

Termination of Pregnancy for Fetal Anomalies: A Qualitative Study of the Informational and Educational Needs of Women

Abstract

Background: Diagnosing congenital fetal anomalies before birth is considered an emotionally devastating experience. To facilitate the process of compatibility with this event, healthcare providers should determine various needs of these women. The present study was conducted to explore the informational and educational needs of women who have experienced pregnancy termination because of fetal anomalies. **Materials and Methods:** The present study was a qualitative content analysis. Forty participants (women, their spouses, and healthcare providers) in Rasht city, Iran, were selected using purposive sampling method with maximum variety and their data were gathered using in-depth interviews and field notes. Data were analyzed using conventional qualitative content analysis with Graneheim and Lundman approach. **Results:** After analyzing the text of the interviews, the informational and educational needs of women who have experienced pregnancy termination because of fetal anomalies were categorized in three main categories of “receiving information tailored to the client’s circumstances,” “learning life skills to cope,” and “getting prepared for the next pregnancy.” **Conclusions:** The results, by exploring and magnifying the informational and educational needs of these women, could present an appropriate context for providing principal care and cultural-based interventions with an emphasis on comprehensive education and counseling. Also, proper implementation of the process of obtaining informed consent from the women to terminate the pregnancy is essential. These could facilitate the conditions for their return to normal life and ultimately promote their health.

Keywords: Congenital abnormalities, needs assessment, abortion, qualitative research, Iran

Introduction

During the last decades, along with the advances in the genetic science and medical technologies, it has become possible to diagnose many of the fetal anomalies during the first stages of intrauterine life.^[1] Losing hope for having a healthy child and making the decision to terminate the pregnancy is a difficult and emotionally challenging issue.^[2] This traumatic event could have long-term outcomes such as post-traumatic stress, severe grief, and depression.^[3] Since, in these cases, the decision to terminate the pregnancy should be made within a short period of time, it would cause significant concerns for the parents.^[4] In this situation, women would encounter severe internal conflicts, in a way that some would start blaming themselves and some would suffer from denial, anger, and depression.^[5] One of the most important responsibilities of

the professional healthcare providers is to clearly explain the current situation and to provide information and counseling without judgment for facilitating informed decision making for the couples.^[6] Results of the study by Asplin showed that these women would require information and counseling constantly at different times.^[7] However, results of various studies have shown that most of the women during pregnancy would not receive the necessary information that they need in this field.^[8-10]

In Iran, therapeutic abortion is legal before the 19th week of pregnancy for fetal abnormalities causing severe maternal suffering, based on authorized periodical ultrasonography and the woman’s consent. Considering the different aspects of the experience of pregnancy termination because of fetal anomalies, determining the educational and informational needs

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of these women could provide an appropriate context for cultural-based interventions and caring programs in the society.^[11-13] Since qualitative research is an approach for describing and conceptualizing the experiences of the participants, it could improve the knowledge and attitude toward human experiences.^[14] Therefore, the present study as a part of a mixed methods study (to develop and psychometric evaluation of needs assessment tool for women who have experienced pregnancy termination because of fetal anomalies) was conducted to explore the informational and educational needs of women who have experienced pregnancy termination because of fetal anomalies.

Materials and Methods

This qualitative content analysis is a part of a mixed methods study which was conducted between October 2017 and April 2018. Participants were 25 women who had experienced pregnancy termination because of fetal anomalies and were referred to the health centers of Rasht city, Iran, two of their spouses, and 13 healthcare providers (two forensic medicine specialists, three gynecologists, one perinatologist, one psychologist, two reproductive health specialists, three midwives, and one nurse) who were selected using purposive sampling method. Women and their spouses were found for the study through the midwifery wards of the hospitals, prenatal clinics, and midwifery, gynecologists and forensic medicine specialists' offices. They were recruited directly or telephone numbers were obtained and they were subsequently telephoned. The inclusion criteria were having the ability to understand the questions and transfer experiences and views, having passed at least 1 year from the pregnancy termination incident and not having any known psychological diseases.

Data were gathered using individual semi-structured in-depth interviews and field notes. The first author, who was a PhD candidate in the field of reproductive health and had 12 years working experience in midwifery, conducted the interviews and field notes. Interviews were started with the general questions of "Please explain how you felt when you realized you had to terminate the pregnancy due to fetal anomalies? What kind of information and education were you willing to receive afterwards?", and after that, the open and interpretive answers of the participants guided the interviews. The interviews with other participants were started with the general question of "What do you think are the educational and informational needs of women who have experienced pregnancy termination because of fetal anomalies?" In this study, 40 interviews (with the duration of 25–100 min) were conducted at the desired places (such as hospital and clinic) by the participants. All interviews were digitally recorded. Interviews were continued until data saturation occurred, that is, no new data code emerged in the interviews.

Data analysis was manually performed and no software was used for this purpose. To analyze the data,

conventional qualitative content analysis with Graneheim and Lundman approach^[15] were used. Simultaneously to performing the interviews and recording them with an mp4 device, the researcher regularly transcribed the interviews. Then the interviews were read repeatedly to achieve a complete understanding of them. After that, the sentences were coded and after formation of the codes, similar codes were merged into each using the inductive method; those with similar concepts were placed in one category and formed the sub-categories. Afterwards, by comparing the sub-categories with each other, categories that had similar concepts were placed in one main category. To secure the credibility of the data, various methods including performing the in-depth interviews at different times and places, combining different data gathering methods of individual interviews and field note taking and selecting the participants with maximum variety (regarding their educational level, socioeconomic status, occupation, age, number of children before the incidence, and the duration passed from pregnancy termination) were used. Also, during some other meetings, transcripts and the coded interviews were given to four of the participants and their final opinions were obtained, so that revision by the participants would be achieved. Opinions of four experts were obtained to assure confirmability and dependability of the data with the participants' statements. In the present study, to increase transferability, results of the study were given to three women with similar inclusion criteria who had experienced pregnancy termination due to fetal anomalies but did not participate in the study, to judge the similarity of the results to their own experiences.

Ethical considerations

The confirmation letter for performing the research was obtained from the ethics committee of the research deputy of the Isfahan University of Medical Sciences (ethical code: IR.MUI.REC. 1395.3.945) and obtaining written informed consent, preserving anonymity, maintaining the confidentiality of the data and providing the right of withdrawal at any time were respected.

Results

Demographic characteristics of the 40 participants are shown in Tables 1 and 2. After data analysis, 33 codes, 10 sub-categories, and three main categories were achieved. Three main categories included "receiving information tailored to the client's circumstances," "learning life skills to cope," and "getting prepared for the next pregnancy" [Table 3].

Receiving information tailored to the client's circumstances

Participating women's experiences were filled with questions that remained unanswered. Sometimes, they had received no information in the required field at all, or the provided information was partial or too specialized.

Table 1: Demographic characteristics of women who have experienced pregnancy termination due to fetal anomalies and their spouse

Participant's No.	Age	Educational level	Occupation	Gestational age (Week)	Number of children	Time passed from pregnancy termination (Month)
1	25	Diploma	Housewife	18	-	3
2	28	Bachelor's degree	Housewife	17	1	4
3	30	Bachelor's degree	Driving instructor	16	1	5
4	34	Bachelor's degree	Accountant	18	1	4
5	29	Elementary school	Housewife	17	2	6
6	32	Bachelor's degree	Teacher	16	1	4
7	24	Diploma	Housewife	16	-	4
8	36	Anesthesiologist	Physician	16	-	5
9	27	Elementary school	Farmer	17	-	7
10	31	Diploma	Hair dresser	16	1	6
11	34	Master's degree	Telecommunication employee	17	-	4
12	27	Bachelor's degree	Teacher	16	-	8
13	28	Diploma	Saleswoman	16	-	5
14	29	Associate's degree	Operating room technician	17	1	4
15	28	Bachelor's degree	Tour leader	16	-	7
16	32	Bachelor's degree	Clerk	19	1	4
17	22	Diploma	Housewife	18	-	3
18	30	Bachelor's degree	Teacher	17	1	4
19	25	Bachelor's degree	Housewife	17	-	5
20	28	Diploma	Tailor	16	-	6
21	21	Diploma	Housewife	17	-	4
22	32	Bachelor's degree	Nurse	17	1	3
23	25	Associate's degree	Saleswoman	18	-	4
24	27	Elementary school	Service provider	14	1	3
25	3	Bachelor's degree	Secretary	16	1	5
26	38	Bachelor's degree	Freelancer	17	1	4
27	30	Diploma	Service provider	16	-	6

Healthcare providers also believed that required information should be provided to the patients relative to their conditions and needs. This main category contained five sub-categories.

Being informed about the cause of anomalies

Most of the participating women had many questions about the causes of anomalies that remained unanswered. According to them, most of the physicians were not willing to provide explanation about the possible causes of anomalies. *"My child had Down Syndrome. My husband and me are not relatives and I was wondering why this had happened? I have no idea what has happened."* (Woman, participant No. 3)

Being informed about the nature of anomalies and their outcomes

Most of the participating women had no correct information about the nature, intensity, and outcomes of anomalies. Even months after the pregnancy termination, they were doubting the accuracy of the tests and also their own decision regarding pregnancy termination and this had caused psychological conflicts and turmoil for them. *"I*

Table 2: Demographic characteristics of the other participants

Participant's No.	Age (year)	Work experience (Year)	Occupation
28	51	13	Forensics specialist
29	49	16	Forensics specialist
30	53	22	Perinatologist
31	44	12	Gynecologist
32	49	16	Gynecologist
33	43	15	Gynecologist
34	44	13	Psychologist
35	44	20	Reproductive health specialist
36	45	12	Reproductive health specialist
37	41	13	Master's degree in midwifery
38	33	10	Master's degree in midwifery
39	45	20	Bachelor's degree in midwifery
40	43	6	Bachelor's degree in nursing

think the fetus had internal problems. I don't know what was the name of the diseases? Well, the doctors don't provide much explanation. That is all I could understand from their words." (Woman, participant No. 2)

Elimination of uncertainty and the challenge of decision making

Most of the participating women narrated a state of confusion after the diagnosis of anomalies and expressed that they were left alone at a crossroad. Many of them even doubted the correctness of the decision about pregnancy termination and revealed that, at this stage, no one had provided the required information to them in relation to their condition and no one had talked to them about the advantages and disadvantages of terminating the pregnancy or the outcomes of keeping the fetus. "... *They would not explain to you what is supposed to happen afterwards and what would be done for you. ...Nobody talks about your problem and what would be done for you.*" (Woman, participant No. 17)

Being informed about the process of care and the pregnancy termination procedure

Most of the participating women were not aware of the process of providing care, the probable duration of time until the abortion, consequences such as hemorrhage and pain, type of drugs used and their side effects, the procedure of terminating the pregnancy, and the necessity of performing curettage (in some cases), and stated that

they had no previous preparation for the performed procedures and the consequences. "...*My before pregnancy terminated with caesarian section and now, how am I supposed to have a vaginal delivery? How can I tolerate? What if my uterine would rupture? And so many another questions.*" (Woman, participant No. 24)

Being informed about next follow-ups

Many of the participating women, especially those who were experiencing their first pregnancy, were feeling dissatisfied with the fact that the healthcare providers had not given them any information about the care and follow-up after pregnancy termination, and the centers or individuals that they could refer to in case of having any psychological problems. They stated that, in most cases, the explanation was not enough to make further questioning unnecessary. "...*It would have been very nice if they would guide us about what should we do? And who should we visit?*" (Woman, participant No. 21)

Learning life skills to cope

Most of the participating women mentioned that they needed education that would improve their adjustment to their new situation and would help them control their stressful situation. They believed that strategies for managing the

Table 3: Codes, sub-categories and main categories extracted from the content analysis

Code	Sub-category	Main category
The need for having information about the cause of fetal anomalies	Being informed about the cause of anomalies	Receiving information tailored to the client's circumstances
The need for resolving doubts about the cause of fetal anomalies	Being informed about the nature of anomalies and their outcomes	
The need for having information about the nature of anomalies	Being informed about the process of cares and the pregnancy termination procedure	
The need for having information about the severity of the fetal anomalies	Being informed about the process of cares and the pregnancy termination procedure	Receiving information tailored to the client's circumstances
The need for having information about the procedure of pregnancy termination	Being informed about next follow-ups	
The need for having information about the care before and after pregnancy termination	Being informed about next follow-ups	Receiving information tailored to the client's circumstances
The need for receiving information about further cares and follow-ups	Elimination of uncertainty and the challenge of decision making	
The need for receiving information about the centers for necessary services	Elimination of uncertainty and the challenge of decision making	Receiving information tailored to the client's circumstances
The need for elimination of uncertainty	Managing the activities for returning balance into life	
The need for having confidence in physician's diagnosis	Managing the activities for returning balance into life	Learning life skills to cope
The need for awareness about her freedom to choose termination of pregnancy	Appropriate communication with family members in the new situation	
The need for having the necessary skills to control the emotions	Appropriate communication with family members in the new situation	Learning life skills to cope
The need for applying the techniques for solving the problems	Being informed about physical preparation for the next pregnancy	
The need for having communicational skills with the husband	Being informed about physical preparation for the next pregnancy	Becoming prepared for the next pregnancy
The need for having communicational skills with family members	Being informed about psychological preparation before the next pregnancy	
The need for having information about consuming drugs and traditional medicines	Being informed about psychological preparation before the next pregnancy	Becoming prepared for the next pregnancy
The need for awareness about primary symptoms of chronic diseases	Being informed about the need for receiving preconception cares	
The need for awareness about the necessity of treating anxiety before the next pregnancy	Being informed about the need for receiving preconception cares	Becoming prepared for the next pregnancy
The need for awareness about the necessity of treating depression before the next pregnancy		
The need for having the ability to control the feelings (fear, concern)		Becoming prepared for the next pregnancy
The need for awareness about the necessity of genetic counseling before pregnancy		
The need for awareness about the necessity of internal medicine counseling with the history of chronic diseases		Becoming prepared for the next pregnancy

tensions that they would experience when encountering others and their blaming looks, their husbands and even other children, had an important role in establishing peace in the family and accelerating the return to a balanced situation. This main theme had two sub-categories.

Managing the activities for returning balance into life

Many of the participating women believed that they had educational needs that, if achieved, would make adjusting to this horrible experience easier. For returning to normal life, they needed to manage their emotions, feelings, and expectations. Also, healthcare providers believed that it was necessary for the client to follow a rational procedure and act realistically when encountering others. *"After I returned home, I felt that the discipline of my life is disrupting... I did not have patience for anyone and anything!!!"* (Woman, participant No. 2)

Appropriate communication with family members in the new situation

Learning communicational skills and the manner of communicating with other children and the husband after returning home were some of the needs that could improve family relationships. Difficulty in correct expression of the needs and emotions and talking about the problems and current situation had created more issues for the women that made them isolated more than before. *"I couldn't tolerate my child... Our relationship was completely destroyed. I didn't want to act like that but I couldn't help it, I swear to God."* (Woman, participant No. 3)

Becoming prepared for the next pregnancy

Most of the participating women did not know what measures they should perform after pregnancy termination to prevent this incidence as much as possible. This main category had three sub-categories.

Being informed about physical preparation for the next pregnancy

Participating women believed that being informed of the necessary care for providing, maintaining and improving health, monitoring and managing the symptoms and signs of disease in patients suffering from chronic diseases, taking up a healthy life style and correct consumption of over the counter drugs were essential before performing any measures for the next pregnancy. *"...I think that there must be some things to consider reducing the risk of having an abnormal child. I mean they should tell us what to do to decrease the risk of anomalies, what are the things that we should observe?"* (Woman, participant No. 4)

Being informed about psychological preparation before the next pregnancy

According to the healthcare providers, one of the most important informational needs of women was being informed about having psychological preparation before the

next pregnancy. Since these women are willing to prove it to others that they could get pregnant and there is no flaw in their health, they would start measures for getting pregnant again in a short time after pregnancy termination. This approach could worsen their undesirable psychological health situation. *"...Studies have shown that problems such as stress and anxiety could have adverse effects on the child's psychological health. Therefore, in these cases, before performing any measures for the next pregnancy, these issues should be controlled."* (Psychologist, participant No. 34)

Being informed about the need for receiving preconception care

According to the healthcare providers, teaching the methods of performing prenatal care and the necessity of performing genetic and psychological counseling in women with a positive individual or family history are some of the matters that should be considered in the education of these women that could decrease their anxiety. *"Many of the parents with abnormal fetus need various counseling sessions such as genetic counseling. Some of them are consuming specific drugs and the dosage of their drugs might require reducing or moderating by a neurologist before the next pregnancy and other similar cases."* (Midwife, participant No. 39)

Discussion

The results showed that receiving information tailored to the client's circumstances, learning life skills to cope and becoming prepared for the next pregnancy were the most important informational and educational needs of the participants. Results of other studies in other cases of fetus loss such as intrauterine fetal death and abortion also have shown that most of the mothers mentioned the needs that, if achieved, this experience would become easier for them.^[16,17] The results showed that most of the participants had too many questions about the causes of fetal anomalies that remained unanswered. Results of the study by Maguire *et al.* showed that pregnancy termination because of fetal anomalies as a specific loss is related to the perceived stigma. Therefore, these women could benefit from appropriate counseling that could resolve their misinterpretations or misunderstandings of the causes of the anomalies.^[18] Also, Facchinetti showed that healthcare providers not providing sufficient explanation about the cause of anomalies would lead to disruption in the process of mourning. Therefore, by educating the parents about causes of fetal anomalies and the risk factors, the next pregnancy could be managed better and the risk of reoccurrence of this incident would be decreased.^[19]

The results showed that lack of sufficient information about the nature of fetal anomalies and their outcomes had caused confusion for most of the participants. Laior showed that describing the anomalies, existence of written information, providing sufficient and in-time information right after the diagnosis of fetal anomalies and referring the parents to

the fetal medicine specialist for confirming the diagnosis of anomalies and counseling were the most important requests of women following the diagnosis of anomalies. According to the participants, observing additional documentation (such as sonography and genetic tests) was necessary in better understanding of the issue and helping in acceptance of the incident.^[20] In the present study, most of the participants were not informed of the process, probable outcomes, and various methods of pregnancy termination and stated that they had no preparation for the performed measures and occurred outcomes. Lafarg showed that informing women about their current situation and empowering them for selecting the correct method of pregnancy termination were some of the most important needs of these individuals.^[21] The results showed that many of the participating women expressed their needs for receiving information about the follow-ups after pregnancy termination, planning for the next pregnancy, and the centers and individuals that they could refer to if they had any problems. Van Dinter showed that information and awareness about the support resources could facilitate provision of care for women, their husbands and families and help finding compatibility with the current situation.^[22] Also, Breeze *et al.* believed that determining the intervals between visits after pregnancy termination to prevent complications is essential.^[23] In the present study, most of the participants mentioned a kind of confusion after the diagnosis of fetal anomalies. The need for receiving information about the advantages and disadvantages of terminating pregnancy of a fetus with major anomalies or the outcomes of keeping the fetus and continuing the pregnancy were requests of most of the participants. Korenromp showed that a high level of doubt during the process of decision making, in most cases, is the predictor of long term undesirable psychological outcomes.^[24] Therefore, education and counseling are necessary to justify the reason for recommending termination of pregnancy. Also, by proper implementation of the process of obtaining informed consent (an informed and free choice to accept or reject termination of pregnancy), these women would experience less stress, doubt, and guilt and facilitate their adaptation to the new situation and their psychological outcomes. If these actions are done correctly, women will experience less stress, doubt, and guilt and facilitate their adaptation to the new situation and the decision for the next pregnancy.

The results showed that, for returning to normal life, participants needed to manage their emotions, expectations, and annoying encounters with others. Keefe-Cooperman believed that counseling interventions were effective in addressing the vulnerability of the sadness of the incident.^[25] The results showed that losing a fetus would affect women's relationship with other family members and friends. Learning communicational skills was one of the needs that would lead to improvement of the disrupted relationships. Also, results of a study showed that parents who have lost their fetus are usually

looking for a way to balance their relationship with their other children, and so they would make efforts to create a sense of safety for their other children.^[22] The results showed that most women, after pregnancy termination, needed to have information and awareness about the necessary measures to perform to get prepared for the next pregnancy and prevent repetition of the incident. Sharma showed that educating women to respect the appropriate time interval before the next pregnancy would provide an opportunity for them to improve their nutritional condition and decrease their stress about the repetition of this incident.^[26] Generalization of the results of this qualitative study should be performed cautiously. Although qualitative studies have no claim about the generalizability of their results, they might seem important from the viewpoint of the individuals who are willing to apply the results of these studies and so it could be considered as a limitation. In this regard, the effort was to improve the rigor and trustworthiness of the results by selecting the participants with maximum variety, guidance and supervision of the experts, and revision by peers. Also, lack of interview with medical ethics specialist as a participant is another limitation of the present study.

Conclusion

The present study showed various aspects of educational and informational needs of women who have experienced pregnancy termination because of fetal anomalies. It seems that exploring and signifying these needs and presenting them to the authorities of the health system, could present an appropriate context for providing principal care and cultural-based interventions with an emphasis on comprehensive education and counseling. Also, proper implementation of the process of obtaining informed consent from the women to terminate the pregnancy is essential. These could facilitate the conditions for their return to normal life and ultimately promote their health.

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Conflicts of interest

Nothing to declare.

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