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## Experiences of Iranian Women with Prenatal Diagnosis of Fetal Abnormalities: A Qualitative Study

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## Experiences of Iranian Women with Prenatal Diagnosis of Fetal Abnormalities: A Qualitative Study

### Abstract

Women are more likely to be diagnosed with congenital anomalies due to advances in new technologies in medical science. Following prenatal diagnosis of fetal abnormalities, women may be forced to make decisions about whether to continue a pregnancy with fetal abnormalities. This can be a dilemma for the women. The aim of the study was to explore women's experiences of prenatal diagnosis of fetal abnormalities. A qualitative study was conducted in a referral women's hospital in Tehran, Iran in 2018. Participants were a purposeful sample of 15 women with prenatal diagnosis of fetal abnormalities. Data were collected by individual, in-depth interviews. The conventional content analysis approach was used to analyze the data. Two main themes "emotional suffering" and "decision-making challenge" were extracted from the participants' experiences. Emotional suffering consisted of subthemes "commiseration," "self-blame," "sense of guilt," and "projection." Decision-making challenge included subthemes "lack of support," "stereotypical beliefs," and "uncertainty." The women's experiences of prenatal diagnosis of fetal abnormalities were associated with emotional suffering and challenges in decision-making to continue or terminate the pregnancy. Strategies need to be employed to improve women's autonomy in decision-making. Healthcare professionals should be trained in communication skills to provide appropriate counseling to support women with diagnosis of fetal anomalies.

### Keywords

congenital abnormalities, malformations, prenatal

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# Experiences of Iranian Women with Prenatal Diagnosis of Fetal Abnormalities: A Qualitative Study

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Women are more likely to be diagnosed with congenital anomalies due to advances in new technologies in medical science. Following prenatal diagnosis of fetal abnormalities, women may be forced to make decisions about whether to continue a pregnancy with fetal abnormalities. This can be a dilemma for the women. The aim of the study was to explore women's experiences of prenatal diagnosis of fetal abnormalities. A qualitative study was conducted in a referral women's hospital in Tehran, Iran in 2018. Participants were a purposeful sample of 15 women with prenatal diagnosis of fetal abnormalities. Data were collected by individual, in-depth interviews. The conventional content analysis approach was used to analyze the data. Two main themes "emotional suffering" and "decision-making challenge" were extracted from the participants' experiences. Emotional suffering consisted of subthemes "commiseration," "self-blame," "sense of guilt," and "projection." Decision-making challenge included subthemes "lack of support," "stereotypical beliefs," and "uncertainty." The women's experiences of prenatal diagnosis of fetal abnormalities were associated with emotional suffering and challenges in decision-making to continue or terminate the pregnancy. Strategies need to be employed to improve women's autonomy in decision-making. Healthcare professionals should be trained in communication skills to provide appropriate counseling to support women with diagnosis of fetal anomalies.

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## Background

Congenital anomalies are major causes of child deaths, chronic diseases and disabilities. Annually "an estimated 303,000 newborns die within the first month of birth, worldwide, due to congenital anomalies" (World Health Organization [WHO], 2016). In Iran, the overall prevalence of congenital anomalies was estimated 2.3% (Vatankhah et al., 2017).

Advances in new technologies in medical science have enabled us to diagnose fatal and life-limiting conditions in early pregnancy and currently women are more likely to be diagnosed with congenital anomalies (Araki, 2010). Despite advances in imaging, early detection of all the abnormalities is not possible. Moreover, restrictions to the 20-week gestation limit for termination of pregnancy create many challenges for parents and healthcare team (Breeze et al., 2007). When severe fetal abnormalities are detected prenatally, there are some options for the couple. One of the non-invasive midwifery management options is natural delivery without trying to revitalize the fetus. In life-threatening conditions, palliative care is another option instead of pregnancy termination (Bhatia, 2006). Both options are associated with some challenges. Pregnancy termination remains a challenging moral issue with the debate usually over the fetus's right to live and a woman's right to choose (Jotkowitz &

Zivotofsky, 2010). Furthermore, it is not clear whether women who choose to naturally complete their pregnancy have negative psychological outcomes such as post-traumatic stress disorder (PTSD), anxiety and depression or not, similar to pregnancy termination (Wool, 2011).

Several studies focused on experience of prenatal diagnosis of fetal abnormalities (Argote-Oviedo et al., 2013; Berman et al., 2018; Hedrick, 2005; Maguire et al., 2015). In a qualitative study by Maguire et al., women undergoing pregnancy termination for fetal anomalies, experienced self-blame, guilt around the termination decision, social isolation and grief triggered by reminders of pregnancy (Maguire et al.). In a focused ethnography on pregnant women with diagnosis of fetal malformations, women experienced a painful process, from which they revealed fear, uncertainty, and culpability about the diagnosis. Because of the late diagnosis during the advanced stage of the pregnancy, the women had to continue their pregnancy and adapt the self-care practices (Argote-Oviedo et al.). In a qualitative study by Berman et al. conducted to understand the parents' perspectives on prenatal consultation for fetuses with congenital anomalies, participants experienced emotions such as fear, anxiety, and self-blame. While surgical consultation reduced anxiety for some, the indefinite outcome enhanced anxiety in others. Despite generating anxiety, they valued learning about all potential outcomes for the fetus (Berman et al.). Review of the literature revealed new scientific advances are changing women's experiences of pregnancy (Hedrick). The initial diagnosis of anomalies for parents is a stressful experience (Lalor & Begley, 2006) and the typical enthusiasm of pregnancy is often replaced by emotions such as, sorrow, anger and grief (Côté-Arsenault & Denney-Koelsch, 2016). Iranian pregnant women following prenatal diagnosis of fetal anomalies, also experienced emotional and cognitive reactions (Irani et al., 2019). Although some studies explored the experiences of women with prenatal diagnosis of fetal abnormalities (Argote-Oviedo et al., Berman et al., Maguire et al.), little is known about it in developing countries including Iran, and it seems women's environment such as culture and beliefs can affect the way they experience the diagnosis of fetal abnormalities (Lafarge et al., 2017).

### **Context for the Study**

In Iran, women face many challenges because abortion is not legally available either in all cases of anomalies, or after ensoulment (the moment the human being gains a soul) (Khitamy, 2013). In fact, religious objections to termination of pregnancy are not essentially intractable in the face of new scientific advances in prenatal diagnosis (Ballantyne et al., 2009). Out of three pregnancies with the diagnosis of congenital anomalies, only one case receives the abortion permit, and in some cases, consent for terminating the pregnancy could not be obtained as the diagnosis/application only occurred after the 20th week of gestation (Samadirad et al., 2012). Most requests for abortion (90.2%) in Iran are due to fetal indications and 53.7% of the requests with fetal indication are accepted. Neurological abnormalities in the fetus are the most common reason for applying for an abortion license. According to Islamic law, therapeutic abortion in Iran is permitted after a definite diagnosis of the abnormalities of the fetus by three specialists and a confirmation by the Legal Medicine Organization. Abortion may be permitted based on fetal conditions leading to afflictions for the mother due to fetal abnormalities, or based upon life-threatening maternal conditions, before ensoulment (19 weeks+2 days) with the mother's consent. Legal abortion is allowed in 51 conditions, of which 22 are related to mother's health and 29 are related to the health of the fetus (Vasegh Rahimparvar et al., 2018).

### **Role of the Researcher**

The issue of prenatal diagnosis of congenital abnormalities has been a professional interest of the first author. The idea for this research came to the researcher's mind when a woman that was prenatally diagnosed with severe nervous system abnormalities, was referred to the researcher for counseling. She had suicidal thoughts because of the great suffering she had endured. Our long experiences as midwives, physicians, or researchers have shown that Iranian women struggle with different problems in case of the positive prenatal screening results or diagnosis of congenital anomalies. Therapeutic abortion law in Iran restricted abortion to very limited cases and we think due to the limited access to therapeutic abortions in Iran, illegality of abortion, the prohibition of abortion after ensoulment in Islam, the dangers of self-induced abortions at home and the lack of access to appropriate prenatal palliative care, the voice of Iranian women with prenatal diagnosis of fetal abnormalities must be heard. We decided to interview women who live in deprived areas in the south of Tehran and are generally marginalized because they have less access to health and educational resources.

## **Methods**

### **Study Purpose and Research Question**

The purpose of this study is to explore how women experience their pregnancy with fetal abnormalities in an Iranian cultural context. Based on the researchers' knowledge, few qualitative studies examined the experiences of prenatal diagnosis of congenital anomalies through new technologies in Iran or Islamic Middle East regions. Notable gaps in the literature include the impact of the cultural and religious values of Iranian society on experiences of women with prenatal diagnosis of fetal abnormalities. Therefore, further research in the social and cultural context of the country is needed. The voice of these women should be heard in designing programs to improve their conditions. We believe that understanding the experience of these women will be helpful to identify the challenges of prenatal diagnosis of abnormalities in Iran.

### **Design and Setting**

This qualitative study was conducted in 2018 using conventional content analysis. "Qualitative content analysis is defined as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278) to achieve a condensed description of the phenomenon (Elo & Kyngäs, 2008). This approach is generally used with a study design whose aim is to describe a phenomenon and is usually appropriate when existing literature on a phenomenon is limited (Hsieh & Shannon).

A total of 25 women with prenatal diagnosis of fetal abnormalities who referred to obstetric clinic of Shahid Akbarabadi hospital in Tehran, were invited to participate in the study. This hospital was chosen because it is a referral women's hospital in which women who have abortion license from forensic medicine are admitted. Participants were selected among women with diagnosis of congenital anomalies in their fetus in the first and second trimester of pregnancy through purposeful sampling with consideration of maximum variation in age, gestational age, gravidity, and type of fetal abnormalities and outcomes. Sampling continued until data saturation was reached. Finally, 15 participants were interviewed for 60 to 90 minutes. Eleven participants were interviewed once, and four participants had an extra interview session for more information and clarification of their experiences because they were

bed-ridden, and the interviews were shortened due to some medical treatments or the visit of physicians.

### Procedures

Semi-structured, face-to-face interviews were used to collect the data. All interviews were conducted by the first author in a quiet and private room in hospital. The interviews lasted 60-90 minutes. Participants were asked to answer this question, "How do you describe your experiences of diagnosis of fetal abnormalities?" All interviews were recorded and transcribed verbatim immediately after the interview.

In order to assure credibility of the study, a maximum variation of participants was chosen, and experts in qualitative research (FR, MG, FO) and reproductive health (FR, MG, SH) contributed to the review and interpretation of data. Prolonged engagement was maintained by the principal researcher in the research field in order to establish rapport and to collect in-depth data. To do so, we spent six months (from July to December 2018) in the field with the participants to develop close relationships and build trust with them. In the interview sessions, we tried to actively listen to the participants and asked them follow-up questions to encourage elaboration. Moreover, to determine the accuracy of the data, all the transcriptions and interpretations were sent to the participants for feedback (member checking) so that they could confirm correct interpretations.

### Analysis

We analyzed the data using conventional content analysis approach, based on the Graneheim and Lundman 2004 strategies (Graneheim & Lundman) as follows: 1. We transcribed verbatim all the interviews and reread them several times to identify a sense of wholeness. 2. We collected the texts which were related to congenital anomalies and put them in one text. 3. The text was divided into condensed meaning units (Table 1). 4. The meaning units were abstracted and coded. 5. The codes were sorted into categories and subcategories based on similarities and differences, reflecting the content of text. 6. The tentative categories were discussed to find agreement in the sorting of the codes. 7. The latent content was formulated into themes. It should be noted that analysis of the data was conducted by all authors.

**Table 1**

*Examples of Text Condensation Leading to Lower Levels of Abstraction*

Text	Meaning units
My husband said you have to do it [abortion]. He was forced me.	Coercion
I have a lot of stress right now but there is no one explaining the situation to me. I haven't received any consultation.	The patient's need to medical counseling
We couldn't afford even the screening tests.	Financial difficulties

### Ethical consideration

The ethics committee of Iran University of Medical Sciences approved the study (IR.IUMS.REC1395.95-03-123-29373). The research objectives were explained to the participants before interviews, and they participated freely in the research. In addition, written informed consent was signed by each participant. The participants' privacy was respected, and

their confidentiality and anonymity were assured through assigning a code to each participant instead of using their names. The participants had the right to leave the study at any time during the study.

## Results

The participants' age ranged from 18 to 40 years, with a mean age of 31.9 years. Most of them had completed high school (46.6%) and were multiparous (53.3%). The range of gestational age was 14 to 28 weeks. A total of 12 participants (93.3%) referred for legal termination of pregnancy, two participants continued their pregnancies because of late diagnosis and one of the participants had illegal abortion. The fetal anomalies included chromosomal (n=6), neurological (n=4), cardiac (n=3) and musculoskeletal (n=2) abnormalities.

Two main themes "emotional suffering" and "decision-making challenge" emerged from the analysis of the data. Emotional suffering consisted of subthemes "commiseration," "self-blame," "sense of guilt" and "projection." Decision-making challenge included subthemes "lack of support," "stereotypical beliefs" and "uncertainty" (Table 2).

**Table 2**

*Themes and Sub-Themes of the Experience of Fetal Abnormalities*

<b>Theme</b>	<b>Sub-theme</b>
<b>Emotional suffering</b>	Commiseration
	Self-blame
	Sense of guilt
	Projection
<b>Decision making challenge</b>	Lack of support
	Stereotypical beliefs
	Uncertainty

### Emotional Suffering

The "emotional suffering" refers to the different aspects of women's feelings after learning about diagnosis of fetal abnormalities. Commiseration (n=134) was one type of feelings that led to emotional suffering in the participants. They showed some aspects of pity and compassion for themselves and the fetus while expressing sadness. Participant 2 said: "I did not want to give birth to a child like this, who will suffer from his condition the most in the future. That is why we made this decision" (Participant 2). One of the participants described the sense of self-compassion as follows: "Why (with emphasis) I just ask why? Why me? Why my child? Why did this happen to me? Someone who has an abnormal child (crying)" (Participant 9).

Self-blaming (n=25) was commonly experienced by the participants due to fetal abnormality or the decision for abortion. Participants attributed the cause of fetal abnormality to their unhealthy lifestyle during pregnancy (such as not eating healthy food, dying hair, and using smart phone). The following quotation was taken from one of the participants in this regard. "If I used contraceptives, it would not happen. If I controlled my blood sugar, I would have a healthy child" (Participant 3). One participant that decided to abort the fetus despite of her willingness because of a major genetically abnormality said: "I am always thinking to

myself I shouldn't have aborted my baby. I talked to my baby like this: I am so sorry for doing this [abortion](crying)" (Participant 7).

Sense of guilt (n=21) was another feeling experienced by the women because of the decision to terminate the pregnancy. These women felt pity for the fetus and had the feeling of guilt for killing it. In this regard, one of the participants said:

Now I feel guilty. I am a murderer. It is difficult to sign the death sheet of your child. I think it is not that different from murder... I feel sorry for the fetus. Maybe it would have been normal when it was born. How can we be sure that it was abnormal? I have doubts. It had a life too (Participant 1).

The pregnancy termination was associated with fear of God's punishment. In order to fight against the feeling of guilt they engaged in, actions such as Istikharah (a prayer recited by Muslims when in need of guidance on an issue in their life) and paying Diyyah (blood money). The following excerpt was taken from one of the participants, "I feel that if we go through with an abortion, I will encounter punishment by God in the future. However, my husband says that we are not to blame since this was a doctor's order" (Participant 4). Lack of effort to find a way to treat the fetus also caused sense of guilt. A participant with experience of illegal abortion because of severe diaphragmatic hernia stated:

I believe in God... It was difficult for me. I felt sorry for it. I said that the fetus has a soul [the ensoulment is occurred]. We even had to pay Diyyah. I do not know why I made this decision. I wish instead of finding a doctor to abort the baby, I should have found a doctor who could treat the baby (Participant 11).

Participants projected the blame onto others (n=38) including God or healthcare professionals to escape the feeling of guilt. They complained of God because of the experience of fetal abnormalities. In this regard, one participant said:

God does not love us! I said it would have been better if we did not have a child at all. We would not suffer this much. I told God that you saw how hard it was for us to get pregnant, so why did you take it away? (Participant 8).

They also blamed the obstetricians or forensic medicine. One participant stated the following: "We are not to blame for this act since the doctors told us to do so. They did not say that we can keep it [the fetus]. They emphasized the abortion" (Participant 4). Those who had missed the abortion deadline believed that complete explanations about the importance of prenatal diagnosis were not provided to them by the healthcare professionals. One participant stated the following:

I told the doctor that I did everything you told me. It's not my fault anymore. You said come on a date, do the test, I did it all. I wish you also had told me to show you the result of this test. I did not know at all that it would be too late and the abortion deadline would be overdue" (Participant 4).

### **Decision-making challenge**

After the diagnosis of anomalies, the participants experienced many challenges in decision-making about the termination or continuation of pregnancy. The challenges and confusion for decision-making were due to lack of support from family, healthcare

professionals and society, stereotypical beliefs and uncertainty in prenatal diagnosis and prognosis.

Lack of support (n=172) from family, healthcare team, government and society was among the factors that made decision-making more difficult for the participants. At the time of the prenatal diagnosis of anomalies, the family not only did not support the women but also, in some cases, pressured them to have abortions. The women were forced to terminate pregnancy due to the fear of being abandoned by the husband. In this regard, one participant said:

I would not agree with abortion, but my husband insisted on terminating the pregnancy. My husband did not let me talk to the doctor. He said doctors had said that the baby had a problem and would die within two months... I wanted to keep it [baby], but my husband did not allow it. He said if you want to keep it, you must return to your mother's house (Participant 2).

Lack of support from healthcare professional was also described by the participants (n=68). They needed accurate information and emotional support to make informed decision. One participant described not receiving sufficient support by the doctors as follows: "I wanted to talk to someone to understand the actual cause of the anomaly. Someone who would guide me in my decision; an advisor who could help me reduce my stress" (Participant 7).

The Participants perceived illegal induced abortion and the time limit for therapeutic abortion as the lack of legal support. One woman described her problem of illegal abortion as follows:

The doctor said she could not do anything since abortion at this gestational age is illegal. The doctor said it is a law and there is nothing we can do about it. I visited some other doctors and all of them ensured me that there is nothing more to do. They only said that I could take a pill to terminate the pregnancy by myself at home... I myself took the pill and was asked to visit the hospital after bleeding. I was not ready for that at all. You don't know how hard it was for me. I wish the doctors would have terminated the pregnancy and I was not forced to do it at home (Participant 11).

Lack of social and government support for the disabled person also raised the participants' concerns about the child's future. Parents were concerned about the care of the child in case of their death. One of the participants said:

My husband asked what this baby would do in the society. I agreed with him. My husband asked who would take care of the child with anomalies after our death? No one will support her in society. Everyone will pity her. (Participant 2).

Some participants pointed to embarrassment of having an abnormal child in the society. In this regard, one participant said: "If an abnormal child is born, both the baby and I will suffer. People will rebuke us...we would be embarrassed in front of others" (Participant 15). In addition, lack of financial support and economic problem (n=27) was another challenge described by some participants. They complained about being unable to afford the treatment costs of a child with anomaly. That is why they made decision to end the pregnancy. In this regard, one woman mentioned: "We have a low-income level and cannot even afford an ultrasound cost... I cannot pay for any possible surgeries for the baby, and I would have to deal with its condition" (Participant 3). Stereotypical beliefs (n=47) were another factor that

influenced the participant's decision-making for pregnancy termination. Since congenital anomaly was thought as the fault of women, some participants were blamed by the husband and his family because of abnormality of the fetus. One of the participants declared:

His family blamed me... there were some conflicts, and I was beaten. They thought that fetal anomalies were my fault. My husband said you must keep it, give birth to it and take care of it by yourself. I [the husband] will leave. It is your child, you have brought it from your father's house, and you must raise it by yourself (Participant 1).

The participants with a female fetus, were more likely to terminate the pregnancy. In this regard, one of the women stated:

When I learned the baby is a girl, I was assured that I have to terminate the pregnancy. It is difficult to be a disabled girl. Girls cannot live like this. They cannot get married easily. Why would I keep it? It is a girl and cannot protect herself (Participant 1).

Uncertainty in prenatal diagnosis and prognosis of fetal anomalies (n= 39) was also experienced by the participants, affecting their decision-making. Six out of the 15 participants reported a lack of trust in the results of tests and ultrasounds and were concerned about terminating pregnancy while the fetus was normal. One participant declared her distrust in anomaly diagnosis with these sentences: "I wanted a miracle to happen and hear that the result was false... I had already seen that they made a mistake. That is why I thought that they worked inefficiently and did not accept their results." (Participant 4). Some other participants regarded indefinite fetal prognosis and the possibility of survival as the causes of their uncertainty about decision-making. One of the participants said:

After echocardiography, they compelled me to terminate the pregnancy. The echocardiographer told me that I could keep the baby if I wanted but there is no guarantee for its health. I had a history of fetal anomalies and I thought what if it would be the same? Then what would I do? If I was ensured that the baby could be cured, I would have given birth to it (Participant 10).

## Discussion

The results of the study showed that participants experienced prenatal diagnosis of fetal abnormalities as emotional suffering and challenges in decision-making to continue or terminate the pregnancy. In our study, unlike other studies, the stereotyped beliefs influenced decision making about pregnancy termination. Participants were upset about their decision to terminate the pregnancy. However, due to lack of support from family, health system, government, and society, they valued the opportunity to legal abortion and preferred to abort their abnormal fetus rather than continue the pregnancy. These findings are supported by previous studies (Berman et al., 2018; France et al., 2013; Maguire et al., 2015).

Participants experienced the emotional suffering as feelings of commiseration, self-blame, guilt, and projection of blame on to others. Since in Iranian society, according to religious teachings of Islam, abortion is forbidden, and persons must pay for the abortion (Diyah), the religious women experienced more emotional suffering if they decided to terminate their pregnancy. Sense of guilt and self-blame have also been reported in other studies (Berman et al., 2018; Ferreira da Costa et al., 2005; Maguire et al., 2015). In the study

of Maguire et al., guilt and self-blame were described as a painful aspect of the grieving process. One of the common reasons for the relative concealment of pregnancy termination following congenital anomalies was a feeling of guilt about their decision and to avoid being judged (France et al., 2013). It should be noted that women may feel guilty even in cases of legal abortion. In addition to self-blame, most participants who had received a forensic license for therapeutic abortion tried to pass the burden of responsibility onto the doctor or forensic medicine. Similarly, Maguire et al., reported that participants stated that they were not the agent who ended the pregnancy, but rather a passive person in a predetermined process (loss or miscarriage). Therefore, providing adequate counseling and support to these women can play an important role in reducing feelings of guilt and self-blame.

After the diagnosis of anomalies, the participants faced a great dilemma, having to decide on termination or continuation of pregnancy. Challenges for decision-making were due to lack of support, stereotypical beliefs, and uncertainty in prenatal diagnosis of fetal abnormalities.

In the current study, lack of adequate support from the spouse, family and society made it impossible for women to make informed decisions about their pregnancy. Due to fear of being abandoned, the participants were coerced by their husbands to terminate the pregnancy. One of the most consistent findings in studies of women with fetal abnormalities is that they often lack adequate support during the decision-making process (Asbury, 2015). Berman et al. (2018) suggest presence of husband and even his family is important in counselling sessions (Berman et al.), to support these women and exterminate the notion that "the mother is always to blame for congenital anomalies". A study from Brazil by Hutti et al. (2015) found that these couples encounter many relationship issues (Hutti et al.). In contrast, the results of studies in developed countries showed that experience of the diagnosis of fetal abnormality had no negative effect on the partner relationship, and partner support was perceived as excellent during the period of decision making (Desrochers, 2011; Ferreira da Costa et al., 2005; Korenromp et al., 2009).

From the participants' point of view, support from the treatment team was inadequate and they did not receive emotional support and sufficient information regarding diagnosis and prognosis of abnormalities. Hedrick (2005) suggested that women should be provided required information about the abnormality, its treatment, and prognosis. Challenge of decision-making about the continuation or termination of pregnancy was more evident especially in cases where there is no legal abortion license obtained, where a certain amount of time has passed since obtaining the license. It seems that providing the technology for detecting abnormalities, which did not have the abortion license under the Iranian abortion law, could cause emotional suffering, confusion, visits to several doctors and a sense of lack of support among the participants. In countries with the abortion restrictive laws, a recommendation for prenatal diagnosis may put couples in moral hazard. To recommend a service, when abortion is illegal, places many poor women in the position of an unfair decision; on the one hand, the choice between the continuation of a pregnancy they cannot afford, and on the other, facing the legal, financial, social, emotional, and physical risks of an unsafe abortion (Ballantyne et al., 2009). Despite the availability of therapeutic abortion in recent years in Iran, many efforts are still needed to convince Iranian authorities to provide more support and required facilities for these families.

Non-acceptance of a disabled child by society because of the social stigma attached to disabled children was another challenge that led to decision-making dilemma for couples of whether to continue or terminate pregnancy. Based on Iranian culture, women are expected to have a healthy and perfect child and the most important reason for ultrasonography in pregnant women is to ensure the health of the fetus (Ranji & Dykes, 2012). Perhaps one of the reasons why the participants did not accept a child with abnormality was that they could not endure

suffering of their child and the community's pity toward these children. From the mother's narratives, it can be concluded that raising a child with anomalies is considered a social stigma, and these women did not tolerate the stigma attached to a child with anomalies. In fact, these women do not want the child because the community does not accept this child. Similarly, in the study of Maguire et al. (2015) pregnancy termination for fetal anomaly was associated with real and perceived stigma. The study of Bijma et al. (2008) also revealed these women were committed to their pregnancy on one side and on the other, they wanted to protect their child, themselves, and the family from the burden of severe disability. Thus, efforts to reduce stigma, connect women to appropriate supportive groups can improve women's grief experiences and in turn their emotional recovery (Maguire et al.).

Lack of financial support, economic problem and inability to afford the treatment costs of a child with anomalies was another challenge in decision-making, which ultimately led to the termination of pregnancy. According to the study of Frederico et al. (2018), economic barriers can limit women's autonomy and make them vulnerable to pressures that force decisions about pregnancy termination.

Stereotypical beliefs such as traditional beliefs about gender roles and preference of male gender and women's lack of decision-making power in the patriarchal society challenged decision-making about continuation or termination of pregnancy. Despite the relative equality of the status of girls and boys in today's societies, the desire to have a son is rooted in Iranian culture (Ahmadi et al., 2015; Razeghi-Nasrabad et al., 2019). Because of these inequalities and gender preferences in the society, participants were more concerned about the future of female fetuses and sometimes considered termination of pregnancy in her favor. By the way, while in Iran, only women's permission is needed for legal abortion, in practice in the patriarchal society of Iran, mostly men are ultimate decision-makers and impose their decision on women. Prior studies from Kenya, Uganda and Ghana have revealed similar findings where gender norms and power imbalances restricted women's decision-making power concerning abortion (Chae et al., 2017; Cleeve et al., 2017; Loi et al., 2018; Schwandt et al., 2013). Surprisingly, in a qualitative study in Nepal, the patriarchal traditional family structure was introduced to be both a barrier and a support for women's decision-making authority regarding reproductive health (Mattebo et al., 2016). Therefore, healthcare providers should consider gender inequality in reproductive decision-making.

Uncertainty about the diagnosis and distrust in the results of screening tests made the decision-making even more difficult. It was difficult for the parents to accept the indefinite conditions, and it led to a preference to end the pregnancy rather than its continuation. Similarly, in the 2013 study of Argote-Oviedo et al. women experienced a painful process, from which they revealed fear, uncertainty, and culpability about the diagnosis (Argote-Oviedo et al.). In the study of Ferreira da Costa et al. (2005) even though these women believed they made the right decision and were satisfied with it, ambivalence regarding the decision to terminate pregnancy was evident. In the present study, some participants blamed doctors for not being clear, accurate and confident. In fact, these women expected to know exactly what would happen to their baby if they continued their pregnancy. However, there is no way to know exactly when and how events will transpire, and health professionals should communicate openly and honestly with patients (Clark, 2008). Therefore, in dealing with these patients, clear communication, and maintaining their decision-making power should be considered. Several limitations to this study need to be acknowledged. The study was conducted at a referral hospital in the south of Tehran whose patients are generally poor in the economic and social groups, and it is difficult to generalize the results to all pregnant women in Tehran or Iran. The findings should be interpreted with caution since decisions about prenatal diagnosis vary based entirely on the socio-cultural, ethnic, and religious background of a community and even in a cultural context, may also be different from one person to

another. Furthermore, in case of illegal abortion, women do not refer to any hospital and therefore, access to these women is difficult. However, we included one of these women in our study.

Our findings can inform policymakers to modify existing laws and establish healthcare guidelines for supporting these women and improving the quality of services. Strategies need to be employed to improve women's autonomy in decision-making. It is essential that women are provided with required information and emotional support to make an informed choice about their pregnancy. Since support is an important source for reducing feelings of guilt and uncertainty in decision-making, healthcare professionals should be trained in communication skills to provide appropriate counseling to support women with diagnosis of fetal anomalies. According to previous studies (Berman et al., 2018; Bratt et al., 2015), a referral process is needed for the pregnancy termination so that patients do not wander. However, this care system is still not in place in Iran, so patients often encounter a number of advisers who have little connection with each other. Further research is needed to explore women's perspective on prenatal diagnosis of fetal abnormalities in different cultural contexts in Iran, helping to provide a more comprehensive perspective of this subject.

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### Declarations

- Ethics approval and consent to participate: The ethics committee of Iran University of Medical Sciences approved this study. The research objectives were explained to the participants before interviews, and they participated freely in the research. Also, a written informed consent was signed by each participant.
- Competing interests: There is no conflict of interest to declare.
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