

## Coping Strategies of Pregnant Women with Detected Fetal Anomalies in Iran: A Qualitative Study

### Abstract

**Background:** Progressing technology has increased the detection of fetal abnormalities in the pregnancy. Detection of fetal abnormalities during pregnancy can cause significant social, physical, psychological, and emotional stress. The aim of this study was to explore the coping strategies of Iranian pregnant women with detected fetal anomalies. **Materials and Methods:** This qualitative content analysis study was conducted on two referral centers for fetal anomaly. The data were collected from April 2017 to January 2018 in Mashhad (Iran) through individual, semistructured, in-depth interviews with 25 pregnant women with a prenatal diagnosis of fetal anomalies. Data were analyzed using conventional content analysis based on Graneheim and Lundman's approach. **Results:** As a result of data analysis, the four categories of seeking information, religiousness and spirituality, cognitive avoidance, and seeking social support, and 12 subcategories emerged. Seeking information consisted of the four subcategories of personal search, visiting different doctors, performing various diagnostic tests and sonography, and seeking peers' experiences. Religiousness and spirituality contained the three subcategories of praying, acceptance of destiny, and reliance on faith. Cognitive avoidance consisted of the two subcategories of avoiding negative information and avoiding situations that remind them of their problem. Seeking social support contained the three subcategories of getting support from family, getting support from friends, and getting support from others. **Conclusions:** The findings showed that pregnant women with detected fetal anomalies reported a variety of coping strategies. Therefore, it is important that healthcare providers encourage mothers to use strategies that are likely to be more effective.

**Keywords:** Congenital abnormalities, coping skills, pregnant women, prenatal, screening

### Introduction

Although neonatal mortality has been decreased by improvements in maternal and neonatal care in recent decades, congenital malformations are still the main cause of death, contributing to 21% of deaths.<sup>[1]</sup> progressing prenatal diagnostics and screening tests are increasingly detecting fetal abnormalities in the first and second trimesters of pregnancy.<sup>[2]</sup> In Iran, all pregnant women undergo ultrasound screening at approximately 18 weeks of gestation and a first-trimester screening for fetal aneuploidy at 10–13 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 a specialist consultation.

Based on the findings and the precision of the ultrasound and the combined test, some verbal information is offered on a variety of topics and amniocentesis might also be recommended. 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 4 months or later after getting the approval of the Legal Medicine Organization (LMO) of Iran as stated in the Therapeutic Abortion (TA) Act of Iran.<sup>[3]</sup> In 2003, LMO offices issued permissions for TA for 29 types of fetal anomalies and 22 maternal diseases.<sup>[3]</sup>

The process of detecting fetal abnormalities based on ultrasound and prenatal screening can cause significant social, physical, psychological, and emotional stress in pregnant women.<sup>[4-8]</sup> The difficulty of this process often requires coping strategies in order to adapt to the situation. Coping has

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been defined as a behavioral and cognitive effort to “manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person”.<sup>[9]</sup> Previous studies show that patients with an ineffective coping style illustrated inappropriate management of their disease. They reported that coping style affected mental health and health behaviors of the patients, which could have an effect on mortality and morbidity due to the disease.<sup>[10]</sup> When health providers know effective coping strategies, they can better help patients to cope with this difficult situation.

A review of the studies conducted on this subject show that the most common coping strategies that patients reported as effective in coping with their disease included comparing one’s situation with something worse, religiousness and spirituality, acceptance of the situation, seeking information, and optimism and positive thinking.<sup>[11-16]</sup> Previous studies have reported that receiving social support after detection of disease can reduce depression, psychosocial morbidity, and post-traumatic stress disorder symptoms.<sup>[17-19]</sup>

Among the studies conducted in Iran, a qualitative study with this subject was not found and all quantitative studies focused on the prevalence of congenital anomalies and their related factors.<sup>[20,21]</sup> In addition, progressing technology has increased the detection of fetal anomalies in pregnancy; thus, this can cause significant social, physical, psychological, and emotional stress in pregnant women. Therefore, identifying and training effective coping strategies can lead to improved maternal health and can help women choose coping strategies in accordance to the contextual factors.<sup>[19]</sup> Consequently, a qualitative study is needed to gain deeper insights into the experiences of these women. Hence, the present study was conducted to explore coping strategies of pregnant women after the detection of fetal anomalies.

## Materials and Methods

The present study was a content analysis qualitative study. The study was conducted at two tertiary referral centers for fetal anomaly at Omolbanin Hospital and Imam Reza Hospital affiliated to Mashhad University of Medical Sciences, Mashhad, Iran. The study population consisted of Persian-speaking pregnant women with prenatal diagnosis of fetal anomalies. All pregnant women with a suspected or definitive diagnosis of fetal anomaly as per ultrasound or combined test (NT, free  $\beta$ -hCG, and PAPP-A) were eligible for participation. The exclusion criteria of the study were lack of willingness to continue participation in the study.

The study data were collected from April 2017 to January 2018. Purposive maximum variation (such as age, education, type of anomaly, and gestational age at the time of diagnosis) sampling was used to select the participants. Individual semistructured interviews were performed with 25 pregnant women in order to gain an

insight into the perspectives and experiences of women with a prenatal diagnosis of fetal anomalies. The interviews were performed at a time and place that was appropriate for the participants. Overall, 13 interviews were conducted at the hospital, 5 at participants’ houses, 4 at the researcher’s office at the university, and 3 at participants’ workplaces. The mean interview duration was 47 minutes (range: 30–95 min).

For gathering the data, a questions interview guide was used to conduct in depth semistructured interviews. The instructions were obtained by reviewing literature, consulting experts, and conducting some pilot interviews. The interview began with general questions, such as “How did 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 kind of problems did you experience at the time of diagnosis and the following weeks? and “How did you deal with these problems?” Probe question, such as “Can you tell me more, please?” were asked to discover further data. Data collection was carried out until data saturation was achieved.

Data were analyzed through conventional content analysis based on Graneheim and Lundman’s approach, with MAXQDA software (version 10, VERBI Software, Berlin, Germany). In this method, codes, subcategories, and categories are extracted from raw data directly through deductive reasoning.<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) were identified.<sup>[21]</sup> The meaning units were condensed and given a descriptive code, and were then organized into subcategories and categories. The categories were sets of different codes that shared the same content.

Guba and Lincoln’s criteria (including credibility, transferability, confirmability, and dependability) were used to guarantee the trustworthiness and rigor of the data. For credibility, the researcher had long and close contact with the participants and spent 3 years in the field searching for data and enough time to collect and analyze the data. For peer checking and reviewing, four participants were asked to approve the precision of the typed texts. Moreover, the research team members coded some of the interviews separately and evaluated their similarities, and in cases of conflicts, they reached consensus after consulting sessions. For transferability, all the procedures must completely be explained. Therefore, we tried to present the participants’ quotes as they were said. In addition, the demographic characteristics of the participants and studied field are demonstrated in detail, so that the reader could decide about using the results. Confirmability was evaluated through controlling the data by outside observers familiar with qualitative studies

and reproductive health, meaning that some parts of the interviews with their codes and extracted subcategories and categories were evaluated and approved by two observers familiar with qualitative studies. Dependability of the stages of the study was carefully recorded and reported.

### Ethical considerations

The present study was approved by the Ethics Committee of Mashhad University of Medical Sciences (Code of Ethics: IR.MUMS.REC.1395.606) and performed according to the Helsinki Declaration.<sup>[21]</sup> The participants received both verbal and written information about the study. They submitted their informed consent after being assured 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

Table 1 presents the demographic characteristics of participants. The interview was arranged 2–23 weeks after the diagnosis (7 weeks' postdiagnosis on average). Among the participants, seven women chose to terminate their pregnancy. These women had a fetus with one of the following anomalies: anencephaly, hydrops, trisomy 21, and diaphragmatic hernia. The remaining women continued their pregnancy.

In this study, eventually, 186 codes, 12 subcategories, and 4 categories emerged from the data analysis. The four categories included seeking information, religiousness and spirituality, cognitive avoidance, and seeking social support [Table 2].

### Seeking information

Most of the women receiving uncertain screening test results believed that, if they search, visit a different doctor, do another sonography, seek peers' experiences, and performed personal research as much as necessary, they can ultimately find definitive information that can help them make an informed decision about their pregnancy. The seeking information category contained the four subcategories of personal research, visiting different doctors, performing various diagnostic tests and sonography, and seeking peers' experiences.

### Personal research

Some mothers with abnormal findings in their ultrasound screening or first-trimester screening tests try to find more information by searching on the internet and reading books. One woman, who was told at 28 weeks that her fetus had polydactyly of the foot and hands, described her search for additional information: *"I started getting really worried that my baby had extra fingers. I searched on the internet and found more information such as association with other anomalies."* (Mother 6).

### Visiting different doctors

Some mothers were confused regarding whether their fetal problems were dangerous because they received conflicting information from midwives and other health providers. These women tried to find high-skilled specialists and visited to them for confirmation of diagnosis. *"When the midwife saw my scan result, she said that the baby's kidneys had serious problems. I was very worried, but when I went to my doctor, she said: "It is not an important problem, it does not matter". I did not know exactly which*

**Table 1: The classification of fetal anomalies and the participants' sociodemographic characteristics**

Description of anomaly based on screening tests	Interviewed (n=25)
Lethal (e.g., anencephaly, renal agenesis, and trisomy 13 and 18)	2
Nonlethal with normal karyotype	
A: likely a physical disability only (e.g., limb abnormality and skeletal deformity)	3
B: likely physical and mental disability (e.g., neural tube defect)	2
Nonlethal with abnormal karyotype (e.g., trisomy 21, and Turner's syndrome)	3
Structural abnormality with an option to repair	2
A: with a significant risk of mortality (e.g., diaphragmatic hernia, abdominal wall defects, and cardiac defects)	3
B: without significant risk of mortality (e.g., talipes, and some renal anomalies)	
Suspicious (structural anomalous findings with normal karyotype)	10
Description of participants' sociodemographic characteristics	Data
Maternal age at diagnosis (year)	26 (21-46)
Education level	
Primary school	7
High school	9
University	8
Other	1
Parity	
Primigravida	10
Multigravida	15

**Table 2: Main categories and subcategories of diagnostic and coping strategies regarding fetal anomalies**

Main categories	Subcategories	Code
Seeking information	Personal search	Searching on the internet Reading books
	Visiting different doctors	Going to a high-skilled gynecologist Visiting a cardiologist
	Performing various diagnostic tests and sonography	Doing further diagnostic tests Doing further sonography
	Seeking peers' experiences	Forming their next step based on peer experiences Following peer experiences on the internet
Religiousness and spirituality	Praying	Reciting the Qur'an Appealing to Imams and prophets
	Acceptance of destiny	Belief in divine providence Destiny is ordained by God.
	Reliance on faith	Belief in God's power Faith in divine power Trust in God
Cognitive avoidance	Avoiding negative information	Reluctant to receive negative information Avoid doing more tests Avoid performing definitive tests
	Avoiding situation that remind them of their problem	Evading questions regarding this issue Avoid going to layette ceremonies
Seeking social support	Getting support from family	Communicating with their mother Getting verbal support from their husband
	Getting support from friends	Calling friends Getting tips from friends to visit a skilled doctor
	Getting support from others	Talking to healthcare providers Trying to find mothers with similar experiences

one to accept. So, I am looking for good doctors. I will go to another physician so he can really tell me what the baby's problem is." (Mother 20).

### Performing various diagnostic tests and sonography

Accurate diagnosis and careful monitoring of fetal health are essential to identify fetal abnormalities for most mothers and specialists. The majority of participants did further diagnostic tests and sonography because they did not trust the results. One woman, who was received at 23 weeks and her fetus had atrial septal defect and ventricular septal defect, described her experience for additional sonography: "I read the ultrasound report. There was a problem with my baby's heart. I could not believe this happened to me and I had an ultrasound again and again., but all ultrasounds reported a heart problem" (Mother 7).

### Seeking peer experiences

Some women looked for people who were diagnosed with the same problems in the clinic waiting room or in the virtual environment. They formed their next step based on their experiences. One woman said that they visited a radiologist with the recommendation of one of the mothers with a similar anomaly diagnosis who was very satisfied with the services of this specialist. "I was looking for people with the same experience as me on the Internet; one of them introduced me to a really good radiologist..." (Mother 9).

### Religiousness and spirituality

Belief in God, divine providence, God's power in helping people, and reliance on God's power through trust in God, and appealing to imams and prophets helped mothers to show a more adaptive reaction. The results of the present study indicate that the belief in God had roots in the mothers' mind, so that they understood it as divine providence and an opportunity to be examined in difficulties even on the first days of its recognition. Religiousness and spirituality contained the three subcategories of praying, acceptance of destiny, and reliance on faith.

#### Praying

According to the mother of a fetus with possible diagnosis of Down syndrome, the reliance on God's power through prayer, vowing, naming children after Imams and prophets, reciting the Qur'an, and praying and appealing to Imams and prophets were mothers' spiritual practices. "I went to the shrine and prayed there. I vowed that I would name my child Reza if I had a son and Fatemeh if I had a daughter" (Mother 15).

#### Acceptance of destiny

The belief in divine providence is another strategy of the spiritual dimension. According to this belief, each person has a destiny which is ordained by God and the destiny in facing problems is in hands of God. This view was

repeatedly stated by mothers and prevented them from falling into despair. *"I told my husband that everything was handled by God, and our destiny was surely like that too, so you should not complain about our destiny"* (Mother 21).

*"It is our destiny, and we cannot do anything about it. God wanted this for us, and we should accept God's intention"* (Mother 16).

*"Everything happens according to God's will, so it is not necessary to change my doctors"* (Mother 5).

### Reliance on faith

Some mothers also believed in God's power in helping humans and stated that if God gave them a problem, he also gave them the ability to tolerate it. They followed the process of diagnosis and treatment through faith in divine power. *"I believe in God and know that God grants the power to tolerate problems. I go on with divine assistance and put my hope in God to see what happens then"* (Mother 11).

### Cognitive avoidance

Avoidance and distance from the source of tension were other maternal strategies of dealing with stress. Some mothers tended to avoid receiving negative information and situations that caused them to remember fetal anomalies. Cognitive avoidance contained the two subcategories of avoiding negative information and avoiding situations that remind them of their problem.

### Avoiding negative information

Some mothers were reluctant to receive negative information about a particular type of anomaly, and this allowed them not to think about possible negative consequences. *"I did not like to hear or read about bad things, and I told myself not to forebode. Let me think it was a mistake and my baby is healthy"* (Mother 5).

### Avoiding situations that remind them of their problem

According to some mothers' experiences, they tried to forget their problems by avoiding situations like going to friends and acquaintances' layette ceremonies or evading their questions about their current pregnancy, childbirth, and pregnancy. After the diagnosis, a mother said: *"I did not like to go anywhere that reminded me of my problem, so I did not go to the layette ceremony of my husband's nephew"* (Mother 17).

### Seeking social support

The mothers believed that social support declined their level of stress, made them feel relaxed and able to tolerate their problems more easily, and improved their psychological disorders. Seeking social support contained the three subcategories of getting support from family, getting support from friends, and getting support from others in the same situation.

### Getting support from family

Family support was an important and necessary resource for maintaining experienced calmness and adaption. One mother expressed her experiences in this regard as follows: *"I only talked to my husband and mother. They always sympathize with me and say that it is not a big problem. My mother always accompanies me to see the doctor and tells me not to be sad; if you abort the baby, you can again have a child"* (Mother 2).

### Getting support from friends

A number of participants also stated that communicating with and speaking to friends relieved their stress. *"One of my friends with a midwifery degree helped me during this period. She would come to my house and say promising words and tell me that the tumor in the child's head is not a big problem and it will disappear soon. She told me that her professor said that this problem will be resolved in the final months of pregnancy"* (Mother 18).

### Getting support from others

Some women had less concern when they met and talked with healthcare providers or other mothers who were diagnosed with anomalies. *"I consulted with several people in the clinic with an experience of amniocentesis before me and they told me not to worry, that they had done it and their results were good. I feel relaxed when I see them"* (Mother 15).

## Discussion

The present study described the coping strategies of pregnant women following the prenatal diagnosis of fetal anomalies. These coping strategies included seeking information, religiousness and spirituality, cognitive avoidance, and seeking social support.

According to the results, seeking information through personal search, visiting different doctors, performing various diagnostic tests and sonography, and seeking peers' experiences were among the most important strategies that were applied by mothers diagnosed with fetal anomalies. Seeking information was used to ensure the correct diagnosis of anomalies. Mothers referred to multiple doctors based on the probability that the diagnosis might be wrong or doctors might be unskilful. Other qualitative studies also indicated that people sought a medical diagnosis by seeking information to better understand and be assured of the diagnosis.<sup>[23,24]</sup>

Religion and spirituality were the most important coping strategies of mothers in the present study. Religion was an effective way of coping with problems due to its important impact on people's lives. Thus, QOL (Quality of Life) and coping strategies can be promoted by improving the individual religious attitude. Allport's view can be referred to in explaining the present findings. Allport believed

that religion and spirituality were a comprehensive issue with organized and internal principles and that religious people honestly believed in their religious teachings. He also believed that religion is the only thing that can improve the individuals' mental health.<sup>[25]</sup> To have a meaning and purpose in life, a sense of belonging to a sublime source, hope to have God's help in difficult and stressful life conditions, and taking advantage of spiritual support are all methods by which religious people can be less damaged while facing stressful life events.<sup>[26]</sup> Using spiritual coping strategies may play a vital role in the coping process in pregnant women with fetal abnormalities. Therefore, religious counseling by midwives or healthcare professionals can increase mothers' mental health and even help them cope with conditions like fetal death and pregnancy loss.

Avoidance of situations which remind them of their issue and receiving negative information were among the strategies applied by mothers in the present study and could reduce the amount of threatening risks for fetal health during the pregnancy. Avoidance was also a common strategy among people diagnosed with cancer and leukemia,<sup>[9,27]</sup> and researchers believed that the avoidance strategy moderated patients' feelings and immediately led to positive results after stressful events, but it did not lead to good results in the long term.<sup>[27]</sup> Considering that avoidance strategy has not been effective in the long term, clinicians and healthcare professionals should be trained to transfer bad news effectively, so that mothers can follow the diagnosis and treatment process in order to have a healthy baby.

According to the findings of the present study, mothers received support from different sources and they received the most support from their family. Attention and support of the family caused hope and assurance in mothers and they felt that they were not alone in facing the problems of anomalies. Among family members, women considered their husbands as important supporters. The results of other studies also indicated that husbands were the most important source of support for women during illnesses.<sup>[28]</sup> The presence of the spouse increased the sense of connection with others, could affect individual health and performance, and increased satisfaction during the diagnosis stage.<sup>[29]</sup> The positive support of peers and doctors also created a sense of hope and strengthened women's spirits. Other studies also indicated the positive impact of social support on adapting to illnesses.<sup>[30]</sup> Therefore, it is necessary for training clinicians and healthcare professionals to support mothers during prenatal care in order for them to adapt effectively to the diagnosis of fetal anomalies. To gain a deeper insight into the subject under study, future studies are recommended to address coping strategies during the pregnancy and after delivery in different cultures.

The main limitation of this study was that participants were heterogeneous and included both pregnant women with confirmed diagnoses and suspected diagnoses which may account for some of the differences in coping strategies. Data were not longitudinal; consequently, no inferences can be made regarding behavioral changes over time.

## Conclusion

The findings showed that pregnant women with detected fetal anomalies reported a variety of coping strategies that included seeking information, religiousness and spirituality, cognitive avoidance, and seeking social support. Therefore, it is important that healthcare providers encourage mothers to use strategies that are likely to be more effective. Future studies should also investigate whether clinicians' attention toward effective coping could assist mothers in coping with detected fetal anomalies.

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## Conflicts of interest

Nothing to declare.

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