

Experiences of Iranian women with prenatal diagnosis of fetal abnormalities: A qualitative study

Fahimeh Ranjbar

Tehran University of Medical Sciences

Fatemeh Oskouie

Tehran University of Medical Sciences

Shahzad Hashemi Dizaji

Tehran University of Medical Sciences

Maryam Gharacheh (✉ gharacheh.m@gmail.com)

Tehran University of Medical Sciences <https://orcid.org/0000-0002-7659-0786>

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Abstract

Background: Women are more likely to be diagnosed with congenital anomalies. 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.

Methods: 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.

Results: Two main themes "emotional suffering" and "decision-making challenge" were extracted from the participants' experiences. Emotional suffering consisted of subthemes "sense of guilt", "self-blame", "questioning of God", "commiseration" and "projection". Decision making challenge included subthemes "distrust", "possible cure", "dark future", "economic problems", "stereotypical beliefs", "coercion" and "lack of support".

Conclusions: The experience of prenatal diagnosis of fetal abnormalities was 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.

Background

Congenital anomalies are major causes of child deaths, chronic diseases and disabilities. Annually an estimated 303000 newborns die within the first month of birth, worldwide, due to congenital anomalies (1). In Iran, the overall prevalence of congenital anomalies was estimated 2.3% (2).

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 (3). 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 (4). 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 (5). 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 (6). Also, 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 (7).

Women undergoing pregnancy termination for fetal anomalies, may experience self-blame, guilt around the termination decision, social isolation and grief triggered by reminders of pregnancy (8). A previous study revealed fear, uncertainty, and culpability about the diagnosis in women following diagnosis of fetal abnormalities (9). Although some studies explored the experiences of women with prenatal diagnosis of fetal abnormalities (8–10), little is known about it in developing countries, and it seems women's environment such as culture and beliefs can affect the way they experience the diagnosis of fetal abnormalities (11). A qualitative study from Iran found that pregnant women following prenatal diagnosis of fetal anomalies, experienced emotional and cognitive reactions including grief reactions during the time of diagnosis; perinatal loss; fears of recurrence in future pregnancies; and a dilemma of hope and worries (12).

In Iran, women face many challenges because abortion is not legally available either in all cases of anomalies, or after ensoulment. In fact, religious objections to termination of pregnancy are not essentially intractable in the face of new scientific advances in prenatal diagnosis (13). 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 (14). 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 (15).

Given the impact of cultural and religious values of Iranian society on final decision of women about pregnancy termination, further research in the social and cultural context of the country is needed. The voice of these patients should be heard in designing programs to improve their conditions. Understanding the experience of these women will be helpful to identify the challenges of prenatal diagnosis of abnormalities. We aimed to explore how women experience their pregnancy with fetal abnormalities in an Iranian cultural context.

Methods

Design and setting

This qualitative study was conducted using the conventional content analysis in 2018. The women with prenatal diagnosis of fetal abnormalities who referred to Akbarabadi hospital; a referral women's hospital in Tehran, were contacted to participate in the study.

Sample

A total of 15 participants were selected through purposeful sampling with consideration of maximum variation in age, gestational age, gravidity, and type of fetal abnormalities and outcomes. Eleven participants were interviewed once and four participants had an extra interview session for more information. Women with diagnosis of congenital anomalies in their fetus in the first and second trimester of pregnancy, were selected. Sampling continued until data saturation was reached.

Procedures

Semi-structured, face-to-face interviews were used to collect the data. An interview guide was developed for the study (supplementary file 1). All interviews were conducted by the first author. Interviews were conducted after obtaining informed consent and with the consideration of all the issues that provided psychological security and privacy for the free expression of thoughts, feelings and perceptions of individuals. The interviews were performed in a quiet environment, and at any place where the participant was willing to be interviewed. They 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.

Analysis

Data were analyzed using conventional content analysis approach, based on the Graneheim and Lundman, 2004 strategies (16) 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, 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.

In order to assure credibility of the study, a maximum variation of participants was chosen, and three experts with qualitative research and reproductive health expertise 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. Also, to determine the accuracy of data, all the transcriptions and interpretations were sent to the participants for feedback so that they could confirm correct interpretations.

The ethics committee of X 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,

written informed consent was signed by each participant.

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 14–28 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 participants' characteristics are summarized in Table 1.

Table 1
Characteristics of participants

Participant number	Educational level	Gravidity	Parity	Gestational Age at interview time (week)	Fetal Anomaly	Outcome
1	9th grade	1	0	18	Spina bifida (Meningocele) and Severe heart disease	Legal abortion
2	HS ¹	3	1	19	Trisomy 13 (Patau syndrome) and Clift lip	Legal abortion
3	6th grade	3	2	26	Trisomy 13, microcephaly Holoprosencephaly	Continuation of pregnancy
4	HS	3	2	19	Trisomy 21	Legal abortion
5	B.S. ²	1	0	17	Spina bifida (Meningomyelocele)	Legal abortion
6	HS	3	2	19	Hypertrophic cardiomyopathy Hydronephrosis	Legal abortion
7	HS	1	0	16	Anencephaly Cleft lip and cleft palate	Legal abortion
8	B.S.	2	1	14	AP4M1 Gene Mutation	Legal abortion
9	5th grade	1	0	28	cardiac hypoplasia	Continuation of pregnancy
10	HS	3	2	17	ASD* and CF**	Legal abortion
11	HS	2	1	-	severe diaphragmatic hernia	Illegal abortion at 25 W

1- HS: High school, 2- B.S.: Bachelor of Science

*Atrial septal defect (ASD)

**Cystic Fibrosis

Participant number	Educational level	Gravidity	Parity	Gestational Age at interview time (week)	Fetal Anomaly	Outcome
12	B.S.	1	0	14	major thalassemia	Legal abortion
13	5th grade	2	1	19	Severe microcephaly	Legal abortion
14	B.S.	1	0	17	trisomy 18 (Edward syndrome)	Legal abortion
15	HS	1	0	16	skeletal dysplasia, micromelia and polydactyly	Legal abortion
1- HS: High school, 2- B.S.: Bachelor of Science						
*Atrial septal defect (ASD)						
**Cystic Fibrosis						

Two main themes “emotional suffering” and “decision-making challenge” were obtained from the analysis of the data. Emotional suffering consisted of subthemes “sense of guilt”, “self-blame”, “questioning of God”, “commiseration” and “projection”. Decision making challenge included subthemes “distrust”, “possible cure”, “dark future”, “economic problems”, “stereotypical beliefs”, “coercion” and “lack of support” (Table 2).

Table 2
Themes and sub-themes of the experience of fetal abnormalities

Theme	Sub-theme
Emotional suffering	Sense of guilt
	Self-blame
	Questioning of God
	Commiseration
	Projection
Decision making challenge	Distrust
	Possible cure
	Stereotypical beliefs
	Coercion
	Dark future
	Economic problems
	Lack of support

Emotional Suffering

As a main theme emotional suffering refers to the feelings of guilt, blame, commiseration, and projection experienced by the participants after learning about diagnosis of fetal abnormalities. Most participants felt guilty and ashamed because of the decision to terminate the pregnancy. 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). They reported the feeling of killing a baby and feared God’s punishment due to this wrongdoing. The feeling of guilt was associated with 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). A participant with experience of illegal abortion stated: “It was difficult for me. I felt sorry for it. I said that the fetus has a spirit. We even had to pay Diyyah” (Participant 11).

Self-blaming for fetal abnormality and questioning of God were commonly experienced by the participants. While expressing sadness, they showed some aspects of pity and compassion for themselves

and the fetus. The following quotation was taken from one of the participants. "If I used contraceptives, it would not happen. If I controlled my blood sugar, I would have a healthy child" (Participant 3). Other 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). 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 follow: "Why? (with emphasis) I just ask why? Why me? Why my child? Why did this happen to me? Someone who has an abnormal child" (Participant 9).

Most participants projected the blame onto others to escape the feeling of guilt. While the recommendation of screening made by obstetricians was rejected by the patients, they believed that complete explanations about the importance of prenatal diagnosis were not provided to them. Although the participants usually shifted the blame onto God and healthcare professionals or considered it their destiny, most participants put their whole trust in the forensic medicine team. 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).

Decision-making Challenge

After the diagnosis of anomalies, the participants experienced many challenges in decision-making about the termination or continuation of pregnancy. Some participants reported a lack of trust in the results of tests and ultrasounds and were concerned about terminating pregnancy while the fetus was normal, considering it to be due to observing similar cases in acquaintances and believing in a miracle. Some other participants regarded indefinite fetal prognosis and the possibility of survival as the causes of their uncertainty about decision-making. 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 saw that they made a mistake. That is why I thought that they worked inefficiently and did not accept their results." (Participant 4). Regarding the possible cure of the fetus, one of the participants said: "Nobody said my baby would be cured... but I was concerned that the baby would be born with anomalies. However, if I knew that it would be cured, I would have had no problems" (Participant 13). Another participant 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).

Traditional beliefs about gender roles had increased the participants' willingness to terminate the pregnancy in case of a female fetus. 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). 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 yourself. I [the husband] will leave. It is your child, you have brought it from your father's house, and you must raise it yourself" (Participant 1). Another participant said: "If an abnormal child is born, both the baby and I will suffer. People will rebuke us" (Participant 15).

Being forced to terminate pregnancy by the husband despite the women's willingness and fear of being abandoned were reported by some participants. 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 have said that the baby has a problem and will die within two months" (Participant 2). Another woman also said: "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). However, in this regard an exception was infertility, in a way that infertile women considered this pregnancy to be a success, and they were willing to continue the pregnancy (even with the diagnosis of fetal anomalies) only to prove their fertility. Infertile women preferred to continue the pregnancy or maintain the fetus until the last chance of legal abortion in order to prove their fertility to their husband, family and acquaintances. One participant remarked: "When they informed me that the baby was diagnosed with thalassemia major, we were really upset. We had concerns regarding high IVF costs. Nevertheless, I said it is ok, and I was happy to hear its heartbeat. We enjoyed being pregnant and hearing the fetal heartbeat like other couples" (Participant 12).

Unclear future of child was another issue that increased the concerns of participants. 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).

The participants complained about economic problems and not being able 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... I cannot pay for any possible surgeries for the baby and I would have to deal with its condition." (Participant 3).

Lack of husband and family support, information withholding by healthcare team, time limit for therapeutic abortion, and problems of illegal abortion were among the factors that made decision-making more difficult. One participant described receiving insufficient support by the doctors as follows: "I wanted to know whether the baby could be cured after birth or not. When I asked the doctor. They did not know the exact problem themselves. Therefore, I did not follow up the issue after that. I said the forensic medicine department is to blame. It was difficult since we have only two-three days. I immediately attempted to obtain an abortion license" (Participant 10). Another woman mentioned: "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). One women described her problems of illegal abortion as follows: "Doctors did not perform the abortion. 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). Another woman remarked the time limit for legal abortion in this way: “The doctor said they 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” (Participant 12).

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. They were upset about decision to terminate the pregnancy. However, due to the social, cultural and economic conditions, they valued the opportunity to legal abortion and preferred to abort their abnormal fetus rather than continue the pregnancy. Some participants even would have gone through illegal abortion if they had exhausted the time for legal abortion. These findings are supported by previous studies (8, 10, 17).

Participants experienced the feelings of guilt, self-blame, commiseration, and projection of blame on to others, as well as questioning of God. Therefore, emotional suffering was perceived by the participants. Although in Iranian society, according to religious teachings of Islam, abortion is forbidden, and persons must pay for the abortion (Diyah), social norms challenged decision-making in even religious people. Thus, despite their willingness, the participants decided to terminate the pregnancy. Guilt and self-blame have also been reported in other studies (8, 10, 18). In the study of Maguire et al. (2015) guilt and self-blame were described as a painful aspect of the grieving process (7). Also, 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 (17). Providing adequate counseling and support to these women can play an important role in reducing feelings of guilt and self-blame. 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. (2015) 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) (8). Therefore, addressing reactions such as a sense of guilt, denial and projection is emphasized more than ever in counseling.

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 indefinite outcomes, unclear future of the child, economic problems, stereotypical beliefs, and lack of support. 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, and where the diagnosis and prognosis of the fetus were indefinite. Uncertainty about the diagnosis and possible cure of the fetus 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. 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 (18). 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 (19). Therefore, in dealing with these patients, clear communication, and maintaining their decision-making power should be considered.

In the current study, stereotypical beliefs such as traditional beliefs about gender roles, and preference of male gender, social stigma attached to disabled children, blaming the woman for the abnormal child, scornful reproaches by others due to giving birth to a disabled child, and women's lack of decision-making power in the patriarchal society challenged decision-making about continuation or termination of pregnancy. Due to fear of being abandoned, the participants were coerced by their husbands to terminate the pregnancy and this mostly exacerbated their marital problems. Similarly, a study from Brazil by Hutti et al. (2015) found that these couples encounter many relationship issues (20). Conversely, the results of the studies from the US showed that experience of the diagnosis of fetal abnormality had no negative effect on the partner relationship (18, 21). 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.

The dark future of a disabled child 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 (22). 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 (8). The study of Bijma, van der Heide and Wildschut. (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 (23). Thus, efforts to reduce stigma, connect women to appropriate supportive groups can improve women's grief experiences and in turn their emotional recovery (8).

Economic problem and inability to afford the treatment costs of a child with anomalies and the additional costs for care of these children was another decision-making challenge, 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 (18).

The lack of support from the spouse, family and healthcare team was perceived by the participants. 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 (24). In contrast, in the study of Korenromp, Page-Christiaens, van den Bout, Mulder and Visser, 2009, partner support was perceived as excellent during the period of decision making (25). However, Berman et al. (2018) suggest presence of husband and even his family is important in counselling sessions (10), to support these women and exterminate the notion that "the mother is always to blame for congenital anomalies". In addition, participants' perceived support from the treatment team was inadequate and they wandered between the views of sonologists, midwives, obstetricians, pediatricians and geneticists. According to previous studies (10, 26), a referral process is needed for the pregnancy termination, so that patients do not wander. It is often worthwhile to maintain regular relationships when caring for pregnant women. 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.

The participants preferred to discontinue pregnancy with abnormalities, due to lack of socio-economic support. Therefore, they were more likely to seek support for the legal termination of pregnancy even in cases that therapeutic abortion was not indicated or the time of legal abortion had passed. 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 (13). 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. 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

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

Conclusions

The experience of prenatal diagnosis of fetal abnormalities was associated with emotional suffering and challenges in decision-making to continue or terminate the pregnancy. In this study, what was different from other studies was inconsistency of social norms with religious and personal beliefs in cases of fetal anomaly diagnosis, which caused moral distress and challenge in decision making.

Our findings can inform policy-makers 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 to make an informed choice and not be forced to pregnancy termination by the spouse, family and healthcare team. 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. Further research is needed to explore women's perspective on prenatal diagnosis of fetal abnormalities in different cultural contexts, helping to provide a more comprehensive perspective of this subject.

Abbreviations

IVF

In vitro fertilization

PTSD

Post-traumatic stress disorder

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.
- Consent for publication: Not applicable
- Availability of data and materials: The datasets analyzed during the current study are available from the corresponding author on reasonable request.
- Competing interests: There is no conflict of interest to declare.
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- Authors' contributions: FR, MG and FO contributed to the concept and study design. FR searched the electronic databases. FR and MG contributed to the initial drafting and critical revision the manuscript, FO and SH contributed to the implementation and analysis of the studies and will also screen potential studies and extract data and assess quality, all authors gave feedback to the final draft of the protocol. All authors read the final manuscript and FR provided feedback and approved the final manuscript.
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