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LIVING WITH CHRONIC ILLNESS DURING PREGNANCY: PREGNANTS' PERSPECTIVE

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ABSTRACT. It is estimated that 20% of pregnancies in Brazil are at high risk. High-risk pregnancy is one in which there is a greater chance of developing complications that harm the life of the pregnant woman and her baby. These complications can be triggered, for example, by chronic diseases prior to pregnancy. Considering the studies scarcity abouthigh-riskpregnancy beyond the biological discourse, the objective was to identify and describe how women living with chronic disease experience a high-risk pregnancy. A qualitative-descriptive study was carried out, anchored in the social constructionist framework. Data were collected using semi-structured interviews, recorded, with 8 pregnant women with chronic health conditions prior to pregnancy, and field diaries. The interviews analysis resulted in the elaboration of the following themes: A) discovery of pregnancy, subdivided in A.1) circumstances of the discovery; A.2) pregnancy planning; A.3) understanding of risks; A.4) fears after the discovery, and A.5) being a mother and B) experiencing pregnancy with a chronic disease, subdivided into B.1) pregnancy impacts; B.2) complications in pregnancy; B.3) expectations, preoccupations and complaints; B.4) learnings. The participants' reports demonstrate that the news of a pregnancy promotes significant impacts on their lives, translated into fears and concerns. The fact that there is a chronic illness prior to pregnancy may have intensified the negative feelings and insecurities. They also demonstrated that living with pregnancy and chronic illness widened their views to the differences of the current pregnancy with previous pregnancies, in addition to changes in emotional aspects and self-care with chronic illness.

Keywords: Maternity; high-Risk Pregnancy; meaning.

CONVIVENDO COM DOENÇA CRÔNICA DURANTE A GRAVIDEZ: PERSPECTIVAS DE GESTANTES

RESUMO. Estima-se que 20% das gestações no Brasil sejam de alto risco. A gestação de alto risco é aquela em que há maiores chances de desenvolvimento de complicações que prejudiquem a vida da gestante e de seu bebê. Essas complicações podem ser desencadeadas, por exemplo, por doenças crônicas anteriores à gestação. Considerando a escassez de estudos sobre gestação para além do discurso biológico, objetivou-se identificar e descrever como mulheres que convivem com doença crônica vivenciam uma gestação de alto risco.Realizou-se um estudo qualitativo-descritivo ancorado no referencial construcionista social. Os dados foram coletados utilizando entrevistas semiestruturadas, gravadas, com 8gestantescom condições crônicas de saúde anteriores à gestaçãoe diários de campo.A análise das entrevistas resultou na elaboração das seguintes temáticas: A)

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descoberta da gravidez, subdividida em A.1) circunstâncias da descoberta; A.2) planejamento da gravidez; A.3) compreensão de riscos; A.4) medos após a descoberta; A.5) ser mãe e B) vivenciar a gestação com a doença crônica, subdividida em B.1) impactos da gravidez; B.2) complicações na gravidez; B.3) expectativas, preocupações e queixas; B.4) aprendizados. Os relatos das participantes demonstram que a notícia de uma gestação promove impactos significativos em suas vidas, traduzidos em medos e preocupações. O fato de existir uma doença crônica anterior à gravidez pode ter intensificado os sentimentos negativos e inseguranças. Também demonstraram que conviver com a gestação e a doença crônica ampliou seus olhares para as diferenças da atual gestação com gestações anteriores, além de mudanças em aspectos emocionais e no autocuidado com a doença crônica.

Palavras-chave: Maternidade; gravidez de alto risco; significado.

CONVIVIR CON ENFERMEDAD CRÓNICA DURANTE EL EMBARAZO: PERSPECTIVAS DE LAS MUJERES EMBARAZADAS

RESUMEN. Se estima que 20% de los embarazos en Brasil son de alto riesgo. El embarazo de alto riesgo es aquel en que hay una mayor probabilidad de desarrollar complicaciones que dañan la vida de la mujer embarazada y su bebé. Estas complicaciones pueden desencadenarse, por ejemplo, por enfermedades crónicas antes del embarazo. Teniendo en cuenta la escasez de estudios sobre el embarazode alto riesgomás allá del discurso biológico, el objetivo es identificar y describir cómo las mujeres que viven con enfermedades crónicas experimentan un embarazo de alto riesgo. Se ha realizado un estudio cualitativo-descriptivo basado en el referencial construccionista social. Los datos fueran recopilados utilizando entrevistas semiestructuradas y grabadas con 8 mujeres embarazadas con enfermedades crónicas antes del embarazo, y diarios de campo. El análisis de las entrevistas dio lugar a la elaboración de los siguientes temas: A) Descubrimiento del embarazo, subdividido en A.1) circunstancias de la descubierta; A.2) planificación del embarazo; A.3)comprensión de los riesgos; A.4) miedo después de la descubierta, y A.5) ser madre y B) vivir el embarazo con la enfermedad crónica, subdividido en B.1) impactos del embarazo; B.2) complicaciones en el embarazo; B.3) expectativa, preocupaciones y quejas; B.4) aprendizaje. Los relatos de las participantes muestran que la noticia de un embarazo promueve impactos significativos y sus vidas, que se traducen en miedos e inquietudes. El hecho de existir una enfermedad crónica antes del embarazo puede haber intensificado los sentimientos negativos y las inseguridades. También demostraron que vivir con embarazo y enfermedad crónica amplió sus puntos de vista a las diferencias en el embarazo actual con embarazos anteriores, además de cambios en los aspectos emocionales y el autocuidado con la enfermedad crónica.

Palabras clave: Maternidad; embarazo de alto riesgo; significado.

Introduction

In Brazil, health care aimed at pregnant women poses challenges to public health. The launch of Rede Cegonha, for example, an initiative that defines care measures for women during their pregnancy-puerperal process, has invested 3.1 billion reais in care actions for this population since 2011 (Brasil, 2017). However, the provision of access and

specialized services aimed mainly at women with high-risk pregnancies is still deficient (Brasil, 2012; Brasil 2019).

Estimates indicate that 20% of pregnancies in Brazil are high-risk (Antoniazzi, Siqueira & Farias, 2019; Brasil 2012; Rodrigues, Dantas, Pereira, Silveira, & Rodrigues, 2017). A high-risk pregnancy is one in which there is a greater chance of developing complications that harm the life of the pregnant woman and her baby. These complications can be triggered, for example, by chronic diseases before pregnancy (Brasil, 2012).

Chronic diseases are multicausal health conditions characterized by their gradual onset, uncertain prognosis, and long or indefinite duration. Their clinical evolution changes over time and may present acute moments and lead to disabilities, which require interventions and changes in the lifestyle of their sufferers, as well as constant professional monitoring (Brasil, 2013). Therefore, having a chronic illness and being pregnant can lead to uncertainty regarding these women's future prospects (Quevedo, Lopes & Lefrève, 2006). In this context, Wilhelm, Prates, Alves, Scarton, & Cremonese (2021) state the need for research to understand the different spheres that these women are part of, thus seeking support strategies suited to their demands.

In this sense, pregnancy is a moment constructed and affected by physical, psychological, social, and economic transformations in the daily lives of women and their families (Balica & Aguiar, 2019; Maldonado, 2017; Wilhelm et al., 2021). This makes it likely that the experience of pregnancy is experienced differently by each woman (Maldonado, 2017), as well as an increase in concerns when diagnosed with a high-risk pregnancy (Antoniazzi et al., 2019; Azevedo, Hirdes & Vivian, 2020; Fernandes & Ferreira, 2020; Santos, Meira, Gonçalves, Mendes, Ramos, Viotto, Pinto Neto, & Lozano, 2021).

According to Tyer-Viola & Lopez (2014), although pregnant women with chronic diseases perceive the need for special care due to their health condition, they also identify pregnancy as something that brings them closer to the feeling of normality. Despite this, research indicates that possible difficulties may arise when adapting to this context (Fernandes & Ferreira, 2020; Santos et al., 2021). Anxiety, fear, and constant worries are feelings inherent to this process, which can be alleviated by the family support network (Antoniazzi, Siqueira & Farias, 2019; Maldonado, 2017; Oliveira & Mandú, 2015).

Recent scientific productions indicate that during the gestational period, women are studied with emphasis on maternity as a unique moment in their life experience (Balica & Aguiar, 2019; Brasil, 2012; Maldonado, 2017). However, without taking into account contexts such as high-risk pregnancy due to chronic illness (Fernandes & Ferreira, 2020; Quevedo ert al., 2006; Tyer-Viola & Lopez, 2014), considering that pregnancy can lead to decompensation in controlling chronic disease, bringing limitations to pregnant women and increasing the level of stress (Oliveira & Mandú, 2015; Quevedo et al., 2006; Tyer-Viola & Lopez, 2014).

Few studies have sought to understand pregnancy beyond the biological discourse (Rodrigues et al. 2017; Silva et al., 2021), valuing the pregnant woman's unique perspective (Silva, Queiroz, Gama, Veras, Barros, Lima Júnior, & Tourinho, 2021), configuring a scenario in that issues related to the psychosocial aspects of these experiences are still poorly understood (Santos et al., 2021; Silva et al., 2021; Wilhelm et al., 2021). The present study aimed to identify and describe how women experience a high-risk pregnancy, as people who live with a chronic disease before pregnancy, as well as possible learning acquired during this trajectory.

Understanding the experiences of high-risk pregnant women was anchored in social constructionism, which is a perspective that invites the promotion of dialogical investigations

sensitive to interpersonal relationships (McNamee, 2017), as well as the identification of processes and the way of understanding the world, described by the participants, thus proposing a sensitive look at traditions, communities and community practices, the focus of investigations and interventions (Gergen, 2009; Spink, 2013).

The research, anchored in social constructionism, values the meanings of phenomena, which are not understood individually but are constructed collectively. It is the expression of reality for those who experience it. From this framework, research can be understood as a relational process in which multiple discourses meet (McNamee, 2017; McNamee, 2020). In this context, language represents more than a tool or way of expressing information. It can be understood as a constructor of reality. To achieve this, the researcher must be open to understanding a multiplicity of truths (McNamee, 2020).

Based on this, this study, anchored in social constructionism, expands the possibilities of psychosocial understanding of the experiences of pregnant women with chronic illnesses participating in the research.

Method

This was a qualitative-descriptive study conducted with 8 pregnant women, over 18 years old, living in the state of Minas Gerais, with chronic health conditions prior to pregnancy. The women were approached and invited to participate in the research while waiting for care in outpatient clinics specializing in the care of high-risk pregnant women, at a University Hospital located in the state of Minas Gerais.

Pregnant women arrive at these spaces referred by primary care, after starting their prenatal care, whenever the characteristics of a high-risk pregnancy are identified. The number of participants was defined by the acceptance of pregnant women invited during the period set for data collection (February to October 2020). The pregnant women were given fictitious names that represent the interviewer's feelings and perceptions, recorded in field diaries, after meeting with each interviewee.

Regarding sociodemographic characterization, the average age was 30.4 years. Regarding education, 2 declared incomplete primary education (Firmeza and Força), 4 reported complete high school (Resiliência, Apoio, Esperança and Equilíbrio), 1 technical course (Gratidão), and 1 incomplete higher education (Autocuidado) as listed in Table 1.

As for work, the occupations mentioned were: unemployed (Resiliência), laboratory assistant (Apoio), housewife (Firmeza), farm worker (Esperança), cashier (Autocuidado), day laborer (Força), nanny (Equilíbrio) and nursing technique (Gratidão). About religion, the interviewees highlighted: spiritist (Resiliência and Apoio), Umbanda (Firmeza), Catholicism (Esperança and Autocuidado), evangelicalism (Equilíbrio and Gratidão), and, finally, one of the interviewees did not define herself as represented by a religion (Strength) (Table 1).

The types of chronic illness identified were: diabetes (Resiliência, Esperança, Força, Equilíbrio, and Gratidão) chronic kidney disease (Apoio), and hypertension (Firmeza, Autocuidado, and Gratidão). One of the pregnant women acquired more than one chronic illness, as was the case with Gratidão. Others, in addition to the underlying disease, also developed psychological comorbidities such as depression, anxiety, borderline disorder (Resiliência), depression, anxiety, and panic (Equilíbrio) (Table 1).

At the time of the interviews, Resiliência was in the first trimester of pregnancy, Firmeza, Esperança, Força, and Equilíbrio were in the second trimester, and Apoio, Autocuidado, and Gratidão were in the third trimester of pregnancy. Gestational ages ranged from 9 weeks and 1 day to thirty-seven weeks.

Table 1. Characterization of the interviewees

Participant	Age	Education	Occupation	Religion	Type of chronic disease
Resiliência	27	Complete High School	Unemployed	spiritist	Diabetes, anxiety, depression, and borderline disorder
Apoio	20	Complete High School	Laboratory assistant	spiritist	Chronic Kidney Disease
Firmeza	37	Incomplete elementary school	Housewife	Umbanda	Hypertension
Esperança	34	Complete High School	Farm worker	Catholic	Diabetes
Autocuidado	21	Incomplete higher education	Cashier	Catholic	Hypertension
Força	36	Incomplete elementary school	Day laborer	No specific religion	Diabetes
Equilíbrio	39	Complete High School	Nanny	Evangelical	Diabetes, depression, anxiety and panic
Gratidão	29	Technical course	Nursing technique	Evangelical	Diabetes and Hypertension

Source: Prepared by the authors.

Regarding the time since diagnosis of the chronic illness, Resiliência had diabetes for 10 years and borderline disorder for 5 years. Apoio had lived with chronic kidney disease for 6 years, Firmeza and Autocuidado with hypertension for 2 years. Esperança and Força highlighted having had diabetes for 1 and a half years and 3 years, respectively. Equilíbrio had been facing diabetes, depression, anxiety, and panic for 10 years, and Gratidão had been living with diabetes and hypertension for 3 years.

The study was approved by a Research Ethics Committee (opinion number 4,228,684). A semi-structured and audio-recorded interview was held with each pregnant woman who accepted the invitation. A field diary was also used, prepared after each interview.

Initially, data were collected at home, resulting in two interviews. However, due to the context of the COVID-19 pandemic, the collection began to be carried out using Information and Communication Technologies (ICTs), making telephone calls the most accepted and viable way to carry out the following 6 interviews. In this case, consent to participate in the study was obtained orally, therefore totaling 8 interviews. The interviews lasted an average of thirty-five minutes.

The information was collected between February and October 2020. The interview addressed the participants' sociodemographic data, as well as their perception of their experiences during pregnancy with a chronic illness. The interview was chosen because it is a discursive practice that helps in understanding what has been experienced and promotes the construction of meanings about the experience of reality (Sionek, Assis & Freitas, 2020; Spink, 2013). In this way, the use of semi-structured interviews in

constructionist research brings possibilities for expressing experiences that are difficult to tell in other contexts, as well as seeking to get to know the participant through their narrative, valuing their perception, and knowledge about what they live and experience. The potential of narrative leads to the discovery of a unique field of knowledge that, when used in research, values its narrator and provides the reader with unimagined knowledge. The speech of several people in a similar context has the potential to reveal stories, capabilities, and challenges (Ferreira, 2022).

Data analysis began with the full transcription of the interviews carried out. Subsequently, all of them were read in an exhaustive (Spink, 2013) and curious (McNamee, 2017) way, together with the field diaries, with the aim that themes could emerge from the participants' speeches and be able to reflect and respond to the objectives of the study.

The first thematic axis identified was titled A) discovery of pregnancy, subdivided into subthemes: A.1) circumstances of the discovery; A.2) pregnancy planning; A.3) understanding risks; A.4) fears following discovery, and A.5) being a mother. The second axis was called B) experiencing pregnancy with a chronic illness, which grouped the subthemes: B.1) pregnancy impacts; B.2) complications during pregnancy; B.3) expectations, concerns, and complaints; B.4) learnings. These data were analyzed and discussed based on the available literature on pregnant women, chronic diseases, and social constructionism.

Results and discussion

Discovery of pregnancy

The discovery of pregnancy can trigger varied feelings and perceptions in women who find out they are pregnant, with the expression of ambiguous emotions, worry, fear, and happiness being common (Antoniazzi, Siqueira & Farias, 2019; Maldonado, 2017; Santos et al., 2021). It can be considered an initial milestone for significant changes in a woman's life, both physical, emotional, and social (Maldonado, 2017), which can be more striking when it comes to a high-risk pregnancy (Azevedo, Hirdes & Vivian, 2020; Brasil 2012; Oliveira & Mandú, 2015; Santos et al., 2021; Tyer-Viola & Lopez, 2014).

A.1) Circumstances of the discovery

The circumstances in which the pregnancy is revealed and its development are important for the construction of pregnant women's perceptions (Soncini, Oliveira, Viviani, & Gorayeb, 2019). Such aspects can be observed in the statements from Autocuidado, Força, and Equilíbrio, presented below.

> For me, it was a shock because it wasn't planned at all, I was studying. (Autocuidado)
>
> Well, I didn't even believe it, because, at the same time I wanted it, I no longer wanted it. I went crazy! (Força)
>
> I was working, then I lost my job, then I found out that I was pregnant and then I did not feel the ground beneath my feet, it seems like... wow it was very hard! (Equilíbrio)

The statements presented show that the discovery of pregnancy occurred at different times and circumstances in the participants' lives (Antoniazzi, Siqueira & Farias, 2019; Soncini, Oliveira, Viviani, & Gorayeb, 2019) and triggered suffering, related to the lack of planning and the unemployment.

A.2) Pregnancy planning

Regarding pregnancy planning, only Firmeza felt happy about being pregnant:

> Wow, I thought it was great! So at the moment, I didn't really want to, right, for now, but when I went for a test I found out, I said "No, now we have to take care of it, right, there's no other way". And my husband also wanted one more, because we only have one boy together (Firmeza)

While Resiliência, Apoio, Gratidão, and Esperança highlighted emotions related to not planning the pregnancy, as can be seen in the following statements:

> Desperation, despair, because every time I planned, that I planned for this pregnancy that I wanted so much, it didn't work out. At a time when I was very far from this dream, I had other plans... it came. (Resiliência)

> It was different in my life. I was very scared. Scared. Yeah... it seems like the penny hasn't dropped. I did two urine tests and one blood test... until it seemed after three months that the penny dropped. (Apoio)

> When I found out I was pregnant, it was a surprise... a surprise, because it was a surprise and it wasn't a surprise, because I knew I could get pregnant at any moment because I wasn't preventing it (...) (Gratidão)

> I wasn't waiting any longer, I was going to plan to do the tubal ligation (...). I felt a little... how do you say... thoughtful, right? (Esperança)

Santos et al. (2019) state that planning and satisfaction with pregnancy are interconnected and influence the provision of prenatal care with better health indicators for mother and baby.

Wilhelm et al. (2015) also point out that not planning a pregnancy can increase negative feelings for pregnant women, as it is an unexpected event. Villamil, Botero & Guzmán (2019) also highlight that a process of assimilation of the discovery of pregnancy is necessary for acceptance.

The negative emotions faced with not planning the pregnancy and its discovery, observed in this study, also reflect findings in the literature in which pregnant women express anguish, sadness, fear, and uncertainty with a high-risk pregnancy (Antoniazzi et al., 2019; Costa et al., 2019; Santos et.al, 2019; Santos & Vivian, 2018; Villamil et al., 2019; Wilhelm et al., 2015).

A.3) Understanding risks

Understanding risks was associated with the possibility of worsening the disease and the importance of closer medical monitoring, as can be seen in the statements from Resiliência and Gratidão, presented below:

> It's bad because you always have to go there (hospital), there is always an assumption that something can happen, that the baby could be born fat, that the baby could have a malformation, that the baby could have heart problems, which are things that result from diabetes, right? (Resiliência)

> So, the only thing that changed was the monitoring, which used to be at the normal clinic, today I do it at the hospital, and with more physicians, you know, the monitoring is different, there's an endocrinologist, a nutritionist, there's even fetal medicine (...). (Gratidão)

The understanding of risks, the need for monitoring, and fears regarding the uncertainties of adequate pregnancy follow-up are also found and confirmed in the literature, demonstrating similarity to the research findings (Oliveira & Mandú, 2015; Quevedo et al., 2006; Silva et al., 2021; Villamil et al., 2019).

Studies in the area highlight the importance of promoting information to pregnant women, considering the context of conception, the risk of complications during pregnancy, and the vulnerability to which these women are exposed, thus the importance of developing prevention and health promotion for this audience (Oliveira & Mandú, 2015; Quevedo, Lopes & Lefêvre, 2006; Silva et al., 2021; Villamil, Botero & Guzmán, 2019). However, such information was not widely known by the interviewees in this study, who reported a poor understanding of the possible complications in the face of a high-risk pregnancy and the need for regular monitoring, known from the experience of the current pregnancy.

However, the greater the promotion of information before pregnancy, the greater the possibility of favoring adequate pregnancy planning, and the better the chances of reducing the risks and vulnerabilities these women may be exposed to (Oliveira & Mandú, 2016; Quevedo et al., 2006; Villamil et al., 2019).

A.4) Fears following discovery

Fears regarding the inadequate development of pregnancy, complications, and risk of death for both mother and baby are constantly experienced (Villamil et al., 2019), as in the statements from Resiliência, Esperança, and Equilíbrio, presented below:

> Because when we get pregnant, we think, now what am I going to do? But the diabetic patient thinks will the baby be born? (...) I will be able to complete this pregnancy? Is it a blessing or a problem that will be born? (Resiliência)
>
> That's when we're on the back foot, you know, we think something is going to happen. (Esperança)
>
> I'm very afraid, not so much of diabetes, I'm afraid of diabetes, of course, because of the baby, every day is different, a fight won because diabetes is treacherous, you know, but thank God it's well controlled, but so I have fear of both diabetes and depression. (Equilíbrio)

According to Costa et al. (2019) and Wilhelm et al. (2015), feelings such as fear, worry, insecurity, anxiety, happiness, and guilt are present daily in the lives of high-risk pregnant women. Resiliência, expresses a feeling of guilt in the face of the lack of control of diabetes "Oh, I get desperate when I see that the insulin didn't have any effect, so I blame myself, it was my fault, I administered it wrong, if I had eaten a little less it wouldn't have gone up, then it's my fault." (Resiliência).

The difficulty in dealing with the decompensation of the chronic disease reported by Resiliência demonstrates her suffering, loneliness, and isolation in her self-care process. In agreement with other studies that found constant concerns experienced by women during a high-risk pregnancy (Costa et al., 2019; Oliveira & Mandú, 2016; Villamil, Botero & Guzmán, 2019Wilhelm et al., 2015).

A.5) Being a mother

When reporting on the discovery of pregnancy, pregnant women also reflected on the process of becoming mothers:

> The people who live, the people who get pregnant, we see it through everything we go through. (...) it's very difficult, very complicated, we don't sleep at night, and we get very sick. For example, I was very nervous during pregnancy... then... so I think that after you experience it, you understand, you understand what it means to be a mother. (Apoio)
>
> (...) nowadays I look at my son and he says "Mom, I love you, Mom, I will never leave you". My kids are so close to me and I look at this and think "Thank you so much". (Gratidão)

Apoio describes that motherhood brought her difficulties with sleeping, eating, and self-care, highlighting that it is a process in which she understands and learns to be a mother. This corroborates Maldonado (2017), for whom the perspective of pregnancy can be understood as a moment of existential transition marked by constructions and restructuring of women's social and identity roles, while Gratidão perceives motherhood as an opportunity for contact with her children and an experience of love, which makes her feel grateful.

Resiliência describes motherhood based on the relationship with her mother "(...) I will take care of her, I will be a good mother and she will love me as much as I loved my mother." (Resiliência). The perspective of a "good mother" based on unconditional and supreme love also reveals social and cultural conceptions that women should shape themselves and be inspired by other female figures, who associate care with being a woman (Del Priore, 2006). However, these prerogatives can also cause discomfort and suffering, due to the obligations prescribed in the social imaginary about being a woman and the experience of motherhood (Cunha, Eroles & Resende, 2020; Del Priore, 2006).

The participants' reports about discovering their pregnancy demonstrate that the significant impacts on their lives, as well as fears and concerns (Antoniazzi et al., 2019; Maldonado, 2017). The fact that there was a chronic illness before pregnancy may have contributed to the surprise upon discovering the pregnancy and intensified the negative feelings and insecurity of the participants (Tyer-Viola & Lopez, 2014).

Therefore, these experiences demonstrate the need for special care for this population (Brasil, 2012; Tyer-Viola & Lopez, 2014; Villamil et al., 2019), such as the development of specific public policies aimed at this group; training of professionals to receive high-risk pregnant women, as well as promoting maternal mental health and preventing new unplanned high-risk pregnancies (Brasil, 2019; Villamil et al., 2019).

A) Experiencing pregnancy with a chronic illness

In addition to the suffering experienced by the pregnant women interviewed when they discovered they were pregnant, the repercussions of the pregnancy for the participants about caring for chronic diseases were also repeatedly reported by the pregnant women.

B.1) Pregnancy impacts

The search for balance between chronic disease care and the physical changes resulting from pregnancy contributes to the development of anxiety, fear, and worry (Antoniazzi et al., 2019; Oliveira & Mandú, 2015; Quevedo et al., 2006; Tyer-Viola & Lopez, 2014) as can be seen below:

> It's been horrible, it's already started horrible. I was already hospitalized, there was a pre-diagnosis that I wasn't progressing, that his heart wasn't beating, so I was desperate because his heart wasn't beating, but wow, there was a little seed inside me, why didn't it survive? So I became desperate and I suffered a lot these last one or two weeks in this uncertainty of not detecting a heartbeat (Resiliência)

> The more effort you make, it seems like they shift because they move, right? Then it got complicated. Then it only started to cause problems after I got pregnant. (Apoio)

> Look, it's difficult, very difficult (...) along with the severe headache, in the beginning, like at the beginning of the pregnancy, it was a headache, it was nausea, right, so I just stayed in bed more and had to do my things. I like doing my own thing and I couldn't do it. (Firmeza)

> Wow, we feel that now it's not just one life, it's two, you know, inside me I carry another life, but if there are any complications it even affects the baby. (Esperança)

> So, it changes your lifestyle a lot, right? I say it changes a lot, and then with pregnancy, we have more responsibility. (Gratidão)

Resiliência, Apoio, Firmeza, Esperança, and Gratidão referred to inconveniences, such as displacement of stones due to chronic kidney disease; severe headaches, resulting from uncontrolled hypertension; fears of complications for the fetus, caused by decompensation or lack of control of the disease, as well as changes in lifestyle and self-care. Thus, apparently, for these women, pregnancy can alter and/or intensify symptoms of chronic pathology, causing additional risk to their health and that of the baby, making monitoring and surveillance essential, thus impacting their daily lives, confirming results in the literature (Quevedo et al., 2006; Tyer-Viola & Lopez 2014).

B.2) Complications during pregnancy

High-risk pregnant women may feel unprepared to have a child, need to change their routine, make frequent visits to the physician, and often undergo hospitalization (Costa et al, 2019; Ferreira & Fernandes, 2020; Wilhelm et al., 2015) due to complications associated with pregnancy.

The need for hospitalization can intensify maternal sensitivity, causing feelings such as fear, anxiety, anguish, and sadness, and such feelings may be superior to positive emotions during pregnancy (Ferreira & Fernandes, 2020; Santos & Vivian, 2018). Feelings that can be observed in the statements from Resiliência, Apoio, Equilíbrio, and Gratidão:

> And you hear reports, you are there in the hospital, and you see other mothers who are also diabetic, I was hospitalized there, there was a mother whose baby was born weighing 4 kilos or so, and the baby died. So, it fed my fear, even more. (Resiliência)

> Then I had to take some medicine, I felt very, very sick. I was also hospitalized, I stayed for about two months or so. (Apoio)

> Then I was hospitalized because... no, I went to the health unit close to home to start prenatal care, ordering, and taking exams, the physician immediately took me off my anxiety medication, so I had a withdrawal crisis (...) it was very difficult. (Apoio)

> So now I've been hospitalized 1 more time and I've been hospitalized 4 times during this pregnancy. (Gratidão)

The experience of hospitalization during high-risk pregnancy is common and can be understood as a necessary alternative to specialized care and monitoring the health of the mother and baby. Nevertheless, this experience can increase the stress and anxiety of pregnant women, as hospitalization promotes separation from daily routines and family relationships, generating even more negative feelings (Antoniazzi et al., 2019; Fernandes & Ferreira, 2020).

Other complications and difficulties may arise during a high-risk pregnancy, such as decompensation of chronic disease, dietary limitations, and constant pain, as reported by Resiliência, Apoio and Força:

> If it is a normal pregnancy where the person has nothing, they know that if they eat too much, they will gain weight, and they are taking the problem into their own hands. Now I don't, I eat very little and suddenly I get hypoglycemia. (Resiliência)

> Ah, very complicated because there's not much to do, right? Then we go to the physician, they look, they say I'm going to have to bear it, they say I'm going to have two births, right... one to remove the baby and one to remove the stones. (Apoio)

> Wow, I'm dying to eat pizza, girl, you have no idea. I told my husband that I was going to buy it, I'm going to go to the teaching hospital, sit there, and say "Look guys, I'm going to eat a pizza, you'll take me in a little while" (laughs). (Força)

Feelings such as hopelessness toward self-care caused by constant glycemic decompensation, fear of having a premature birth, discouragement in carrying out daily activities, crises due to abrupt withdrawal of medication, crying, and thoughts of death are expressed as other complications and difficulties experienced by these women, such as those presented below:

> Decompensation, which sometimes happens to me, I go there and apply X amount of insulin, because it's high, it goes down and I go to eat, then when it's time to eat it doesn't go down, but what then? What will I have to do? Will I have to take insulin? What am I doing wrong? (Resiliência)

> I was entering the seventh month and they wanted to induce labor, you know, so they could do the surgery because it was descending and was not releasing urine from the kidneys. The kidneys were swollen. Finally, they (stones in the kidneys) moved otherwise the baby would have to be born. (Apoio)

> I'm the one who takes care of my things here at home, so if I have to go out to pay a bill, I have to go quickly and come back, because I start to feel sick, you know, I want to sit down and there's no place to sit. So today I can't wait until I have the baby so I can see what happens. (Firmeza)

> After I left the hospital, which is when I started to have withdrawal crises, you know... I didn't sleep, I didn't sleep for 15 days, I couldn't wash a glass, I couldn't do anything, just crying, crying, crying and despair, the only thought of suicide came into my head (...) (Equilíbrio)

A high-risk pregnancy can have great emotional impacts on women (Azevedo et al., 2020). The importance and need for social support are highlighted as a preponderant factor in strengthening this population during the experience of a high-risk pregnancy (Antoniazzi et al., 2019).

Family members and/or friends who play a significant and affective role in pregnant women's lives can promote acceptance, coping with adversities, and the experience of negative feelings. The health professionals who accompany these women in their pregnancy-puerperal process are also important figures of care, being able to work with the prevention and promotion of maternal mental health (Antoniazzi et al., 2019).

B.3) expectations, concerns, and complaints

Considering the experience of a high-risk pregnancy due to a previous chronic illness, Apoio, Esperança and Força reported:

> Wow, I just keep thinking that I just want her to be born soon so I can stop feeling so much pain. (Apoio)

> And we also remain in that... that expectation that something could go wrong at any moment, it's complicated, right? (Esperança)

> The complicated thing isn't even when it's time to have the child, it's that you have to deal with the amount of problems that I have, it's very complicated, my lady! (Força)

These experiences indicate that high-risk pregnancy can promote and intensify feelings commonly felt during pregnancy, such as fear and anxiety (Antoniazzi et al., 2019). Soncini, Oliveira, Viviani and Gorayeb (2019) highlight that, comparing Brazilian women with high- and low-risk pregnancies, there is a higher incidence of feelings such as anxiety and depression in high-risk pregnant women than in low-risk pregnant women.

Expectations of complications reflect the anguish of these women about not completing the pregnancy, which are fears frequently found in high-risk pregnant women

(Fernandes & Ferreira 2020; Oliveira & Mandú, 2015; Quevedo et al., 2006; Tyer-Viola & Lopez 2014; Wilhelm et al., 2015), but which cannot be naturalized.

B.4) Learnings

Regarding the lessons learned during a high-risk pregnancy, understood here, as positive aspects observed by the participants about what they experienced, Resiliência, Apoio and Autocuidado state:

> I have learned to this day that each pregnancy is different. (Resiliência)
>
> Ah, I think it's a learning experience for every woman, right? Because I think we learn a lot during pregnancy. Our feelings are different. Yes, we learn to be another person because we get very sentimental during pregnancy. (Apoio)
>
> Today, because of my pregnancy, I worry more. I try to take care of myself more. (Autocuidado)

The participants brought references to expand their views on the differences from one pregnancy to the next, changes in emotional aspects, and self-care with chronic illness. These reports reflect the ways found by these women to give meaning to the experience of pregnancy, despite its complications and challenges.

On the other hand, the learning contributed to the expansion of pregnant women's identities, as well as helping to develop a positive outlook on pregnancy, demonstrating that pregnancy is an event capable of promoting significant changes in the lives of women who experience it (Maldonado, 2017).

Final considerations

The pregnant women participating in this study described varied experiences associated with high-risk pregnancy, with the chronic illness causing significant impacts on the daily lives of the interviewees. The discovery of pregnancy, unplanned by most, led to significant changes in the lives of these women. The experience and control of chronic disease proved to be challenging with the discovery of pregnancy, awakening fears, uncertainties, changes in daily life, and complaints.

The impacts produced, such as hospitalization, revealed that for these women this experience is burdened by negative emotions. Despite this, lessons learned were highlighted, including the appreciation of self-care in the quest to control chronic disease, triggering expectations for the proper development of pregnancy.

Based on the above, this study presented only a portion of the population of high-risk pregnant women, due to chronic illness before pregnancy, living in a municipality in the state of Minas Gerais. Therefore, such aspects may represent a limitation of this study, and the data cannot be generalized.

However, the results presented favor the understanding of the difficulties experienced by the participants, their learning, and their needs for specialized care, as well as describing the experiences and constructions of meaning produced by the group participating in the study.

The suffering experienced by the participants, during a high-risk pregnancy, could be minimized with the adequate provision of information and the acceptance of feelings and complaints verbalized by pregnant women by trained health professionals, and the encouragement of psychological support during pregnancy. This represents a relevant contribution to the care provided to maternal and child health, recognizing the emotional and

social impacts of chronic illness during pregnancy and the need for care, support, and early intervention.

Finally, the importance of investing in research and assistance for high-risk pregnant women is highlighted, valuing their psychosocial perspective on the experience of pregnancy, thus minimizing possible harm to their mental health.

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