

Original Article

Sin and Suffering: Pregnant Women's Justifications for Deciding on Pregnancy Termination Due to Beta-Thalassemia Major in Southeast of Iran

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ABSTRACT

Background: Religious restrictions and moral grounds, such as fear over committing a sin, are the major causes of opposing therapeutic abortions. **Objectives:** This study aimed to describe pregnant women's justifications for deciding on pregnancy termination due to beta thalassemia major (β -TM) in the sociocultural context of Sistan and Baluchestan province, Iran. **Methods:** In this qualitative study, in-depth semi-structured interviews were conducted with 27 pregnant women and their husbands. Purposive sampling was used to recruit pregnant women who were able to speak and understand Persian, had no known mental illnesses or psychiatric problems and had fetuses with β -TM. Data were analyzed using narrative thematic analysis. **Results:** At the time of receiving, the results of chorionic villus sampling for β -TM screening, the age and the gestational age ranges of the participants were 19–42 years and 11–18 weeks, respectively. Women's justifications for deciding on pregnancy termination due to β -TM were explained in three main themes, namely, child's physical suffering, negative psychological consequences, and attempting to be good parents. **Conclusion:** Providing families with information about the long-term effects of β -TM on the child and family members can help them make informed decisions on pregnancy continuation or termination.

KEYWORDS: Abortion, Beta-thalassemia major, Decision-making, Iran, Narrative analysis, Sin

INTRODUCTION

Beta-thalassemia major (β -TM) is a serious hereditary hemoglobin disorder, which causes different complications, including severe life-threatening transfusion-dependent anemia.^[1] Around 70,000 new cases of β -TM are annually born in the world.^[2] It is most prevalent in the region called the thalassemia belt. Iran is one of the countries on the belt with an average thalassemia gene prevalence of 4%.^[3,4] Around 8000 of all annual pregnancies in Iran are at risk for β -TM,^[5] with the highest rate of new cases (i.e., 2050 cases) in Sistan and Baluchestan province.^[6]

The only treatments for β -TM are hematopoietic stem cells and bone marrow transplantation.^[7] However, these treatments are too expensive and are provided in leading

healthcare settings; thus, most patients, particularly those in remote areas and in low-resource countries, cannot access or afford them.^[8,9] Consequently, prenatal β -TM screening tests are performed for prenatal β -TM diagnosis and pregnancy termination to prevent the birth of an affected child.^[10] Therapeutic abortion is the most commonly used modality for the affected fetuses.^[2,8]

Although the highest rate of β -TM in Iran is in Sistan and Baluchestan province,^[6] and although women whose

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fetuses are diagnosed with β -TM are very anxious about the future of their fetus,^[11] many of them decide against abortion.^[12] Studies in Malaysian parents^[9,13] and in pregnant Pakistani women living in the North of England^[14] showed that the most common reasons behind opposing abortion are religious restrictions and moral grounds such as fear over committing a sin. Some studies also showed that religious beliefs play important roles in couples' opposition to therapeutic pregnancy termination.^[9,13] As nurses and midwives are responsible to provide suitable information to parents who are prone to bring a child with β -TM and due to the effects of cultural factors in this regard, it is very important to know which factors affect pregnant women's justifications for deciding on pregnancy termination due to β -TM.

Objectives

This study aimed to describe pregnant women's justifications for deciding on pregnancy termination due to β -TM in the sociocultural context of Sistan and Baluchestan province, Iran.

METHODS

This qualitative study was carried out as part of a mixed methods research which aimed to evaluate the effects of shared decision-making consultation on decisional conflict and regret among pregnant women whose fetuses were affected by β -TM. A narrative approach was used in this study. Narratives are central to identities, are strategic, functional, and purposeful in everyday life,^[15] and can shed light on certain experiences.^[16] The study was conducted from August 1st, 2016 to January 1st, 2017 in a prenatal diagnosis center in Ali Asghar hospital, Zhaedan, Iran.

Participants and data gathering

Participants were purposively recruited from women who had received a definite diagnosis of β -TM for their fetuses in the study setting. Inclusion criteria were the ability to speak and understand Persian, no affliction by mental illnesses or psychiatric problems, and willingness to participate in the study. The exclusion criterion was an unwillingness to stay in the study. We contacted eligible women over the phone, informed them about the study, and asked them to participate in the study together with their husbands. Those who agreed to participate were invited to attend a decision-making consultation session on their pregnancy termination.

In sessions, in-depth narrative interviews were conducted for data gathering. Each woman was interviewed together with her husband only once and in a private room located out of the study setting. Interviews were

conducted by the first and the second authors before the final decision for pregnancy termination and lasted 90 min, on an average. An interview guide was developed to address pregnant women's justifications for deciding on pregnancy termination due to β -TM. To open each interview, we asked the following broad questions from each interviewee to assess her knowledge of β -TM, "May you please explain about β -TM?" and "Could you please tell me about stories that you have heard about β -TM?" Besides, women with alive thalassemia-afflicted children were asked to explain their experiences of caring for their children using the following question, "Tell me your story of living with a child who has β -TM." During interviews, we mainly focused on any indication of religious restrictions the women might have been faced and the justifications they provided during the process of decision-making for pregnancy termination. Participants were also encouraged to talk about their experiences, justifications, and dilemmas using probing questions such as "Can you tell me more about this?" and "May you provide an example?" In total, 27 women were interviewed. Three women attended the consultation session with their parents (i.e. father, mother, or mother-in-law) and the other women with their husbands. Sampling and data gathering were stopped when we were convinced that we had understood the meaning of participants' narratives^[17] and nothing new was obtained from the interviews.^[18]

Data analysis

Data analysis was performed using the narrative thematic analysis^[16] in the following six steps:

1. Familiarizing with data: All narrative interviews were listened and transcribed verbatim. The first and the second authors read the transcripts for several times to understand different aspects of participants' experiences
2. Generating initial codes: The codes were generated based on the collected data
3. Searching for themes: When the dataset was coded, all relevant codes were grouped into primary themes and subthemes
4. Reviewing themes: The generated themes were reviewed and refined to assure the validity of each theme about the whole data set and also to identify the overall story the themes recounted about the data
5. Defining and naming themes: This phase aimed to determine how each theme fitted into the overall story and how it was related to the study aim. Finally, each theme was labeled with a name
6. Producing the report: We tried to provide an analytic narrative to present findings about the study aim.^[19]

Trustworthiness

As a midwife, the first author had great experience in working with couples whose fetuses were afflicted by β -TM and also had prolonged engagement with the study and persistent observation of the study setting. Moreover, she had already performed research studies on patients with β -TM and their families. The generated codes were provided together with interview transcripts to some participants to judge the accuracy of our interpretations. The members of the research team worked together on the generated themes to provide an in-depth explanation of the phenomenon.

Ethical considerations

This study was performed after obtaining ethical approval from the Ethics Committee of Zahedan University of Medical Sciences, Zahedan, Iran (on July 10th, 2016, with the code of IR. ZAUMS. REC.1395.119). Permission for the study was also secured from the relevant authorities of the study setting. We explained the objectives of the study to the participants and ensured them that participation in the study would be voluntary and data would be analyzed and reported confidentially. They were also granted the right to voluntarily withdraw from the study at their will. Written informed consent was obtained from all participants.

RESULTS

In total, 27 women with an age range of 19–42 years were interviewed. At the time of receiving the results of chorionic villus sampling for β -TM screening tests, participants' gestational age ranged from 11 to 18 weeks. The mean numbers of children with β -TM in participants' own families, among their own relatives, and among their husbands' relatives were 2.20, 0.66, and 0.70, respectively. Table 1 shows participating women's characteristics.

At the beginning of the interviews, women asserted religious prohibition of and public opposition to pregnancy termination. For instance, one woman said, *"People condemn those who have abortion. It is considered as a sin in Islam"* (age: 26; gravida 2). Most participants tended to independently decide on their pregnancies irrespective of others' advice. *"We ourselves are the most competent individuals for deciding what is harmful and what is useful to us"* (age: 32; gravida 8). Another stated, *"We don't listen to the relatives' advice. They would understand us if they had an afflicted child"* (age: 22; gravida 2). Women's justifications of pregnancy termination, as a religiously prohibited sin, were categorized into three main themes, namely child's physical suffering, negative psychological consequences, and attempting to be good parents. These themes are explained in the following paragraphs.

Table 1: Participant's demographic characteristics (n=27)

Characteristics	Frequency (%)
Gravidity	
First	2 (7.4)
Second	4 (14.8)
Third and more	21 (77.8)
Women's religious affiliation	
Shiite Muslim	2 (7.4)
Sunni Muslim	25 (92.6)
Husbands' religious affiliation	
Shiite Muslim	6 (22.2)
Sunni Muslim	21 (77.8)
Women's educational level	
Illiterate and elementary	11 (40.7)
Secondary	14 (51.9)
University	2 (7.4)
Husband's educational level	
Illiterate and elementary	5 (18.5)
Secondary	19 (70.4)
University	3 (11.1)
Number of prior abortions for β -TM	
0	23 (85.2)
1	3 (11.1)
2 and more	1 (3.7)
Number of affected sons	
0	18 (66.7)
1	8 (29.6)
2 and more	1 (3.7)
Number of affected daughters	
0	19 (70.4)
1	8 (29.6)

β -TM: Beta-thalassemia major

Theme 1. Child's physical suffering

Participants justified pregnancy termination due to β -TM by referring to the great physical suffering caused by β -TM for a child.

Painful procedures

Participants frequently commented about the afflicted child's physical suffering induced by diagnostic and therapeutic procedures for β -TM. The most commonly cited procedures were frequent blood transfusion and regular blood tests. *"Children experience suffering during injection. God knows how painful it is"* (a husband; age: 30).

Painful procedures are regularly performed every 15–30 days, causing parents great suffering. *"He cries every time we take him to hospital for blood transfusion and complains by saying, Do you think God loves you when you put me under this painful procedure?"* (age: 32; gravida 8).

Some participants expressed their own bad feelings during the procedure. *"The poor baby is innocent and*

does not deserve such pain and suffering from birth onward" (age: 30; gravida 5). "I really feel sad when he cries. It is very difficult for me" (age: 24; gravida 4).

Distressing consequences

A number of participants who had an alive child with β -TM noted to the child's lifelong dependence on blood transfusion and the distressing consequences of the disease and blood transfusion (including redness, itching, infectious diseases, hepatitis, and the need for surgeries). "Our child spleen was enlarged and therefore, it had to surgically been removed. However, spleen removal improved his health status by only 2%, which is of no practical importance" (husband; age: 36). In addition, participants reported changes in the appearance of their afflicted children and expressed, "Children with thalassemia have a different appearance compared with healthy people" (husband; age: 27). Such appearance not only negatively affects the children but also exhausts their families. "It is a very difficult experience. Children are upset about their appearance. We feel real pain in our hearts when looking at their faces" (husband; age: 44). "It is very upsetting to see the discomfort of your child" (age: 27; gravida 4). "Whenever he cries, my heart, as a mother, hurts" (age: 32; gravida 8). Therefore, participants concluded that "Why should we keep the baby to suffer in the future?" (age: 22; gravida 2).

Early death

According to the participants, β -TM treatments are useless and children with β -TM will die in early adolescence due to disease-related and transfusion-related complications. "One of our neighbors died in the age of 20 due to β -TM" (husband; age: 42). Children with β -TM also witness the death of their peers. "When we go for blood transfusion, we often see that the children who were in the hospital last session are not there anymore. When we ask about the reason, they say those children have died" (husband; age: 42). Therefore, a majority of participants affirmed, "They have no future; they don't stay alive very long" (husband; age: 44).

Theme 2. Negative psychological consequences

Another main justification provided by participants for pregnancy termination was the negative psychological consequences of β -TM. These consequences are explained below.

Disappointment

According to the participants, children with β -TM are at risk for psychological problems due to problems such as fatigue and skeletal facial deformities. By referring to the fact that these children often compare themselves with their healthy peers, two husbands said, "He says

why he cannot run like other children and why he is so weak" (age: 30; gravida 5). "Our children suffer and feel frustrated in front of other people and kids" (age: 34; gravida 4).

These children's pain and suffering and lack of any effective cure for β -TM had made the participants and their husbands frustrated. They pointed to their adherence to all medical recommendations, including the use of camel or donkey milk, hoping that their children might be cured. "They recommended camel milk for my baby. We have tried it since he was three months old" (husband; age: 42). However, when they found that treatments do not cure the disease, they desperately noted, "My child will never be cured and the only option is transfusion" (age: 22; gravida 2).

Some participants also noted that they cannot use more advanced treatments such as hematopoietic stem cells and bone marrow transplantation due to their high costs, lack of appropriate donors, lengthy transplantation preparation processes, and lack of local transplantation centers. "They recommended bone marrow transplantation; but we cannot afford it" (age: 30; gravida 5).

Social stigma

Participants declared that their children are sometimes called by the name of their disease instead of their own names. "My child comes to me and says that everyone calls him 'thalassemia'. This is very upsetting both to me and my child" (age: 30; gravida 55).

Such type of labeling leads to isolation. "People look at him as if he is different and as if he must be isolated like tuberculosis patients (husband; age: 35). Moreover, people and even close relatives pity these children. "[Our relatives] say that these children do not live a long life and thereby, pity my child. I don't want them to talk about my child like this" (husband; age: 30). Such social stigmatizations along with physical disabilities result in losing many opportunities such as marriage and employment. "People in our area behave towards patients with thalassemia in such a way that no one marries them. They have to have absences from school or drop out of it. Therefore, these children have no future" (husband; age: 29). Participants and their husbands felt disappointed and frustrated. One of them quoted his child as saying, "We neither have a life nor a future" (husband; age: 35). Moreover, the severe conditions of children with β -TM place heavy psychological burden on their families. "The fact that these children have no future is a psychological challenge for me" (husband; age: 33).

Death wishes

According to the participants, children with β -TM feel so desperate that they prefer death. “My cousin, who has thalassemia, says that it was better if he was dead” (husband; age: 25). “We know an afflicted child who has grown up. He says that you don’t know how difficult it is. It is better to die” (husband; age: 35). A participant also referred to her current pregnancy and concluded, “When my child is born, he may tell me that he wishes he was never born” (age: 34; gravida 4).

Theme 3. Attempting to be good parents

During interviews, all participants primarily described afflicted children’s physical and psychosocial problems and then, explained how their decisions about pregnancy termination were made based on the fear of judgment and criticism by the fetus and also based on their assessment of the fetus’ best interests.

Fear over the child’s judgment and criticism in the future

The fear of being judged and condemned by the child was one of the major concerns of our participants. “Currently, my baby cannot reason; but...(in the future), she will blame us for her disease and this makes me really worried” (husband; age: 33). Moreover, in Baluchi culture (i.e. the culture of the place where the participants lived), respecting older adults, particularly parents, is of great importance. Yet, our participants referred to many instances of disrespectful and aggressive behaviors by their afflicted children against their parents. “My child is always in a bad mood. I told him to respect his father and avoid being so hard on him...However, he replied, Why? What he has done for me?” (husband; age: 29). A husband cited his first-hand experience by saying that her child says, “It is your fault that I was born and am suffering” (husband; age: 35).

The best interests of the fetus

Another major factor affecting the decision to terminate pregnancy was the fetus’ interests. One participant’s husband noted, “When our first child found that our new fetus is also afflicted, he complained that why we didn’t have an abortion when he was a fetus and insisted on aborting this fetus (husband; age: 30). Another participant justified their decision for abortion by saying, “We are more certain about abortion since we don’t know what to tell him in the future” (age: 26; gravida 2). Finally, participants referred to their responsibility to make a medical decision on behalf of the fetus to maintain his/her best interests. They justified their decision for pregnancy termination against the religious prohibition of abortion by saying things like this, “Currently, there is the possibility to diagnose this disease (before birth). Therefore, we have to prevent something that will bring

suffering and huge expenses in the future” (husband; age: 29). Another woman’s husband said, “People say that abortion is a sin according to our God’s principles. However, it is both religiously and logically a sin to keep the fetus because he or she will experience suffering in the future” (husband; age: 44).

DISCUSSION

This study revealed that the best interests of the fetus, as an unborn patient, and fear over the child’s judgment and criticism in the future had significant roles in justifying pregnancy termination due to β -TM. According to Wong *et al.* religious prohibition of abortion is not always the main concern for parents in their decision-making to terminate pregnancy due to β -TM because parents also consider their moral responsibility towards the future of their children as well the social consequence of the birth of children with β -TM.^[20]

Like some other Islamic countries, pregnancy in Iran can be legally terminated before a gestational age of 120 days in case of some certain disabling genetic disorders such as β -TM.^[9] However, our findings also showed that parents sometimes avoid pregnancy termination mainly due to the fear of committing a sin.^[12,21] Moreover, in line with previous studies,^[22,23] our findings indicated that parents consider pregnancy termination as a moral obligation to prevent the birth of disabled children. Participants considered it religiously and logically a sin to keep a fetus who is known to experience suffering in the future.

This study also indicated that parents who were aware of the severity of β -TM complications and its negative impacts on the child’s life were more inclined toward pregnancy termination. Findings showed that the suffering experienced by the afflicted children not only was due to painful medical procedures but also the associated social stigma, isolation, and marginalization, which were in turn affected by the immediate sociocultural context. Therefore, parents attempt to prevent a condition that would cause suffering and huge expenses in the future. A qualitative study into abortion-related decision-making also reported that parents regarded their fetuses as moral agents who have their own “beneficence/non-maleficence interests and engage in surrogate decision-making.”^[24]

One of the major drawbacks of the present study was that most participants had no previous history of therapeutic abortion due to β -TM and hence, had a wider range of viewpoints compared to those who had the history. Hence, the findings may not represent the views of women with frequent therapeutic abortions. Another drawback of the study was the fact that it was

conducted on women who referred to a PND in Sistan and Baluchestan province, which is one of the poorest provinces in Iran. Thus, findings may have limited generalizability.

CONCLUSION

This study shows that fear over the afflicted child's judgment and criticism in the future and the child's best interests have the most important roles in deciding on pregnancy termination due to β -TM. Nurses and midwives are responsible for providing suitable information to parents who are prone to bring a child with β -TM. Providing families with information about the long-term effects of β -TM on the child and family members can help them make informed decisions on pregnancy continuation or termination on behalf of their children. The results of this study have implications for the provision of genetic counseling services. Counselors may need to avoid judgment about the role of religious values in decision-making for the termination of pregnancies affected by β -TM.

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Conflicts of interest

There are no conflicts of interest.

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