneously with the questionnaire.

Two patient members of the Isfahan Thalassemia Society accompanied the author as research assistants in the questionnaire and interview process in the Thalassemia Center. They orally explained the purpose of the research to the patients and distributed the printed questionnaire to the participants who gave their consent. Participants answered the questionnaire by themselves during their blood transfusions on beds or chairs. The author sat down next to the participants who agreed to have interviews and had conversations with them. Individual meetings were arranged for people who wanted to have an interview where more privacy was ensured. Following some patients' wishes, conversations were not recorded, but the author took notes.

The research was approved by the Research Ethics Committee of the Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, though all discussion in this article is the author's responsibility. There are no relevant financial or non-financial competing interests to report.

In the following sections, 9 individual cases reconstructed from the interviews will be discussed to give insight into their experiences, along with the research questionnaire results, the information gained through the literature review, and ethnographical data in Iran and eight other countries. Since the purpose of this paper is to provide an outline of the opinions and problems of Iranians with a genetic disease in their choice of marriage and reproduction, typical cases are chosen, and the statistical data of the questionnaire is kept simple in numbers and percentages. For privacy protection, all individuals in the cases are given pseudonyms, and personal information has been altered to the extent that it does not affect understanding of the situation.

3. The clinical environment and social situation of people with TM in Iran

With a population of about 80 million, Iran is a middle-income country in terms of economic development (The World Bank Group 2021). Large cities have many medical facilities that provide a variety of services, including highly specialized medical care. In recent years, universal health care coverage has been promoted, and it is reported that 90% of the population have some form of health insurance (Mehrbad 2009). In 2019, 17,342 people with TM received regular medication in 198 health care facilities in Iran (Hadipour et al. 2019). Blood products for transfusion and iron chelators (Iranian generic drugs), essential for survival, are provided at low cost. Imported foreign brand-name drugs are less accessible with higher prices but covered by medical insurance. These blood products have a high quality standard (Pourfathollah and Hadipour 2019, WHO 2017).

In some countries, blood banks for supplying products derived from donated blood have not been developed, and the risk of viral infection through blood transfusion is high. Additionally, they do not have the capability to produce generic drugs and are obliged to purchase expensive products from Western pharmaceutical companies. Compared with the limited situations in those countries, the clinical environment of people with TM in Iran was relatively secure in 2014-2019 when the field research was conducted.

Before the 1990s, many children with TM in Iran died in their teenage years. However, papers published in 2015 reported that 80.5% of patients in Hamadan lived to the age of 30 (Zamani et al. 2015), and 63% of patients living in Shiraz survived into their 40s (Rajaeefard et al. 2015). This implies that young people with TM can now plan their lives with expectations to pursue higher education, have a job, marry, and have children.

In Iran, a pilot project of the combination of premarital thalassemia carrier screening and genetic counseling was launched in 1992 in Isfahan province and became operative as a mandatory national program in 1997. Prenatal diagnosis of both-carrier married couples and the abortion of fetuses with TM became legalized after the Supreme Leader's approval *fatwa* (Islamic decree) issued in 1997 (Shamsi Gooshki 2014:75). Since then, the number of newborn cases with TM has decreased, and in 2015, the annual birth-rate of TM had reduced by 90% of the estimated figure (Hadipour et al. 2019).

The thalassemia prevention programs being carried out in some countries vary from a mandatory national program to a voluntary regional project (Cousens et al. 2010). The Iranian program is mandatory, in that all couples have to submit the result of a blood test for thalassemia traits when they register for their official marriage. The registry tracks carrier-carrier couples and their children (MOHME 2012). Prenatal diagnosis and abortion are not coercive, but 85% of the at-risk couples proceeded with prenatal

diagnosis in 2010 (Zeinalian et al., 2013). Though this is conducted through governmental enforcement, opinions critical towards the Iranian thalassemia prevention program are rarely seen, especially in association with eugenics (Alwan and Modell 2003, Saniei et al. 2008, Strauss 2009).

On the other hand, Dr. Hadipour, a proponent of prevention policy and a leader of the Iranian thalassemia community identified that overaccentuating the negative aspects of TM is a reason for their marriage and employment discrimination. In the campaign, the hardship and unfavorable dimensions caused by TM are emphasized to prevent at-risk couples from having affected children. For example, expressions such as "a healthy city without thalassemia patients" are shown on a billboard. The implied denial or negation of life with TM in these catchphrases leaves a negative impression in the public eye. Consequently, there are parents or relatives opposing marriage with a person with TM, or companies or offices reluctant to employ them. According to Dr. Hadipour, these problems are rooted in the implementation phase rather than the underlying philosophy of the national prevention program (Hosoya 2019:68).

4. Results and Discussions

1) The Characteristics of the research participants

143 valid responses were collected from participants (Table 1 and 2). The number of valid responses differs slightly for each question as participants were told they did not have to answer questions if they did not wish to do so. In the following sections, all the percentages shown are the proportion of respondents to the whole participant population of 143. The respondent numbers of answers to the questions asked only of married participants or allowed multiple answers are shown in the actual count.

Of the respondents, 48.3% were male, and 51.7% were female. The average age was 28.2 years (18-49 years old) for male participants and 27.9 years (19-41 years old) for female participants. Regarding age distribution, 61.5% of respondents were between 23 years and 31 years old. The population of both the younger and older generations was smaller, given that the number of births with TM had gradually declined since the introduction of the national thalassemia prevention program, and many of the older generations had died at a younger age. The respondents' age distribution was not significantly different from that of people with TM across Iran (Hadipour et al. 2019). Most of them were of reproductive age.

There is a discrepancy in access to health care between urban and rural areas in Iran, as most health care facilities are located in urban areas, and patients living in remote villages need extra time and transportation expenditure. In the questionnaire, 80.4% of the participants were urban residents (Q1). In this research, 15.4% of the respondents had lower than high school education. Although their complications start to exteriorize during adolescence (Malik 2009) and make it difficult for them to continue their education. 44.1% had completed high school, and 39.9% had an associate's degree or higher (Q2).

Iran has a chronic unemployment problem (The World Bank Group 2021). Under this circumstance, obtaining a job with a stable income is a significant challenge for people with TM; 36.4% reported that they were currently employed. On the other hand, 60.1% had never worked (Q4), but fewer (46.9%) said they received financial support from their family members (Q5). Based on the ethnographical interviews, it could be understood that those living with family members did not view their living costs as financial support, and several of them received a regular unearned income, for example, a bereaved family pension.

In Iran, husbands are legally obliged to provide living expenses. Out of the 22 married men participating in the questionnaires, 14 were employed, while 8 men had never worked. As can be inferred from this data, having an economically independent life is not absolutely necessary for marriage for men. In Iranian culture, family members usually pay for daily expenses after the marriage if it is necessary. Their families' opinions are strongly reflected in their lives, especially when there is employment discrimination against people with TM.

The questionnaire included items regarding whether participants approved of each procedure designed to prevent the birth of offspring with TM. Of the participants, 95.8% answered that preventing the birth of offspring with TM (referred to as premarital carrier screening in this context) is necessary (Q20); 74.8% approved of prenatal diagnosis of fetuses with TM (Q21); 78.3% of them thought that the abortion of fetuses with TM is ethically acceptable (Q22). Most respondents answered that carrier screening does not harm anyone, but regarding the procedures associated with ending a pregnancy, some respondents indicated their opposition.

The questions about sterilization for people with TM were added because male Iranians with TM asked the author whether sterilization is enforced in other countries. In Iran, when a person with TM decides to marry a partner with TM, they will be introduced to the local health center for genetic counseling. A genetic consultant or a health-care worker will suggest that the male partner should have a vasectomy to avoid pregnancy. This is not compulsory, nor is it written in the guideline (MOHME 2012). However, all the married men with TM I met in Isfahan understood that it was obligatory (see case 9). This misunderstanding was caused by inadequate informed consent, though the situation may differ in other provinces.

The results show the participants' ambivalent attitudes, presumably because these questions about sterilization mean direct physical intervention to themselves. Regarding tubal ligation for women with TM, 46.9% agreed with the procedure, but 42.0% disagreed (Q23). Regarding vasoligation for men with TM, 47.6% agreed with the procedure, but 39.2% were against it (Q24).

Most people with TM accept the prevention program. However, their opinions can be deeply influenced by the perspective of the Iranian government and non-TMs around them, because people with TM are aware that their lives cannot be maintained without state subsidies, philanthropic charities, and volunteer blood donations. In addition, they witness their family's struggle whenever their health conditions deteriorate (Hosoya 2019).

2) Whom they prefer to marry

In Iran, having a premarital sexual relationship between men and women is not legally or socially acceptable, so it is difficult to develop an intimate relationship without marriage, despite dramatic changes seen in the youth culture in recent years. (Ghorashi 2019:1275). In such circumstances, 60.1% were single, and 39.9% said they had married or were in the process of legal marriage (Q3). The percentage of those married in this research was higher than in previous surveys (Zafari and Kosaryan 2014).

Regarding the question of how important marriage is, 54.5% of both married and single participants answered 'very important' (Q12); 64.3% of them had fallen in love with someone and thought of marrying that person (Q13), and 59.4% said they had made or been given a marriage proposal (Q14). Some of their marriage proposals were not successful. As to why their marriage proposal was unsuccessful, 11 respondents answered that they did not like the condition of the proposal (10 were women because men make marriage proposals), but 21 respondents said one or both families were against the proposal (Q15).

This shows that the opinions of the family members of the women (especially of fathers) as well as of their own are important for marriages.

In the following discussion, 9 cases with TM are divided into two categories, depending on whether they chose a person with TM as a marriage partner. This categorization is somewhat provisional, as marriage choice must be a dynamic and variable process. However, during my research in Iran, it seemed that people with TM had strong opinions about whether their marriage partner had TM because it affects the offspring's genetic expression.

3) Marriage to a partner without the thalassemia gene

Case 1 Sara (female, in her 30s)

Sara had received a marriage proposal from a man with TM. She had been fond of him but wanted to have a child, so she made the agonizing decision to turn down his proposal and married a healthy man (means a person without thalassemia gene) whom her relatives had recommended. After her marriage, Sara was diagnosed with infertility. This caused the couple to quarrel, and she began to suffer from depression and ill-health.

Sara was facing the choice between marrying a man with TM or a man without the thalassemia gene. As far as the author was able to observe, marriage between people with TM was not considered a realistic option in some places. In countries with fewer people with TM, the chances of meeting mates with TM are not very high. Alternatively, in economically less developed countries where even blood transfusions are not sufficiently available, most people with TM cannot reach a suitable age for marriage.

Alternatively, according to the author's fieldwork, it was not uncommon for a person with TM to be considered a potential marriage partner in Turkey and Iran, despite the possibility that the marriage may not occur. In the questionnaire, 51 out of 57 married respondents stated to whom they were married. 16 were married to a partner with TM whilst 31 were married to a partner without the thalassemia gene (hereafter referred to as non-thalassemia), and three were married to carriers (Q26). 39.2% of the married and single participants indicated that they had considered marrying a TM, and 57.3% said they had not (Q18).

In the questionnaire (Q18), the most common reason for considering marriage to a partner with TM was 'we can understand each other's pain' (40 respondents). Some would not choose a partner with TM. The most common reason given for this was that they did not want to add another person with TM to their family (38 respondents) because it would amplify the familial burden and worries, or in order to have a 'healthy child' (37 respondents), as all the children born to couples where both partners have TM would also have TM. A 'healthy child' here does not mean a child without the thalassemia gene but a carrier born between a person with TM and her/his partner without the thalassemia gene. Carrier children are described as 'healthy' since they do not need regular medication.

For people with TM, the choice of a marriage partner inevitably involves the decision to have or not to have children in the future. Under the prevention program, if they want to have children, they must avoid a partner with TM. In Iran, where fertility and the ability to foster children are highly valued, 53.1% of the participants chose having children as 'very much important' (Q19). The respondents who did not consider having a child to be important may have known that they had irreversible infertility problems or may have chosen a person with TM as a marriage partner.

Although their priority was having children, Case 1 Sara and Ahmad in the next case 2 were disadvantaged by their infertility, as it can be a legitimate cause for divorce in Iran.

Case 2 Ahmad (male, in his 20s):

He had married a non-thalassemia woman. After marriage, he was diagnosed with infertility. His wife always wanted to have children, so she asked him to divorce her. Later he remarried a woman with TM. His new wife said that having a child was not important, but Ahmad was considering adopting a child.

In the questionnaire, only 12 out of 57 married participants answered that they had at least one child (Q25), and 11 said that they had fertility problems (Q29). In Iran, where masculinity is prominent and male infertility must be hidden (Tremayne 2012), it is surprising that six men answered that they had infertility problems.

The infertility problems were discussed among people with TM during the author's fieldwork. Despite this, Sara and Ahmed did not seriously consider having a fertility test because they thought the tests were designed to proceed to sterilization in order to avoid pregnancy.

Case 3 Fariba (female, in her 20's):

Fariba had a bone deformity of her head and upper jaw and had short stature. She had accepted a marriage proposal from a non-thalassemia man, but the marriage did not take place because one of his family members objected, saying that thalassemia was a genetic disease. Therefore, Fariba's appearance would be inherited by the child. Fariba gave up hope for marriage after this hurtful event because 'it is difficult for a woman of my appearance to marry a healthy man.'

Case 4 Maryam (female, in her 20s):

She had accepted a marriage proposal from a non-thalassemic man. After their engagement, his female relatives found some articles explaining that people with TM were doomed to die early. The marriage proposal was rescinded because he was persuaded that Maryam was not suitable to be a mother.

80.4% of the questionnaire participants answered that having TM 'always' or 'sometimes' had a negative impact on their lives (Q16). In the question of 'which one has a negative impact on your marriage?' (Q17), 64 respondents answered the 'symptoms and complications of TM.' Some people indicated that their appearance (35 respondents) or employment discrimination (36 respondents) had a negative influence, but the 'negative image of TM in society' was chosen the most frequently (71 respondents) as inflicting a discouraging influence on marriage.

In Iran, along with the expansion of the thalassemia prevention program, information about thalassemia is distributed among the population, but it mainly focuses on preventing TM births between both-carrier couples. Issues related to TM's pathological or hereditary characteristics, not carriers, are rarely discussed or brought up in the media, which creates the wrong image of TM in society.

As mentioned in the previous chapter, bone deformities are preventable complications and are not inheritable, and the life expectancy of people with TM has been remarkably extended. Therefore, the opposition of the families of Fariba (case 3) and Maryam (case 4) was based on misinformation about thalassemia genetics, which they were not able to rectify. Among lay people, the distinction between correct and incorrect medical knowledge is not clear. The medical terminology or concept of genetic medicine can be used anytime to discriminate against people with TM, even though it is not accurate.

Furthermore, Maryam's case evokes the issue of the disclosure of their illness to the partner and their family before marriage. In the questionnaire, 53 of the 57 married participants answered. Of these, 29 answered that their partner had already known about their illness, and 24 married respondents revealed their illness during the process of marriage (Q27). In marriages between two people with TM, they usually know about each other's illness because many couples meet through mutual friends with TM, and non-thalassemia partners who are relatives often know about the diagnosis as well.

Illness disclosure becomes a sensitive issue when they want to marry a non-thalassemia partner who is a distant relative or is unrelated, as it is likely to raise serious problems not only for the couple themselves but also for the family. Many married participants had talked about their illness early on in their marriage process, but early disclosure may cause rejection from the partner's family, as Maryam experienced.

Case 5 Soheila (female, in her 20s):

She had married a non-thalassemia man whom she met at university. She became pregnant soon after their marriage and gave birth to a boy. Subsequently, she became ill and required hospitalization. Her husband and his family had never imagined that her condition could be so serious since she looked normal and healthy. They divorced because he wanted a healthy wife. After their divorce, the child was taken by her husband's family due to Soheila's health condition. (She was depressed and started to skip necessary treatments. She died of heart failure three months later).

Many TMs were treated by regular medical care for their complications. 51.7% of questionnaire respondents said they had some complications (Q9). The most frequent symptom was osteoporosis, but

some had diabetes, hepatitis C, and heart and liver dysfunction that could be fatal, especially during their perinatal period. However, through the participant observation, the author realized that it was difficult for people with TM to explain every detail of their symptoms, coping strategies, and necessary treatments to their non-thalassemia partners.

Even though medical care is essential for the survival of people with TM, misunderstandings about whether they are able to carry out their duties as spouses and parents can occur. Soheila, who was in an acute and critical situation, was more likely to be condemned as an unsuitable wife or mother. In Iran, these problems occur after marriage, as men and women are not allowed to have intimate relationships before marriage.

It was not rare to see that people with TM intentionally or unintentionally skip necessary treatments after or during frustrating events, as Sheila did. The questionnaire also shows that 44.1% of the participants had refrained from iron chelation therapies 'always' or 'sometimes' during the past 3 months (Q11), and 17.5% of participants did not keep to the daily regimen of treatments or prevention for these complications (Q10). Poor adherence to iron chelation therapies will lead to the emergence of organ dysfunction in a few years, and unfortunate consequences may follow. Although many health care studies have been done to support patients' adherence (Emami Zeydi 2017), patients tend to be blamed for non-compliance, with those around them having little understanding of the TM's situation.

In the questionnaire, there was a question, 'Did you add specific descriptions related to your illness in the marriage contract?' (Q28). In Iran, couples sign a marriage contract, which states the terms of their agreement on marriage, including the amount of the goods paid by the groom to the bride. The implication of this question is whether the marriage contract contains specific conditions referring to their illness; for example, no divorce can be allowed on account of thalassemia-related issues.

Divorce is not uncommon in Iran. Based on the statistics, the ratio of divorce to registered marriage reached 29% in 2017 (BBC Persian 2018). Therefore, some patient advocacy groups have recommended adding such conditions to their marriage contract. In the questionnaire, among the 57 married respondents, only six indicated that they had exchanged a contract containing some specific conditions (Q28). Those who did not add any additional conditions, explained that both sides implicitly agreed with anticipated conditions or that they thought it would be disrespectful to the prospective partner's family.

During the field research, distressful events were related more often, and pleasant stories were less frequently told. However, there are people with TM who have a happy life with their non-thalassemic partners and children. Leila spoke about the following.

Case 6 Leila (female, in her 20s):

Leila did not talk to others about her illness because it was not evident from her appearance. Her non-thalassemia husband, also a distant relative, understood her situation very well and always tried to support her. She had undergone fertility treatments and delivered a child. She said that raising a child was hard, but she was happy.

4) Marriage to a person with TM

Apart from genetic concerns, medical professionals and family members take the view that TM-TM marriage should be avoided because there are more risks if two sick people live together.

During the field research, there were some examples of people with TM whose parents opposed their marrying a partner with TM. Although their family relationships were understood as preferable ties

rather than restrictions, the family's opinion does not always match the preference of people with TM. In the questionnaire, 11 people answered that they had not thought of marrying a person with TM because their parents would not have accepted it (Q18).

Case 7 Reza (male, in his 20's):

Reza wanted to marry a girl with TM, and the girl also wanted to marry Reza, but her father objected to the marriage. Because she could not persuade her father to agree to the marriage, she lost hope, stopped chelation therapy, and died of pneumonia a year later. After her death, Reza had stopped his regimen, and he was constantly in and out of the hospital due to his worsened health.

Distressful stories such as Reza's experience could be seen in any youthful love life. However, because interruptions in the treatment, especially chelation therapies, can lead to fatal complications, young people with TM do not have the same kind of freedom for emotional reactions as people who are not living with chronic diseases.

People with TM seem to emphasize their ties to people with TM. This tendency can be understood as an influence of the patient community (Hosoya 2019). TM patients in Isfahan had frequently been attending the same transfusion center since childhood (in the questionnaire, 89.5% of the participants had blood transfusions two to four times per month, Q8), 53.8% of them said that at least one of their siblings, cousins, uncles, aunts, and paternal or maternal relatives had TM (Q6). Additionally, 39.9% of the respondents had lost someone close to them who had TM, mainly siblings and close friends (Q7).

As shown in the previous section, the most common reason for considering marriage to a partner with TM was 'we can understand each other's pain.' This can be explained by the atmosphere of mutual

compassion in the community. Painful experiences such as the death of a close person with TM, bullying at school, failure in finding a job, trouble in medical centers, pain and fatigue specific to TM, diagnosis of infertility, or refusal in marriage can be discussed with friends or partners. Reza (case 7) and the girl with TM had also been friends since their childhood.

In the following two cases, Mina (case 8) knew of problematic events that had happened to friends with TM, such as Reza. She decided to be strategic to avoid causing adverse reactions from their families.

Case 8 Mina (female, in her 20's):

Mina's mother had been involved in the activities of the Thalassemia Society. Mina had been in love with a man with TM for a long time. Since his childhood, Mina's mother had known him as a good boy, but she was strongly opposed to the marriage as both Mina and the man had TM. (Over two years later, Mina persuaded her mother to agree, and the couple married).

During the field research in Iran around 2014 and 2015, all of the parents and medical professionals the author met were firmly against marriage between both partners with TM. The atmosphere gradually changed around 2016, presumably because they had seen some sad deaths, as shown in Reza's case. In May 2017, at the International Thalassemia Day event in Tehran, many couples both with TM took the stage to celebrate their marriages. More parents and medical professionals started to show a growing tolerance and understanding towards the decisions of people with TM. On the other hand, along with the increase in the number of marriages between both partners with TM, the problems occurring around their marriages became apparent.

Case 9 Pedram (Male in his 30's)

Pedram married his partner with TM. Before their marriage, because the results of his semen analysis had shown that he was fertile, Pedram had undergone vasectomy surgery to avoid pregnancy, as he was convinced that it was obligatory and never doubted it. The vasectomy was the most humiliating and embarrassing situation of his life. Later, a couple both with TM in a neighboring province had a TM baby, which engendered considerable dispute throughout the thalassemia center. The medical professionals, as well as the people with TM at the center, perceived it as ethically contradictory in terms of social norms under the prevention program. At this moment, Pedram found out that the sterilization of TM-TM couples had never been legally mandated.

As stated in the previous chapter, sterilization is recommended to TM-TM couples to avoid pregnancy because their offspring will have a 100% chance of having TM. Some men with TM were even asked to bring a medical certificate of a vasectomy or having azoospermia, though it has no legal basis. The thalassemia prevention program is carefully designed to avoid coercive processes legally and practically, but genetic counseling in the clinical setting could differ from the ideal of the patient-centered psycho-educational model, as examples in other countries show (Raz 2005:186).

A systematic review of marital status and paternity of people with TM (De Sanctis et al. 2019) shows that assisted reproductive technologies, including gamete donation and child adoption, are being practiced in some countries. Therefore, The Iranian Thalassemia Society recommends that both TM couples, if they are both fertile and want to have children, should use donated gamete from a non-TM third party to avoid having a baby with TM.

Additionally, there are some other new issues which people with TM have recently found that restrict life options for them. For example, Case 2 Ahmad, who wished to adopt a child, later found out that the revised 2013 Iranian law on adoption and fostering children states that a person with an 'incurable illness,' such as TM, cannot adopt children. Child adoption always requires a careful ethical discussion, but some social policies such as child adoption indeed exclude people with impairments and illnesses.

5. Concluding remarks

The example of 9 cases and the contexts presented through the results of questionnaires and participant observation conducted in Isfahan demonstrates that people with TM consider their marriage and reproduction within the framework of preventing births of affected children. However, they sometimes persevered in their wishes even though they were not ideal choices. Their wishes could be fulfilled, but many of those with TM who strove for their aims were sometimes forced to follow social norms or follow their parents' expectations by the opposition or rejection of family members or of the partner, which led to agonizing consequences.

This situation was not derived only from their physical conditions, such as their genetic traits, infertility, appearance, or need for chelation therapy and regular blood transfusions. The social factors such as the norm of avoiding the childbirth of babies with TM, excluding societal institutions, harmful and inaccurate perceptions of people with TM and their physical conditions, and inadequate genetic counseling due to misunderstanding were the barriers to marriage and reproductive freedom.

The author witnessed the alteration of medical professionals' and families' viewpoints towards marriage between couples of both people with TM during the fieldwork in Iran. Similarly, the views towards people with TM and the preferable choices may shift in the future, after the COVID-19 pandemic,

which has drastically transformed the clinical and economic environment. Additionally, when the population of people with TM of reproductive age decreases due to the prevention program, the perception of people with TM may undergo a transformation. This transition can be compared with the experiences of people with TM in other countries, as well as the choices of patients with other genetic illnesses or the claim for sexual or reproductive freedom from people with other impairments. These discussions will contribute to more fruitful insights into the ethical issues surrounding the lives of people with genetic diseases.

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TABLE 1 Numbers of valid responses for each question about marriage and reproduction (for all participants, N=143, male69, female74)

Question No.	Questions	Answer Options		Male	Female
Q1	Residential area	Isfahan province urban area		54	61
		Isfahan province rural area		8	10
		other province		1	0
		Total		63	71
Q2	Education	under high school diploma		14	8
		high school diploma (diploma)		31	32
		over associate degree (fouq-diploma)		24	33
		Total		69	73
Q3	Marriage status	single (never married)		47	39
		married (ever married)		22	35
		status	engaged	2	4
			aqd (marriage contract exchanged)	0	2
			married	19	24
			divorced	1	4
			widowed	0	1
		Total		69	74
Q4	Employment	currently working		30	22
		never had a job		37	49
		had a job before		2	1
		Total		69	72
Q5	Economic support from family members	yes		35	32
		no		34	37
		Total		69	69
Q6	Do you have any other TM in your family?	yes		33	44
		no		36	30
		Total		69	74
Q7	Have you experienced a death (or deaths) of any close person with TM?	(a) yes		33	24
		of whom (multiple answers allowed)	siblings	13	6
			cousins	0	8
			other relatives	4	2
			close friends	14	12
			spouse	0	1
		(b) no		33	48
		Total (a)+(b)		66	72

Question No.	Questions	Answer Options	Male	Female
Q8	Frequency of blood transfusion	every 2 weeks	25	16
		every 3 weeks	30	43
		every 4 weeks	6	8
		other period	2	6
		Total	63	73
Q9	I have compli-cations	yes	43	31
		no	24	41
		Total	67	72
Q10	Last 3 months, I have abandoned necessary treatments	always	4	4
		sometimes	8	9
		never	49	55
		Total	61	68
Q11	Last 3 months, I have abandoned chelation therapy	always	6	5
		sometimes	25	27
		never	35	40
		Total	66	72
Q12	How important is marriage for you?	very much important	44	34
		not so important	13	32
		not important at all	10	4
		Total	67	70
Q13	Have you ever fallen in love with someone and thought of marrying that person?	yes	45	47
		no	16	20
		Total	61	67
Q14	Have you ever made (been made) a marriage proposal?	yes	32	53
		no	30	17
		Total	62	70
Q15	Marriage proposal was not successful because (multiple answers allowed)	the person did not like me/I did not like the person	1	1
		I did not like the condition of the proposal	1	10
		both families were against the proposal	0	2
		male side family was against the proposal	0	5
		female side family was against the proposal	9	5
		other reasons	9	12

Question No.	Questions	Answer Options		Male	Female
Q16	How much does Thalassemia have negative impact on your life?	always		31	30
		sometimes		22	32
		not at all		9	8
		Total		62	70
Q17	Which one has a negative impact on your marriage? (multiple answers allowed)	symptoms and complications of TM		36	28
		negative image of TM in the society		27	44
		appearance of TM		19	16
		employment discrimination		26	10
		others		8	9
Q18	Have you ever thought of marrying with TM?	(a) yes		29	27
		why yes? (multiple answers allowed)	we can under-stand each other's pain	17	23
			comfortable	5	9
			it just happened	5	6
			other reasons	2	2
		(b) no		36	46
		why no? (multiple answers allowed)	I don't want to add another TM in my family	16	22
			my parents do not accept marriage with TM	5	6
			I want to have healthy children	17	20
			other reasons	2	3
		Total (a)+(b)		65	73
Q19	How important is having children for you?	very much important		39	37
		not so important		14	21
		not important at all		11	15
		Total		64	73
Q20	Do you think that prevention of TM birth is necessary?	yes		64	73
		no		2	0
		other opinion		0	0
		Total		66	73

Question No.	Questions	Answer Options	Male	Female
Q21	Do you ethically approve of prenatal diagnosis of TM fetuses?	yes	49	58
		no	15	12
		other opinion	0	0
		Total	64	70
Q22	Do you ethically approve of abortion of TM fetuses?	yes	57	55
		no	9	17
		other opinion	0	0
		Total	66	72
Q23	Do you ethically approve to conduct tubal ligation for wife of both TM couple?	yes	32	35
		no	28	32
		other opinion	1	0
		Total	61	67
Q24	Do you ethically approve to conduct vasoligation for husband of both TM couple?	yes	28	40
		no	34	22
		other opinion	1	0
		Total	63	62

TABLE 2 Numbers of valid responses for each question about marriage and reproduction (only for married participants, N=57, male22, female35)

Question No.	Questions	Answer Options	Male	Female
Q25	Number of children	no child	12	26
		1 child	4	6
		2 children	2	0
		Total	18	32
Q26	What kind of person is your marriage partner?	person with thalassemia major	7	9
		person with thalassemia minor	1	2
		person does not have thalassemia trait but has affected family member(s)	1	0
		person has neither thalassemia trait nor affected family member	10	21
		Total	19	32
Q27	When did you tell your marriage partner about your illness?	already knew about it	12	17
		when we get to know each other	3	12
		sometime after we met	1	3
		when we decided to marry	0	2
		before marriage proposal	2	0
		after marriage proposal	1	0
		Total	19	34

Question No.	Questions	Answer Options	Male	Female
Q28	Did you add specific descriptions related to your illness in marriage contract?	yes	2	4
		no	16	29
		Total	18	33
Q29	Do you have infertility problems?	yes	6	5
		no	11	24
		Total	17	29