

ORIGINAL ARTICLE

Women's Concerns and Experiences of Fetal Anomaly Screening Process: A Qualitative Study

Zohreh Khakbazan¹, PhD; Farnaz Farnam¹, PhD; Parsa Abdollahi², Student candidate; Mitra Arjmandifar¹, PhD

¹Department of Reproductive Health, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran;

²Student of Medicine, School of Medicine, Tehran Medical Sciences, Islamic Azad University, Tehran, Iran

Corresponding Author:

Mitra Arjmandifar, PhD; Department of Reproductive Health, School of Nursing and Midwifery, Nosrat st. Tohid sq, P.O. Box: 14197-3317, Tehran, Iran

Tel: +98 21 66914368; Fax: +98 21 61054170; Email: m-arjmandifar@alumnus.tums.ac.ir, arj7087@yahoo.com

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ABSTRACT

Background: Advanced technologies in antenatal screening provide complex and accurate information about the fetus that allows for early intervention, but it increases pregnant women's concerns about fetal health. This study aimed to investigate the concerns and experiences of Iranian pregnant women in the fetal anomaly screening process.

Methods: This qualitative study was performed from September 2018 to June 2019 in Tehran, Iran. Twenty pregnant women who referred to prenatal care clinics, four specialists, and two midwives took part in this study. The sampling was done purposefully until data saturation. Qualitative interviews were analyzed using the content analysis approach and Graneheim and Lundman's method. The MAXQDA 10 was used for data management.

Results: The pregnant women who participated in the study were 22-40 years old. The following 4 themes were obtained from the analysis: the challenge of deciding to perform the tests, bitter pregnancy experience, challenges of facing an abortion, and unmet needs of pregnant women by the health system.

Conclusion: The findings indicate that pregnant women need real information and support. Designing and implementing interventions that reduce the psychological impact of performing fetal anomaly screening tests can highlight the potential benefits for pregnant women's health.

Keywords: Maternal serum screening tests, Pregnant women, Qualitative research

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INTRODUCTION

Fetal anomaly screening tests (FASTs) are now part of routine pregnancy care in most countries. Despite the fact that advanced technology in prenatal screening provides complex and detailed information about the fetus, which allows for early interventions and special care, it also increases pregnant women's concerns about their baby's health. Invasive diagnostic procedures (Chorionic villus sampling and amniocentesis) provide a definitive answer as to whether or not the fetus is abnormal; however, they carry a small risk of miscarriage. Women opt for diagnostic tests since they desire to ensure their fetus's health and ease their worries.^{1,2} On the other hand, hesitation is not eliminated when deciding on invasive diagnostic procedures. Most women have to wait for additional tests, which increases their anxiety and distress.³ Pregnancy per se, regardless of ultrasound examinations and tests, is associated with stress and anxiety for most women.⁴ Fetal health is the mothers' most common concern.⁵

The study of maternal concerns during pregnancy is of particular importance since there is a relationship between maternal mental state and the consequences of pregnancy, such as low birth weight and cesarean section.^{6,7} These worries and concerns affect the maternal sleep status and quality of life.⁸ Anxiety during pregnancy can increase the incidence of postpartum depression.⁹

Since the mothers' concerns during pregnancy have cultural, social, economic, and medical dimensions, it is essential to conduct qualitative studies as the first step in understanding this concept. It arises from the fact that qualitative studies lead to in-depth information that can shed light on various and unknown dimensions of complex human phenomena such as pregnancy concerns. Furthermore, identifications of the mothers' worries during pregnancy make it possible to find solutions to improve their health, quality of life, and experiences during this period.^{5,10}

Qualitative studies have investigated

the experiences of women in the FAST process from different perspectives, such as the preference of Muslim pregnant women about FAST counseling, the views of pregnant women on the use of decision-making support for performing FAST, and the experiences of women and their husbands with a high-risk result while awaiting the results of diagnostic tests.¹¹⁻¹⁶ However, a study that specifically addresses the concerns of pregnant women during the process of performing FAST has not been done.

Some studies show that healthcare providers do not seem to allocate adequate time to educate pregnant women prior to screening tests and ultrasounds. Lack of proper education leads to concerns for parents and a reduction in their informed choices.^{14,17} In a study conducted in Iran, researchers underlined the need for further research into challenges associated with screening tests as a necessity to reduce the families' and physicians' decision-making pressure and provide relevant ethical guidance.¹⁸ Having understood this gap, and since appropriate research has not been carried out in the existing socio-cultural context in Iran, the researcher intended to address the concerns of pregnant women in the FASTs process.

METHODS

This qualitative study was conducted from September 2018 to June 2019 in Tehran, Iran using conventional content analysis. Considering the high rate of acceptance and referrals to comprehensive health service centers (CHSC) and hospitals affiliated with the Tehran University of Medical Sciences, we attended these centers to interview the pregnant women. Then, other interviews with pregnant women were performed in private midwifery and perinatology offices to achieve maximum variety. Finally, four interviews at the perinatology clinic of Vali-Asr Hospital, four at the perinatology clinic of Moheb Yas Hospital, four at the perinatologist's office, two at the midwifery office, three at Niknejad CHSC,

and three at the Mystham CHSC were done. The pregnant women who participated in the study were selected with a maximum variation in age, gravity, parity, job, education, type and stage of performing the screening tests, and history of a child with Down syndrome or other abnormalities (Table 1). The inclusion criteria included the Iranian pregnant women referring to perinatal care centers, ability to speak and

understand Farsi, and willingness to participate in the study. The exclusion criteria were the use of psychiatric drugs and lack of consent to participate in the study after the interview.

In-depth personal face-to-face interviews were used to collect the data by the corresponding author. Interviews were conducted in a location comfortable for participants and started with communication

Table 1: Characteristics of the pregnant women in the study

Participant	Age (Year)	Education level	Occupation	Gravidity (No)	Parity (No)	Child birth (No)	Abortion (No)	History of childhood with congenital anomaly	Test status
1	22	Diploma	Housewife	2	1	1	0	No	a&b
2	40	Diploma	Housewife	2	1	1	0	No	a&b
3	40	Diploma	Housewife	3	1	1	1	No	a&b
4	31	Associate degree	Housewife	3	1	1	1	No	a&c
5	34	Diploma	Housewife	2	1	1	0	No	a&b
6	34	Master's degree	English teacher	1	0	0	1	No	a&b
7	37	Diploma	Housewife	2	1	1	0	No	d
8	30	Bachelor's degree	Housewife	4	2	2	1	No	a&e
9	34	Bachelor's degree	Housewife	2	1	1	0	No	d&f
10	24	Secondary education	Housewife	2	1	1	0	No	g&h
11	37	Diploma	Housewife	3	2	2	0	Yes	i&j
12	36	Bachelor's degree	Teacher	3	1	1	1	Yes	k
13	31	Bachelor's degree	Housewife	2	1	1	0	No	l&m
14	37	Master's degree	Justice employee	1	0	0	0	No	g&n
15	28	Bachelor's degree	Teacher	2	1	1	0	No	a&e
16	40	Bachelor's degree	Bank clerk	2	1	1	0	No	a&b
17	38	Diploma	Housewife	3	2	2	0	No	g&l
18	36	Bachelor's degree	Employee	2	1	1	0	No	o&b
19	28	Bachelor's degree	Housewife	2	0	0	1	No	p
20	42	Master's degree	Employee	3	1	1	1	No	q

^aHigh-risk first-trimester screening, ^bReferral for amniocentesis, ^cNormal Noninvasive Prenatal Testing (NIPT), ^dNormal first-trimester screening, ^eNormal result of karyotype obtained from amniocentesis, ^fNormal second-trimester screening, ^gDiagnosis of Down syndrome with karyotype, ^hReferral for legal abortion, ⁱHistory of having a child with Down syndrome, ^jNormal result of karyotype obtained from chorionic villus sampling, ^kReluctance to undergo fetal screening, ^lExpiration of legal abortion opportunity, ^mDiagnosis of Trizomi 13 with karyotype, ⁿPerforming legal abortion, ^oAbnormal Nuchal Translucency, ^pPerforming a legal abortion in a previous pregnancy due to the diagnosis of fetal Down syndrome, ^qMother's age over 40 years and performing NIPT

to win their trust. The participants were asked to express their views on their concerns about the FASTs. Some other questions asked included: “How did you feel when were prescribed the screening tests?”, “How did you feel when you were waiting for the test result?”, “How did you feel when the test result was known?”, and “What is the most important thing about screening tests in your mind?” Subsequent questions were asked based on the participant’s initial answers and the interview guide. Besides, questions, such as “What do you mean or explain more please,” were asked, if needed. Purposive sampling was used until data saturation was achieved. Data saturation was reached after 26 interviews were conducted with 20 pregnant women, 4 specialists (2 perinatologists and 2 obstetric and gynecologists), and 2 midwives (Table 2). Interviews lasted between 45-75 min. The interviews were recorded with the voice recorder and the participants’ permission.

In this study, qualitative content analysis was performed according to Graneheim and

Lundman’s method.¹⁹ After each interview, the content was transcribed at the earliest convenience by the corresponding author. The statements were read word by word several times to gain a general understanding. The semantic units were then identified from the content of each interview. The meaning units - groups of words or phrases that have the same content- were coded. Then, primary codes that center around a central concept were placed in a similar subcategory. Afterward, all authors reviewed the subcategories several times and checked for similarities and differences. Consequently, categories and themes were formed. Attempts were made to have the highest homogeneity within the categories and find the most heterogeneity between the categories. The MAXQDA 10 was used for data management.

Trustworthiness of the data was ensured through Lincoln and Guba’s four criteria: credibility, dependability, transferability, and confirmability.²⁰ Several methods were used to confirm the credibility, including member

Table 2: Characteristics of the health care providers in the study

Participant	Age (Year)	Education level	Occupation	Years of experience in health care
21	63	Medical doctor	Fellowship of perinatology	33
22	57	Medical doctor	Fellowship of perinatology	27
23	48	Medical doctor	Obstetric and gynecologist	18
24	52	Medical doctor	Obstetric and gynecologist	22
25	41	Bachelor’s degree	Midwife	18
26	35	Bachelor’s degree	Midwife	10

Table 3: Categories and subcategories of the study

Subcategories	Categories
The need for more information about interpreting the test results	The challenge of deciding to perform the tests
Uncertainty about the appropriateness of the test	
Bitter days of waiting	Bitter pregnancy experience
Diagnosis shock	
Concerns about repeating anomalies in next pregnancy	
Accedence to abortion	The challenge of facing an abortion
Hesitation in having an abortion	
Loneliness and abandonment after the end of legal time abortion	
Lack of adequate support	Unmet needs of pregnant women by the health system
Lack of integration in performing national fetal screening	

check, external check, peer debriefing, prolonged engagement with the data, and maximum variation sampling. External check and peer debriefing were used to confirm dependability, and samples of scripts and codes were presented to the participants to monitor the data analysis process and receive their comments. The researcher tried to accurately record the research path and the decisions made in this process and write her dissertation on the subject to enable other investigators to have a correct estimate of the transferability of the findings. To ensure confirmability, interview transcripts and extracted codes and categories were provided to the research team and a faculty member to verify the accuracy of the process.

This study was approved by the Ethics Committee of Tehran University of Medical Sciences, Tehran, Iran (IR.TUMS.FNM.REC.1397.099). All procedures performed in studies involving human participants were in accordance with the ethical standards of Tehran University of Medical Science and based on the 1964 Helsinki declaration and its subsequent amendments or comparable ethical standards. Written informed consent was obtained from all participants. In addition, the anonymity of the participants was considered and the right to withdraw from the study was considered for the participants without any change in their pregnancy care process.

RESULTS

Twenty pregnant of the women aged 22 to 40 years who were referred for prenatal care and were in the process of performing screening tests were interviewed. A total of 810 codes were extracted from the interviews, which were compared based on content similarity and organized into four categories and ten subcategories. Table 3 shows the categories and subcategories of the research.

1. The Challenge of Deciding to Perform the Tests

This category has two subcategories,

including “The need for more information about interpreting the test results” and “Uncertainty about appropriateness of the test.”

1.a. The Need for More Information about Interpreting the Test Results

Pregnant mothers were unfamiliar with the medical terms used by the medical staff or in the laboratory and ultrasound reports, which caused their worries. They needed training in the interpretation of the tests and terminology to make the right decision. A woman stated:

“I thought that when the high-risk results came, it means that the fetus should be aborted. I did not know that this is a screening test and only shows the level of risk.” (P4)

In this regard, one of the midwives who participated in this study stated: *“People don’t know the difference between screening tests and diagnostic tests, so they get stressed out.”* (P26)

Some mothers used the Internet to find out about their tests. They were obsessed with receiving information and seemed to be looking for answers to their questions to reduce their stress and make correct decisions. In this case, one of the participants said:

“I was constantly surfing the net; I needed to get more information about screening tests to make correct decisions, but it was stressful because I wasn’t reading anything good about it, and it was all about illness, physical or mental disorders, etc., which made me more stressed.” (P13)

1.b. Uncertainty about the Appropriateness of the Test

Three other important issues in the mothers’ decision-making process raised concerns for mothers. One of these issues was a lack of trusting accuracy of the test results since test errors would lead either to the birth of a disabled child or miscarriage of a healthy child, both of which were distressing.

“I didn’t have the tests because I heard that in most amniocentesis cases, babies are healthy, and in some cases, like my friend, had a ‘premature rupture of membranes’ and had to abort the baby.” (P12)

In this regard, one of the obstetrician-gynecologist participating in this study mentioned: *"The problem we have in requesting screening tests is that people don't accept the detection rate lower than 100%; however, each screening test has the diagnosis error percentage."* (P23)

The second issue was the challenge of choosing between 'costly non-invasive screening tests' and 'invasive diagnostic tests.' The price of the test was also sometimes challenging in deciding the type of the test. A woman stated:

"I couldn't choose, and I was skeptical. The NIPT test was expensive, and amniocentesis had the risk of miscarriage. Finally, I chose amniocentesis because the result was definite, and the cost was lower." (P20)

The third issue was the fear of adverse effects of invasive tests. Another woman expressed:

"I was worried about how amniocentesis was done. They said it was done with a big needle in the abdomen. I didn't know how it was, so I was very worried about it." (P14)

2. Bitter Pregnancy Experience

This category contains three subcategories, including "Bitter days of waiting", "Diagnosis shock", and "Concerns about repeating anomalies in next pregnancy."

2.a. Bitter Days of Waiting

Participants, while they were waiting for test results, sometimes hoped for a negative test result, and sometimes experienced frustration, felt preoccupied, and thought about keeping or aborting the fetus.

"I always hoped that the test result would be good, but sometimes I thought if my child had a problem, how would I deal with it? Would I have an abortion? What would I say to those around me? Could I get pregnant again?" (P16)

During this period, due to the long time before receiving the test results, preoccupations such as the fear of missing the legal window of time for abortion and

worry about the future disrupted the pregnant women's routine life. One of the participants equated this period to a *limbo*:

"While waiting for the genetic test results, I had a headache all the time and did not take any painkillers for fear of the side effects of the drug on the baby. I kept thinking if it had been clear soon. I knew what to do; that's why, I call it a limbo; I have terrible memories of those days." (P14)

2.b. Diagnosis Shock

Pregnant women who received a high-risk test result were initially skeptical and hesitant to accept the test result. In this regard, one of the participants said:

"I couldn't believe it! There was no such thing in our family at all; when I heard the high-risk result, I was very upset, and I just cried and cried." (P4)

Most of the participants stated that they experienced emotional turmoil after receiving the high-risk results. These experiences were manifested as 'intense tension and stress', 'experience of dismal days', 'occurrence of unusual behaviors', 'desire for isolation', and 'living in secrecy'. *"That period was so bad that I decided to see a psychologist."* (P18)

2.c. Concerns about Repeating Anomalies in Next Pregnancy

After the initial shock of the test results and bitter days of waiting, pregnant women who received high-risk results and were over 35 years old or had consanguineous marriages experienced feelings such as fear of the recurrence of the problem in future pregnancies. They were worried that they would no longer be able to have a healthy child.

One participant said: *"Now that I had a miscarriage due to Down syndrome, I'm worried, and I guess the next pregnancy will be the same because age can't be changed, and we couldn't find the main reason."* (P14)

3. The Challenge of Facing an Abortion

This category has three subcategories, including 'accedence to abortion,' 'hesitation

in having an abortion,' and 'loneliness and abandonment after the end of legal time abortion.'

3.a. *Accedence to Abortion*

Women who consented to abort had a variety of reasons, including fear of the social stigma of having a disabled child.

In this regard, one of the expert participants said: *"People have problems with expenses, care, and stigma of a disabled child. There aren't such problems in other societies; for example, because they have a child with Down syndrome, they're stigmatized and their sisters lose their chances of marriage."* (P21)

It is obvious that caring for a child with a disability is tedious, and not all parents may be able to deal with it. Most women who agreed to have an abortion expressed this concern. For example, one of the pregnant women said:

"Raising a child with these problems is very difficult; you should have nerves of steel to be able to raise such a child. The situation is very difficult, so if they say the fetus definitely has a problem, I want to have an abortion right now." (P18)

Some mothers believed that a disabled child would suffer from his/her problems and considered it their duty to perform an abortion.

"If God forbids, the amniocentesis result shows that the fetus has a problem, wisdom dictates that I should have an abortion. We know there're problems for people with disabilities and their families, so my husband and I will definitely agree to legal abortion and say goodbye to this baby." (P16)

Concern about the lack of organizational and economic support was another reason for the families to opt for abortion. A woman stated:

"I think it's costly and worrisome to get tested now, but if a baby with Down syndrome is born, he/she needs special care; the costs for the baby are too high." (P3)

It was reassuring for mothers that Islamic jurists issued a fatwa permitting legal and religious abortion in case of a definitive

diagnosis of fetal chromosomal abnormalities. This reassurance prevented the sense of being guilty in mothers; consequently, they decided to have an abortion with no concerns. Participant 9, who majored in jurisprudence, in response to the question, "If the test result shows Down syndrome, will you have an abortion?" said, *"Yes, I will, because the jurists have legally approved it."*

3.b. *Hesitation in Having an Abortion*

Some pregnant women whose tests showed fetal abnormalities were hesitant to have an abortion since it contradicted their maternal sense. Some mothers felt this motherly feeling by seeing the fetal heart move or hearing its heartbeat on the ultrasound monitor screen. One of the mothers stated:

"I have a special feeling, and I think about what I would do about the abortion if there was a problem. My baby has a heart now; I feel it and I can't decide to abort it." (P8)

Some women were concerned about the miscarriage of a mildly disabled baby. They believed that caring for these children was not very challenging. Therefore, they were reluctant to have an abortion. One of the pregnant women stated:

"I had the amniocentesis, and there was a problem. I hesitate to have an abortion because I don't think Down syndrome is an acute problem. People that have Down syndrome can do everything on their own." (P10)

3.c. *Loneliness and Abandonment After the End of Legal Time Abortion*

In some cases, fetus abnormalities were confirmed after the end of the legal abortion period. According to Islamic law in Iran, abortion is not allowed after the soul has been breathed into the fetus (19 weeks gestation). They either had to continue their pregnancy and give birth to a disabled child or have an abortion in isolation illegally with or without the help of medical staff. These sufferings and the lack of medical and legal support frustrated the women and caused them to feel abandoned and depressed. One of these

women stated:

“Because the time for legal abortion had passed, every doctor told me that there was no legal way and if I wanted to abort it, I had to do it myself. I felt I had reached a dead-end, and no one could help me.” (P13)

4. Unmet Needs of Pregnant Women by the Health System

This category has two subcategories including ‘lack of adequate support’ and ‘lack of integration in performing national fetal screening’.

4.a. Lack of Adequate Support

Some mothers mentioned the medical staff's lack of understanding of their feelings and concerns about screening tests and the lack of proper answers to their questions. They expressed that the medical staff delivered bad news to them inappropriately; thus, they were shocked. Therefore, the mothers' needs and expectations of the medical staff remained unmet.

“We are not counseled at all; there's nothing to calm us down, and they just say that you should do this test, or they simply say that if there's a problem, you should have an abortion. When it's told suddenly, we get shocked and nervous.” (P8)

Since state insurances do not cover the cost of the tests, some pregnant women stated that they could barely afford the expenses. Obviously, few participants had fewer financial worries since supplementary insurance covered part of the expenses.

“The costs are very high, especially if someone is a worker. The government should think about the test costs, so that financial worries are not added to families' worries of whether the baby is healthy or not.” (P15)

4.b. Lack of Integration in Performing National Fetal Screening

In the screening system for fetal genetic and chromosomal disorders in Iran, a specific protocol has been provided by the Ministry of Health. Most healthcare providers do not

adhere to this protocol. Requests for parallel tests, conflict in medical staff's opinions to request and interpret tests, uncertainty in deciding, and unnecessary referrals from other towns cause confusion, waste of money and time, loss of legal time for abortion, and unnecessary worries for mothers and families. In this regard, a perinatologist stated: *“I don't agree with the protocol because it only considers the costs, while the patient has the right to have access to up-to-date information to make a decision.”* (P22)

There were discrepancies in P13's test results, and the medical staff requested several tests for her. She said, *“My first-trimester screening was high risk for Down syndrome and low risk for trisomy 13, but then the NIPT result showed trisomy 13, and I was left wondering why the results of the two tests were so different. Sorry for this, but during this time, I hated all tests and doctors.”*

The subjectivity of physicians in requesting tests or ultrasounds and refusing other colleagues' opinions confused the patients. In this regard, a participant said, *“I took the anomaly scan to my doctor, and she said there weren't any problems, but when I referred to another doctor, she ordered to have it again done at a certain clinic!!”* (P3)

DISCUSSION

The present study was conducted to explain the concerns of Iranian pregnant women in the process of FASTs. According to the results, pregnant women's concerns included ‘The challenge of deciding to perform’, ‘the bitter experience of pregnancy’, ‘the challenge of facing an abortion,’ and ‘unmet needs of pregnant women by the health system.

Most of the participants in this study had challenges to perform the tests. Also, another study that investigated the factors affecting pregnant women's use of decision-making aids on prenatal screening in Iran concluded that some pregnant women were unable to participate in the decision-making process and stated that they would make decisions

based on the physician's prescription.²¹ This delegation of decision-making by women and their husbands seems to be due to a lack of information about FAST, and uncertainty about appropriateness of the test. Although one of the ethical principles regarding prenatal screening is women's autonomy while opting for tests,²² few healthcare providers make consistent efforts to facilitate patients' participation and even fewer tailor care to patient preferences. However, both shared decision-making interventions and longer consultations can improve this issue.²³

In this study, some mothers used the Internet to find out the answers to their questions about FASTs. Using the Internet relieved some mothers of worry, yet it caused some others to become highly stressed. It seems that lack of proper education and counseling causes the pregnant women to search the Internet and receive invalid information about prenatal tests.²⁴

Despite the stress, pregnancy can be a pleasant and exceptional experience for a woman. However, in our study screening tests have turned it into a bitter experience and awaiting the test results was excruciating. Also, a study on exploring strategies to cope with concern while waiting for diagnostic results after a high-risk prenatal screening result found that all couples experienced anxiety and distress as they waited to receive diagnostic test results.¹⁴ Women's stress and concern in early pregnancy were probably related to the lack of correct information about FAST and the screening nature of these tests. The results of these tests only show the numerical value of a risk and there is no definitive diagnosis.

According to the present research and other studies, the diagnosis of fetal abnormality is unexpected and distressing.^{25, 26} Similar to the present study, several qualitative studies demonstrated the importance of timely access to accurate information and supportive and non-judgmental care for women and their partners in the process of FAST to reduce the diagnosis shock.^{24, 27}

In this study, each woman had a different perspective toward aborting a fetus with a genetic defect. Women's views caused a challenge, and going through this stage could have numerous psychological consequences for pregnant mothers. The qualitative studies found that once Down syndrome was diagnosed, the majority of women tended to terminate the pregnancy, while a minority deliberately delayed the decision-making process; also, the participants who decided to terminate their pregnancies were afraid of negative judgment from others.^{24, 28} Part of this matter is due to differences in cultural, conventional, religious, and legal issues in different societies.

It is potentially challenging to decide on the results of a screening test indicating high-risk pregnancy. It is well established that women do not seek information about the complexities of biomedicine; instead, they have confidence in health professionals for obtaining information, guidance, and counseling in challenging circumstances.²⁹ Muslim Moroccan pregnant women in prenatal counseling for congenital anomaly tests preferred to discuss ethical issues and their relationship with their religious beliefs and values to facilitate informed choices about performing screening tests. They also preferred a counselor who was aware of the Islamic laws on anomaly tests and respected their beliefs as Muslims.¹¹ Muslims generally consult with family members or religious counselors before autonomous decision-making about abnormality screening.³⁰ The issuance of a fatwa permitting legal abortion in case of a definitive diagnosis of fetal chromosomal abnormalities in Iran prevented the mothers from feeling guilty; consequently, they chose to have an abortion with no worries.

Some pregnant women who tested positive for fetal abnormalities were hesitant to abort since it contradicted their maternal sense. This finding was in line with a qualitative study investigating the factors influencing the decision to terminate the pregnancy in Muslim

Arab women who had fetuses diagnosed with congenital anomalies. These women stated that they felt the fetal movements and that abortion of the fetus was indeed ignoring the motherly feeling.³¹ Most studies on Muslim women's decision to continue the pregnancy, despite the results of congenital anomalies tests, indicate that their decisions are influenced by religious, economic, social, cultural factors, and worldviews about the belief in destiny.^{31, 32}

In this study, the majority of the pregnant women, while emphasizing the importance of healthcare providers' role in reducing their concerns in the FASTs process, noted that their needs were not met by the medical staff. Other studies have also addressed this issue. According to Iranian women participating in a qualitative study, prenatal screening information is not integrated, and information provided by physicians and health centers is insufficient.²² Also, in Japanese women's experiences regarding prenatal testing, three main issues were identified after thematic analysis: "insufficient understanding of genetic risks", "inadequately informed choices about prenatal testing", and "need for more information from health professionals".³³ In a systematic review and meta-ethnographic synthesis of the expectant parent and health worker's experiences, researchers concluded that the provided information to pregnant women about obstetric ultrasound results was inadequate, often misleading, contradictory, and sometimes negative.³⁴ Moreover, in a study, several pregnant women reported that such information increased their stress.¹⁶ Therefore, pregnant women need to receive comprehensive and necessary information about the FAST from the medical staff.

In studies on prenatal care training, delivering bad news was one of the identified educational needs for health professionals.³⁵ In the present study, some mothers stated that the medical staff delivered bad news to them inappropriately. Previous studies have similarly reported that women who terminate their pregnancies due to fetal

abnormalities need compassionate and supportive care, yet they are being ignored by health professionals.³⁶ The exchange of useful information between healthcare providers and pregnant women is an essential factor in coping with disease and stress management.³⁷ The results of the present study regarding insufficient information transfer to pregnant women in the FASTs process were consistent with the results of other studies.^{38, 39}

According to the present study, the tests were too costly for the families, and it raised concerns about affording such expenses. The women said that they did not have the necessary financial and government support and raised this issue as an unmet need. Studies in the United States have likewise shown the effect of test costs, particularly among socioeconomically disadvantaged and minority populations, on access to and performing prenatal screening.⁴⁰

The strengths of this research were that the pregnant women were semi-structured interviewed at different stages of performing the tests; in this way, the roots of all pregnant women's concerns, both low-risk and high-risk, were determined. Also, the interview with experts in this research was one of the other strengths that can help correctly understand the concerns of some mothers.

There were some limitations in this study. The potential influence of high-income samples was one of them. In our study, pregnant women with high-income status were less likely to visit university medical centers and private clinics. Naturally, qualitative research is not targeted at representativeness, but it appears that the views of high-income pregnant women have not been fully explored. In addition, due to the nature of qualitative studies, our findings are not generalizable to other contexts.

CONCLUSION

FASTs are preventive in nature and have beneficial results for families and the community due to decreasing the number of children with

disabilities. Despite their usefulness, performing these tests is associated with mental anxiety, worry, and emotional turmoil for mothers. Concerns about making the right decision about whether or not to perform screening tests, awaiting the test results determined, shock at receiving undesirable test results, concerns about future pregnancies, fear of and remorse for abortion, and concerns about social stigma are among the pregnant women's concerns in the screening process. Because of these concerns, mothers and families have bitter recollections of pregnancy. On the other hand, since most women receive normal diagnostic results after performing high-risk screening tests, these concerns impose an unreasonable burden on their minds and souls. The inadequate support of the health system for mothers further adds to the difficulty of this process. The results of this study indicate the design of interventions to reduce the concerns of pregnant women in the process of performing FASTs.

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