

The Needs of Women Who Have Experienced Pregnancy Termination Due to Fetal Anomalies: A Literature Review

Abstract

Background: Pregnancy termination due to fetal anomalies is associated with emotional, psychological, and social injuries for women. Determining the needs of women with these experiences is the key for programming to provide high quality and desirable care. Hence, the present study was conducted to determine the needs of women who have experienced pregnancy termination due to fetal anomalies. **Materials and Methods:** The present literature review was conducted in March 2018 by searching databases such as Irandoc, SID, MagIran, Iranmedex, Cochrane, Science Direct, ISI Web of science, PubMed, Google Scholar, and Scopus. The used keywords for the search included “fetal anomalies,” “pregnancy termination due to fetal anomalies,” “therapeutic abortion,” “need assessment,” and “care program.” Publication date was restricted to 2004–2017, and publication language was restricted to English and Farsi. Article search was conducted by two independent reviewers, and all of the studies were evaluated by these two individuals. The searches resulted in finding 88 articles related to the subject from which 16 articles that had more appropriately covered the topic were selected for the present study. **Results:** From the results, the needs of these women could be categorized into two groups of “needs related to the care system” and “needs related to the husband, family members, friends, and peers.” **Conclusions:** Considering that women who have experienced pregnancy termination due to fetal anomalies have different needs, educating healthcare providers and husbands, family members, friends, and peers for providing comprehensive care tailored to the needs of these individuals seems necessary.

Keywords: Birth defects, congenital abnormalities, induced abortion, therapeutic abortion

Introduction

Advanced diagnostic technologies in the field of reproduction have led to extensive application of monitoring tests and pre-birth diagnosis of fetal anomalies.^[1] Congenital anomalies are all the structural and genetic defects that would occur at the time of conception or during the intrauterine development period.^[2] Approximately, congenital anomalies occur in 2% to 3% of the pregnancies and have various prevalence in different populations; from 1.07% in Japan to 4.3% in Taiwan.^[3] While pregnancy is considered a forward development for the mother and the family, diagnosis of fetal abnormalities is an unexpected incident during this period and is associated with severe emotional injuries for women. This issue would encounter women with many challenges such as continuing the pregnancy without any intervention, selective pregnancy

termination, or experimental treatment of the fetus in special cases. In most cases, especially when the fetal anomaly is severe and lethal, the parents would decide to terminate the pregnancy.^[4] Deciding to terminate the pregnancy would cause a great responsibility for the mother regarding the loss of the fetus; furthermore, in comparison to other situations, less social support exists for these cases according to the cultural context of the society, women might be blamed for deciding to terminate the pregnancy or for the existing fetal anomaly; Hence, they probably would not be able to easily share their decision with others, which might lead to their loneliness and more vulnerability.^[5] The active role of women in terminating the pregnancy is a unique topic that would distinguish its mourning process from the sorrow following abortion or fetal death and is associated with long-term psychological outcomes.^[6] Almost all of the studies have

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reported evidences of these outcomes during the following weeks or months after pregnancy termination.^[7] However, some of the studies have reported that these psychological outcomes might not reduce for a long period of time after the incidence; for example, results of the study by Maguire *et al.* showed that some women might experience the symptoms of post-traumatic stress for 2 to 7 years after the pregnancy termination.^[8] In addition, this incidence is associated with other psychological symptoms including the feeling of guilt and humiliation, low self-esteem, anxiety reactions, fury, doubt about the correctness of the decision, and the pressure caused by the fear from social judgment.^[4] Results of the studies showed that these women would not receive sufficient social support and even, due to lack of information about this kind of loss, they would not be able to show their mourn for their child loss appropriately. Although the emotional and psychological outcomes following pregnancy termination due to fetal anomalies have been reviewed in various studies, few studies have been conducted to determine the needs of these women especially the appropriate and desired care and supportive needs during the compatibility period following the loss of the fetus. No special supportive systems exist for these women. Although, currently, in some countries, some online groups have been created to support women who have experienced pregnancy termination due to fetal anomalies, it is still not clear whether this kind of support is in accordance with the needs and desires of this group or not.^[7] Results of the studies have shown that the quality of the received emotional support from family and friend is different and would fade gradually that would lead to a feeling of loneliness in this sorrow. This lack of support would cause more need for sources of care that women have not predicted it at the time of terminating their pregnancy. Result of the study by Ramdaney *et al.* showed that although most women are aware of the support sources at the time of pregnancy termination, only half of the women would feel this need. Following up the participants for a couple of months after pregnancy termination showed that most women would not be able to adapt with the existing conditions and are prepared for the psychological outcomes of pregnancy termination.^[9] Because experiencing pregnancy termination due to fetal anomalies has various aspects,^[10] determining the needs of women with these experiences is the key for programming to provide high quality and desirable cares. Hence, the present study was conducted to determine the needs of women who have experienced pregnancy termination due to fetal anomalies.

Materials and Methods

This literature review was conducted in March 2018. In the present study, to achieve the intended information, published articles in national journals, Scientific Information Database (SID), Iranian Medical Sciences Articles Database (IranMedex), Iranian Research Institute for

Information Science and Technology (Irandoc), and Iranian Magazines Database (Magiran) were searched using the keywords (in Farsi) of “fetal anomalies,” “pregnancy termination,” “therapeutic abortion,” “need assessment,” “care program,” and their possible combinations in the abstracts, titles, and the keywords; for this purpose, “and” and “or” operators were used. English databases including Science Direct, Google Scholar, Scopus, Cochrane, ISI Web of science, and PubMed were searched using the English Mesh equivalents of the Farsi keywords including “needs,” “fetal anomaly,” “termination of pregnancy,” “health care needs,” “social and professional support needs,” “support needs,” “health care professionals supporting,” and “care plan”; “and” and “or” operators were used for combined searching. All of the articles from 2004 to 2017 were searched for this study.

After the primary search of different databases, 88 full texts and abstracts of articles were found. The extracted articles were evaluated according to the inclusion criteria in two steps. During the first step, 28 articles out of 88 were eliminated because of being a duplicate. During the second step, 44 articles were eliminated for having different (irrelevant) titles and goals and also due to lack of a full text. Eventually, 16 articles, 11 qualitative studies, and 5 quantitative studies were enrolled for final evaluation [Figure 1]. It must be noted that article search was conducted by two independent reviewers, and all of the studies were evaluated by these two individuals. Any disagreement between these two was resolved through discussion and by considering the goals of the study, and the opinion of a third person was requested, if necessary. The achieved information from the articles including title, authors, time of the study, and details of the study such as aim, study design, participants, ethical considerations, results, and limitations were evaluated. Eventually, the selected articles were studied to determine the needs of women who have experienced pregnancy termination due to fetal anomalies.

The inclusion criteria were being published from July 2004 to December 2017 on different aspects of women's needs who have experienced pregnancy termination due to fetal anomalies, having relevant titles and being in Farsi or English languages. Articles that were presented in the conferences and seminars, review articles, case reports, and letters to editor were excluded; also lack of access to the full texts of the articles was considered as an exclusion criterion.

Ethical considerations

Research ethics confirmation (ethics code: IR. MUI. REC.1395.3.945) was received from the Ethics Committee of Isfahan University of Medical Sciences. In the present review study, the gathered information from the research was only used regarding the scientific goals and commitment to protect the intellectual property in reporting and publication of the results.

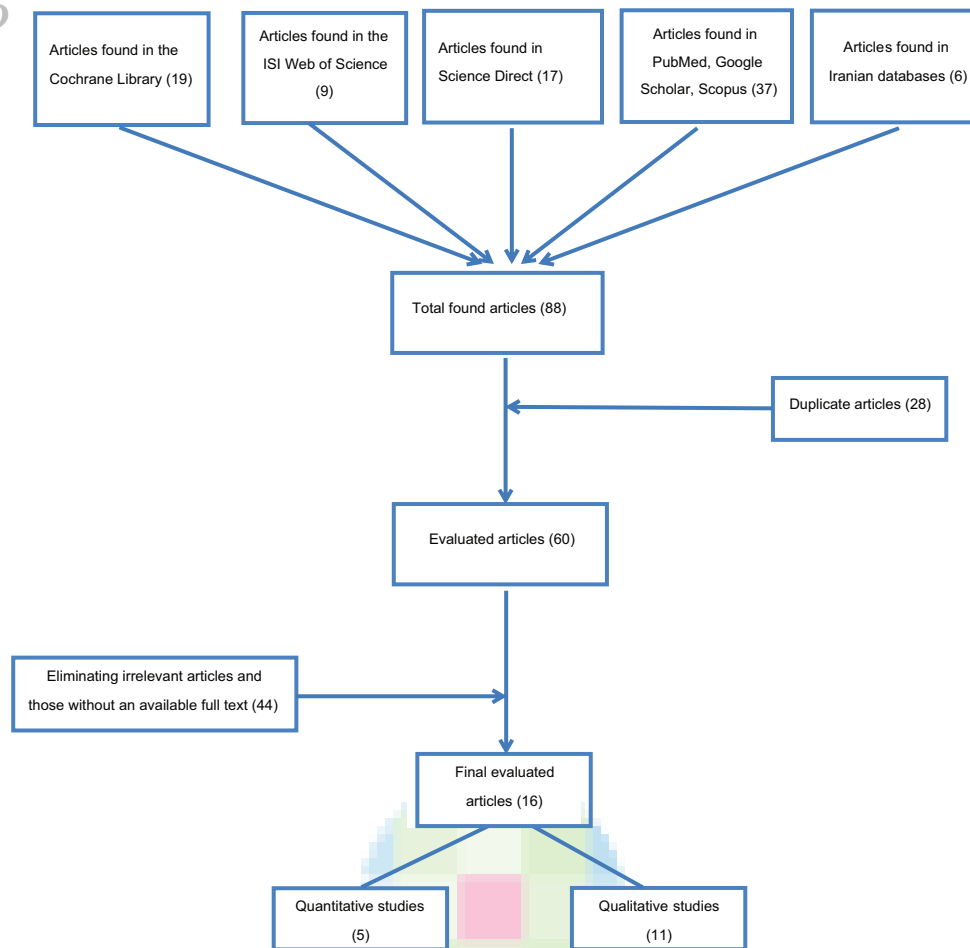


Figure 1: The flowchart for the selection process of the articles

Results

Study selection outcome

After reviewing the results of various studies, considering the extensive and various needs of women, the needs were categorized into two classes of (1) needs related to the care system and (2) needs related to the husband, family, friends, and peers.

Needs related to the care system

Most women would experience a range of unpleasant feelings in reaction to the diagnosis of fetal anomaly including sorrow, feeling of emptiness and loneliness, exhaustion, anger, and disappointment.

According to the studies, these women would benefit from receiving appropriate counseling that could resolve misunderstandings and misconceptions about the reasons for the anomalies.^[9] In-time presence of experienced caregivers after hearing the news about anomaly besides the parents, approving the women's feelings by the caregivers, continuity of the care by the caregivers, existence of a standard care program from the number of caregivers,^[10] pain management, the ability to manage

different needs and requests of the patients,^[11] informing women about the current conditions, empowering women for selecting the right method of pregnancy termination and the type of cares,^[12] having up-to-date information for the caregivers,^[10] providing the conditions for seeing the fetus after abortion for having a better adaptation with the reality,^[13] and providing the opportunity for visiting with gynecologists after the surgery and answering their questions and planning for future pregnancies (especially in the elder patients)^[10] are essential for facilitating the process of decision-making and compatibility with this loss; otherwise, they might feel abandoned in this sorrow.

In addition, the need for having an appropriate communication and respecting their privacy,^[14] responsibility of the caregivers, being friendly and speaking and behaving politely toward the women, providing psychosocial supports,^[15] empowering women for attracting emotional supports and improving the process of adaptation,^[16] and respecting their religious beliefs and fulfilling their spiritual needs^[17] are some other needs of women who have experienced pregnancy termination due to fetal anomalies in relation to the care system. According to the studies, in most cases, the discussion about the existence of

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supportive resources usually starts when the women or the couple has decided to terminate the pregnancy. Healthcare providers, especially genetic counselors, are willing to provide services and supportive measures for these people. However, most women would decide to terminate their pregnancy right after finding out about the fetal anomaly and are not aware of the consequences and the required supports in the future.^[9] Effective professional supports would fulfill the expectations and needs of women, especially when provided from a reliable and sincere person. Providing a developed supportive-care plan along with sufficient number of caregivers has an important role in attracting women's satisfaction with the provided cares. However, lack of optimal cares would lead to inconsistency in providing care for these women.^[13]

Needs related to the husband, family, friends, and peers

The need for the presence and participation of the family members in the labor room to reduce the feeling of loneliness and insecurity,^[13,18] receiving sympathy,^[19] and sufficient and constant emotional and psychological support from the husband, family members, and the friends to shorten the recovery period,^[10,15,20] the need for receiving support from family members for protection against others' judgment,^[21] and the need for visiting others with similar situations, anonymously and online^[9] were the most important needs of women related to the husband, family, and friends in women who have experienced pregnancy termination due to fetal anomalies.

According to the studies, no specific care system exists for these women. Although in some countries there are online groups for supporting women, who have experienced pregnancy termination due to fetal anomalies, it is still not determined whether this type of support is proportionate to the needs and desires of this group or not. Results of previous studies have shown that the quality of provided support by the family and friends is variable and would fade over time, which could lead to the feeling of loneliness along with the sorrow. This lack of support would cause more needs for supportive resources that has not been predicted at the time of terminating the pregnancy.^[9] A summary of the results is shown in Table 1.

Discussion

The present study determined the needs of women who have experienced pregnancy termination due to fetal anomalies. From the results, needs of these women could be categorized into two groups of needs related to the care system and needs related to the husband, family, friends, and peers.

Most of the studies revealed that women would experience a critical period of psychological problems, especially during the first months following the diagnosis,^[4,22] while they need to relieve their psychological sufferings, they could not realize this need because of the priority of the fetus loss.^[7]

A review of the conducted studies showed that in response to the unexpected loss of the fetus, women would express reactions such as anger and fury, sorrow, and crying with various intensities.^[8] The most threatening problem for the women who have experienced pregnancy termination due to fetal anomalies is failure to fulfill their psychological needs because their sorrow would be underestimated by others. This might lead to various psychological problems including depression in the clients, their husbands, and children. The role of medical and psychosocial supports that would be provided by professional caregivers is valuable to women and would lead to less negative mental reactions.^[19] Undoubtedly, professional support along with the support from the husband and presence of a friend or a relative would be effective in relieving their concerns and adapting with this incidence.^[24]

Reviewing previous studies showed that empowering women to attract emotional support and providing long-term supports along with compact professional support from a specialist team could lead to less psychosocial outcomes.^[19] Previous studies revealed that women's experiences have indicated unanswered questions, which despite the months passed from the incidence, still had not found any rational answers for. These questions are not specified to any stage of the process, and the need for information has repeatedly been reported from at all the stages of diagnosis, pregnancy termination, and afterwards. In the study of Asplin, the need for receiving new information, speaking about the time of the next pregnancy especially for the elder women, and visiting specialists after the surgery and finding answers to their questions were also described important by the women.^[10] In the study of Lalor *et al.* receiving sufficient and in-time information (immediately after the diagnosis of fetal anomaly), referring the parents to the fetal specialist for confirming the diagnosis, and observing additional documentations for better understanding the subject were some of the most important requests of women. The importance of receiving information is so much that it has been considered as one of the criteria for service evaluation by the participants and their caregivers.^[19]

Reviewing previous research indicated that to provide high-quality services that could attract clients' satisfaction, various factors such as patient's access to standard physical care,^[18] and principle psychological and social cares that would be provided by professional caregivers are valuable and would cause less undesirable psychological reactions.^[8] Hence, service providers should have the necessary abilities and skills in the field of their expertise and provide services in the framework of the standard and update information and also improve their competency by appropriate behavior, work ethics, responsibility, and respecting privacy.

In different studies, another important group of the women's needs to improve their health and return to normal life after experiencing pregnancy termination due to fetal anomalies

Table 1: Studies in the field of the needs of the women who have experienced pregnancy termination due to fetal anomalies from 2004 to 2017

Authors and publication year	Type of the study	Sample size	Place of the study	Data gathering tools	Results
Ramdane <i>et al.</i> (2015) ^[9]	Longitudinal study	51 pregnant women candidate for pregnancy termination	America	Questionnaire	In this study, most of the participants were aware of the support resources but only half of them felt the need for receiving support from these resources. Easy access and willingness to visit with others who experienced similar situations, anonymously and online, were considered as effective factors for participating in support systems. Most of the women expected support from their family and friends. Only four participants mentioned that lack of support from their family and friends might be effective in their decision about searching for other support systems. Unwillingness to establish a communication with the caregivers during the follow-up period to avoid remembering the memories and the willingness to continue the pregnancy in half of the participants prevented them from receiving support
Chaloumsuk (2013) ^[18]	Qualitative	12 women with the experience of pregnancy termination due to fetal anomalies, and 11 women with the experience of abortion	Thailand	Interview	In this study, from data analysis, three themes were extracted in both groups; experiencing disappointment, balancing the emotions, and the need for intervention. Although most of the outcomes in both groups were similar, the most important difference between them was the context of the loss of pregnancy in both groups. While abortion in an inevitable incidence and requires immediate treatment, diagnosis of fetal anomalies would encounter women with mixed emotions for making the decision of pregnancy termination. These women require more knowledge and care coupled with intimacy and sympathy. Participation of the family members in the labor ward is effective in reducing the feeling of loneliness and insecurity. Results of this study showed the necessity for educating the caregivers in providing cares in accordance with the needs of these women
Lafarge <i>et al.</i> (2014) ^[12]	Qualitative	361 individuals	London	Interview	In this study, experiences of the nurses in providing care are different. Receiving an appropriate level of care, providing care in a specific time, and location frame that would lead to the patient's peace, the role of the professional caregivers and organizations, informing women about the existing situation, and empowering women in selecting the right method for pregnancy termination were some of the effective factors in women's understanding of the type of care. Results of this study showed that women had no chance in selecting the type of care

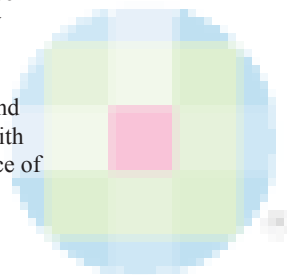


Table 1: Contd...

Authors and publication year	Type of the study	Sample size	Place of the study	Data gathering tools	Results
Asplin (2013) ^[10]	Qualitative	11 individuals	Sweden	Interview	In-time presence of experienced caregivers beside the parents after realizing the news about fetal anomalies is essential in facilitating the process of decision-making and adaptation with this loss, for the parents; otherwise, they would abandoned in this sorrow. They expressed dissatisfaction about the fact that the caregivers were not aware of the situation and did not have update information in this regard
Sutan and Miskam (2012) ^[14]	Qualitative	16 Muslim mothers	Malaysia	Focus group	All of the participants had experienced psychological problems such as confusion, frivolity, and concern. Two of the participants were feeling angry, and one was feeling guilty. They complaint about lack of an appropriate relationship and privacy during the period of mourning in the hospital. They constantly reminded themselves that everything that happens is a test from God, and this would give them relieve from the sense of blame or guilt
Nicholson <i>et al.</i> (2010) ^[11]	Qualitative	Seven nurses	England	Interview	Experiences of nurses who have taken care of women following pregnancy termination due to fetal anomalies showed that they considered this experience as emotional and stressful. Challenges in accepting the fetal anomalies and its following pregnancy termination, the strategy for managing the needs and different requirements of the patients, and their encountered challenges were the most important themes extracted from data analysis. In addition, results emphasized on the important role of the nurses in providing principle care for these women
McCoyd (2009) ^[21]	Qualitative	30 individuals	America	Interview	After making the decision to terminate the pregnancy due to fetal anomalies, women would experience a sorrow that indicates losing a wanted pregnancy. This special sense of responsibility in making the decision about terminating the pregnancy would increase the intensity of sorrow after pregnancy termination. They usually believe that they do not deserve this kind of sorrow. Intentional decision-making about pregnancy termination usually occurs because of social reasons. The shame of pregnancy termination and having an abnormal fetus would make them worry about others' judgment; hence, they would not be able to share their sorrow with others. Consequently, they would not receive sufficient support in this regard

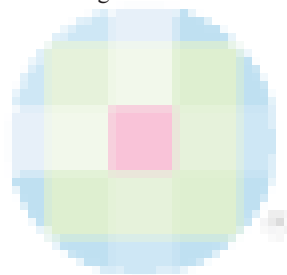


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Authors and publication year	Type of the study	Sample size	Place of the study	Data gathering tools	Results
Ekelin <i>et al.</i> (2008) ^[22]	Qualitative	Nine women and 14 men	Sweden	Interview	Results of the study showed “unpredictable change in the life” as the main theme with four subcategories including being deceived with the sense of peace of mind or fake security, facing the reality, sadness and grief, and re-informing. In fact, parents were not prepared for anomalies incompatible with life. Furthermore, in reaction to this crisis, they would realize that the sense of security that would guarantee the health of the fetus owing to technology and science advances has been false. Results of the study also showed that, despite the numerous presences of the caregivers, existence of a principle caring program is necessary
Davies <i>et al.</i> (2005) ^[23]	Cohort	30 individuals	London	Questionnaire	Results showed high levels of psychological distress in both groups of women following pregnancy termination due to fetal anomalies during the first and second trimester of pregnancy, and the total mean score of the “incidence’s impact” scale remained high during the entire follow-up period. In addition, women who experienced pregnancy termination during their second trimester had higher levels of post-traumatic stress six weeks after pregnancy termination. In general, results of this study showed that psychological complications following pregnancy termination due to fetal anomalies are common and long-term
Lalor <i>et al.</i> (2007) ^[19]	Qualitative	38 individuals	Ireland	Interview	Providing sufficient and in-time information immediately after diagnosis of the anomaly to the parents and referring to a fetal specialist for confirming the diagnosis of the anomaly were the most important request of the women after hearing the news about fetal anomalies. Observing additional documentations is necessary for better understanding and helping these women. Constant care from the caregivers and showing empathy in the current situation is valuable to these women. Results of this study emphasized on the role of nursing and midwifery specialists in providing principle and appropriate support in this situation
Geerinck-Vercammen and Kanhai (2004) ^[15]	Qualitative	89 couples	Netherland	Interview	Most of the parents had the ability to adapt with the decisions that were made in this situation. Feelings such as doubt, failure, guilt, shame, fury, and anxiety existed for a couple of weeks following pregnancy termination, but they were almost resolved in six months. They believed that the supportive role of the family and relatives was helpful during the recovery period.

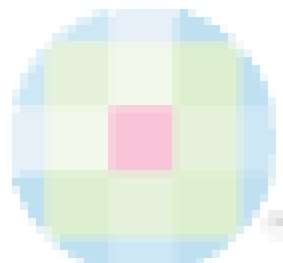


Table 1: Contd...

Authors and publication year	Type of the study	Sample size	Place of the study	Data gathering tools	Results
					However, they also stated that these supports were short-term. Results also showed that the role of medical and psychosocial supports that were provided by professional caregivers was valuable to these women and caused lower negative psychological reactions. In this study, women who chose to see and touch the fetus experienced less anxiety reactions and considered it as a confirmation for the diagnosis of the fetal anomalies. In general, results showed that women would experience less psychosocial complications in six months following pregnancy termination due fetal anomalies by receiving support from a specialized team, and after this period of time, they were able to bring back the balance of their life and live with this loss
Korenromp <i>et al.</i> (2005) ^[24]	Cross-sectional	254 individuals	Netherland	Questionnaire	Pregnancy termination due to fetal anomalies is associated with long-term complications in some women. Some of the determinants in these outcomes were gestational age, support from the husband, and the educational level
Cowchock <i>et al.</i> (2011) ^[17]	Descriptive exploratory	None mothers and five fathers	Carolina, America	Interview	The most important need of these women was guidance from a higher power or someone who would pray and cry for them to God. Unlike other patients, they did not expect to talk about their beliefs with the caregivers. They mostly wanted to receive support from their spiritual leader or hospital's priest
Andersson <i>et al.</i> (2014) ^[13]	Mixed method	31 individuals completed the questions, and 23 were interviewed	Sweden	Questionnaire and semi-structured interview	Professional supports along with the support of the husband or the presence of a friend or relative was effective in resolving the concerns and adapting to the situation. Before pregnancy termination, most of the women were not willing to see their fetus, but women who have seen their fetus considered this experience as a way for realizing the reality and an opportunity for saying goodbye to their child
Korenromp <i>et al.</i> (2009) ^[20]	Longitudinal	147 individuals	Netherland	Questionnaire	Four months after pregnancy termination, 46% of the women showed levels of post-traumatic stress that was decreased to 20.5% after 16 months. Regarding depression, these levels were 28% and 13%. Late-onset of the adaptation process usually would not occur. The outcomes during four months following pregnancy termination are mostly strong predictors for permanent undesirable psychological outcomes. Other predictive factors included low self-esteem, high levels of doubt in the process of decision-making, lack of support from the sexual partner, being religious, and advanced gestational age.

Table 1: Contd...

Authors and publication year	Type of the study	Sample size	Place of the study	Data gathering tools	Results
Fisher and Lafarge (2015) ^[16]	Qualitative	27 individuals	London	Online interview	The sense of remorse and regret about the decision was observed in 2.7% of the women. In addition, results of this study showed that pregnancy termination due to fetal anomalies had specific mental outcomes for more than one year after pregnancy termination in 20% of the women Women would mostly use coping strategies, but their experiences indicated lack of sufficient support after the incidence. Results of this study showed that indirect and sensitive cares are helpful in adapting with and accepting this special situation. Empowering women for attracting emotional supports, improving adaptation processes, and providing long-term supports might be effective in improving psychological adaptation with the conditions of pregnancy termination due to fetal anomalies

is supportive needs. These needs would be fulfilled by different groups who are related to the women. Most of the women would expect to be supported by their family and friends, and lack of sufficient support from these groups might be effective in their decision about seeking support from other resources.^[7,23] While the shame of the abortion and having an abnormal fetus might make women concern about others' judgment, they also would not be able to share their sorrow with others, and hence, they would not receive sufficient support in this regard.^[12] Women would mostly use coping strategies but their experienced revealed lack of sufficient support in this situation.^[25]

Losing the fetus, for any reason, might cause religious confusion for anybody, but in most cases, people would again manage their beliefs, and in most cases, it would lead to more closeness to God. In the study of Cowhock *et al.*, providing the necessary facilities for performing religious acts during the period of hospitalization was mentioned by the participants.^[17] These people believed that praying, vowing, repenting, and charity would increase individual's resistance and tolerance against the crisis and is a powerful resource for people that could increase the speed of their recovery.^[26] Some patients would consider their illness a divine experiment and believe that they could survive, if they would have strong believes. In the study of Sutan and Miskam, participants repeatedly reminded themselves that everything that happens is a test from God and believed that this reminding would decrease their sense of blame or guilt.^[14]

One of the limitations of the present study was lack of access to some of the databases and also the full texts of some of the articles. In addition, because in the field of losing the fetus and its related cares, mostly the focus has

been on abortion and intrauterine fetal death, eliminating studies on these topics was another limitation of the present study.

The results of the present study about different needs of women who have experienced pregnancy termination due to fetal anomalies can be used to make decisions and finding strategies to improve the quality of care and treatment services as well as training on the supporting role of the husbands, family members, friends, and peers.

Conclusion

Reviewing previous research showed that women who have experienced pregnancy termination due to fetal anomalies have different needs. Hence, educating healthcare providers and husbands, family members, friends, and peers for providing comprehensive cares tailored to the needs of these individuals to decrease their psychosocial outcomes seems necessary.

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Conflicts of interest

Nothing to declare.

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