



## Vulnerability of high-risk pregnancy in the perception of pregnant women and their families

Vulnerabilidade da gravidez de alto risco na percepção de gestantes e familiares

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**Objective:** to describe the perception of pregnant women and their relatives about the vulnerability of a high-risk pregnancy. **Methods:** qualitative research with eight pregnant women and ten relatives. Data were collected through semi-structured, audio-taped interviews, which, after transcription, were submitted to content analysis in the thematic modality proposed by Bardin. **Results:** three categories emerged: Experiences of relatives and pregnant women in relation to the diagnosis of a risky pregnancy; The family as the structuring axis of care in a high-risk pregnancy; and Invisibility of relatives in prenatal care. **Conclusion:** both the relatives and the pregnant women experienced worry, anxiety, fear and stress in the face of vulnerability, but the pregnant women perceived themselves to be more protected and safer with the support of the family, which although did not perceived to be valued by health professionals during prenatal consultations, plays an important role in encouraging and supervising care during pregnancy.

**Descriptors:** Pregnant Women; Prenatal Care; Pregnancy, High-Risk; Family; Health Vulnerability.

**Objetivo:** descrever a percepção de gestantes e familiares sobre a condição de vulnerabilidade de uma gravidez de alto risco. **Métodos:** pesquisa qualitativa realizada com oito gestantes e dez familiares. Os dados foram coletados por meio de entrevistas semiestruturadas, audiogravadas, que após transcritas, foram submetidas à análise de conteúdo, modalidade temática proposta por Bardin. **Resultados:** emergiram três categorias: Vivências do familiar e da gestante frente ao diagnóstico de uma gravidez de risco; A família como eixo estruturante do cuidado em uma gestação de alto risco; e a Invisibilidade do familiar no acompanhamento pré-natal. **Conclusão:** tanto familiares como gestantes vivenciam preocupação, ansiedade, medo e estresse frente à condição de vulnerabilidade, porém, as gestantes se percebem mais amparadas e seguras com o apoio da família, que embora não se percebe valorizada/considerada pelos profissionais de saúde durante as consultas de pré-natal, tem papel importante no incentivo e fiscalização dos cuidados durante a gestação.

**Descritores:** Gestantes; Cuidado Pré-Natal; Gravidez de Alto Risco; Família; Vulnerabilidade em Saúde.

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## Introduction

Gestation is a physiological phenomenon and its evolution occurs, in most cases, without interurrences. However, approximately 10.0% of the pregnancies present risk situations related to the previous reproductive life and/or factors associated with the current gestation, which require specialized monitoring<sup>(1)</sup>. Among these women, the prevalence of deaths in the intrapartum and postpartum periods stands out<sup>(2)</sup>. The possibility of developing complications by itself already implies the need for greater attention to maternal-fetal health throughout the puerperal-pregnancy cycle for all women, especially those at higher risk.

In Brazil, women's health care policies are among the ones that most received financial investments in the last decades. Strategies to improve the quality of care offered have been discussed with the implementation of the Program of Comprehensive Care to Women's Health since 1984. In 2000, the Program for Humanization of Prenatal and Birth Care was implemented, and a drop of 51.0% in the number of maternal deaths has been observed since then. In 2011, the Stork Network was implemented with the objective of increasing the quality of maternal and child care, with emphasis on risky pregnancies<sup>(3)</sup>. In the state of Paraná, from 2012, with the implantation of the *Rede Mãe Paranaense* (Paraná Mother Network), pregnancies began to be stratified according to the presence or absence of risk factors into low, intermediate and high risk<sup>(4)</sup>. According to this Program, pregnant women classified as being at high and intermediate risk need to be monitored simultaneously by primary care teams and referral services<sup>(3-4)</sup>.

Thus, although the implementation of these policies has resulted in well-established medical procedures and protocols and in the assurance of qualified care, women still feel insecure, fearful and powerless sometimes, denoting the veiling of science to the subjective dimension<sup>(5)</sup>, causing damage to the maternal health and, consequently, greater vulnerability. The notion of vulnerability understood here seeks to consider, in addition to the risks, the effects of the interlacing between individual and contextual conditions in the exposure of pregnant women not only to diseases, but

also to suffering and to the limitation of potential to cope with unfavorable situations<sup>(6)</sup>.

Several studies have already addressed the experiences and perceptions of high-risk gestation<sup>(5-9)</sup>, but most correlate the perception of gestation with a specific obstetric problem. Few current studies deal with the subject discussed here. Among them, some studied the daily routine of a high-risk pregnancy from the perspective of pregnant women<sup>(5)</sup>, the therapeutic itinerary of pregnant women at high risk<sup>(7)</sup>, emotional support to pregnant women<sup>(10)</sup> and adolescence as a risk factor<sup>(11)</sup>. In these studies, the susceptibilities of pregnant women were not addressed in the perspective of vulnerabilities, although some considered factors other than the biological ones. Thus, considering the relevance of health care that transcends biological and individual aspects and valuing comprehensiveness as a guiding principle of care, the objective of the present study was to describe the perception of pregnant women and of their relatives about the condition of vulnerability implied in a high-risk pregnancy.

## Methods

This is a qualitative study carried out in a municipality in the northwest of Paraná, Brazil. The healthcare network to pregnant women in the city consists in six Basic Health Units, two polyclinics which are reference for high-risk and intermediate-risk pregnancy (place where the pregnant women were initially approached in this study), an emergency unit, and a hospital.

The informants in the study were pregnant women and their relatives. The criteria for inclusion of pregnant women were: women in the third trimester of high-risk pregnancy according to the *Mãe Paranaense* Network, especially related to the presence of diseases prior to gestation and clinical interurrences during the current gestation<sup>(4)</sup>, and women who had already attended at least two consultations in the referral service. For the relatives, the inclusion criterion was indication by the pregnant women as having a significant presence/role during their pregnancy. The time of prenatal follow-up is important because it allows the report of care in the referral service. Women with problems

that made their participation difficult and of relatives under 18 years old were to be excluded, but such cases were not observed.

Access to family members occurred after contact of the principal investigator with the pregnant women in the waiting room of the two polyclinics. Thirteen pregnant women were invited to participate in the study. At the moment of the invitation, the objective of the research was presented and the women were asked about which relative was most present during the gestational period. After acceptance, the clinical diagnosis was confirmed in the records of the Polyclinics and the most appropriate day and time were scheduled with the pregnant women and their relative(s) to perform the interview at the home by the principal investigator.

Of the 13 invited women, two refused, alleging lack of availability of the relative. Two other women did not meet the inclusion criteria (one was in the second trimester and one had attended only one consultation at the high-risk outpatient clinic) and one woman was hospitalized for childbirth at the time of the visit for the interview. New participants were included until the information of interest was complete, that is, when it was observed that the content of the interviews became repetitive and further data collected added no new information to the understanding of the phenomenon. When this was detected, the search for new informants ceased<sup>(12)</sup>. Thus, 18 people (eight pregnant women, five husbands, three maternal grandmothers and two maternal grandfathers) participated in the study.

Data were collected in July 2018 through semi-structured interviews, audio-taped after authorization. The pregnant woman and her relative(s) were present during the interview, as it was considered in this study that the understanding about the vulnerability of the pregnant woman was the product of a construction and the experience as family. All interviews were conducted by the same researcher. They lasted from 30 to 45 minutes and during this time, an instrument elaborated by the first author was used to guide the interview. The instrument was initially applied to two women with normal risk pregnancy to check the understanding of the questions, which were reformulated after presentation and discussion in group of the research

group of the supervisor:

The instrument used in the interviews consisted of two parts: one with objective questions about the characterization of the participants, and the other with the following guiding questions: Were you informed about why the prenatal care should be performed in the Polyclinic and not in the Basic Health Unit? Talk about it. How has it been for you to live with the condition of risk during pregnancy?

The interviews were transcribed verbatim by four of the authors and submitted to content analysis in the thematic modality<sup>(13)</sup>, respecting the steps pre-established by the methodological framework, covering pre-analysis, material exploration, and data processing<sup>(12)</sup>. Three categories emerged from this process: Experiences of relatives and pregnant women in relation to the diagnosis of a risky pregnancy; The family as the structuring axis of care in a high-risk pregnancy; and Invisibility of relatives in prenatal care.

It should be pointed out that, in order to obtain greater methodological rigor, during the analysis of the data, the emerging results were peer reviewed and the researchers' previous conceptions were left in aside so as to avoid their direct impact on the analysis.

Ethical precepts established by Resolution 466/2012 of the National Health Council were respected. The study was approved by the Standing Committee on Ethics in Research with Human Beings of the State University of Maringá under Opinion nº 2,797,554. All participants signed two copies of the Informed Consent Form and to ensure their anonymity, the pregnant women and their relatives were identified according to the order of the interview, degree of kinship, and risk status of the pregnancy, e.g. R1, Maternal grandmother of the pregnant woman with gestational diabetes - to identify the relative; and P1, gestational diabetes - to identify the pregnant woman.

## Results

Eighteen participants were interviewed; eight were pregnant women and 10 were relatives. Figure 1 presents information about the pregnant women, confirmed in the medical records of the Polyclinics, and the degree of kinship of the relatives.

Order of interview	Risk condition of the pregnant woman	Gestational age (weeks)	Age of the pregnant woman (years)	Nº of the current gestation	Relative(s) participating
R1	Hypertension and diabetes mellitus	32	18	1 <sup>st</sup>	Husband, maternal grandparents
R2	Cardiopathy and hypertension	35	35	3 <sup>th</sup>	Maternal grandmother
R3	Previous abortion and depression	30	20	2 <sup>nd</sup>	Maternal grandfather
R4	Diabetes, syphilis, history of pregnancy with low birth weight newborn, preterm labor, and obesity	36	32	6 <sup>th</sup>	Husband
R5	Endometriosis, polycystic ovaries, deformity of fallopian tubes, and hormonal problems	32	34	1 <sup>st</sup>	Maternal grandmother
R6	Gestational diabetes	36	38	2 <sup>nd</sup>	Husband
R7	Previous abortion and asthma	31	22	4 <sup>th</sup>	Husband
R8	Hypothyroidism	37	20	2 <sup>nd</sup>	Husband

**Figure 1** – Characteristics of the pregnant women according to risk condition, age, ordinal number of the current gestation, and relatives interviewed

### Experiences of relatives and pregnant women in relation to the diagnosis of a risky pregnancy

In the report of their perceptions about vulnerability, relatives and pregnant women with pre-existing clinical conditions showed difficulty in accepting the gestation, considering the possible obstacles/difficulties that this prior condition could cause during the evolution of the pregnancy-puerperal process: *We told her: be careful to not get pregnant, because this problem of yours has already caused lots of trouble. She was always hospitalized, we were the ones who accompanied her all the time and we always warned her; we asked her. She was going to do the bariatric surgery, but when the surgery came up, she had nausea and we discovered the pregnancy* (R2, Maternal grandmother of the pregnant woman with hypertension, cardiopathy and obesity). *It was not planned, but it happened, I was scared because of that problem of my girl, because in her case, I was younger, but what can we do now? We have to deal with it* (P4, Diabetes, syphilis, history of pregnancy with low birth weight newborns, preterm labor, and obesity).

In dissonance, the pregnant women and the relatives who discovered the risk of the present gestation had a more welcoming attitude towards it. However, they experienced worry, anxiety, fear and stress in the face of lack of knowledge of what could the new condition cause and to which extent it impact on the life of the pregnant woman

and the newborn: *He said like this [referring to his wife], your diabetes is 127, he said that the baby could be suffering in the womb because she had diabetes, which was very altered, she came out crying and I was shocked because the baby could be a super baby, that could die* (R4, Husband of the pregnant woman with Diabetes, syphilis, history of pregnancy with low birth weight newborn, obesity, and previous abortion). *The pregnancy was going very well until I went to do the ultrasound and the doctor said a lot of things; at that time I was almost crying, we were desperate, we went to the doctor and he said he would try to control with food, if it did not work I would have to use medicines* (P6, Gestational diabetes).

It is worth considering that, regardless of whether the risk was pre-existing or diagnosed during pregnancy, all the relatives were cooperative in the care of the pregnant woman, being present and offering support in this moment of physical and emotional fragility, minimizing the context of vulnerability, which gave rise to the second category.

### The family as the structuring axis of care in a high-risk pregnancy

The relatives showed concern about the risk condition and were always willing to be together with the pregnant women, accompanying them whenever possible in consultations or examinations and also guiding the daily

care with pregnancy: *I want to be close, I want to know what is happening. This Friday for example she has a consultation and I've already told her I'm going with her. The day she will have the baby, I also said in my work, I have five days off, I'll be there every day* (R6, Husband of the pregnant woman with diabetes). *I went with her a few times; when I'm not able to go, her husband goes. Sometimes, if the husband can't, a friend goes, she never goes alone, we like to be close, aware of all things* (R5, Maternal grandmother of the pregnant woman with endometriosis, polycystic ovaries and hormonal problems).

The presence of the family in the care of the women during pregnancy, especially when there is a risk condition, was perceived by the pregnant women as positive, assisting in their daily activities and providing them support in times of need: *Yesterday I wasn't feeling very well, then he [husband] made the dinner and helped me with my boy* (P8, Hypothyroidism). *She [referring to the mother] takes very good care, she supervises me, the food she does it, and it's almost without salt because of me* (P2, Heart disease and hypertension).

Family support for day-to-day care is essential especially in circumstances in which pregnant women do not appreciate the risk and the need for care. This can make them more prone to the complications of their condition, which can lead to damage to the life of the pregnant woman and the child. Some family members expressed these circumstances: *Like yesterday she carried the gas cylinder; I told her ... and she said that it was not heavy, but it is, she has to take care of herself* (R1, Maternal grandfather of the pregnant woman with hypertension and diabetes). *These days I went in the consultation with her and she was riding a motorcycle, then I told the doctor: 'Is it ok for her to ride a motorcycle?' And he said this: 'Quite the contrary, pregnant women cannot ride a motorcycle at all.' I had to tell him, because it's dangerous ... Her husband now takes her to the bus stop and she goes by bus* (R5, Maternal grandmother of the pregnant woman with endometriosis, dysfunction of fallopian tubes, and hormonal changes).

However, some relatives did not recognize the condition of vulnerability and thus could not size the risk to the health of the mother-child binomial, which may denote a lack of guidance about the presence of the disease: *Nothing has changed in our lives because for me, as I told her; this is not a risk, there are a lot of other things that would be risky ... this pregnancy is being very soft* (R7, Husband of the pregnant woman with second pregnancy with hypothyroidism). *The doctor wrote on the card, high risk, but he did not say anything, problems, he said that everything was okay with the baby, that she was okay, everything normal, so I guess I do not have risks* (R8, Husband of the pregnant woman with asthma and previous abortion).

In summary, in this category, it was possible to identify the family as an agent to which care is extended, showing concern about the condition of gestational risk, willingness to help and to be on the side of the woman, alerting about daily care as well as. The positive perception of the pregnant women regarding the care given by their families was also evident.

### Invisibility of relatives in prenatal care

The presence of the relative during the prenatal consultations, in the perception of the pregnant women and of their family members, is an important dimension of the care in case of high-risk pregnancy. This is because the family almost always received the information and acted as supervisor of the follow-up of the guidelines provided by health professionals, which may stimulate and favor self-care. In the present study, it was observed that most of the family members recognized the need for a differentiated follow-up for high-risk pregnancies, as well as the importance of adhering to the guidelines received from professionals: *I take care of her closely, a little ago, for example, I told her: you use the medicine as required, because you're not a little girl anymore, you're older. In food too, if she eats salty food, even a little, I already call her attention* (R2, Maternal grandmother of the woman with cardiopathy and hypertension). *We had to change our food, because pizza is the food he [husband] loves the most, we used to have it almost the whole week. Soda he also used to drink a lot, we had to control that* (P6, Gestational diabetes).

The pregnant women reported that they felt more confident when the relatives were present in the consultations, as they shared the responsibilities of care besides receiving support when they were informed about possible complications. *I like that he comes with me, it's good, I feel safer* (P1, Hypertension and diabetes mellitus). *When the doctor said that I could have another abortion, oh God, I held his hand tight. And we heard very carefully what I had to do* (P7, Previous abortion and asthma).

However, some relatives in the study (husbands, mothers and fathers of pregnant women) reported feeling little inserted in the gestational process and prenatal care. They said that health professionals did not welcome or encourage their participation during the consultations, as can be seen in the following speeches: *I'm a nobody there [laughs], I sit*



*there, keep looking, but they never said anything* (Husband of the pregnant woman of a second baby, with diabetes). *But he [the doctor] never wanted to talk to me. So, the right thing to do was for me to do the prenatal care of the husband, just like they do here in the medical post, but he never said anything* (R4, Husband of the pregnant woman with Diabetes, syphilis, history of pregnancy with low birth weight newborn, obesity, and previous abortion).

It was noteworthy that the care given by the family members to the pregnant women was poorly perceived by the health professional, as it can be observed in the following speech: *I went to a consultation with her there; it was of high risk; a woman went to consult alone and fell off the stretch. My Goodness, it was a huge noise, then she left the office crying. Our turn came, I did not even ask, I went in and I arrived at her side when it was time to get on the stretch. The doctor even looked at me in a weird way, but I had to protect my wife* (R6, Husband of the pregnant woman with diabetes).

The statements show that prenatal care is exclusively focused on the pregnant women. The relatives, although present in most of the consultations, are not perceived as a support network by the professionals. In some situations, relatives are even misinterpreted when they try to participate more actively in the consultation.

## Discussion

As a limitation of this study, it is pointed out that it was carried out in a single municipality and this may have limited the diversity of obstetric problems encountered, as well as the individual perception of the vulnerability experienced. Thus, investigations are needed in other Brazilian municipalities where the socioeconomic level and the obstetric profile of the clientele may vary and consequently demand new and different perceptions of high-risk pregnant women and their relatives about their vulnerability.

Among the study participants, it was observed that regardless the diseases determining the risk condition being established before or after the pregnancy, there was always concern and feelings of anxiety and stress among the pregnant women and their relatives. Data aligned with this research were identified in a study carried out in Cuiabá, Brazil, with 12 pregnant women undergoing prenatal care, which presented insecurities, fears and anxiety before the diagnosis of gestational risk<sup>(6)</sup>.

Similar to the national data, a study in Southwest China revealed that relatives of pregnant women with complications that culminated in preterm labor felt stressed. However, the authors emphasized that, in this context, family resilience plays an important role in reducing stress and providing support<sup>(14)</sup>.

It is, therefore, observed that the emotional dimension of the pregnant woman and her family should be particularly taken into account in the context of high-risk pregnancies, as it may result in complications and, consequently, worse perinatal outcomes, besides affecting family relationships because of changes in the mental health status<sup>(8)</sup>.

All the relatives in this study demonstrated to provide support to the women in the gestational period, expressing it in different ways. Data in line with this research were found in a group of high-risk women in Mato Grosso, where they reported receiving family support, manifested through help in domestic tasks, care of the other children, company to consultations in specialized services, and also help in financial difficulties<sup>(6)</sup>.

Another form of support was observed in an Australian study, which pointed out the satisfaction of women with the support they received from partners regarding alcohol consumption during pregnancy, and some women reported that their partners stopped drinking as a way of ratifying this support<sup>(15)</sup>, demonstrating support in this context of vulnerability.

In contrast, a study conducted in Bangladesh and India with 36 pregnant women and their families addressing the knowledge, attitudes and practices related to exposure to passive smoking at home found that most husbands never tried to stop smoking at home and had poor knowledge on the risks of passive smoking during pregnancy. The study also indicated that the companions accept the guidance/requests of health professionals better than the wives, which may impact on their behavior<sup>(16)</sup>.

Thus, it is observed that the relatives of the pregnant women need to be truly present and their company should be encouraged in the consultations, so as to bring mutual benefits to the family nucleus. Although most of the partners in the present study demonstrated support and care for the risk condition, some of the spouses did not recogni-

ze or perceive the possibility of repercussions on the quality of life and health of the wife and the child. It is noteworthy that, coincidentally, the companions who shared this view were precisely those who did not accompany their wives in prenatal consultations. In view of the above, pregnant women at risk with fragile support may experience limiting situations, expressed by sadness, discouragement, guilt, insecurity, lack of affection and support, preventing the meeting of the needs in their living process. Thus, group activities can be presented as a means by which pregnant women can socialize and experience coping opportunities, with encouragement before difficulties, in dealing with the new situation<sup>(17)</sup>, feeling supported and empowered to overcome the possible adversities of the gestational process.

In Brazil, the distance of relatives, especially of the partner, which is often excluded from prenatal consultations, was discussed in the new policy of comprehensive care to health of men, culminating in the proposition of implantation of prenatal care for partners. This new policy stimulates the presence of the father/partner in the process of pregnancy, taking into account the benefits that it provides for the biopsychosocial well-being of the mother, the baby and of the men themselves<sup>(18)</sup>.

Stimulating the partner's participation throughout the gestational process seems to be critical. However, although there are already public and normative policies that advocate the inclusion of the partner in this assistance, according to the narratives of the family members interviewed, they are still not effective, because they were perceived invisible in the eyes of professionals. This result reinforces what was found in a study carried out with adolescent pregnant women in Rio de Janeiro which showed that the companions were unaware of the fact that they could participate in prenatal consultations<sup>(19)</sup>, reflecting, therefore, a care focused exclusively on pregnant women.

It is noted that when the health service works articulately with the pregnant woman and her family, this initiative expands the approach that is originally

focused only on reproductive risks. Thus, risks and vulnerabilities can be better understood and the family and the community bond strengthened. On the other hand, the less extensive and strengthened are the family and community social network, the more vulnerable the women can be. The same occurs when health services/health professionals do not consider the comprehensiveness and specificity of the needs experienced by pregnant women at risk, and those with health implications, as well as devalue the actions of the family and community social network<sup>(7)</sup>.

Despite the numerous discussions on the humanization of care, it is still necessary to draw attention to the importance of understanding the individual in an comprehensive way. This is because care is often based on the precepts of the biomedical model, where the focus of care is the disease and its negative influence on the life of the woman and the baby, neglecting the emotional and social aspects that permeate the life of the pregnant woman<sup>(10)</sup>.

Thus, health professionals involved in obstetric care must focus on the identification of risk factors for maternal morbidity and mortality and incorporate into their clinical practice approaches that contribute to the promotion of gender equity and women's human rights. Accompanying and/or caring for these women includes, in addition to the differentiated attention to the determinants of risk, respect for the desire to be a mother, cultural and social aspects, and the provision of a humanized and embracing care<sup>(20)</sup>.

## Conclusion

The results of the research demonstrated that both relatives and pregnant women experience worry, anxiety, fear and stress in the face of vulnerability. However, the pregnant women felt supported and safe with the help of the family, which although did not feel appreciated during prenatal consultations, had an important role in encouraging and supervising the care during pregnancy.

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## Collaborations

Vieira VCL collaborated with planning and designing, analyzing and interpreting the data and writing the article. Marquete VF, Souza RR and Fischer MMJB collaborated with the writing of the article and final approval of the version to be published. Barreto MS and Marcon SS contributed with the writing of the article, critical review of the intellectual content, and approval of the final version to be published.

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