Perceived Risk in Women with High Risk Pregnancy: A Qualitative Study

Abstract
Background: Risk perception in high-risk pregnancies influences the mothers’ adherence to medical treatments and recommendations. Because of the lack of information about the women’s perception of risk, the aim of this study was to explain perception of risk in high-risk pregnancies. Materials and Methods: This qualitative study was conducted on 25 women with a high-risk pregnancy in educational hospitals of Mashhad, Iran, from August 2017 to August 2018. Data were collected through semi-structured interviews and data saturation was reached after 29 interviews. Data collection and analysis were simultaneously carried out using the qualitative content analysis method adopted by Elo and Kyngäs in MAXQDA software. Results: Data analysis resulted in the four main categories of perception of risk control ability (risk controlling through experience, risk tolerance through relying on a higher power, and risk tolerance to reach family goals), wrong estimation of risk (wrong calculation of possible risks based on wrong beliefs and knowledge, and incorrect risk estimation caused by misunderstanding), possibility of mutual vulnerability of pregnancy and risk condition (possibility of vulnerability of the fetus to risk factors, and possibility of the mother’s vulnerability to risk factors), and induced risk (risk induced by negative experiences, induced threat of unknown pregnancy outcome, and fear of ambiguous medical terms). Conclusions: The results of this study promoted our understanding of risk perception in women with high-risk pregnancies. Therefore, it will help to establish a better link between women with a high-risk pregnancy and the health team, enhance and improve maternal and fetal care.

Keywords: High Risk, Iran, pregnancy, qualitative research, risk assessment

Introduction
High-risk pregnancies are accompanied by a sense of fear and loneliness caused by stress. Risks have a mental structure, which is influenced by perceptions and expectations;[1] previous life experiences, adaptation strategies, the context in which risk occurs, the degree of perceived control, and the information received from various sources.[2] According to the researchers, factors affecting risk perception in nulliparous women include pregnancy anxiety, gestational age, medical risks, perceived internal control, and maternal age.[3] Perceived risk severity depends on several factors. Deficiency of women’s knowledge and mothers’ attitudes regarding maternal risk factors,[4] medical risk, psychological elements, clinical characteristics of the risk, gestational age, and healthcare providers’ perspectives are the factors influencing the level of risk perception.[5]

The severity of risk perception is effective on attitude toward treatment, maternal decisions in pregnancy, and adherence to medical procedures and recommendations.[6] The acts of mothers during pregnancy are to maintain their health and that of the fetus, but this does not necessary guarantee conformity to all medical advice.[7] Women ignore the recommendations that they did not believe in.[8] Risk is based on biomedical factors from the perspective of experts, and according to the perspective of nurses and midwives, pregnancy and childbirth is a natural process in life.[6] Risk perception during pregnancy is personal, and is not exclusively based on medical diagnoses.[7] Health service providers’ perceptions are affected by religious backgrounds, and their scope of practices and training and values. Pregnant women’s risk perception is personal[8] and affected by concerns for the wellbeing of their babies.[9] Therefore, risk may be perceived differently by healthcare providers and pregnant women, which is influenced by perceptions and experiences.
resulting in misjudgment, problems in interacting, and consequently, dissatisfaction of healthcare supervision.\(^\text{[10]}\)

If women feel that their concerns are unrecognized, they interact less with health services, and this can potentially be associated with increased risk. Better understanding of risk perception of pregnant women may improve the prediction of health behavior during pregnancy, and help healthcare providers identify risk dimensions that could increase the effectiveness of prenatal interventions. There are few studies that highlight the experiences of high-risk women during pregnancy and too little is currently known about women’s perception of pregnancy risks in Iran. Hence, the qualitative content analysis method was used to explore perceived risk issues among women with a high-risk pregnancy. The purpose of this study was to explore and describe the risk perception of women with a high-risk pregnancy.

Materials and Methods

The current study was a qualitative research that used conventional content analysis approach. This study was conducted on 25 women with high-risk pregnancies in Mashhad, Iran, from the 20\(^{th}\) of August 2017 to 30\(^{th}\) August 2018. The participants were selected using purposeful sampling method from among women referred to health centers and educational hospitals. The study inclusion criteria included Iranian women with high-risk pregnancies, awareness of the risk before pregnancy, wanted pregnancy, interested in expressing experiences, ability to communicate verbally to provide the researcher with detailed information. Moreover, the exclusion criterion was the existence of any congenital fetal abnormalities during the pregnancy.

Semi-structured, face-to-face interviews were conducted in one of the rooms of the health center or hospital in a quiet environment for the duration of 25–50 min. The first author conducted all interviews after completing the required certification and gaining the approval of professors in this field. In the beginning, the interviewer assured the participants of that their data would remain confidential and explained the purpose of the study and recording of interviews. The interviews started after obtaining informed consent from the participant and continued until data saturation (when no new data was obtained).

The interviewer began with an open question such as: “Has anything worried you so far during this pregnancy? What is this?”, and continued the interview with targeted questions on risk perceived structure (such as, “Did you find anything difficult during the pregnancy? Why? How did you imagine your pregnancy? “What was not as you thought it should be?” “What do you think about medical advice regarding the risk of pregnancy? Can you explain in more detail?”). Interviews were repeated for participants 4, 5, 8, and 16 in order to obtain further explanations and data on the women’s percept. Data saturation was reached after 29 interviews with 25 women with a high-risk pregnancy.

The inductive content analysis method of Elo and Kyngas was used for the analysis and interpretation of textual data, which consisted of preparation, organization, and reporting phases.\(^\text{[11]}\) The interviews were audio-recorded, and then written and analyzed. In the preparation phase, each interview was transcript verbatim and each text was read several times to insure immersion in the data. In the organization phase, the transcripts were reviewed several times according to the context of the finding and perceived risk structure in order to explore the content related to the perceived risk category. According to the definition of risk perception, the concept was coded based on the preliminary meaning units. After emerging of codes, similar codes were categorized, and then the main subcategories and categories were obtained. The final category was formed after the final agreement was reached between the research team members.

The Guba and Lincoln criteria were used for the rigor of findings.\(^\text{[12]}\) Interviews were performed with participants with maximum variation in terms of risk factors (sort of disease, age, parity, and pregnancy history). Moreover, the accuracy of data and code extraction was reviewed by participants and were corrected if necessary in order to improve the credibility of data. To enhance dependability, two external reviewers appraised the data and relevant supporting documents for accuracy, and confirmed them. To ensure transferability, we presented participants’ reported experiences during the study to other women with a high-risk pregnancy and their opinions were obtained. To ensure confirmability, data collection and data analysis were continuously recorded step by step, so that other researchers can review all the steps. The MAXQDA software (version 10; VERBI Software GmbH, Berlin, Germany) was applied for data processing.

Ethical considerations

This research was approved with ethical code IR.MUMS.REC.1396.126 in Mashhad University of Medical Sciences, Iran. Ethical considerations were observed by taking informed consent from the participants and permitting them to leave the study whenever they wanted. All participants were informed of the procedures and objectives of the study and they were assured that their information would remain confidential.

Results

The participants’ demographic data are presented in Table 1. From the data, four main categories and 10 subcategories were extracted. The four categories extracted included perception of risk control ability, wrong estimation of risk, possibility of mutual vulnerability of pregnancy and risk condition, and induced risk. The subcategories of the main categories are listed in Table 2.

Perception of risk control ability

Most women perceived themselves as prepared to accept risk and had a good sense of control ability both in terms of their life situations and their health.
Risk controlling through experience

Previous information and experience was the most common subject that women accepted the risk relying on it. Women claimed that they are able to deal with the risk and risk is not unbearable, because of the experience that they had gained from the pregnancies of others or their previous pregnancy. They had become pregnant with the perception that this experience would help them control the risk. “I am a little worried because of my age. I am 41 years old, but I myself had a patient who was 44 years old, she came here to give birth. Her baby had no problems. It was healthy. Also, I have information and experience after two pregnancies; I will do screening tests and no problem will occur,” Participant 1 (P1).

Risk tolerance to reach family goals

Other issues to controlling risk in women with a high-risk pregnancy were the prioritization of maintaining family, and fulfilling the goal ofchildbearing. Some women prioritized achieving of family goals over the risks. Goals such as meaningful living with a child, trying to solve marital problems by having a child, and achieving married life goals. “I wanted a baby, I got pregnant..... I love babies, pregnancy is good, you get busy, life without a baby has no meaning, it is not good, and having a baby makes everything alright” (P20).

The purpose of this pregnancy for some women was to maintain their family and trying to solve marital problems by having a child. “I and my husband wanted a baby....., it was important for my husband to have another child. If I did not get pregnant, we would have had more problems. For this reason, I did not consult with a doctor before getting pregnant” (P4).

Another reason for pregnancy in at risk women was purposefulness of pregnancy in marital life. “Pregnancy is a big goal for me, I am pursuing it, and I strive to achieve my goal. This is mostly for my husband; he accepted me despite my illness and married me, he loves me and I love my life and want to get pregnant. My husband has the right to have children” (P9).

Risk tolerance through relying on a higher power

Other sources through which a great number of women controlled risk was turning to God, having a risky personality, and being financially fit. Turning to God at all stages, from the decision to get pregnant to pregnancy, and the time of occurrence of problems, has been mentioned as a spiritual asset in all women. “I relied on God from the very beginning and became pregnant, so I was sure there would be no problem, and although the doctors said that pregnancy is a risk for you, no serious problem occurred” (P4).
Table 2: Generated categories and subcategories

| Codes                                                                 | Subcategories                                                                 | Main categories               |
|----------------------------------------------------------------------|------------------------------------------------------------------------------|--------------------------------|
| Risk contrallability through repeating pregnancy problems             | Risk controlling through experience                                          | Perception of risk control ability |
| Risk contrallability through overcoming previous problems             | Risk tolerance through relying on a higher power                             |                                |
| Risk tolerance through having a risky personality                     | Risk tolerance to reach family goals                                          |                                |
| Risk tolerance through having enough money                            | Wrong calculation of possible risks based on wrong beliefs and knowledge     | Wrong estimation of risk        |
| Risk tolerance through turning to god                                  | Incorrect risk estimation caused by misunderstanding                         |                                |
| Risk tolerance for having a child and meaningfulness of life          | Possibility of vulnerability of the fetus to risk factors                    |                                |
| Believing in poor pregnancy outcomes due to maternal nutrition       | Possibility of the mother’s vulnerability to risk factors                    | Possibility of mutual vulnerability of pregnancy and risk condition |
| Believing in Fetal abnormalities due to maternal behavior in the past | Possibility of increasing vulnerability to risk factors                      |                                |
| Believing in usefulness of pregnancy in curing some diseases         | Risk of recurrent negative pregnancy experience                              | Induced risk                    |
| Lack of doctor’s advice, unpredictable risk                           | Risk appearance of adverse pregnancy outcomes in others                       |                                |
| Not prescribing medication, Unpredictable risk                         | Fear of unexpected adverse events during pregnancy                           |                                |
| Possibility of disease transmission from the mother to the fetus and child | Worried about the ahead uncertainties during the pregnancy                 |                                |
| Possibility of abortion associated with maternal risk factor         | Fear of specialized medical terms applied by the health team                 |                                |
| Possibility of prematurity associated with maternal risk factor      | Fear of medical terms recorded on the ultrasonography                        |                                |
| Possibility of worsening of disease during pregnancy                 |                                                                             |                                |
| Possibility of harmful effects of pregnancy on maternal health       |                                                                             |                                |
| Possibility of death during childbirth                               |                                                                             |                                |
| Risk of recurrent negative pregnancy experience                       |                                                                             |                                |
| Risk appearance of adverse pregnancy outcomes in others              |                                                                             |                                |
| Fear of unexpected adverse events during pregnancy                    |                                                                             |                                |
| Worrying about the ahead uncertainties during the pregnancy          |                                                                             |                                |
| Fear of specialized medical terms applied by the health team         |                                                                             |                                |
| Fear of medical terms recorded on the ultrasonography                 |                                                                             |                                |

Some women believed that they have always been risky in life, so they can also overcome this risk by using appropriate solutions, and it will not be a problem. “After the heart surgery, the doctor said you should never get pregnant I gave myself hope in this situation, and told myself that if other women can become pregnant and live through it, so can I. They said that you must be hospitalized for some time during pregnancy…. I told myself that I can do it” (P5).

According to the women’s opinion, a high-risk pregnancy requires more referrals, tests, and treatments, which mean higher costs than normal pregnancies, and thus it requires the financial resources of the family. Therefore, women who had financial problems, despite the advice of their doctor, had chosen the time of pregnancy according to their financial conditions. “During pregnancy, I had to be controlled and take drugs for my blood pressure, but all is good when there is money. I had no money for my previous pregnancy, I had problems, but this time I had money…… I can also buy the drugs and take the medication I need” (P7).

Wrong estimation of risk

Some women misinterpreted the information they were given. There was difference between the term “risk” and expected real threat.

Wrong calculation of possible risks based on wrong beliefs and knowledge

Some women had gained wrong information from the community and wrong beliefs about the risk of their conditions, and this had led to misconception of risks including the women’s conditions. “I knew that pregnancy was not good for my heart, but as soon as I got married, I took no contraception in order to get pregnant, because people say that if you take contraception, it may lead to infertility” (P9).

Some women do not believe the medical advice they receive and do not seek medical services because of fear of gaining information and the possible problems. They believed that fetal diseases have increased and by gaining information, these problems may occur for them. “Heart diseases are more common than brain diseases in the fetus. Now I have no stress at home and no bad history…… So, if I seek information for these problems in the fetus, my baby’s heart may be perforated” (P15).

Some women believed that risk cannot be prevented during pregnancy, so there was no reason to do many tests before the pregnancy. They believed that if a problem is meant to occur, there is nothing they can do: “Even if I was sure I would get pregnant next month, I might still not be looking
to prevent fetal abnormalities anyway because I think that nothing can be done” (P1).

Incorrect risk estimation caused by misunderstanding
Some women believed that it was not possible to obtain feedback between them and the physician at the least time, and so they would have to wait until the next visit. Therefore, they have to interpret the doctor’s recommendations for themselves and act accordingly. Thus, the recommendations may be interpreted very differently by the women and most of the women interpreted the recommendation in their favor and considered the risk to be lower for themselves. “Pregnancy does not make heart disease worse because the doctor said ...should have delivery in a special hospital for cesarean section and should be monitored in the hospital’s intensive care unit for up to 24 hours after delivery.... it does not hurt me much; if it was life threatening, I would not get pregnant” (P10).

Possibility of mutual vulnerability of pregnancy and risk condition
Some women may recognize that their condition presents a degree of risk to their wellbeing and/or that of their babies.

Possibility of the mother’s vulnerability to risk factors
The factor which was most worrisome for women with a high-risk pregnancy, and a secondary condition was vulnerability to their condition and disease. The maternal health threat was caused by pregnancy and worsened the disease, and resulted in infertility; thus, the mother endured more pregnancy complications because of risk factors. “During my pregnancy, nausea has increased. I am always worried that something will happen. Under these conditions, my asthma attacks may increase. Tolerating pregnancy is so difficult for me” (P11).

Possibility of vulnerability of the fetus to risk factors
The possibility of malformations, premature birth, fetal death, and transmission of the disease to the baby were the mothers’ concerns for the fetus in this study. “I have diabetes. The doctors say that my baby may have diabetes in the future; the possibility is low, but it may happen. I am more worried about this” (P4).

The mothers were less concerned about fetal malformations because of performance of screening tests, but women of over 35 years of age and women who used medication during pregnancy had concerns about the occurrence of fetal malformations because of these risk factors. “I have to always take warfarin. I have been using heparin from 6th weeks, but heparin is also a drug that has its own side effects and can cause problems in the baby, such as problems in the hands or feet” (P10).

Induced risk
There were multiple conditions that led to further understanding of the risk. This depends upon the meaning of obstetrical conditions and the verbal and nonverbal messages received from the healthcare team.

Risk induced by negative experiences
The perceived risk in some women was not related to their high-risk pregnancy, but to their environmental conditions or lack of knowledge. Some women believed that any negative experience during their previous pregnancy or that of others and only heard of could be a cause of stress and lead to a greater feeling of risk. “I still have fear, because I see so much. I search the internet, and I see problems in the photos of fetuses. Our company engineer has a 3-year-old child with a tiny hole in his heart ....; I am always concerned that my child might have problems even though everything was normal in the sonography” (P15).

Induced threat of unknown pregnancy outcome
Some women were concerned about the unknown outcome of pregnancy. Concerns such as an emergency event may occur during the pregnancy, the doctor may not be available, the test results may be wrong and the baby may be born with anomalies, an unexpected problem may occur at the time of delivery, and other ambiguities about the outcome of pregnancy led to increased perceived risk in some women. “I am scared, I do not know what might happen, the doctor may not be available, test results may be wrong, or I may tolerate pain, and then, have to perform cesarean. I would like to have a friend with me: I am scared that a problem may occur on the day of my delivery” (P6).

Fear of ambiguous medical terms
Medical terms exchanged between health personnel and during the sonography that are incomprehensible for some women lead to increased fear and risk perception of the current condition. “I was scared of the sonography notes. I saw that it was written that no anomaly was seen in long bones; I always expected that something be seen, not that nothing would be seen. Every time I go for ultrasound or a test, I am fearful of these notes” (P21).

Specialized treatments recommended for women with a high-risk pregnancy, which differ from that recommended for other mothers, or was just asked for high-risk mothers, and led to a greater sense of risk. “When I went to the health center; “High-Risk Mother” was stamped on my notebook. I was so scared. They told me to refer to a specialized hospital, but they did not tell the other mothers. I did not know what that meant for me, and no one explained it to me” (P24).

Discussion
The main aim of this study was to explain perceived risk in women with high-risk pregnancies. The results showed that mothers interpret pregnancy risk for themselves within the context of their beliefs, values of life, and knowledge gained from their surroundings; thus, women’s risk perception was reported as threat and vulnerability of the
fetus and mother, wrong estimation of risk, perception of risk control, and induced fear.

All of the participants in our study perceived vulnerability to a variety of risks, including problems during pregnancy and delivery. Adverse consequences for the mother and fetus included threat to the wellbeing of the mother and fetus, fetal or maternal death, preterm birth, malformation, need for Intensive Care Unit (ICU), and others. A study conducted on high-risk women in Canada achieved results similar to that of our study.[7] Furthermore, worsening of the disease with pregnancy and disease transmission to the baby were reported in the present study. Fetal health concerns including abnormalities, prematurity, fetal death, and disease transmission in the case of maternal disease have been reported in previous studies.[13‑15] Perception of medication risk was also reported in our study. In line with our findings, it is reported that risk perception in mothers who used medication included side effects of the drug on the fetus.[16]

Wrong estimation of risk was one of the categories of risk perception in our study. Incorrect perception occurred following wrong beliefs and knowledge. Individuals’ perception of the world around them is the result of knowledge obtained from the environment and evaluation of this knowledge. In a review study, researchers found that high-risk mothers of over 35 years of age sought pregnancy information from other sources in the community because of inappropriate interaction of healthcare providers, which increased the likelihood of receiving false information about pregnancy.[14] In another study, women had more or less perceived risk compared to healthcare providers, because care providers consider risk only based on medical risk, but mothers calculate risk in the context of other aspects of life such as family, job, and the information received from different sources.[2] Another study showed that limited information and not receiving the vaccine resulted in lack of consent to receive vaccination.[17] In relation to the incorrect perception of the risk of alcohol use during pregnancy, another study found that physicians and healthcare providers sometimes encouraged women to use low doses of alcohol for relaxation.[18] Sex partner, family, friends, and inadequate information of healthcare providers and the internet contributed to incorrect perception of the risk of alcohol use, and low knowledge with low perception about the risk of AIDS in pregnancy,[19] which is consistent with the present study findings. In our study, women gained their information during pregnancy from various sources including internet, associates, healthcare providers, and community beliefs. Incorrect perception was because of incorrect information or lack of sufficient information as a result of misunderstanding or lack of referral to a doctor.

Our results showed that the perception of risk control had led to choosing to become pregnant despite the high-risk condition. Participants believed that risk is controllable through relying on resources such as experience, money, risky personality, and turning to God. These women prioritize between the recommendations for childbearing and their needs, and the effects of treatment on different areas of life. Given that childbearing for women is one of the most important goals of marital life, they use different strategies and apply recommendations they believe best for their family life. In line with our findings, in some studies, becoming a mother had increased self-esteem and hope of improvement of disease.[10,21] Moreover, other causes of women’s efforts to become pregnant were social expectations of women and their duty for bearing a child and achieving social value.[22] Furthermore, in our study, achieving the purpose of marital life was a high priority, despite the risk. Previous pregnancy experience was another source that participants relied on for overcoming pregnancy problems and managing the risks. In a study on women with heart disease in Ghana, most women, who had successful previous pregnancies and their husbands believed that more fertility was possible, even despite their physicians’ recommendation.[23] Another study showed that religious beliefs helped in coping with a high-risk condition in pregnant woman.[3] Elements constructing women’s perceived control resulted in decreased risk perception and preparation for pregnancy complications.

Some participants perceived risk because of induced fear. In our study, negative experiences of women caused by the negative experiences of others or previous pregnancies led to increased risk perception. The recommendations of other mothers who had similar experiences are more trustworthy than the recommendations of healthcare providers.[2] Thus, if the experience is negative, it leads to increased maternal fears. Moreover, medical care and confronting ambiguous medical terms increased maternal fears. Researchers believe that maintaining safety at birth leads to a range of interventions, resulting in an increase in anxiety and fear.[24] In a study based on social show theory, most perceived risk in mothers was when the mother was referred for more specialized measures, or hospitalized without the mother’s knowledge and understanding of the circumstances, or when prenatal care was done specifically for the mother.[25] In our study, referral to specialized centers, repeated referrals to various specialists, and special prenatal care for high-risk pregnancies led to a greater sense of risk. In a study, risk of drug exposure in pregnancy overestimated by family physician residents.[26] In another study in Switzerland, gynecologists, midwives, pediatricians, and pharmacists had over-perception about the risk toward teratogenicity of the drugs, which led to inducing this fear to pregnant women,[27] which is inconsistent with our findings. Common hearings or unbeknown medical words used by personnel had led to induced risk in our study, this indicates the need for these women to have more specialized training and training specific to each mother’s condition.

One of the limitations of this study was the difficulty of interviewing some women because of the lack of sufficient time and illiteracy. Other high-risk pregnant women
requiring hospitalization did not participate in the study, which was another limitation of the study. Exploring perceived risk specifically in high-risk pregnancies was the strength of this study that will enable mothers to have a clearer understanding of risk perception in clinical risk management by professional care providers.

**Conclusion**

All women with high-risk pregnancies perceived the risks for the fetus and mother uniquely based on their personal, family, and social life individually. Past negative experiences, fear of unknown pregnancy outcomes, and ambiguous medical terms were more likely to be perceived as risk. Protective resources for controlling the risk were less likely to be perceived as risk. An analysis of the concept of risk perception may help professionals and midwives to determine the factors that make pregnant women feel at risk. Future research can help the better understanding of risk by determining what information about risk is obtained during the decision-making process, and how to professionally assess risk and develop risk perception standards. This research will establish a better link between women with high-risk pregnancies and the health team, and thus, enhance and improve maternal and fetal care.

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**Conflicts of interest**

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