

# Emotional and Cognitive Experiences of Pregnant Women Following Prenatal Diagnosis of Fetal Anomalies: A Qualitative Study in Iran

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**Received:** 1 July 2018    **Revised:** 2 September 2018    **Accepted:** 21 September 2018

### ABSTRACT

**Background:** Pregnant women are often ill-prepared for the health of their unborn child in the case of abnormal findings, and experience several difficulties following the detection of fetal anomalies. Therefore, this study was conducted to explore the emotional and cognitive experiences of pregnant women following prenatal diagnosis of fetal anomalies in Mashhad, Iran.

**Methods:** This qualitative conventional content analysis study was designed through two referral centers for fetal anomaly. The data were collected from April 2017 to January 2018 in Mashhad (Iran) through individual semi-structured in-depth interviews, from 25 pregnant women with a prenatal diagnosis of fetal anomalies.

**Results:** Four categories and 10 subcategories emerged. Category one, grief reactions during the time of diagnosis, contained two subcategories: shocked and panicked, and distressed and disbelieved. Category two, perinatal loss through a pregnancy termination, contained four subcategories: guilt and shame during pregnancy termination, loss of their expected child, suffering and emotional distress process, and unmet needs by health professionals. Category three, fears of recurrence in future pregnancies, had two subcategories: worried about inadequate prenatal care in the future pregnancies and worried about abnormal fetus in next pregnancies. Finally, Category four, a dilemma between hope and worries contained two subcategories: hope for normality and worried about future.

**Conclusion:** It is important to monitor emotional reactions of women following prenatal anomaly diagnosis. So, training clinicians and health-care professionals for proper response to grief reaction in post therapeutic abortion is essential.

**KEYWORDS:** Cognition, Emotional, Fetal anomaly, Pregnant women, Prenatal diagnosis

**Please cite this article as:** Irani M, Khadivzadeh T, Asghari Nekah SM, Ebrahimipour H, Tara F. Emotional and Cognitive Experiences of Pregnant Women Following Prenatal Diagnosis of Fetal Anomalies: A Qualitative Study in Iran. IJCBNM. 2019;7(1):22-31.

## INTRODUCTION

Prenatal screening for fetal anomalies is part of the prenatal care services recommended to all pregnant women and has been more commonly practiced in the last decade.<sup>1</sup> Nearly all (98%) pregnant women in Iran undergo an ultrasound screening at approximately the 18<sup>th</sup> week of gestation.<sup>2</sup> The main purpose of this ultrasound screening is to calculate the gestational age, identify multiple pregnancies, and check for fetal anomalies.<sup>3</sup>

Ultrasound and prenatal screening have led to an increase in the detection rate of fetal anomalies, and most pregnant women have optimistic expectations about this screening and rarely feel concerned about the potential results of their ultrasound; they may, therefore, be unprepared for the prenatal diagnosis of fetal anomalies<sup>4, 5</sup> and experience a stressful period, involving a number of psychological difficulties.<sup>4, 6</sup>

Following the detection of a fetal anomaly, women may be offered the option of terminating the pregnancy that needs many informational and ethical considerations.<sup>7-11</sup> According to the current Iranian laws, terminating pregnancy before the ensoulment is allowed when the life of the mother is in danger, or when the fetus has a serious anomaly. However, the mother needs approval from the judicial authorities for induced termination of the pregnancy. In accordance with clinical practice, approval is not given after soul creation (4 months and 10 days) because Iran is an Islamic country, the legal system of which based on holy Qur'an and Shi'a resources.<sup>12</sup>

For women who continue the pregnancy, evaluation of the emotional and cognitive reactions is essential, as routine screening means there that is a real potential for a large number of anomalies.<sup>13</sup> The results of a quantitative study in Iran showed the relationship between the prenatal screening tests with worry, state anxiety, and trait anxiety in pregnant women.<sup>14</sup> Previous quantitative studies have indicated that women who continue their pregnancy show high levels

of anxiety and depression during pregnancy.<sup>15</sup> When the pregnancy is terminated, women show depression, anxiety, grief, and post-traumatic stress disorder.<sup>17, 18</sup>

In addition, Iranian women are confronted with some problems that are specific to the Iranian context because termination of pregnancy is legally available neither in all cases of anomalies, nor after soul creation.<sup>11</sup> To the best of our knowledge, no study has examined the emotional and cognitive reaction on the experiences of pregnant women following prenatal diagnosis of fetal anomalies. Thus, a deep understanding of Iranian pregnant women who experience this crisis is essential.

A review of the studies conducted in Iran showed that a qualitative study on this subject was not found and all quantitative studies focused on the prevalence of congenital anomalies and their related factors.<sup>19</sup> Likewise, evaluating the quality of these studies has an insufficient reporting on the methods and results sections.<sup>20</sup> Consequently, qualitative studies are needed to gain deeper insights into the experiences of these women. Therefore, this study was conducted to explore the emotional and cognitive experiences of pregnant women following a prenatal diagnosis of fetal anomalies in Mashhad, Iran.

## MATERIALS AND METHODS

This study was conducted, using a qualitative method and a conventional content analysis approach at two tertiary referral centers for fetal anomaly at Mashhad University Hospitals, Omolbanin Hospital and Imam Reza Hospital in Mashhad, Iran. In this country, all pregnant women undergo ultrasound screening at approximately 18 weeks of gestation and a first-trimester screening for fetal aneuploidy at 10 to 13 weeks of gestation, using a combined test of nuchal translucency (NT), maternal serum-free  $\beta$ -human chorionic gonadotropin (free  $\beta$ -hCG), and pregnancy-associated plasma protein-A (PAPP-A). Suspected malformations are then referred to a perinatologist for specialist

consultation. Following the diagnosis made by the perinatologist, the pregnant woman is presented with the option of choosing to terminate her pregnancy before the gestational age of four months or later after getting the approval of the Legal Medicine Organization (LMO) of Iran as stated in the Therapeutic Abortion Act of Iran.<sup>21</sup> In 2003, LMO offices issued permissions for therapeutic abortion (TA) for 29 types of fetal anomalies and 22 maternal diseases.<sup>12</sup>

The sample studied consisted of Persian-speaking parents with prenatal diagnosis of fetal anomalies at the gestational week of 12-27. All the pregnant women with a suspected or definitive diagnosis of fetal anomaly as per the ultrasound or the combined test (NT, free  $\beta$ -hCG and PAPP-A) were eligible for participation. The exclusion criterion of the study was lack of willingness to continue participation in the study. Purposive maximum variation sampling was used to select the participants, and semi-structured interviews were held with 25 mothers aged 21-42 years in order to gain an insight into the perspectives and experiences of women with prenatal diagnosis of fetal anomalies.

During April 2017 and January 2018, 25 women with different fetal anomalies were invited to participate in this research. A total of 25 pregnant women accepted the invitation. The interviews were held at a time and place appropriate for the participants. Overall, 13 interviews were conducted at the hospital, five at participants' residence, four at the researcher's office at the university, and three at their workplace. The interview was arranged 2 to 23 weeks after the diagnosis (seven weeks post-diagnosis on average). The mean interview duration was 47min (range: 31-75 min). The interviews were recorded and transcribed verbatim by the first author.

The interview began with general questions, such as "*How do you experience your detection of fetal anomaly as a pregnant woman?*" and moved to more specific, detailed questions as the interview advanced, such as "*What was it like to be informed about the malformation?*", "*What was it like to*

*terminate the pregnancy?*", "*What was it like to continue the pregnancy?*", "*What were your thoughts and feelings at that moment?*", "*How would you describe your feelings and thoughts at the time?*". Data collection and analysis were performed concurrently by the main researcher (MI).

Data were analyzed using conventional content analysis based on the Graneheim and Lundman's approach, with MAXqda software (version, 2010).<sup>22</sup> After listening to the recorded interviews, the researcher transcribed and read them repeatedly in order to gain a deeper understanding of their data. In the next step, meaning units (words, sentences or paragraphs) that were related to each other through their content and context were identified.<sup>22</sup> The meaning units were condensed and given a descriptive code; then, they were organized into subcategories and categories. The categories were sets of different codes that shared the same content. Themes, then, formed from the categories as their underlying meaning and hidden content. In this study, eventually 156 codes, 10 Sub categories, and four categories emerged from the data analysis. (Table 1)

Guba and Lincoln's criteria were used to assure the trustworthiness and rigor of the data. The researcher had a long and close contact with the participants and spent a long time in the field searching for data and enough time to collect and analyze the data. Furthermore, the participants were selected from a range of gestational ages and different anomalies to access a variety of experiences. In addition, data collection was conducted until saturation was reached and no more categories emerged in the analysis. In the process of analysis, all researchers were engaged. Also, the findings were supplemented with suitable quotations to improve credibility. Interview guide, experts' comments, and revision by the participants and co-workers were used to improve the dependability. Finally, to ensure transferability of the results, clear descriptions were provided about the context,

**Table 1:** Example of meaning units, condensed meaning units, and subcategories

Meaning unit	Condensed meaning unit	Code	Subcategory	Category
“I think positive that well-being come when the baby is born“	To have positive thinking about coming birth	Hope for Healthy baby	Hope for normality	A dilemma; hope and worries
“In an ultrasound examination, they (sonographer) told my friend that her fetus had a problem with the head, but when the baby was born, he was healthy... It will happen to me, too”	Hope for wrong ultrasound examination	Hope for wrong result		
“I know this may not be a successful surgery for the heart defect and my boy is being cared for NICU and neonatal specialist ... but I can't help but worry about a heavy bill”	Worry about postoperative mortality and high costs of medical care	worried about the postnatal situation	Worried about future	

the process of participants' selection with data collection, and the process of analysis.

The present study was approved by the ethics committee of Mashhad University of Medical Sciences in Iran (Code of Ethics IR.MUMS.REC.1395.606) and performed according to the Helsinki Declaration.<sup>22</sup> The participants received both verbal and written information about the study. They submitted their informed consent after being ensured of the voluntary nature of participation, their right to withdraw from the study at any time, and the confidentiality of all their information. Each participant took an assumed name for privacy purposes.

## RESULTS

Tables 2 and 3 present the classification of fetal

anomalies and the mothers sociodemographic characteristics.

Seven women (five primigravida and two multigravida) chose to terminate their pregnancy. These women were having a fetus with one of the following anomalies: Anencephaly, hydrops, trisomy 21 and diaphragmatic hernia. The remaining women continued their pregnancy.

Four categories and 10 subcategories emerged from the data analysis about emotional and cognitive experiences of pregnant women following the prenatal diagnosis of fetal anomalies. The four categories themes included: i) Grief reactions during the time of diagnosis; ii) Perinatal loss through a pregnancy termination; iii) Fears of recurrence in future pregnancies; and iv) A dilemma: hope and worries (Table 4).

**Table 2:** The classification of the fetal anomalies

Type	Description of anomaly based on screening tests	Interviewed (N=25)
1	Lethal (e.g., anencephaly, renal agenesis, Trisomy 13 and 18)	2
2	Non-lethal with normal karyotype	
	A: likely physical handicap only (e.g. limb abnormality, skeletal deformity)	3
	B: likely physical and mental handicap(e.g. neural tube defect)	2
3	Non-lethal with abnormal karyotype (e.g. Trisomy 21, Turner's syndrome)	3
4	Structural abnormality with an option to repair	
	A: with a significant risk of mortality (e.g. diaphragmatic hernia, abdominal wall defects, cardiac defects)	2
	B: without significant risk of mortality (e.g. talipes, some renal anomalies)	3
5	Suspicious (structural anomalous findings with normal karyotype)	10

**Table 3:** The mothers sociodemographic characteristics

Description	Data
Age at diagnosis	25(21-46yr)
Education level	
- Primary school	7
- High school	9
-University	8
-Other	1
Parity	
-Primigravida	10
- Multigravida	15

#### Grief Reactions During the Time of Diagnosis

Grief reactions described as a painful tragedy had been a complete emotional shock. When they were told about the suspected anomaly at the initial ultrasound examination or screening test, the participants felt shocked, panicked, distressed and disbelieved.

*“I was shocked when I heard about the diagnosis. I never thought that such a thing would happen to me”* (mother 12 pregnancy continued)

The waiting time between the initial detection and the consultation with the perinatologist was described as very difficult, involving alterations to sleep patterns and many worries. When the perinatologist or gynecologist confirmed the anomaly, women considered the diagnosis as unreal and unfair and there was a feeling of ‘it couldn’t happen to me’.

*“When I heard [from the radiographer], I was so worried about my son. The coming days, I did not even close my eyes; it [the abnormality] circulated in my head the whole time and I could not wait to see my doctor”*(mother 7 pregnancy continued)

#### Perinatal Loss Through a Pregnancy Termination

Most of the participants with experience of pregnancy termination explained the condition as painful and emotionally stressful, involving difficult ethical and legal issues. The pregnancy termination was an emotionally stressful process due to the loss of a baby.

*“The moment of delivery was very painful; my husband and I cried a lot ... we lost everything that we had hoped for... you know ... we had planned for it (having a child)”*(mother1, pregnancy terminated)

Some women express negative experiences of illegal abortion and caregiver. One talked about pregnancy termination as a disaster, with stressed and unprofessional caregivers. Another described her vulnerable situation, and said that the professionals did not care about her needs.

*“I had to go to a traditional midwife to perform abortion, so that I could not have abortion in a hospital ... it was very difficult and painful ... I was unconscious and lost a lot of blood”*. (mother 8, pregnancy terminated)

After the abortion, these women experienced psychological consequences and the loss of their expected child. Moreover, they described feelings of guilt and shame over their decision, and thought how their situation would have been if the pregnancy had continued.

*“I’m quiet psychologically affected by pregnancy loss. I think most about my pregnancy when we had done abortion. It is that day in certain that remains in my mind”*. (mother10, pregnancy terminated)

**Table 4:** Main categories and subcategories

Main Categories	Sub-categories
Grief reactions during the time of diagnosis	<ul style="list-style-type: none"> <li>● Shocked and panicked</li> <li>● Distressed and disbelieved</li> </ul>
Perinatal loss through a pregnancy termination	<ul style="list-style-type: none"> <li>● Guilt and shame during pregnancy termination</li> <li>● Loss of their expected child</li> <li>● Suffering and emotional distress process</li> <li>● Unmet need by health professionals</li> </ul>
Fears of recurrence in future pregnancies	<ul style="list-style-type: none"> <li>● Worried about inadequate prenatal care in next pregnancies</li> <li>● Worried about abnormal fetus in next pregnancies</li> </ul>
A dilemma; hope and worries	<ul style="list-style-type: none"> <li>● Hope for normality</li> <li>● Worried about future</li> </ul>

### *Fears of Recurrence in Future Pregnancies*

Women who experienced a terminated pregnancy described worries about the risk of recurrence in future pregnancies. These worries were very difficult to cope with, as new pregnancies were consecutively longed for. As a way to cope with these worries, they express a need for more prenatal examinations such as genetic counseling in future pregnancies. Women who have experienced the prenatal detection of a fetal anomaly altered their opinions about ultrasound examinations, improving understanding of its medical purposes and influencing their feelings about more careful examinations in future pregnancies.

*“I am afraid that it happens again; for the next pregnancy, I should plan to visit a genetics specialist. I should do anything necessary for well-being of my baby, so I am afraid that it will happen again and I try to delay my next pregnancy”.* (mother10, pregnancy terminated)

### *A Dilemma; Hope and Worries*

Women who continued their pregnancy expressed feeling of hope about the future, but at the same time they were worried about the post-birth situation. In general, women carrying babies tried to keep a positive attitude towards the birth, as a way to cope with the situation. They were hopeful about the best possible outcome or return of normality. Some women hope that the problem for the health of their unborn child in the case of abnormal findings will be resolved or is minor anomaly.

*“Additional fingers defect is not so serious; certainly, it is, and I try to be calm about it because a postpartum outpatient operation resolves the problem”* (mother6, pregnancy continued)

Pregnant women also expressed many concerns about continuing their pregnancy and the postnatal situation. For example, these worries included the status of continuing pregnancy, status of the baby after birth, threats of planned surgical treatment, and handling the care of other children during

the period after birth. During the remainder of the pregnancy, when the couples searched to find more information about the detected defect, they could be re-traumatized due to the further bad news.

*“You know...we could not be really calm ... When my husband searched on the Internet about the detected defect , we became more worried and stressful because it might be a sign of other abnormalities like the heart and kidneys anomalies”* (mother24, pregnancy continued)

## **DISCUSSION**

According to the results of this study, pregnant women who confronted with prenatal diagnosis of fetal anomalies experienced emotional and cognitive reactions in four categories of grief reactions during the time of diagnosis; perinatal loss through a pregnancy termination; fears of recurrence in future pregnancies; and a dilemma of hope and worries. The participants who were faced with fetal anomaly experienced disbelief, distress, panic, and shock during the time of diagnosis. When their pregnancy was terminated, women experienced perinatal loss such as guilt and shame during pregnancy termination, loss of their expected child, suffering and emotional distress process, with unmet needs by health professionals, and fear of recurrence in future pregnancies in two subthemes of worry about inadequate prenatal care and abnormal fetus in the future pregnancies. When the pregnancy was continued, women described ambivalence between the sense of hope and worries about birth in two subthemes of hope for normality and concern about future.

In line with the results of this study, from the findings of previous studies showed that mothers and fathers faced with prenatal detection of fetal anomaly experienced a strong emotional shock and felt panicked and disoriented in association with detection.<sup>23, 24</sup> In this situation, previous studies showed a highly stressful period for parents who experienced prenatal diagnosis of congenital

malformations needed clinical attention.<sup>25, 26</sup> Midwives and other health-care professionals should pay attention to the fact that mothers are not always completely aware of the implications of routinely offered prenatal screening test and the choices they may finally face based on the results of that test.<sup>26</sup> It is essential for midwives to make sure women are wholly informed about their options about prenatal screening and testing. Furthermore, women need a basic understanding of the choices and decisions they may need to make if the results of those tests are abnormal. If midwives and other health-care professionals are unable to entirely disclose those issues, referral to an obstetric care provider or genetic counselor would be applicable.

There are some theories of grief and bereavement that have common stages. The 'grief wheel' theory explains the stages involved in grief that is not often a static process. However, other models, like the dual process model of coping with grief, offer a more flexible way to the understanding and management of grief. It explains how a bereaved individual copes with the experience of loss in everyday life and with other lifestyle changes occurring as a consequence of that loss.<sup>27</sup> Therefore, clinicians need to have the required knowledge and understanding about various factors that influence the grieving process. It empowers them to offer insightful support to women who grieve for their unborn child in the case of abnormal findings.

This study increases the understanding about the emotional reactions among women confronted with perinatal loss through a pregnancy termination and worries about the risk of recurrence in future pregnancies. Some studies stated that women suffered from psychological consequences after the pregnancy termination following a fetal anomaly.<sup>28-30</sup> In a previous study, during the whole process of pregnancy termination, the participants reported both physical and emotional pain and women with fetal anomalies focused more on the mental rather than physical pain, while women

with unintended pregnancy paid more attention to the physical pain.<sup>31</sup> Termination of pregnancy following a prenatal diagnosis of a fetal anomaly is an emotionally painful situation that requires considerate care, free of judgment.<sup>31</sup> Women undergoing termination of pregnancy need support from health professionals as caregivers have a major influence on satisfaction with experience of childbirth.<sup>32</sup> The care during anomaly detection or termination of pregnancy needs more attention, so the professionals are able to provide compassionate and supportive care on an individual basis in prenatal and postnatal period.<sup>33</sup> On the whole, studies emphasize the importance of parental support by multi-professional teams, particularly during pregnancy, when the emotional distress which women feel is combined with the reality of outcome, due to fetal anomaly, leading to empowerment of the parents.<sup>34, 35</sup>

Following the termination, women express worries about the risk of recurrence in future pregnancies, which needs to be addressed and supported with realistic prospect regarding their reproductive futures. Also, following the anomaly diagnosis, pregnant women move from sorrow to preparation as the pregnancy advances,<sup>36</sup> and they are worried about various issues.<sup>37</sup> Some studies showed that parents with fetus anomaly need continuous care and support during the rest of the pregnancy.<sup>23, 37</sup> Learning general communication skills can enable the clinicians to break bad news in a manner that is less uncomfortable for them and lead to less psychological distress for women and their families. Previous studies have shown that focused educational interventions improve the clinicians' ability and skills in delivering bad news.<sup>38-40</sup> Consequently, health providers should be aware of the anomaly diagnosis which may result in an increased risk of developing psychopathological warning sign for pregnant women when pregnancy is continued also, health providers must assess their needs for psychosocial support.

Qualitative investigation of the perceptions of women with fetal anomaly for the first time

in the cultural context of Iran was an innovative aspect of the current study. The strength of this study was that the participants included women with both experience of continuation and termination of pregnancy following a prenatal anomaly diagnosis and collection of data from women in different stages in life as well as different fetal diagnoses and different ages and educational levels. The study from the perspective of the mothers rather than a couple was one of the main limitations of this study.

### CONCLUSION

The findings of the study can provide the midwives and other health-care professionals with deeper recognition and understanding of these women in order to identify psychosocial needs. It is necessary to train the clinicians and health-care professionals for breaking bad news and proper response to grief reaction in post-therapeutic abortion. Hence, it is extremely important to monitor emotional reactions of women following a prenatal anomaly diagnosis throughout the period between the prenatal and postnatal stages.

### ACKNOWLEDGEMENT

The authors appreciate all the study participants for their contributions. The present article was extracted from the thesis written by Morvarid Irani and financially supported by Mashhad University of Medical Sciences with grant no. 951375.

**Conflict of Interest:** None declared.

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