

Perception of women with heart disease about their high-risk pregnancy

Percepción de mujeres cardíacas sobre su embarazo de alto riesgo

Percepção de mulheres com doenças cardíacas sobre sua gravidez de alto risco

*Silmara Meneguín*¹, ORCID 0000-0003-3853-5134

*Camila Fernandes Pollo*², ORCID 0000-0003-0264-5841

*Jhenifer Melissa de Souza*³, ORCID 0000-0003-2003-8738

*Cariston Rodrigo Benichel*⁴, ORCID 0000-0003-2781-0292

*Miriane Garuzzi*⁵, ORCID 0000-0002-6026-5313

^{1 3} *Nursing Department, Botucatu Medical School, Paulista State University – (Unesp). Brazil*

^{2 4 5} *Program in Nursing at Botucatu Medical School, Paulista State University – (Unesp). Brazil*

Received: 02/17/2020

Accepted: 09/23/2020

Abstract: Framework: Although gestation marks some of the most important moments in a woman's life, it becomes complex when associated with the problems, limitations, and risks inherent in heart disease. Objective: to comprehend the meanings women with heart disease attribute to their high-risk pregnancy and to identify their perception of the risks to the mother-child binomial. Methodology: A quantiquantitative study involving 39 pregnant women with heart disease from a public university of an inland city of São Paulo, Brazil, was conducted. Data were collected through interviews with patients and analyzed using the Discourse of the Collective Subject. Results: This study showed high-risk gestation is a process linked to personal satisfaction and fulfillment of a dream, often associated with a lack of planning, uncertainties and fears. Some participants anchored in religion/spirituality to overcome difficulties, while others used self-reliance as a support. The risks are poorly understood and often underestimated. Conclusion: High-risk gestation is a process associated with personal satisfaction, fulfillment of a dream and even a common experience, often permeated by negative feelings about the inevitable risks to the mother-child binomial.

Keywords: high-risk pregnancy; coronary diseases; qualitative research; nursing

Resumen: Marco contextual: Aunque la gestación marca algunos de los momentos más importantes en la vida de una mujer, se vuelve compleja cuando se asocia con los problemas, las limitaciones y los riesgos inherentes a la enfermedad cardíaca. Objetivo: entender los significados que las mujeres con enfermedad cardíaca atribuyen a embarazos de alto riesgo e identificar su percepción de los riesgos para el binomio madre-hijo. Metodología: Fue desarrollado un estudio

cuanti-cualitativo con 39 embarazadas cardíacas en una universidad pública en el interior de São Paulo, Brazil. Los datos fueron recolectados mediante entrevistas con pacientes y analizados mediante el Discurso del Sujeto Colectivo. Resultados: Este estudio reveló que el embarazo de alto riesgo es un proceso vinculado a satisfacción personal y cumplimiento de un sueño, muchas veces asociado con una falta de planificación, incertidumbres y miedos. Algunas participantes se apoyaron en la religión/espiritualidad para superar dificultades, mientras otras utilizaron la autoconfianza como apoyo. Hay poca comprensión y muchas veces subestimación de los riesgos. Conclusión: El embarazo de alto riesgo es un proceso asociado con satisfacción personal, cumplimiento de un sueño e incluso con una experiencia común, muchas veces permeada por sentimientos negativos sobre los riesgos inevitables para el binomio madre-hijo.

Palabras claves: embarazo de alto riesgo; enfermedad coronaria; investigación cualitativa; enfermera

Resumo: Marco contextual: Embora a gestação marque alguns dos momentos mais importantes na vida de uma mulher, ela se torna complexa quando associada aos problemas, limitações e riscos inerentes às doenças cardíacas. Objetivo: compreender os significados que mulheres cardiopatas atribuem à gravidez de alto risco e identificar sua percepção sobre os riscos para o binômio mãe-filho. Metodologia: Foi realizado um estudo quantitativo com 39 gestantes cardiopatas de uma universidade pública de uma cidade do interior de São Paulo, Brasil. Os dados foram coletados por meio de entrevista com os pacientes e analisados por meio do Discurso do Sujeito Coletivo. Resultados: Este estudo mostrou que a gestação de alto risco é um processo atrelado à satisfação pessoal e realização de um sonho, muitas vezes associado à falta de planejamento, incertezas e medos. Alguns participantes se ancoraram na religião / espiritualidade para superar as dificuldades, enquanto outros usaram a autossuficiência como suporte. Os riscos são mal compreendidos e frequentemente subestimados. Conclusão: A gestação de alto risco é um processo associado à satisfação pessoal, realização de um sonho e até mesmo uma experiência comum, muitas vezes permeada por sentimentos negativos sobre os riscos inevitáveis para o binômio mãe-filho.

Palavras-chave: gravidez de alto risco; doença arterial coronariana; pesquisa qualitativa; enfermagem

Correspondence: Silmara Meneguín; e-mail: s.meneguín@fmb.unesp.br

Introduction

Gestation is a physiological phenomenon in a woman's life, which usually evolves without intercurrent. Gestation is a physiological phenomenon in the life of a woman that usually evolves without intercurrent. However, there is a small portion of pregnant women, called high risk, who, because they have a disease or suffer some health problem, are more likely to have an unfavorable evolution (1).

Pregnant women with cardiopathy are included in this group, as their obstetric and fetal risks are potentialized during the pregnancy-puerperal cycle. Heart disease is considered the largest non-obstetric cause of maternal morbidity and mortality in the world (2).

The occurrence of cardiovascular diseases in pregnancy ranges from 0.2% to 4% in Western countries and its complications are related to thromboembolic events, heart failure, and arrhythmias, among others (3).

In Brazil, the incidence of heart disease during pregnancy exceeds international statistics, with a rate of 4.2% (4). This percentage is attributed to the high incidence of rheumatic disease that affects childbearing-age women, representing 80% of cardiopathies during gestation (5).

Rheumatic disease, in turn, is considered an important etiology of valvular heart disease, since the scars from the inflammatory process that affects all heart follow-ups during the outbreaks of this disease cause heart valve deformation (6).

In pregnancy and in the postpartum period, cardiovascular changes associated with pregnancy may contribute to clinical deterioration in these patients and often to the initial diagnosis of valvular heart disease (7). In this period, circulating blood volume increases by approximately 30% to 50%. Concurrently, systemic vascular resistance substantially reduces, and blood pressure decreases. These changes begin in the first trimester and peak at 24 weeks' gestation, with an additional increase in the immediate postpartum period (2).

Although gestation is a biological and social event that marks some of the most important moments in a woman's life, it becomes complex when associated with the problems, limitations, and risks inherent in heart disease (8).

In addition, considering that pregnancy is a choice for women who desire this experience is necessary; their decisions may be based on several conscious and unconscious reasons such as deepening a man-woman relationship, concretizing the desire for continuity and hope of immortality, maintaining a broken bond, competing with family members, and filling an internal void, among others (8). These factors help many women to desire pregnancy despite the high risk.

However, little is known about the experience of high-risk gestation in women with heart disease. In general, the literature has focused on the cardiovascular repercussions and clinical outcomes of gestation (9).

Faced with the lack of studies, this investigation aims to answer the following questions: What meanings do women with heart disease attribute to their high-risk pregnancy? What is your perception of the risk for the mother-child binomial?

Thus, this study aimed to comprehend the meanings women with heart disease attribute to their high-risk pregnancy and to identify their perception of the risks to the mother-child binomial

Methodology

This is a qualitative-quantitative study, which used the Discourse of Collective Subject, based on the Social Representation Theory (10).

In an empirical study, the thought, materialized in the form of discourse, is a qualitative variable. However, as it is a collective thought, it is also characterized as a quantitative variable when considering it expresses the individuals' opinions (10).

This study was conducted in a gynecology and obstetrics outpatient clinic at a public hospital in the interior of São Paulo, Brazil. Data collection was performed from November 2011 to May 2015. The data collection period was extended because the study was conducted at a general hospital that serves few pregnant women with cardiopathies.

The inclusion criteria were: to be pregnant with heart disease as of the second trimester of pregnancy, to be receiving prenatal care in the institution, and to consent to participate. The choice of this period was due to the increase in blood volume, which peaks at 24 weeks' gestation and is 40% larger than the pregravid volume (1). The exclusion criteria were: unavailability to participate in the interview and self-reported verbal inability to speak.

A sample was composed of thirty-nine pregnant women who met the previously established inclusion criteria. This sample consisted of the total of patients cared for in the data collection period. All participants consented to participate in the interview, which was not interrupted. Data were collected using semi-structured interviews and an instrument with sociodemographic (age, education level, marital status, number of children) and clinical data (previous abortions, family planning, gestational age, participation or not in a family planning group, etiology of the heart disease), as well as two leading questions: "In your opinion, what does being a mother with heart disease mean to you? Were you aware of the risks posed by this gestation before getting pregnant?"

The interviews were conducted individually and in a private environment. Among the researchers, there was a PhD-qualified professor with experience in the DSC technique who conducted the analysis of the interviews, as well as undergraduate and graduate students. No one had any kind of bond with the participants.

The ICF contained the researchers' information provided to the patients when the latter were invited to participate in the study. The transcripts of the interviews could not be sent back to participants for comments.

After the 39 interviews, the discourses were transcribed and the discourse analysis was started, using the methodological approach of the Discourse of the Collective Subject (DSC) (10). Methodological figures such as central ideas and anchoring, as well as their respective key expressions were used for transcription. Key expressions and anchoring are pieces or fragments of material (discourse) comprising literal descriptions of the testimonies, disclosing the essence of the representation content and their underlying theories. The central idea is a name or expression disclosing and describing, in a brief and accurate manner, the meanings behind the testimonies, which will result in the DSC (10).

The methodological steps followed from the interviews to the synthesis of the discourses were:

- Reading of the testimonies collected from the interviews;
- Reading of the answer to each question, writing down the key expressions selected;
- Identification of the central ideas of each answer;

- Analysis of all key expressions and central ideas, homogeneously grouping their similarities;
- Identification and designation of the central idea of the homogeneous group, constituting the synthesis of the central idea of each discourse;
- Construction of discourses of the collective subject after spotting the central ideas and key expressions that named these discourses. The discourse of the collective subject proposes reconstructing an empirical collective subject, whose opinions are expressed through a discourse in the first person singular.

After analyzing the transcripts, the recordings were deleted.

The data were obtained after approval of the project by the Research Ethics Committee of the institution under No. 3911/2011, and the participants signed the informed consent form after being assured of anonymity.

Results

The participants were 39 pregnant women with a mean age of 25.3 years. Nearly half (53.5%) had completed high school and only two (7.1%) had higher education. Regarding marital union, most had a partner (30; 76.9%), that is to say, they were married and lived with a partner. In addition, more than half of the interviewees (27; 69.2%) were progenitors.

Regarding clinical and obstetric variables, 13 (33.3%) pregnant women had previous abortions and 25 (64.1%) had not planned the current pregnancy. In addition, 26 (66.6%) had already been pregnant, and most of them (73.0%) had been pregnant more than once. The mean gestational age was 27 weeks ($SD = \pm 2.69$). Most of the participants (84.6%) did not participate in family-planning groups and did not use a contraceptive method (82.0%).

Regarding the etiology of heart diseases, 16 (41.0%) pregnant women had a predominant rheumatic fever, followed by valvular heart disease (14; 35.8%), arrhythmias (4; 10.2%), mitral valve prolapse (2; 5.1%), myocardopathies (2; 5.1%), and congenital heart disease (1; 2.5%).

By analyzing the transcripts, key expressions and central ideas were identified, and the discourses of both themes, derived from the leading questions, were constructed.

Quadro 1. Synthesis of central ideas and collective subject discourse related to the theme meanings of high-risk pregnancy.

Central ideas	Discourse of the Collective Subject
Personal satisfaction Realization of a dream	For me, motherhood is a marvelous experience, I fell fulfilled and happy, nothing matters when a dream comes true. It's very satisfactory. I'm sure I did the best thing ever, I feel great and fulfilled now. I would definitely do it all again for the experience of being able to generate a life.
Common experience	But I would do it all again, of course I would do it to give birth a baby. It was difficult only in the first month, but the other things are normal. The disease did not change my life. I'll be a mother just like other women.
Miracle	However, it was a miracle of God. I consider the fact I'm alive a godsend. God watched over me all this time, otherwise I wouldn't be here anymore.
Unexpected surprise	I got pregnant unexpectedly, it was a surprise, I could do nothing about it. As it was unplanned, I couldn't regret it. I imagined it couldn't happen to me, I thought I wouldn't get pregnant because of my condition. I was shocked when I knew I was pregnant.
Fear of death.	What I'm experiencing now is great, but the fear of death, of stop living is enormous. Many times, I thought I would die when I felt sick. The fear is constant, you don't know if you'll be alive to see your baby. I've never felt like this before.

Quadro 2. Synthesis of central ideas and collective subject discourse related to the theme meanings perception of the risks inherent in the gestation.

Central ideas:	Discourse of the Collective Subject
Unawareness	"I didn't know the risks when I got pregnant. I always wanted to get pregnant and experience motherhood, but the risks never crossed my mind. In addition, concerning my condition, the cardiopathy, I knew neither me nor the baby's health would be at risk.
Underestimation	The first time I got pregnant, the heart disease caused some complications, and I haven't thought that would happen to me again. But there was no interference... nothing prevented me from being a mother. I was only afraid that my daughter could have a disease, but that won't happen, God willing. If God had allowed me to get pregnant, he would make me strong to go on, that's why I have not afraid of becoming sick, because I believe in God and I placed it in God's hands. I'm sure He's watching over me and my daughter. I always believed deeply that nothing worse would happen to me, I was sure. It makes me handle it. I can't regret this situation; I have to go on".

Discussion

The limitations of this study are related to the fact that it was developed in a single health service with local characteristics. However, the results provide an understanding of the magnitude and the complexity of a relevant public health problem that affects developing countries, in which the sequelae of fever represent 60% of all cardiovascular diseases in children and young adults (11).

This disease is often associated with poverty and poor living conditions, with a high socioeconomic burden not only for the health services, but also for patients and their families due to chronic sequelae in the early life stages (12). A Brazilian study performed in a cardiology hospital involving 650 pregnant women with heart disease showed 50% of the participants had valvular heart disease (13).

However, in spite of the recognized importance of the problem and the existence of proven effective strategies of prevention and treatment of the disease, the health actions developed to date in Brazil have proved to be insufficient for the adequate control of the fever, as shown in this study, in which 41% of participants had rheumatic heart disease (14).

In this sample, adult women with an average age of 25 years, who had a partner and a complete secondary education level predominated. These data were corroborated in a study carried out with healthy pregnant women, in which the education level of most of the participants was over 11 years (15). The pregnant women's education level is relevant, given that it is associated with neonatal mortality, especially in developing countries, in addition to reflecting the mother's socioeconomic status (16). Despite the complexity involved in gestation in women with heart disease, this fact should also be considered when interpreting the results.

Although gestation is a dynamic, subjective and diverse process, the testimony showed it was the crowning of some participants' personal desire, and even a dream, built from the perspective of the sociocultural and family context experienced by these women. In addition, one must consider that pregnancy can sustain and consolidate the feminine identity for many of these women, despite the fact that it is a choice and the fear of the real consequences for the mother-child binomial (17).

In some situations, even if it is properly oriented, the desire to bear children contradicts the medical indication, as shown in the literature and in the results of this investigation (8). This attitude is likely linked to the intimate need to adhere to the female role of procreation, which seems to be associated with their model of feminine identity.

In addition, pregnancy can also help them in overcoming their personal limits, so it is not planned but desired. This may be linked to the fact that more than 80% of the participants did not use contraceptive methods.

This reality is a very different from that of a recent study conducted in North America involving 505 women with complex congenital heart disease. In this investigation, although 86% of the interviewees used contraceptive methods, the authors recognized that health education and family planning practices were still deficient for these patients (18).

Another interesting element revealed by the study participants was the negative feelings about the developments that permeate a high-risk pregnancy, ratified by the fears, uncertainties, and insecurity present in the interviewees' discourse. A qualitative research conducted with 19 women with peripartum cardiomyopathy in Sweden corroborated these data. In this investigation, anguish, insecurity, and emotional discomfort were the most prevalent feelings in the pregnant

women's discourse, besides not feeling properly cared for and informed by health professionals (19).

This study also highlighted the ignorance of the risks of gestation indicated by the participants. The absence or insufficiency of knowledge that women have about their health and complications interferes with their autonomy, often preventing them from making decisions about gestation, delivery, and treatment. A national study involving pregnant women with preeclampsia and specific gestational hypertensive disease showed they were unaware of the disease and its risks during this period, which contributes to aggravating the consequences of high-risk pregnancy (20).

However, when risks become a concrete possibility, one realizes that religion/spirituality is the protection they seek to face a situation marked by impotence and uncertainties. The attachment to religion/spirituality revealed in the interviews reaffirms the premise that this can be a source of relief and protection to address difficulties.

A recent study involving 17 cardiac patients showed the need to transcend the care relationship based on the biomedical model to reach an existential relationship in which women are considered to be endowed with possibilities. In this investigation, the authors highlight the importance of a care consistent with the real objective and subjective needs of pregnant women with cardiopathy (21).

Therefore, the management of pregnancy in these circumstances requires a humanized care, from the perspective of integral care, guided by reception and guidance.

Despite the concern with high-risk pregnancies in the country, there is still a gap with regard to the establishment of public policies that ensure care associated with the unique expectations and needs of these women. The study contributes so that health professionals perceive the problem, considering the subjective aspects involved in high-risk pregnancy. Furthermore, this study highlights a neglected social and health problem in Brazil, with family, socioeconomic and cultural influences.

Conclusion

The results of the study indicate that high-risk gestation is a process associated with personal satisfaction and fulfillment of a dream, often permeated by negative feelings about the inevitable risks to the mother-child binomial.

The risks are not always known and may be underestimated; for these women, the risk seems to be less important than being a mother. However, religion/spirituality support them in facing adversity and overcoming fears. Thus, health professionals should approach high-risk pregnancies focused on subjective issues experienced by these women. In addition, this study became a neglected social and health problem in this country visible. This fact demonstrates the importance of establishing public policies that ensure reception and multidisciplinary care in the health care network for these women.

References

1. Hollier L., Jr JNM, Connolly H, Turrentine M, Hameed A, Arendt KW, et al. Clinical management guidelines for obstetrician – gynecologists pregnancy and heart disease. *Pract Bull Pregnancy Hear Dis.* 2019;133(5):320–56.
2. Regitz-Zagrosek V, Roos-Hesselink JW, Bauersachs J, Blomström-Lundqvist C, Cífková R, De Bonis M, et al. 2018 ESC Guidelines for the management of cardiovascular diseases during pregnancy. Vol. 39, *European Heart Journal.* 2018. 3165–3241 p.
3. Roos-Hesselink JW, Ruys TPE, Stein JI, Thilén U, Webb GD, Niwa K, et al. Outcome of pregnancy in patients with structural or ischaemic heart disease: Results of a registry of the European Society of Cardiology. *Eur Heart J.* 2013;34(9):657–65.
4. Tedoldi CL, Freire CM V, Bub TF. Diretrizes da Sociedade Brasileira de Cardiologia para Gravidez e Planejamento Familiar da Mulher. *Arq Bras Cardiol.* 2009;93(9 Supl 1):e110–78.
5. Watkins DA, Sebitloane M, Engel ME, Mayosi BM. The burden of antenatal heart disease in South Africa: A systematic review. *BMC Cardiovasc Disord* [Internet]. 2012;12(1):23. Available from: <http://www.biomedcentral.com/1471-2261/12/23>
6. Wilkins GT, Weyman AE, Abascal VM, Block PC, Palacios IF. Percutaneous balloon dilatation of the mitral valve: An analysis of echocardiographic variables related to outcome and the mechanism of dilatation. *Heart.* 1988;60(4):299–308.
7. Van Hagen IM, Thorne SA, Taha N, Youssef G, Elnagar A, Gabriel H, et al. Pregnancy outcomes in women with rheumatic mitral valve disease: Results from the registry of pregnancy and cardiac disease. *Circulation.* 2018;137(8):806–16.
8. Foeller ME, Foeller TM, Druzin M. Maternal Congenital Heart Disease in Pregnancy. *Obstet Gynecol Clin North Am* [Internet]. 2018;45(2):267–80. Available from: <https://doi.org/10.1016/j.ogc.2018.01.011>
9. Cribbs MG, Briston DA, Zaidi AN. Current attitudes and clinical practice towards the care of pregnant women with underlying CHD: A paediatric cardiology perspective. *Cardiol Young.* 2017;27(2):236–42.
10. Lefevre F, Lefevre AMC, Marques MC da C. Discurso do sujeito coletivo, complexidade e auto-organização. *Cienc e Saude Coletiva.* 2009;14(4):1193–204.
11. Levav I, Rutz W. The WHO World Health Report 2001: New understanding - New hope. *Isr J Psychiatry Relat Sci.* 2002;39(1):50–6.
12. Milanesi R, Caregnato RCA. Intra-abdominal pressure: an integrative review. *Einstein.* 2016;14:423–30.
13. Ávila MB. Direitos sexuais e reprodutivos: desafios para as políticas de saúde. *Cad Saude Publica.* 2003;19(suppl 2):S465–9.
14. Sociedade Brasileira de Cardiologia. No Title. 2009;
15. Lapolla A, Cianni G Di, Benedetto A Di, Franzetti I, Napoli A, Sciacca L, et al. Quality of Life , Wishes , and Needs in Women with Gestational Diabetes : Italian DAWN Pregnancy Study. 2012;2012.
16. Wang H, Liddell CA, Coates MM, Mooney MD, Levitz CE, Schumacher AE, et al. Global , regional , and national levels of neonatal , infant , and under-5 mortality during 1990 – 2013 : a systematic analysis for the Global Burden of Disease Study 2013. 2013;957–79.
17. González-chica DA, Cesar JA. Gravidez não planejada no extremo Sul do Brasil :

- prevalência e fatores associados Unplanned pregnancy in Southern Brazil : prevalence and associated factors. 2011;27(10):1906–16.
18. Miner PD, Canobbio MM, Pearson DD, Schlater M, Balon Y, Junge KJ, et al. Contraceptive Practices of Women With Complex Congenital Heart Disease. *Am J Cardiol* [Internet]. 2016;119(6):911–5. Available from: <http://dx.doi.org/10.1016/j.amjcard.2016.11.047>
 19. Patel H, Schaufelberger M, Begley C, Berg M. Experiences of health care in women with Peripartum Cardiomyopathy in Sweden : a qualitative interview study. *BMC Pregnancy Childbirth* [Internet]. 2016;1–9. Available from: <http://dx.doi.org/10.1186/s12884-016-1178-3>
 20. Hipertensiva AD, Da E. Percepções de um grupo de mulheres sobre a doença hipertensiva específica da gestação. 2011;32(2):316–22.
 21. Amorim TV, Souza ÍE de O, Salimena AM de O, Melo MCSC de, Paiva A do CPC, Moura MAV. The everyday of a heart disease high-risk pregnancy: phenomenological study of care relationships. *Esc Anna Nery - Rev Enferm*. 2016;20(4):1–6.

Funding: FAPESP (Protocol number 2011/14897-7)

How to cite: Meneguín S, Pollo CF, Souza JM, Benichel CR, Garuzzi M. Perception of women with heart disease about their high-risk pregnancy. *Enfermería: Cuidados Humanizados*. 2020; 9(2): 160-169. Doi: <https://doi.org/10.22235/ech.v9i2.2087>

Authors' participation: a) Conception and design of the work; b) Data acquisition; c) Analysis and interpretation of data; d) Writing of the manuscript; e) Critical review of the manuscript. M.S. has contributed in a,c,e; CFP in E; JMS in d; BCR in d; GM in e.

Scientific editor in charge: Dra. Natalie Figueredo