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Informational needs of pregnant women following the prenatal diagnosis of fetal anomalies: A qualitative study in Iran

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Abstract:

INTRODUCTION: An appropriate exchange of information between the health-care provider and the family is an important component of coping with stress following the prenatal diagnosis of fetal anomalies. Therefore, this study was conducted to explore the informational needs of pregnant women following a prenatal diagnosis of fetal anomalies in Mashhad, Iran.

SUBJECTS AND 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: Three categories and nine subcategories emerged. Category 1, information needed for clarifying the diagnosed anomaly and making a decision, containing four subcategories: The need to know the reasons of doing more diagnostic tests; The need to know the facts regarding the anomaly and its cause; The need for more information to gain control over the situation; and The need to know about legal permission for therapeutic abortion. Category 2, Information needed for preparing to the future, containing three subcategories: Practical and economic issues; The delivery and postnatal situation; and Future mortality and morbidity of especial anomaly. Category 3, the adequacy of the information provided, containing two subcategories: Information overload and Inadequate information.

CONCLUSIONS: Pregnant women receiving a prenatal diagnosis of fetal anomaly have a variety of information needs that are not adequately met by the health-care providers. Further research is required for finding a means to meeting this information need.

Keywords:

Congenital abnormalities, pregnant women, prenatal diagnosis, qualitative research, informational needs

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Introduction

In Iran, 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.[1] Nearly all (98%) pregnant women in Iran undergo an ultrasound screening at approximately the 18th week of gestation.[2,3] The main purpose of this ultrasound screening is to calculate gestational age, identify multiple pregnancies, and check for fetal anomalies.[4] 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 a prenatal diagnosis of fetal anomalies.[5-7] Ultrasound and prenatal screening have led to an

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increase in the detection rate of fetal anomalies. In cases where severe structural defects (e.g., anencephaly) and chromosomal abnormalities are detected, women might decide to terminate their pregnancy.[8]

There is a limited time between the diagnosis of an anomaly, that is, approximately 18–20th week of gestation and the making of a decision about the future of the pregnancy.[8] According to current Iranian laws, terminating a pregnancy before ensoulment is legal in cases where the mother's life is threatened or when the fetus has a serious anomaly. Nonetheless, the mother needs approval from the judicial authority for the induced termination of the pregnancy. In clinical practice, such approval is not given once the fetus gains a soul, that is, at 4 months and 10 days of gestation.[8]

The process of making an informed decision about the future of a pregnancy is associated with several difficulties for women and might entail psychological distress,[9,10] acute grief reactions,[11] and ethical dilemmas.[12] In addition, Iranians women are confronted with some problems that are specific to the Iranian context because termination of pregnancy is neither legally available in all cases of anomalies and nor after soul creation.[8]

Meeting mothers' information needs are essential for helping cope with the situation following the prenatal diagnosis of fetal anomalies,[13] and studies have shown that the partners of women receiving a diagnosis of fetal anomalies also have certain information needs.[14] To the best of our knowledge, no study has examined information need on the experiences of pregnant women following a prenatal diagnosis of fetal anomalies. Thus, a deep understanding of Iranian pregnant women who experience this crisis is essential.

Based on the conducted studies 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.[15] Likewise, evaluating the quality of these studies has an insufficient reporting on the methods and results parts.[16] In addition, mothers' information need is different accordance to the contextual factors. Consequently, qualitative study is needed to gain deeper insights into the experiences of these women.

As no Iranian study was found on the above subject, and as researchers of this study are of extensive experience in prenatal caring for women following the prenatal diagnosis of fetal anomalies, they are familiar with these mothers' great needs for proper support. Thus, it is necessary to identify the above needs so that appropriate support programs at prenatal care for reducing these mothers' problems can be designed. This qualitative study was conducted to explore information needs of pregnant women following the prenatal diagnosis of fetal anomalies in Mashhad, Iran, so that their information needs are deeply understood, and proper support is provided for reducing their problem and enabling them to cope.

Subjects and Methods

Design

This study was conducted using a qualitative design, which helps gain an insight into specific phenomena[17] and allows researchers to explore participants' experiences and information needs following the prenatal diagnosis of fetal anomalies.

Context

The study was conducted at two tertiary referral centers for fetal anomaly at Mashhad University Hospital, 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 10–13 weeks of gestation using a combined test of nuchal translucency (NT), maternal serum free β-human chorionic gonadotropin, and pregnancy-associated plasma protein-A (PAPP-A). Suspected malformations are then referred to a perinatologist for specialist consultation. Based on the findings and the precision of the ultrasound and the combined test, some verbal information are offered on a variety of topics and amniocentesis might be recommended too. 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.[16] In 2005, LMO offices issued permissions for TA for severe fetal anomalies and life-threatening maternal diseases.[18]

Participants

The sample studied consisted of Persian-speaking pregnant women 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 HCG, and PAPP-A) were eligible for participation. Purposive maximum variation sampling was used to select the participants, and semi-structured interviews were held with 25 mothers aged 21–42 years to gain an insight into the perspectives and experiences of women with a prenatal diagnosis of fetal anomalies. A total of 15 participants had confirmed diagnoses and 10 had suspected diagnoses.

Sampling and data collection

Between April 2017 and January 2018, 25 prospective pregnant women with different fetal anomalies were invited to participate in this research. A total of 25 mothers accepted the invitation. The members of the research team had specialized in qualitative research and had 5 years of experience as a midwife in prenatal care centers. The interviews were held at a time and place appropriate for the participants. Overall, 13 interviews were conducted at the hospital, five at participants' houses, four at the researcher's office at the university and three at his/her workplace. The interview was arranged 2 to 23 weeks after the diagnosis (7-week postdiagnosis on average). The mean interview duration was 52 min among those who continued the pregnancy (range: 30–95 min) and 42 min among those who terminated the pregnancy (range: 32–65 min). The interviews were recorded and transcribed verbatim by the first author. In the sessions, the parents were first asked about their age, number of children, education, and diagnosis being definitive or suspected and associated anomalies. The exact type of anomaly and gestational age at the time of diagnosis were collected from their medical records. The parents were asked to focus on what information they needed when they learned of the diagnosis.

Data collection

Women were asked to focus on what information they experienced that they needed when they received the diagnosis. The key questions were: (1) What was your experience when the information was provided about anomalies diagnosis? (2) How did you find out offered information from the health-care provider? (3) What kind of information did you think you would need at the time of diagnosis and the following weeks? 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 analysis

Data collection and analysis were performed concurrently by the principal researcher (MI). Data were analyzed using the inductive, qualitative content analysis based on the Graneheim and Lundman's approach, which allows researchers to examine individual experiences.[19] 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.[19] 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. Themes then formed from the categories as their underlying meaning and hidden content. This analysis repeatedly moved back and forth and ongoing discussions were held with the responsible author (TKH) until consensus was reached.

Trustworthiness

For assessing the rigor and trustworthiness, 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, participants were selected from a range of gestational age and different anomalies to access a variety of experiences. In addition, data collection was conducted until saturation was gained and no more categories emerged in the analysis. In the process of analysis, all researchers were engaged. This method allowed researchers to make sure that the category covered all data and thus decreased the risk of data exclusion as a result of misidentification. Furthermore, the findings were supplemented with suitable quotations to improve credibility. Interview guide, experts' comments, and revision by the participants and coworkers used to improve dependability. Finally, to ensure transferability of the results, clear descriptions were tendered about the context, the process of participants' selection with data collection and the process of analysis.

Ethical considerations

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.[19] 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 1 and 2 present the classification of fetal anomalies and the women's' sociodemographic characteristics.

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.

Three categories and nine subcategories emerged. The three categories included: (i) Information needed for clarifying the diagnosed anomaly and making a decision; (ii) Information needed for preparing to the future; and (iii) The adequacy of the information provided [Table 3].

Table 1: The classification of the fetal anomalies

Type	Description of anomaly in based on screening teats	Interviewed (*n*=25)
1	Lethal (e.g., anencephaly, renal agenesis, trisomy 13 and 18)	2
2	Nonlethal 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	Nonlethal 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)	2
	B: without significant risk of mortality (e.g., talipes, some renal anomalies)	3
5	Suspicious (structural anomalous findings with normal karyotype)	10

Table 2: The participants' sociodemographic characteristics

Description	Data
Age at diagnosis	26 (21-46 year)
Education level	
Primary school	7
High school	9
University	8
Other	1
Parity	
Primigravida	10
Multigravida	15

Table 3: The emerged categories and subcategories

Main categories	Subcategories
1. Information needed for clarifying the diagnosed anomaly and making a decision	1-2: The need to know the reasons of doing more diagnostic tests
	1-1: The need to know the facts regarding the anomaly and its cause
	1-3: The need for more information to gain control over the situation
	1-4: The need to know about legal permission for therapeutic abortion
2. Information needed for preparing to the future	2-1: Practical and economic issues
	2-2: The delivery and postnatal situation
	2-3: Future mortality and morbidity of especial anomaly
3. The adequacy of the information provided	3-1: Information overload
	3-2: Inadequate information

Category 1: Information needed for clarifying the diagnosed anomaly and making a decision

Parents needed to understand their situation encountered in order to making a decision about whether or not to continue or terminate the pregnancy.

The category consists of four categories: "The need to know the reasons of doing more diagnostic tests," "The need to know the facts regarding the anomaly and its cause," "The need for more information to gain control over the situation," and "The need to know about legal permission for therapeutic abortion."

The need to know the reasons of doing more diagnostic tests

When the prenatal screening gave a suspected diagnosis of fetal anomalies, the parents needed to have some information about why they had to do more diagnostic test and What problems did the previous tests have. Because they have to spent a lot of money on the testing "…when the doctor said that you should undergo amniocentesis and get more examinations done based on the scan results, I asked to get more information about potential diagnoses, but she didn't give me any of that information and didn't tell me why exactly I had to take those tests…you know. The cost of testing is too high (Mother 2).

The need to know the facts regarding the anomaly and its cause

Some parents stated that they needed to know more about whether the scanning and screening test results could be false. Detailed information about the specific abnormality facilitated understanding. Drawings of the body system combined with short information about function of the system, similarity what was wrong about that system helped the parents to get a picture of the anomaly and how slight or severe the anomaly was.

"…I don't really know how the heart system works in the body. So I ask my doctor explain me more about the heart system. He draws a heart and says short about its function …so then I understood how the heart was worked and then I also understood what it was wrong about my baby in scanning report…" (Mother 25)

A number of mothers wanted to know the reason for the occurrence of abnormalities.

"…I didn't understand why this happened… My husband and I are not related by blood and my older son is healthy…"(Mother 16).

The need for more information to gain control over the situation

A few women stated that they needed more information to gain control over their new situation and to be able to cope with the stress of the possibility of having a fetus with anomalies.

"…When the doctor said that my boy had something worrying in his head, I felt terrible. I didn't understand what was happening. Everything seemed dark at first. But later, I realized that it wasn't so important and the thing went away after 8 months. I think that maybe my

doctor should've said something about how to deal with that problem and how to follow-up with the next examinations" (Mother 9).

The need to know about legal permission for therapeutic abortion

The mothers needed to learn quickly of what was wrong with their fetus. Understanding the anomaly was crucial to their making a decision about whether or not to continue or terminate the pregnancy; because they have time limitation for abortion. One woman said that they had not had enough time for proceeding with an abortion.

"First, they said that we should undergo amniocentesis and then do this and that. We got the results 4 weeks later. I had thought that, after getting the results, we could go on with the abortion. But then the midwife said that it was too late for getting permission for abortion because our baby was 24 weeks old and so over the legal age of 4 months" (Mother 3).

Category 2: Information needed for preparing to the future

The parents had several thoughts regarding the future such as mortality and morbidity and economic issues, as well as the future quality of life for the child with abnormalities. The Category consists of three categories: "Practical and economic issues," "The delivery and postnatal situation", and "Future mortality and morbidity of especial anomaly."

Practical and economic issues

The practical and economic issues occurring after the suspected diagnosis of fetal anomalies comprised a big concern for the mothers. Their information needs in this area included the steps that have to be taken for getting a definitive diagnosis, the steps for a successful surgery if there are specialist surgeons available to perform corrective operations in the hospital and the economic burden of their child's disease.

"I expected the midwife to explain the practical issue. Like, when can we perform surgery for correcting the heart defect? Which hospital has a good specialist for heart surgery? How successful of an operation is it or how much does it cost?" (Mother 25).

The delivery and postnatal situation

The concerns associated with childbirth and delivery and a stay at children's hospital in the early days was sometimes a distress. The participating women wanted to know more about childbirth; for instance, which type of delivery was the best for them.

"I liked to know about my delivery. Where should I go for delivery? Is vaginal delivery better or cesarean section?" (Mother 13).

The mothers wanted a guarantee that any medical information relevant to the child's health was available to the skilled health providers that helped them through the process of delivery; as such arrangement reinforced their sense of safety. They valued getting detailed information about the series of events they had to expect after the delivery. This information included whether the parents would be allowed to hold the baby right after the delivery or if he/she had to be taken directly to the Intensive Care Unit and also if it would be possible to breastfeed.

"…Will skilled nurses or doctors be available? Where will the baby go? Will it be possible for me to be by his side?" (Mother 16).

Future mortality and morbidity of especial anomaly

Several pregnant women said that they wanted to know more about the prognosis of the disease and the future development of the condition and its potential complications (including long-term complications). This information would allow them to make the necessary life adjustments and prepare for the future and discuss health management strategies for supportive treatment, such as in the case of cleft lip and polydactyly.

"When the doctor talked to me about potential future problems, I had already prepared myself for the situation" (Mother 3).

Category 3: The adequacy of the information provided

The parents experienced both excess and scarce information regarding prenatal diagnosis anomalies. The category consists of two categories: "Information overload" and "Inadequate information."

Information overload

Immediately after the prenatal diagnosis of fetal anomalies, some women experienced difficulties understanding the information conveyed to them due to different reasons, such as the use of medical terminology and the large amounts of information. They felt overloaded with some types of information. An acute stress reaction made it even more difficult to comprehend and understand all the information conveyed by the health provides.

"I can't understand a lot of what my doctor said about something being wrong with the kidney I think. I was so distressed and worried and she was telling me lots of things" (Mother 3).

Inadequate information

Most of the mothers in this study felt that the information delivered to them was insufficient. There is certain information that is mandatory for the mothers to learn if they are to properly manage the care provided to

their child; for example, the process of performing amniocentesis and getting permission for TA. Nevertheless, the interviewed mothers were unhappy with the amount of information they received on these crucial subjects.

"They just told me to get the amniocentesis, and so I went to a private doctor's office and did as told. But afterward, I couldn't move my body to get me home. I had severe pain in my stomach. You know… I was there alone and waiting for a very long time and my doctor hadn't said anything about how an amniocentesis would be like and I had thought that it would be just like a regular blood test." (Mother 4).

The mothers felt that they needed further explanations about what exactly was wrong with their fetus (i.e., the diagnosis), the management of the condition (i.e., the mechanism of occurrence of the anomaly and the examinations needed), and the expected outcomes of its treatment.

The clinic was very crowded and the number of patients was many. The doctor told me that your baby has a problem, but didn't explain how there was a risk for it to be Turner's syndrome and what Turner's syndrome was like. She didn't have enough time to give me that information!" (Mother 2).

Discussion

The present research explored these needs and found that women have a variety of information needs, including the need for information about the prognosis and daily management of the condition and the process of making a decision about the future of the pregnancy**.** The exchange of useful information between the health-care provider and the pregnant women is an important component of coping with disease and stress management.[20] Lalor *et al*. (2008) found similar results and showed that individuals seek information in order to rebuild their sense of control and confidence about the future.[13]

The participants who were initially faced with a suspected anomaly described their unmet information needs to be mostly concerned with the defects in the process of medical diagnosis. They described the information conveyed to them as insufficient, whether from the obstetricians or the midwives. This finding is consistent with the results of qualitative studies conducted by Carlsson *et al*.(2015 and 2016) and Bratt *et al*. (2015), which explored the information needs of parents, following the prenatal diagnosis of congenital heart disease and showed that the information needed for them to decide about terminating their pregnancy is not adequately met by the health-care providers or the internet.[21-23]

Nonetheless, little is known regarding the actual information needs of pregnant women following the prenatal diagnosis of fetal anomalies. The insufficient amount of information conveyed to the women about the process of diagnosing their fetus' anomaly and the process of terminating the pregnancy meant that they had many unanswered questions and were not prepared for the future.

Health-care providers are responsible for addressing information needs of pregnant women with regard to the health of their future child. Women have different information needs that are affected by different personal issues and individual concerns. This individuality makes it difficult to properly address their information needs and convey knowledge without raising their stress and anxiety.[24] Information needs are often recognized as an important component of coping with stress following the prenatal diagnosis of fetal anomalies.[13]

The main limitation of this study is that the data were only collected from the perspective of the mothers and their reliability might thus be compromised. To gain a deeper insight into the subject under study, future studies are recommended to address the perspective of both the parents and the health-care providers in order to compare the assumptions of health professionals and midwives with those of the patients.

Conclusions

Pregnant women with a prenatal diagnosis of fetal anomalies have a variety of information needs which are not adequately met by the health-care providers. More research is required on this subject in order to further explore the parents' information needs.

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Conflicts of interest

There are no conflicts of interest.

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