The everyday of a heart disease high-risk pregnancy: phenomenological study of care relashionships[a]

Cotidiano da gravidez de risco por cardiopatia: estudo fenomenológico das relações assistenciais

Cotidiano del embarazo de riesgo por cardiopatía: estudio fenomenológico de las relaciones asistenciales

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Abstract

Objective: To unveil care relationships of women in high-risk pregnancy due to heart disease. **Methods:** Qualitative phenomenological research. Qualitative phenomenological study conducted with 17 participants, who were interviewed in a reference institution for maternal risk, and the meanings expressed were analyzed under Martin Heidegger's philosophy. **Results:** Women said that they were questioned by doctors about their pregnancy and while they knew that cardiologists may give their opinions, obstetricians were the ones who would decide the type of childbirth they would undergo. **Conclusion:** Care relationships ruled by pathophysiological view of gestational follow-up and scarcity of the nursing staff providing care for pregnant women were in evidence. If on the one hand the results point to the need for an existential relationship that considers women as *beings* endowed with possibilities, on the other hand, they reveal the importance of nursing care in addressing the needs of pregnant women with heart disease, in the prospect of making it perceived and announced by *being-care*.

Keywords: High-risk pregnancy; Heart diseases; Professional role; Qualitative research.

Resumo

Objetivo: Desvelar o cotidiano das relações assistenciais do ser-aí-mulher na gravidez de alto risco por doença cardíaca. **Métodos:** Pesquisa qualitativa fenomenológica. Dezessete participantes foram entrevistadas em instituição referência para risco materno e os significados expressos foram analisados à luz do pensamento de Martin Heidegger. **Resultados:** As mulheres significaram terem sido cobradas pelos médicos por engravidarem e; saberem que o cardiologista dá o parecer, mas o obstetra é quem vai decidir a via de parto. **Conclusão:** Evidenciaram-se relações assistenciais pautadas na ótica fisiopatológica de acompanhamento gestacional e invisibilidade da equipe de enfermagem junto à gestante. Se por um lado os resultados apontam a necessidade de transcender para uma relação existencial que considera a mulher como *ser-aí* dotada de possibilidades, por outro anuncia a importância do cuidado de enfermagem congruente às necessidades de gestantes portadoras de cardiopatia na perspectiva de se fazer percebido e anunciado pelo *ser-cuidado*.

Palavras-chave: Gravidez de alto risco; Cardiopatias; Papel Profissional; Pesquisa Qualitativa.

Resumen

Objetivo: Develar el cuidado de las relaciones del ser-ahí-mujer en embarazo de alto riesgo por cardiopatia. **Métodos:** Investigación cualitativa fenomenológica. Diecisiete participantes fueron entrevistados en institución referencia para el riesgo materno y los significados fueron analizados a luz del pensamiento de Martin Heidegger. **Resultados:** Las mujeres significabam que fueron acusadas por los médicos por quedar embarazada y; sabiendo la opinion del cardiólogo, pero el obstetra decidirá el tipo de parto. **Conclusión:** Fueran evidentes relaciones de cuidado basadas en la visión fisiopatológica del acompañamiento gestacional con mujeres embarazadas y invisibilidade del personal de enfermería. Si por un lado, los resultados indican la necesidad de trascender a una relación existencial que considera las mujeres como ser-ahí dotado de posibilidades, por otro anuncia la importancia de la atención de enfermeria de acuerdo com las necessidades de las mujeres embarazadas com cardiopatias en perspectiva de si hacer percebido y anunciado por el ser-cuidado.

Palabras clave: Embarazo de alto riesgo; Cardiopatías; Rol profesional; Investigación cualitativa.

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INTRODUCTION

The inclusion of women in the labor market and their association with harmful health habits such as smoking, alcohol use, sedentariness, obesity and stress, have contributed to the development of heart diseases, especially of ischemic origin. Because of its slow and gradual evolution the diagnosis of heart disease is usually made after the age of 30 years, which is also presently a common period for the occurrence of pregnancy. In these cases, the pregnancies are classified as high-risk. It is important to note the scientific advances regarding surgical corrections of congenital defects, which have led to the increase of pregnancies in women with congenital heart disease[1,2].

Nurses and other health professionals must be prepared for early detection and subsequent categorization of pregnant women with heart problems, as well as for the possibility of the disease's development during their pregnancy. This is because heart diseases represent the leading indirect obstetric cause of maternal mortality[3].

Among the aspects to be considered by professionals who monitor pregnant women with heart disease, emotional and psychosocial aspects stand out. Anxiety, fear, anguish and feelings of uncertainty concerning the future are often expressed during high-risk pregnancies. In the emotional dimension, the distress may be deeper, considering the culpability that pervades the inner soul of pregnant women with cardiac disease, once they realize the possibility of death, as well as the possible death of the conceptus. Another aggravating factor is also present; that of the possibility of genetic heritage which might increase the mothers' sense of guilt, especially in women with congenital heart disease[4,5].

Public Policies have evolved that direct attention and healthcare services to Women's Health in pregnancy, childbirth and puerperium areas. Nevertheless, a series of ministerial propositions and other studies on the topic value the biomedical model to the detriment of subjective questions that come up for pregnant women with heart disease[3].

Such reductionism may be implicated in the increase of maternal morbidity, aggravating the public health problem in the face of basic pathology, as well as the distancing of the health system from care relationships and the psychosocial realities that pervade the everyday life of women.

In this respect, health professionals must be aware of the need for a care relationship that considers the plurality of pregnant women with heart disease, resulting in the movement of health care toward the knowledge of subjectivities. Hence, care can be provided in a wider perspective, considering both meaning and facts, and also the lived experience of the women[6,7].

This study is specifically aimed in that direction, once the state of the art was raised concerning the interest topic, it was evidenced that nursing and health science in general proved to be separated from the actual phenomenon of childbirth, focusing instead on the facts of the heart disease and the risk for the pregnancy. The repercussion of inattention to the subjective dimension inhibits possibilities of rethinking nursing and health care, based on women and the meanings that they give to pregnancy.

Therefore, the existential reality of women with heart disease in care relationships in relation to professionals who monitored their daily high-risk pregnancy was questioned, having Martin Heidegger's phenomenology as a theoretical and philosophical framework. In order to answer such a question, the objective of the present study was to unveil the everyday realities of care relationships of the *being-women*[b] in high-risk pregnancy by heart disease.

METHOD

Qualitative and descriptive study, based on the theoretical, philosophical and methodological framework of Martin Heidegger phenomenology. Such a framework seems to be appropriate for opposing the circumscription that natural sciences give to human situations[8]. The object of this study came close to the framework of aiming healthcare relationships on the experience of pregnancy as a phenomenon that was undergone by women with heart disease in a particular time of their lives.

The study sought to access the *entity*, which represents the human being, and only this being is endowed with ontic and ontological possibility, i.e., it moves from the factual to the phenomenal dimension of *being*. The sphere of facts is based on *tradition*, which is a term used by Martin Heidegger to denominate the evidence of natural sciences[8].

What is related to the *being* is in the ontological sphere, where phenomena are experienced in a particular way, which for phenomenology should be considered primary for showing the original understanding of each human being concerning a particular fact or occurrence in their life. In search for such understanding, Heidegger developed a method establishing the scientific rigor based on the reduction of the researcher's assumptions[8].

The *entity*[8] who were accessed in this study were pregnant women with heart disease in the research scenario or survey area where they experienced their pregnancy with risk classification: this was a reference hospital for maternal risk in the southeast region of Brazil.

The field stage occurred from July to December 2014. Records of the follow-up of pregnant women in high-risk prenatal care were accessed, identifying personal data and phone numbers of the possible participants. Retrospective search of women who experienced pregnancy from June 2014 to July 2013 was used as a strategy - taking the diagnosis of heart disease as a starting point.

The research participants were, women with heart disease who were experiencing or had experienced pregnancy in a particular time of their life, regardless of the type of disease; women who performed prenatal follow-up in the hospital's outpatient care of the referred scenario or who were hospitalized in the institution during their pregnancy/puerperium cycle; and women who conceived in risk condition, regardless if pregnancy was terminated or not. Women with mental disorders or under the age of 18 were excluded.

Previous contacts by phone with the possible participants were carried out, explaining the objectives of the study and inviting them to participate voluntarily in it. Seventeen women agreed to participate in the study, and meetings were scheduled according to their preferences, most of whom preferred to be interviewed in the research scenario.

The interviews were recorded by digital means, making transliteration easy and had an average duration of 32 minutes. Seventeen interviews were considered sufficient for allowing the immersion of the phenomenon with enough meaning to meet the objective of the study.

Attentive readings and listening were carried out as many times as necessary for the apprehension of the phenomenon, which happened in two methodical stages. The first stage derived from the approximation to meanings or parts of the interviews that revealed the everyday nature of care relationships, allowing for the development of two Meaning Units.

These units allowed for the achievement of vague and median understanding. For Heidegger, this understanding is revealed in the factual sphere and must express the understanding of the participants concerning the phenomenon questioned[8].

The second methodical time, also called hermeneutics, allows the unveiling of the phenomenon in the ontological dimension by means of interpretation of meanings in the light of Heideggerian concepts[8].

The discussion of this study was concentrated in the hermeneutics of *being-women-who-conceived-being-with-heart disease* - combined with other authors who discuss the topic under study.

To preserve the participants identity and ensure their anonymity, privacy and confidentiality of information observed or revealed, an alphanumeric code represented by the "P" letter followed by corresponding and sequential number of interviews (P1, P2, P3... P17) was adopted.

Because this is a study concerning human beings, precepts of Resolution no 466/2012 were followed, and the field stage was conducted in an ethical way, with approval and deferral of Research Ethics Committees, under protocols number 1.103.165 and 1.139.507.

RESULTS

The mean age among the 17 participants was 30 years. The mean number of pregnancies, childbirths and abortions was 2.4/1.7 and1.2 respectively. It is worth mentioning that six women had previous abortions. On average, the length of stay in the hospital during the pregnancy of nine women was 16 days.

Diagnosis of heart disease previous to the pregnancy concentrated on, rheumatic heart disease (6), with three concomitant with heart murmurs, mitral valve insufficiency and mitral valve lesion respectively; myocardial ischemia (2), with one accompanied by arrhythmia; congenital heart disease (1); arrhythmia (2) with one of them Wolff-Parkinson-White Syndrome; mitral valve insufficiency (4); dilated cardiomyopathy (2) with one accompanied by peripartum.

In response to the guiding question and the objective of this study, the hermeneutic analytical movement allowed for the development of two Meaning Units: Having been questioned by doctors on becoming pregnant; knowing that while cardiologists may give their opinion, obstetricians will decide the way of delivery.

These Units came from meanings expressed, based on the existential movement of women with heart disease in the care relationships which was established with professionals who followed them in the everyday life of the their high-risk pregnancy.

In 'Having been questioned by doctors for becoming pregnant', the participants referred to the cardiologist's reaction during the consultation when they spoke about the pregnancy:

> *It was a shock for her (doctor), who did not say that I could not, that the risks I would be taking, but said: Now that you are under treatment, will you get pregnant? (P1).*
>
> *[...] the doctor from the medical clinic looked at me and said: Are you crazy, are you mad, get pregnant with a heart of this size? (P3).*
>
> *My cardiologist, when I told her I was pregnant, she almost had a heart attack, but she said: since it happened, you have to stop taking all your medications and she referred me here (P10).*
>
> *And even the doctors said: you knew you could not get pregnant, and then I said: I know it is a lot of responsibility, I know that I could not get pregnant (P13).*
>
> *I even heard from a health professional: you have a heart problem, you have celiac disease, so why did you get pregnant? (P17).*

Women explained that the cardiologists warned them before becoming pregnant about their risks, since pregnancy would raise the risks to the heart. They understood that although in some situations they did not tell them directly that they should not get pregnant, they did tell them to be careful, according to the meanings:

> *[...] Because the doctors told me that I could not be a mother, because of my heart problem, because it forced the mechanical valve and I have high blood pressure, I have high cholesterol... (P4).*
>
> *[...] Because my cardiologist told me: If you ever become pregnant again, do it until 40 years old, because you should not try after (P5).*
>
> *The doctors were always very clear in speaking about this, not to hide, and that is why I became more worried... Then the doctor told me that my life was on risk, that I could not come through until the end of pregnancy, then that I should terminate it while it was in the beginning, to perform this surgery, which was very risky... (P6).*

[...] Because she told me this: since you are under this risk, I would not try to have more children if I were you. She said to me and my husband: what you have is serious and each day it might become more serious (P14).

[...] (doctor's advice) It was no since I had my daughter in 2007 after I had a heart attack. Then it came the clinical report: you cannot this... I heard it many times: why not adopt? It is so beautiful (P15).

In 'knowing that cardiologists may give their opinion, but obstetricians will decide the way of delivery', women recalled that cardiologists gave their opinion concerning the best type of childbirth in each case according to the type of heart disease. Constituents that explain this understanding are as follows:

[...] the doctor (obstetrician) wanted to wait until 41 weeks to be a normal childbirth... (the cardiologist said) No, this childbirth has to be a cesarean section, because the pain will make them crazy, they will not know who to save, if they take the child, if they take the mother because their heart will not stand, it will accelerate... I cannot tell them to make a cesarean section because I know about heart and they know about babies, I have to give my opinion, but they have to decide on the type of childbirth (P2).

It could not be cesarean section, the doctor (cardiologist) told me that for me, it was better to have a normal childbirth than a cesarean section, because of more risk of bleeding (P4).

They were afraid of cesarean section, it was normal (P9).

It was normal at the beginning, I did everything they asked me... but there was no progression, I had to perform a cesarean section (P11).

The pressure was 23x 10, the doctor said: so let's have the childbirth. I asked: Is it risky doctor? He said: yes, if you trust in God, this is the right time to pray, to ask him. We are here to do our best, we do everything to save the mother and the child (P12).

The doctor who took care of me here in this emergency room thought that I should talk to my doctor, they entered into an agreement to hospitalize and induce me (P14).

The cardiologist indicated normal childbirth with anesthesia... I arrived here, and the doctor: you are a blessing, you came prepared, you are already with four of dilatation (P15).

It will be cesarean section. I would prefer normal childbirth, but since you had to perform this protocol because of your gestational diabetes, now we have to submit to it (P17).

DISCUSSION

The hermeneutics of Martin Heidegger as an interpretive understanding of *being-women-who-conceived-being-with-heart disease* achieved the unveiling of understandings that configure in theoretical framework as *publicity, impropriety, impersonality, occupation and being-with*.

Conceiving with heart disease opens up possibilities of specific relationships for women with high-risk pregnancy, which are established with themselves, their families and professionals who take care of them. These approaches to Heideggerian concepts unveil care relationships in one's own world, the surrounding world and public world[8], respectively.

Such world dimensions are not consistent in the geographical aspect, but as ontological instances - of the *Being*- in which women see themselves with possibilities of being their own decision makers and assuming responsibilities or delegating care to other entities who surround them. These others may be close or far away in the character of *public*[8].

When the pregnancy was discovered, it was seen from the heart disease point of view and was shown in *publicity to be* ruled by obfuscation since its revelation to the doctor. Professional discussion privileged the factual aspects of high-risk pregnancy without understanding the phenomenon, in other words, how it felt for the woman to conceive with heart disease. Therefore, the care relationship being limited to the risk condition overcame the possibility of an existential relationship that also considered subjectivities in the light of a intersubjective relationship.

The everyday care of being-woman contributed to the existential movement of veiling it in *impropriety*. In the follow-up of pregnancy, "everything" was already decided by "everyone", represented by existing protocols and technical dialogues considered by *tradition.* The women were dictated to and for them the possibility of choice did not exist. This prevented them from being themselves during their pregnancy.

At the same time, *impersonality,* reproduced in speech, creates different risk classifications based on the understanding that they had from medical reports. For the science that establishes care on a biomedical model, the risk classification depends on the degree of functional capacity of the cardiovascular system: The higher the organ failure, the riskier it is for the pregnancy, for conception, for giving birth and for the fetus being born with disorders[3,9]. In the levelling that categorizes pregnant women with heart disease, the original person loses her particular value and everything becomes leveled as something known for a long time. The *impersonality* that *moves away* from *being and* turning it into *levelled* reaffirms the *public*[8:184].

Nonetheless, it is worth mentioning that women did not show themselves as *impersonal* and *inappropriate* misrepresenting or distorting what they understood based on *publicity* of high-risk pregnancy. The women moved existentially, acting in the ways that prevail in the *public world* and that reassure her, as she acted in the ways that "everybody" else did[8].

The evaluation of a pregnancy in women with heart disease in the multidisciplinary context of advice and management consists of stratifying and estimating pregnancy risk by informing and guiding women in case they decide to plan or avoid pregnancy. Little attention to family and cultural values stands out, when compared to the appreciation of the impact of pregnancy during the underlying disease[10].

In their *surrounding world* - which they approached as a being-woman-with-heart-disease - the everyday dimension of *occupation* with the follow-up of the pregnancy-puerperal cycle and pregnancy risk was unveiled. Therefore, they are *dedicated* along with the referral to an institution for pregnancy risk, along with consultations with several professionals, with medications maintained, introduced or suspended for the heart disease, with exams and along with hospitalizations, according to the guidance and recommendations of technical manuals[3].

By means of this *occupation*, other people of the *surrounding world* get close, unveiling the meaning of *being-with*, in which relationships of *concern* were established. In the Heideggerian hermeneutics, *concern* is a way of being that is established in every and any human relationship, and it can be presented as relationship of *positive and deficient concern*[8].

In the relationship established with the doctors, the understanding of *deficient concern*[8] was unveiled, showing indifference from the pregnant women, since they understood they would be questioned by doctors for becoming pregnant. The focus on cardiac and obstetric professional attention was centered on pregnancy risk by heart disease and not in women, in *being-themselves.* Since they were told about the pregnancy, the professionals showed themselves in *occupation,* way that prevail in everyday care. The *professional concern* did not project to women for self-care. Health promotion remained veiled in the hospital environment.

Furthermore, professionals' perspectives were directed toward prescriptive behaviors of following risky pregnancies, providing on women's possibilities, tutoring them. In care relationship, the professionals showed as being-with "disregarded who count on others without taking them in account seriously, without having anything with them"[8:182].

Considering that, they were moved by the technique as interpellation that overlaps the *being*[11]. In other words, the biomedical model prevailed over subjectivities as means and end to achieve better results in the care view intended by obstetric *tradition* to high-risk pregnancy.

In this perspective, they used technical fields of medicine, laboratory, imaging, surgery, termination of pregnancy, decisions regarding induction and type of birth control, supporting women through technologies. This is because "this wish to control becomes more urgent when the technique threatens to escape from the human control"[11:376].

Nevertheless, although the technical is valued, it is worth highlighting that in the context of high-risk pregnancy by mellitus diabetes, a chronic condition like heart disease, essential prenatal care was neglected. A study that analyzed records of 50 pregnant women with diabetes revealed absence of evaluation of blood glucose, blood pressure, fundal height and fetal heartbeats in 32% of patients in addition to 60% of women not having participated in health education activities[12].

Non-compliance to orientation provided by the health staff and difficulty in accepting the diagnosis are the main reasons for non-adherence to treatment in pregnant women with diabetes. Based on this evidence, communication between professionals and women should be more effective, with the perspective of openness to dialogue, trying to listen and understand difficulties experienced, beliefs and values. Such difficulties might come from family situations along with household tasks, socioeconomic conditions, recreational deprivations and other limitations[13,14].

Otherwise, frequent hospitalizations during pregnancy and the puerperal cycle of women with heart diseases awaken feelings of fear, stress, anxiety, doubt, sadness and social isolation. Major interactions occur with the multidisciplinary team, since families cannot always be present[15]. It is worth mentioning the difficulty of interaction between doctors and patients, especially when clinical conditions are unpredictable during pregnancy and childbirth, can exacerbate the lability of heart conditions.

A study was conducted with 52 women and 26 doctors to investigate awareness of perceptions concerning interrelationships of hospitalizations of high-risk pregnant women. Of these, 50% had difficulties in being empathic and 35% considered it important to have psychologists present as mediators or facilitators of communication and as an emotional support for patients and staff. Most professionals felt that they should pay more attention to patients, offering them greater consideration, encouraging them more often and being emotionally closer[16].

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

When unveiling the everyday of care relationships of the *being-women* in high-risk pregnancy by heart disease, it was found that they can be seen in *publicity, impropriety, impersonality, occupation and being-with*.

Such indications point to important future directions, with implications for the clinical practice of conceiving and giving birth. It was proven that doctors were the professionals who related more directly with high-risk pregnant women and that the care relationship was ruled by a pathophysiological view of pregnancy and the puerperal cycle. Dialogue and medical statements announced through meanings of participants suggest the need for expansion of the clinical view, which also considers the subjectivities inherent to the *Entity* for whom the doctors care.

At the same time, it is worth mentioning the invisibility of the nursing staff. It is true that the basic pathological condition mainly directs women toward prenatal follow-up with the medical staff; however, both in secondary and tertiary attention level, the nursing staff represent professionals who are with the pregnant women in most of the 24 hours of the day and in every day of the week.

If on one hand the results of the present study point to the need for transcending the care relationship ruled on the biomedical model to a more existential relationship, based on the understanding of women as *beings* endowed with possibilities, on the other hand, they point to the importance of nursing care coherent with objective and subjective needs of pregnant women with heart diseases, in the perspective of being perceived and announced by the *being-care*.

With these observations, the applicability of care practice methods is suggested, which considers the ontological sphere, viewing the concepts of Heideggerian phenomenology as an important support in care and existential relationships between high-risk pregnant women and health professionals in face of care. This is not an end, but a means that contributes for the *can-being* more *appropriate* for women.

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[a] Extracted from the thesis "*Gestar Sendo-portadora-de-cardiopatia: contribuições para o cuidado em Saúde da Mulher*", Anna Nery Nursing School, Federal University of Rio de Janeiro, 2015.

[b] An italic expressions are proper to the Martin Heiddegger's theoretical-philosophical-methodological.