







PERCEPTIONS OF PREGNANT WOMEN ADMITTED TO A HIGH-RISK REFERENCE SERVICE

PERCEPÇÕES DE GESTANTES INTERNADAS EM UM SERVIÇO DE REFERÊNCIA EM ALTO RISCO

PERCEPCIÓN DE MUJERES EMBARAZADAS INTERNADAS EN UN CENTRO DE REFERENCIA EN EMBARAZO DE ALTO RIESGO

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ABSTRACT

Objective: to understand the perceptions of pregnant women admitted to a high-risk reference service about having a child with a pre-existing disease and to describe their feelings when going through the experience of developing a high-risk pregnancy. **Method:** this is a descriptive study of a qualitative approach, conducted through a semi-structured interview with 18 pregnant women who were in the maternity ward of the *Hospital Regional do Sudoeste do Paraná*. Data was collected between April and June 2017. **Results:** two categories were delineated and it was found that these pregnant women often feel unprepared to have a child, to change their whole life and to place their future in the hands of God, raising fear, concern, insecurity, anxiety, happiness and guilt. **Conclusion:** the study revealed the need that these pregnant women have to express their feelings; however, this aspect of motherhood is often neglected, and the significant influence on the development of pregnancy is not evidenced by the professionals.

Keywords: Pregnancy Complications; Pregnant Women; High-Risk Pregnancy.

RESUMO

Objetivo: conhecer as percepções de gestantes internadas em um serviço de referência em alto risco sobre gerar um filho com alguma doença preexistente e descrever a expressão de sentimentos ao vivenciarem a experiência de desenvolver uma gestação na situação de risco. **Método:** trata-se de estudo descritivo de abordagem qualitativa, realizado com 18 gestantes que se encontravam na maternidade do Hospital Regional do Sudoeste do Paraná, por meio de entrevista semiestruturada. A coleta foi realizada entre os meses de abril e junho de 2017. **Resultados:** delinearam-se duas categorias e foi possível constatar que essas gestantes sentem-se muitas vezes despreparadas para gerar um filho, mudam toda sua rotina de vida e entregam seu futuro nas mãos de Deus, vindo à tona o medo, preocupação, insegurança, ansiedade, felicidade e culpa. **Conclusão:** o estudo revelou a necessidade que essas gestantes apresentam de expressar seus sentimentos, porém, esse lado da maternidade é, muitas vezes, negligenciado, não sendo evidenciada pelos profissionais a influência significativa que oferece no desenvolvimento da gestação.

Palavras-chave: Complicações na Gravidez; Gestantes; Gravidez de Alto Risco.

RESUMEN

Objetivo: conocer la percepción de mujeres embarazadas internadas en un centro de referencia en embarazo de alto riesgo sobre tener un hijo con alguna enfermedad preexistente y analizar sus sentimientos durante el embarazo. **Método:** estudio descriptivo, cualitativo realizado con entrevistas semiestructuradas a 18 mujeres internadas en la maternidad del Hospital Regional del Sudeste del estado de Paraná. Los datos se recogieron entre abril y junio de 2017. **Resultados:** se delinearon dos categorías y se observó que las mujeres suelen sentirse despreparadas para tener

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un hijo, que alteran su rutina y dejan el futuro en manos de Dios, lo cual refleja preocupación, inseguridad, ansiedad, felicidad y culpa. Conclusión: el estudio reveló la necesidad de las embarazadas por expresar sus sentimientos y que los profesionales no siempre tienen en cuenta este aspecto de la maternidad, sin percibir su importancia para el desarrollo del embarazo.

Palabras clave: Complicaciones del Embarazo; Mujeres Embarazadas; Embarazo de Alto Riesgo.

INTRODUCTION

Although most pregnancies evolve physiologically, there are a small number of pregnant women who, due to their risk characteristics or diseases, are more likely to have a difficult pregnancy. This group represents the so-called high-risk pregnancy, which currently corresponds to 20% of pregnancies with maternal risk.¹ This pregnancy is increasingly present in our reality, often leads to limitations, prevents women from playing roles established by society and, consequently, significantly changes the routine and quality of life of these pregnant women.

Feelings, thoughts and expectations of these pregnant women have key relevance for the good development of pregnancy because, when they receive the diagnosis, they go through a stressful experience due to the risks to which the fetus and mother are subjected.² During pregnancy, parents manifest varied feelings such as guilt, fear, anxiety, consternation and stress, and if not understood and oriented correctly, may have difficulties to cope with adversity.³

According to the *Ministério da Saúde* (BR) Ordinances Nº 1,020/GM/MS, of May 29, 2013, and Nº. 1,481, of July 13, 2017, care for high-risk pregnant women should be the responsibility of an interdisciplinary team whose main objective is to reduce the risks of an unfavorable outcome for the mother and/or fetus.⁴ Comprehensive care for this patient is extremely important in any pregnancy, as the quality of care is directly related to the reduction of maternal and perinatal mortality. However, the participation of Nursing stands out, since it is the educators that act in counseling and early detection of risk situations and, thus, are able to avoid complications that may lead to unwanted events.⁵

In Brazil, the main causes of risk pregnancy are related to urinary tract infection, obesity, high blood pressure and gestational diabetes. These diseases, as evidenced in a study conducted in the city of *Francisco Beltrão* by Costa *et al.*,⁶ in 2016, affect around 21.3%, 52.5%, 52.4% and 1.6% of the women, respectively.

Thus, understanding the perception of these pregnant women is extremely important to health professionals because, when they are referred to a high-risk reference hospital, they

feel insecure and afraid and may hide their feelings. This is the moment when the professionals should welcome and guide them, offering a qualified care.¹

In this context, the following guiding question emerges: What is the perception of high-risk pregnant women about their hospitalization in a reference service in the Southwest of Paraná? In the search for answers to this question, the research was created to understand the perceptions of pregnant women admitted to a high-risk reference service about having a child with a pre-existing disease and to describe their feelings when experiencing a high-risk pregnancy.

It is believed that the results may contribute to the implementation of new methods and techniques to better assist them, from a humanized perspective, assisting them and contributing to their quality of life at this unique moment that is pregnancy.

METHOD

The qualitative approach was the methodological foundation of this descriptive study. The scenario chosen was the *Hospital Regional do Sudoeste Walter Alberto Pecóits* (HRSWAP), located in the city of *Francisco Beltrão, Paraná*, which receives intermediate- and high-risk pregnant women, according to the care protocol.

To define the intentional sample, the following inclusion criteria were met: pregnant women admitted to the HRSWAP who were in the high-risk rating according to the criteria of the *Rede Mãe Paranaense* Program's Guideline. Intermediate-risk pregnant women and postpartum women were excluded from the study.

Data was collected from April to June 2017. Initial contacts were made through field visits, using a semi-structured interview script prepared by the authors themselves, based on relevant literature, with clear and accessible language, and composed of the following guiding questions: "What is your perception of having a child with a pre-existing disease?" and "What feelings emerge from experiencing a high-risk pregnancy?"

To identify the personal characteristics of these pregnant women, they were questioned regarding their age, schooling, marital status, occupation, number of previous births, number of abortions and the diseases that characterize high-risk pregnancy.

To define the number of participants in the research, a conceptual tool called theoretical saturation⁷ was applied, which enables ceasing the inclusion of participants from the moment the objectives are achieved and the results are repeated and do not contribute or add little to improve the analysis.

After the field research was carried out, the analysis process was started. Bardin's content analysis was used⁸ for handling the statements, composed of the stages of pre-analysis, coding, categorization, processing of results, inference and interpretation. The interpretation of the collected information occurred in view of the national scientific production and of the Brazilian legislation that focuses on the subject.

This research follows the orders of the *Conselho Nacional de Saúde* (CNS) –Resolution Nº 466/2012, *Diretrizes e Normas Regulamentadoras Envolvendo Seres Humanos*, and was approved by the *Comitê de Ética em Pesquisa da Fundação de Ensino e Pesquisa em Ciências da Saúde* (CEP/FEPECS), under Opinion Nº 1,753,731, of September 29, 2016, and CAEE Nº 59367516.2.0000.0109. To guarantee the anonymity of the pregnant women, the letter P was used to identify the statements, followed by the chronological sequence of the interviews.

RESULTS

Of the 18 pregnant women interviewed, there was a prevalent age group between 19 and 39 years old. Regarding the level of education, two had incomplete elementary school, 11 had completed high school and five had higher education. There was a predominance of women with a stable union, and as for their occupation, 15 had jobs and three were unemployed. In addition to these aspects, there were multiple births among the women, since 12 of them had multiple pregnancies and, as for abortion, six have experienced this situation.

Among the factors that characterized them as high-risk pregnant women were pre-term labor, systemic arterial hypertension (SAH), endocrine and liver diseases, low fetal weight, malformation and placental insufficiency, with a greater number of pre-term labor (six women) and hypertension (five women).

In the analytical procedure, the intention was to understand the perception of the pregnant women when giving birth to a child with a pre-existing disease and what feelings emerge in this situation. These aspects generated two thematic categories. The first one: "the perception of the pregnant women who give birth to high-risk babies"; and the second category: "the feelings of the pregnant women who experience high-risk pregnancy".

THE PERCEPTION OF THE PREGNANT WOMEN WHO GIVE BIRTH TO HIGH-RISK BABIES

According to the perceptions, the following subcategories were identified: the moment of faith in pregnancy, feeling helplessness during pregnancy, intensified self-care and the fragility in gestational planning.

Regarding experiencing a high-risk pregnancy, faith was present in several statements of pregnant women, who revealed that faith and confidence are necessary to face this moment and that in any case it will be a way of learning:

I have confidence and faith that everything will work out. What changed was that I learned the true way to love (P3).

It was a unique experience, because at no time did I stop loving her and trusting God. I know God has a purpose for our lives (P5).

For me giving birth to a child is a blessing, I can't explain what is happening [...], but I believe God would not give me a burden greater than I can bear. I will learn it anyway. It is a lesson (P9).

The intense helplessness they feel in the diagnosis and childbearing is remarkable, as in many cases they are not solely and exclusively responsible for improving pregnancy development:

It's a feeling of helplessness, because we can't do anything. We can just take care of ourselves to avoid other problems (P7).

It is a feeling of immense powerlessness, as it greatly affects the emotions and the pregnant woman values her baby's health and well-being. Knowing that something is not going well with the baby makes us totally sad and distressed (P2).

I feel helpless, because there is nothing I can do, there is a treatment but I cannot do anything else (P4).

The interviewees expressed the intensification of the care required during pregnancy, since it is considered a period in which pregnant women need to concentrate entirely on the fetal development, doing what they can to avoid more serious complications:

Everything changed! It changes the entire routine! I have to take it easy, stop living my life to take care of hers (P10).

At the beginning it seems that all problems are solved, but in the end it requires a lot of care and that is what I really have to do, to take care of myself and follow the medical advice (P12).

This pregnancy changed my whole life, I stopped doing many things (P17).

The answers also showed the flaws in gestational planning, since what is desired during pregnancy does not always have a favorable evolution:

It's knowing that we can't plan everything, let alone his life. Conceiving a child is always very special, but under these circumstances we realize how fragile life is and how we should value every second (P15).

Giving birth to a little person who barely knows what's going on out here, who stays months inside us, and when they leave, they are totally dependent on us (P6).

THE FEELINGS OF THE PREGNANT WOMEN WHO EXPERIENCE HIGH-RISK PREGNANCY

From the analysis of the perceptions it was possible to identify the exacerbation of feelings in this period. This category was predominated by fear, concern, insecurity, anxiety, happiness and guilt.

Fear was evidenced in most of the statements, referring to a period of disturbance before a risk or a threat, as highlighted by the interviewees, who mentioned the loss as one of the reasons for the real feeling of fear:

Fear of failing, you know? Of losing again (P10).

In fact, my fear was never thinking that she might have something, but that I would lose her (P5).

Then I'm afraid of miscarriage, afraid of something unforeseen happening, afraid of the risk I'm taking (P11).

Other statements highlight the fear related to the role of being a mother. Many women, when experiencing high-risk pregnancy, wonder if they are really prepared and if that was the right time for a pregnancy:

In fact, the fear was because it wasn't a planned pregnancy; it wasn't supposed to happen now. Will I be a good mother? (P4).

I'm afraid of not being good enough to generate a new life with everything it needs for a proper development (P2).

The feeling of concern was also expressed by pregnant women, associated with several characteristics, including the uncertainty of pregnancy development, as mentioned below:

There is endless concern, will it be all right? It involves everything, the physical, the mental, the emotional and everything (P13).

Oh, I worry about the human being growing in my belly, I don't know what will happen [...] (P16).

We worry, right?! Especially when the doctor gives me bad news, I think about everything (P14).

In some reports it was possible to identify that the concern was linked to negative thoughts, such as fetal anomalies:

I'm always concerned, will it be a pre-term birth? Am I ready? What if the baby is born with a health problem? (P15).

Ah, I worry if everything is ok, because if the baby is born with a health problem, it changes everything, right?! (P18).

There was also a feeling of insecurity that is often related to the uncertainty of events or associated with pre-term birth:

I feel insecure because everything is unexpected. I don't know what will happen, especially knowing that it is a pregnancy that needs a lot of care (P14).

I fear that I may not have the ability to hold it until the end. I never celebrated for fear, maybe it won't work, I'll suffer a lot (P6).

Because of the diagnosis I'm insecure, I don't know whether there will be a premature birth or not (P15).

The pregnant women's statements show anxiety, considered a mixture of feelings. One of the factors associated with anxiety was the desire for the pregnancy cycle to end quickly and in the best possible way so that these moments of struggle would end, according to the following reports:

My emotions are shaken because there are so many new discoveries and this fear of the "new" generates this anxiety of not knowing what the future will be like (P2).

We get anxious. It's hard to keep calm at these moments (P8).

I can't wait for these nine months to pass so that I can see that everything will work out (P11).

As I already have a problem I can't wait for the baby to be born in good health, so that this suffering can end (P1).

I hope labor doesn't take too long. I want to see the little face, to check whether it looks like me or not (P6).

Feeling guilty was mentioned; in addition, the interviewees believe that they could have done something different to avoid this risk or, even, to improve pregnancy development:

I feel guilty knowing that part of what is happening is my fault. The doctors told me what I couldn't do but I did it anyway. It's my fault [...] (P14).

Maybe if I had been more careful at the beginning of my pregnancy, if I had eaten healthier, I would have been able to keep my pregnancy up to 40 weeks (P17).

Happiness was linked to a sense of true emotion and based on two factors: the discovery of pregnancy and the mere fact of being a mother. Some pregnant women described their feeling of happiness in simple, but meaningful phrases, as follows:

Being pregnant is a wonderful feeling! For each moment the baby moves, choosing the name and the little things for the future child, in short, each new discovery is an immense joy (P2).

There is nothing more important, right? The best thing we have in life, despite fears and worries it is the most important thing! (P1).

Happiness to know there is one more fighter coming (P8).

DISCUSSION

During this study some aspects related to the perceptions of the pregnant women with high-risk pregnancy were understood, which makes the need and support that these women find in religion absolutely clear. These results corroborate those of a similar study conducted in Bahia,⁹ in

which the pregnant women studied place their destiny in the hands of God.

Women diagnosed with a high-risk pregnancy seek support in many ways and, despite being a time of intense fragility, it is possible to identify in these pregnant women the willpower and faith in believing that everything will work out.

Another aspect presented was the perception of impotence before the diagnosis and childbearing. This feeling is part of the process of being a mother, a greater feeling, a responsibility that she carries, as mentioned in a study in the city of *Porto Alegre - RS*¹⁰ in which pregnancy is considered as a period of many physical, psychological and emotional changes, when fantasies, tensions and fears emerge.

With regard to the intense self-care that is necessary during the gestational period, it can be evidenced that the phrase "conceive a child in special conditions" already demonstrates many changes in the woman's life, as it is a dynamic and diverse process.¹⁰ Pregnancy comes with countless changes, as projects are often interrupted and new responsibilities, goals and dreams emerge. After all, it is a new reality. Such changes usually raise uncertainties and doubts that cause pregnant women to totally change their routine to improve the quality of life of their child.¹¹

Based on this necessary transition during the gestational process, receiving quality health care is the right of every individual. However, this qualification does not depend on a single factor, but on a series of components. In this sense, the *Programa de Humanização no Pré-Natal e Nascimento* (PHPN) was implemented in 2000, aimed at improving the quality of care based on holistic precepts.¹²

Thus, it is expected that the care for pregnant women be increasingly valued and that the team may be able to promote actions that emphasize emotional aspects, because it is essential to know these pregnant women, their habits and beliefs, so that they can list the changes from pregnancy in their life.

It is noted that fragility is an aspect present in high-risk pregnancy. Through a study¹³ conducted to describe the feelings of women who experienced this condition, it was shown that, after the diagnosis, they feel vulnerable, as they absorb the impact of the news in their daily lives and, consequently, emotional fragility comes up.

Through the perceptions identified in this research it was possible to verify the main feelings expressed by these pregnant women in this phase, which is considered risky. The moment a woman faces this gestational threat, she becomes more vulnerable to negative thoughts, which can lead to psychological symptoms and scenarios or even aggravate pre-existing diseases, further impairing a good pregnancy development.

The attitudes of affection and sensitivity expressed by the multi-professional team to these pregnant women create a stronger bond between them, thus facilitating preventive and health promotion actions.¹⁴ Often, the professionals focus only on the physiological aspects of pregnancy and on clinical and therapeutic diagnosis. Without disregarding this relevance to health, however, it was possible to see these women's real need to be welcomed by a qualified service that guarantees the expression of feelings.

When the woman's suffering becomes prevalent and she has no space to talk, express or even better understand what is going on, fear arises, evidenced in most of the statements and that can be characterized as an emotional state resulting from a threat or a danger.¹¹

During this high-risk period, women experience intense tension: although they are happy about the pregnancy, they feel uncertainty about the unforeseen events that can happen and often wonder if they are really prepared to be a mother, as the mere high-risk rating and the hospitalization process make these pregnant women feel different from the others.

Concern and insecurity were present in the statements of the pregnant women and are in wide connection, since this is a very vulnerable moment.¹⁵ Many questions during this period cannot be answered at the time of diagnosis, requiring time, which represents an endless universe for them.

During this time they feel the fear of prematurity, as they often do not have adequate information and knowledge about their health condition. And this is when the professional should empower the pregnant woman about the events taking place around her.¹⁶

Anxiety represents distress and the desire for pregnancy to come to an end as soon as possible. In conducting the study to investigate the reason behind these feelings, researchers¹³ related anxiety to the emotional state and the results showed the widespread manifestation of a diffuse sense of fear, causing women to organize their life in a completely different way from what is expected. It is this organization process, however, that enhances the anxiety they feel.

Among so many feelings, some pregnant women feel guilty. Researchers¹⁷ explain that the lack of care in gestational planning is closely related to the concern experienced at this time.

Therefore, this data reinforces the idea that, at no time in the pregnancy cycle, the development of complications is foreseen. This premise may be justified by the technological advance, allied to the media, which has been highlighting what a dazzling process it is, failing to explain the other outcomes and changes that pregnancy may entail in women's lives.

A research conducted in a maternal and child health hospital¹⁸ highlights that technological advances give more

security for a healthy pregnancy development; however, the emotional and psychological aspects should be considered by the multidisciplinary teams.

Despite the emotional fragility and all the conflicts experienced by them, the feeling of happiness was present, an inspiration that carries a sense of emotion, which demonstrates the actual "being a mother". Given this context and based on a study conducted in the state of *Paraná*,¹⁹ it is possible to notice that, although pregnant women develop a feeling of ambivalence regarding the desire to have a child, the maternal instinct prevails, and thus gives rise to the intense satisfaction and joy of this experience.

The limitation is the reality of care during hospitalization, since it does not allow and does not offer the opportunity for the study participants to express perceptions and feelings during hospitalization.

FINAL CONSIDERATIONS

It can be concluded that this study achieved the proposed goal by highlighting the perceptions of high-risk pregnant women, including faith in the gestational period, the impotence in the process of bearing a child, the need for intensified self-care and the fragility in gestational planning, as well as feelings of fear, concern, insecurity, anxiety, happiness and guilt.

Although the sample is relatively small, it made it possible to identify the reality of the environment where the research was developed. At the same time, the similarity with other regions of Brazil could be stated. It is valid to suggest that new instruments that evaluate perceptions and feelings should be incorporated in the literature, in order to analyze a larger group of high-risk pregnant women.

By emphasizing that the Nursing team is, in its majority, linked to technical assistance practices, it is shown that dialog and qualified listening are disregarded. It is believed that the implementation of new instruments and technologies in this area may contribute to the training of health professionals; in addition, considering the perspective of pregnant women will undoubtedly favor a good pregnancy development.

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