



ENSAYOS

The phenomenology of the study of the experience of high-risk pregnancy

La fenomenología para el estudio de la experiencia de la gestación de alto riesgo

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Palabras clave: Fenomenología descriptiva; investigación cualitativa; vivencias; experiencias; gestación de alto riesgo.

ABSTRACT

Qualitative research captures social reality through humane eyes, though an ample, flexible and profound approach. Inside, descriptive phenomenology accounts on human experiences of perceived phenomena, told in first person and presented as structures of meaning. This has turned into an important contribution to the ways of thought and development of nursery; therefore, there is an insight in this paper about the tradition to deal with past experiences of women during a high-risk pregnancy. To do this, general principles of Phenomenology and scientific research results about this phenomenon are presented.

Convenience of this phenomenological approach is highlighted in order to get closer to the past experiences during a high-risk pregnancy allows evaluation of the objective and subjective needs of women and their families during prenatal attention, and hospitalization during delivery and puerperium; it allows deep analysis of established relationships among expecting women and health professionals, changes caused to family and potentiality to be developed, and to get closer to pregnant women's emotions and feelings. So, an approach from this reference it is imperative, for an insight from interaction with expecting women and life experiences can be obtained, in order to improve nursery care quality beyond biological dimension.

RESUMEN

La investigación cualitativa capta la realidad social a través de los ojos de los seres humanos, mediante un enfoque que permite la amplitud, flexibilidad y profundidad. Dentro de ella, la Fenomenología descriptiva da cuenta de las experiencias humanas sobre fenómenos vividos, descritos en primera persona y presentados en estructuras de significados. Esto se ha convertido en una importante contribución al pensamiento y desarrollo enfermero; por lo anterior, en este artículo se reflexiona acerca de la utilidad de la tradición para el abordaje de las vivencias de las mujeres durante una gestación de alto riesgo. Para esto, se presentan unas generalidades de la Fenomenología y de resultados de investigación científica del fenómeno propuesto en este artículo de reflexión.

Se resalta la conveniencia del abordaje fenomenológico ya que aproximarse a la vivencia durante una gestación de alto riesgo permite evaluar las necesidades objetivas y subjetivas del cuidado de las mujeres y sus familias durante la atención prenatal, y la hospitalización durante el parto y el puerperio; permite profundizar en las relaciones establecidas entre las gestantes y los profesionales, las alteraciones que causa en la familia y las potencialidades que esta puede desarrollar; como acercarse a las emociones y sentimientos de las gestantes. Así, se concluye que es imperioso acercarse desde este referente, ya que mediante la interacción con las gestantes y sus experiencias de vida se propicia una reflexión que aportará a mejorar la calidad en el proceso de cuidado de enfermería, más allá de una dimensión biológica.

INTRODUCTION

The complexity of the human being and the social realities that he creates and lives in, shows the urgent need to use a research approach different than positivism to get closer to scientific knowledge. Thus, with the diversity of heritage originated in the social sciences, qualitative research has become a valid alternative to study and understand human and social phenomena, as it is impossible to "divide, reduce or cut" these realities.

According to Bonilla and Rodriguez ¹, the qualitative approach has as a main feature to attract the interest of social reality "through the eyes" of the people that is being studied, from the perception of the subject their own context. It does not make any assumptions derived from theory, but seeks to conceptualize the reality based on the behavior of the people studied, systematically exploring the knowledge and values shared by individuals in a particular spatial and temporal context. To this is added that "qualitative research as fundamental attitudes requires openness, flexibility, power of observation and interaction with the researchers and social actors involved".²

Therefore, in addition to allow to go depth into different aspects of reality, this approach also makes it an ideal resource to extend and complement the results of the quantitative inquiry, either by the process of triangulation or the use a mixed research design.³ In the case of Nursing allows a holistic, comprehensive and contextualized vision of the phenomena related to health care.⁴

This research approach uses a group of research traditions from which start the study of the objects and individuals. Also called "Research strategies", are qualitative research approaches that have a distinguished history in one of the social sciences disciplines⁵. Within this range is the phenomenology, considered a philosophical and methodological orientation that comes from philosophy. There are two phenomenology schools, the transcendental or descriptive and the interpretative or hermeunict⁶. The first one, important in this article, was founded by Edmund Hursell during the first decade of twenty century and between their representatives are Maurice Merleau Ponty, Gabriel Marcel and Jean Paul Sartre.⁷

This article pretends to present the utility of the descriptive phenomenology for the approach of a phenomenon of particular interest to nursing: the experiences of women who have had a high risk pregnancy and the different implications.

Beyond positivism to the research nurse: the Phenomenology.

Husserl (1970)⁸, considered the transcendental or descriptive phenomenology as "the science of the essence of consciousness" and focused the definition of the concept of intentionality and meaning of the experiences from the first person point of view. He stated that the meaning of the experiences can be deciphered only through one to one transactions between researcher and research objects. These transactions should involve a careful listening, interaction and observation to create a representation of reality more sophisticated than in previous understandings.

In other words, his intention is to understand the phenomena in their own terms to provide a description of human experience as experienced by the same person⁹, or reconstruction of the inner world of the subject's experience, as each individual has his own way of experiencing temporality, spatiality, materiality. But each of these coordinates must be understood in relationship with others and within their world.¹⁰

The focus of phenomenological research is the experience of the person in relation to a phenomenon. In this regard, the experts in this research tradition assume that experiences give meaning to each person's perception about a particular phenomenon, being their objective full description of the experience and perceptions that she express⁶. This suggests the representation of the overall structure of lived experience, including the meaning that these experiences have for individuals who participate in them, worrying about comprehension and not the explanation.¹¹

This research tradition has been used to incorporate phenomena of Nursing, given the weight of intersubjectivity that is set in the relationship between the nurse and the patient. Thus, as stated by *Tierra et al*⁶, when the nursing research tries to understand the meaning of human experience, in the Phenomenology has found an important contribution to nursing thought for understanding the reality of day by day in which is immersed. It needs to dive into subjectivity and in the essence of human being who cares, without forget the objectivity of it. In this way, the essence means the possibility on one hand, the reading of the reality of the phenomenon and lived experience, and on the other, the subjectivity as a feature of the subject that reinforces its human aspect of being unique and singular.

But why study the particular phenomenon of the experience of women who have experienced a high risk pregnancy from this philosophical and methodological reference? From the position of nursing as a discipline and profession, is necessary to get close to this problem to understand how pregnant women live, experience and attribute meaning to this particular phenomenon, as well as seek for the meaning that it has for them and the feelings it generates. In the interaction with women, it is necessary to learn their life experiences to find what they hide. There are many conflicts that a woman with a high risk pregnancy could feel: uncertainty about the outcome, anxiety and fear generated by his life and his son. Thus, in this process the connection and relationship of women to their unborn child are threatened. Therefore, in the struggle of women to alleviate the stress generated by perinatal complications

and subsequent hospitalization, they establish an existential search for meaning and value that can be severe.

Indeed, these experiences can be described from scientific research, as units of meaning that give reason for the creations that pregnant women make about this phenomenon. In terms of Jeorge, Fiúza and Queiroz ¹², the Phenomenology allows a human vision on these experiences. In this case, the experiences of high risk pregnant women, facilitating the recognition in each of them, a being who lives a unique experience whose meaning, when understood, makes it possible to understand the meaning of this event.

Thus, in a medicalized world, in addition to the need to rescue the other view, the view of person who experiences the pains and sufferings, it is urgent to consider the subject beyond the biological and physiological part. It is precisely to explore how they live the illness and how this disease also affects this process. In this sense, and for nursing, phenomenological studies have proven to be a door for reflection and the pursuit of quality in the care process.¹³ In the process to seek for the meanings and consciousness through this tradition, the individuals needs are known with better understanding and it opens important ways for making changes in nursing care processes and that can bring about a comprehensive understanding of these phenomena particulares.¹⁴

The Phenomenology is the starting point, is "to go back to things themselves," recognizing the priority of practice, scope of decisions and act on the thought and reflection. Experience is not only the human capacity to represent the world through cognitive processes, as it has in itself "meanings" or "significant ideal units." For it, the primary operation is the lack of significance of the expression separately and is a phenomenon sensitive to the body (and not a mere question of "subjectivity").¹³ Thus, the phenomenological method is addressed to look at the meanings given by the experiences.

Which are the women experiences with high risk pregnancy?

Some research experiences have proven the validity of the Phenomenology to the approach of the experiences of women during pregnancy high risk. Below are some of them.

In Brazil, *Souza et al* ¹⁵, analyzed the experience of women facing a high risk pregnancy with preeclampsia. The women reported lack of knowledge and ignorance in their health disorder, as well as factors related to premature birth, as gestational hypertension. In perception and knowledge of the disease, women cited factors such as religion, family problems and errors of the woman herself. This ignorance contributed to poor preventive care and caused the early hospital because of the seriousness of women. Moreover, the experience of having her newborn hospitalized generated feelings of sadness and despair for the seriousness of the baby's health and for the equipment connected to their children in the Neonatal Intensive Care Unit (NICU), the difficulties during the baby's hospitalization: the inability to handle his son for his serious condition, fear by nasogastric tube feeding, the impression made by phototherapy, and suffering that led to the different procedures, although be aware of their need for the survival of her son. However, they also expressed feelings of joy and

happiness when they interacted for the first time with the child: took the baby in their arms, listened him cry and the suspension of the different procedures.

Azevedo, Araújo, Costa and Medeiros ¹⁶ established the experience also in women who had a pregnancy with preeclampsia, emerging three categories: conceptions, appearance and feelings about the disease. The first showed perceptions of disease risk related to three aspects: the death, the consequences of the disease and uncertainty about what might happen. The first two were seen because the close bond between mother and child in the utero. The occurrence of preeclampsia was "unexpected" and "unpredictable" and its causes were related to heredity factors, emotions (anger, anxiety and stress), problems with the couple i.e. some kind of violence against women, the lack of a proper care during pregnancy and the emergence of hypertension. In the case, that it was suffered by a relative or the woman herself, was defined as a natural event. Health Alteration caused concern and anxiety considered serious and something unknown. However, given the perception of these risks, women said they were not heard by health professionals.

In Brazil, Souza, Cecatti, Parpinelli, Krupa and Osis ¹⁷ studied the experiences of women who had survived serious complications related to severe maternal morbidity. The heartbreaking statements of an unexpected and unfamiliar event created feelings of anxiety, worry and fear of imminence death and transience of life, which is often reinforced by the appearance of unpleasant experiences such as pain, dyspnea and frustration at the interference with the natural progression of pregnancy. To this was added the experience of physical changes such as weight gain by fluid retention and the difficult process of treatment and recovery, and physical discomfort associated with the disease. The derangement appeared when the women felt alienated to events like the birth of his son from process as their illness and treatment. For them, this time generated the need for support from relatives and spouse or partner.

Even more heartbreaking were the stories of women whose children past away. From them emerged another category: "memory gaps and need for information" referred to the altered state of consciousness caused by being under sedation or coma; at the "awakening" they learned of significant events such as death or funeral their children. These facts, of paramount importance, were configured as negative and many had the feeling that part of his life has gone from the "movie" of their existence. This was very difficult to accept within the experience of life¹⁷.

Carvalho, Tonete y Parada ¹¹, study the above phenomenon in a similar population and they got similar categories, they found that this situation triggered the emergence of emotions and feelings of guilt because severe maternal morbidity is represented as failures associated with the mother during pregnancy, following the dismissal of his body to the fetus causing guilt. It also represented a conflict with the unexpected, like a great challenge to women in their child required much care, causing, suffering. But also, meant a new life experience for the women and made possible the experience of motherhood. Therefore, the postpartum period was identified and described as difficult because the emotional instability and the serious situation of the newborn. This also represented the need to reorganize their lives and economic resources, which meant insecurity and fear in women, in addition to socio-economic difficulties and limitations in everyday life involving little time to care for themselves.

From another angle, Price, Lake, Breen, Carson, Quinn and O 'Connor ¹⁸ explored the experiences, from the spiritual experiences, such as support for a high-risk pregnancy

in postpartum in Canada. The pregnancy meant feelings of fear, uncertainty, loneliness, frustration and sadness to the possibility of death or health problems of the wanted child, and the separation of women from their families because early hospitalization or bed rest. Therefore, the joyful experience of waiting became a discouraging situation in your life, feeling anxious and alone. Thus "the search for a spiritual language," as cultural and religious concepts, helped to understand and articulate the personal and spiritual experience against the disease, although sometimes was not enough to respond to the uncertainty of this.

Spiritual practices ranged from having a transcendent and sacred relationship with a superior being for those professing the Christian faith, attending church, participating in personal prayer and formal, and live by values and beliefs set by their religious faith. Other women defined in religious terms but not connected to any particular religion, a relationship with souls, spirits or energies that were present in and around people. The atheistic women expressed their spirituality in terms of relationships, emotions and memories, practices as the contact with nature, expressing emotions, living intimate moments with their families and friends, and according to their moral and spiritual dialogue. These actions were taken like an act of prayer or dialogue with herself for a positive result against the condition that calmed the fears and soothed the feelings of loneliness, which helped women feel calm, relaxed, safe and confiadas.¹⁸

On the other hand, several papers extend the approach of these family experiences, showing how the experience of women who have had a high risk pregnancy is not limited to them. Thus, this event causes many changes in the conditions of mothers and children and also modifies the expectations of women and families about the gestación.¹⁹

In this order, Sittner, DeFrain and Brage²⁰, found that the family emerged as a social cell of support, identified the following strengths to meet the challenge of a high risk pregnancy: the ability to face up the disease, focusing on social support, individual resistance and to manage stress and crisis effectively, keeping open channels of communication (through hospital visits and phone calls), family participation in prenatal visits, spending nice time together, demonstrations of gratitude by the pregnant woman and her family all the support, spiritual wellbeing expressed by faith in God and the church as a social support and guidance during the process, and family involvement.

On the other hand, Silva, Cordova, Chachamovich and Záchia²¹ identified the impact of preeclampsia in pregnant women and their families in a group of Brazilian women. In the first group, the condition meant the loss of independence and control in their lives, as well as desist in the planning of subsequent pregnancies. It also involved objective activities as self-care, home and family care, and subjective activities as the need to take all the events in a less traumatic way, acceptance process and rituals of mourning. In families meant the need for support to increase security during the experience of pregnancy, being essential husband and family involve in the facilitator process of the objective and subjective reorganization facilitator in the experience of women and a mediator in situations of stress.

Another element present in the stories in pregnant women was the impact that caused the forced hospitalization for care and attention given by the threat on her life and the unborn child. On this, Leichtentritt, Blumenthal, Elyassi, Sigi and Rotmensch²² described the experience from frustration, loss, anger and loneliness that it generated

in a study in Jewish women with high risk pregnancies in an Israeli hospital. This was related with various events such as the lack of a specific problem that could be treated to be discharged, the feeling of loneliness and the experience of a strong social and family isolation. Also the fear and anxiety added related with the health of the fetus and the fear of giving birth to a disabled child, and the situation of the rest of the family for the temporary abandonment of the home. Along with the those feelings, others also emerged: hope and trust in health care workers and in God to save his son, and this was born healthy. Finally, they expressed an ambivalence in the emotions that were present throughout his narrative: first, they wanted to prolong their pregnancy as long as possible for the wellbeing of his son, but in the other side, they want to give birth in order to end this stage of their life.

Richter, Parkes and Chaw-Kant ²³ in Canada found two major topics expressed by pregnant women during hospitalization: the stressors associated with bed rest restrictive and needs associated with this. The first topic was related to a "loss of control" over her pregnancy and the performance of the functions and daily activities, both professional and home. In addition, prevailing feelings of being a "burden" to their families posed by changes in their lives, especially in the financial issue, care of children by their husbands and the movement of those to visit, as well as disability of self-care and meeting their own needs. Within the "needs" associated with rest, expressed the most privacy, source of discomfort for the visits continue and the possibility that family members and spouses could hear their clinical condition. Others such as those caused by sudden changes in diet, for more information on their health by professional and recreational against boredom of hospitalization. Other needs were those of a closer contact with their families and husbands of the latter increase awareness about their situation and more personalized care of pregnant women and their husbands by staff.

Barlow, Hainsworth and Thornton ²⁴ also addressed the experiences of women, but in this case when they were suddenly hospitalized for the threat of premature birth in a hospital in the United Kingdom. The results showed the experiences of uncertainty and the search for meaning to the event of hospitalization for care, as they perceived the event as sudden, unexpected and a great degree of uncertainty about what would happen to the live of their children for the premature birth. They experienced anxiety about the physical symptoms and the ignorance of the causes of their status were also experiences described by these women. To this was added the fear of childbirth, both for the life of his son and by the fear of pain. In the end, the women expressed that their feeling were not been taken into account by the medical staff that attended, making it difficult to experience this event.

Finally, relations with the health staff is also an emerging issue to be studied in phenomenological research in women with high risk pregnancies.

Oliveira and Madeira ²⁵ analyzed the interaction between the interdisciplinary health team and women. The information received from professionals about their status was considered weak, contradictory, unclear, and which was related to risk but without explained to them what it was. Also, they established "rules" transmitted vertically, that women should follow to decrease risk, but those rules didn't decrease their fears and doubts.

Silva, Cordova, Chachamovich and Záchia ²¹ found ignorance of the meaning of hypertensive disease in the pregnancy in most of the participants in a study in Brazil.

Those who reported to have some knowledge, reported that the source of knowledge were not the professionals who attended for antenatal care or hospitalization, but others such as the Internet. In addition, when they were informed of the diagnosis by physicians, this was perceived as negative by the lack of dialogue and guidance on the pathology. Therefore, the women expressed the desire for greater attention and support for professionals who provided prenatal care.

Another look is the experience of women during the hospitalization of premature baby in the NICU presented by *Souza et al*¹⁵. This event was a prolongation of hospital stay, and it became worst because the hospital did not include programs that favor the development of healthy activities to reduce stress and promote maternal socialization. Thus, the resources to meet the needs of listening and support of the woman were the relatives, the interaction between mothers, the faith and some professionals. He also revealed attitudes and relationships of conflict and doubt among professionals and the woman with her child in the NICU. Although there were not any obstacle to maternal participation in child care, they said they lacked the ability to interact effectively, revealing that the NICU staff was not aware of these difficulties. Thus, the professionals did not provide sufficient information and use of technical language that promoted the creation of a distorted reality.

By way of closing

Research results presented in this brief review highlights the utility of the qualitative approach and descriptive phenomenology to the approach to an issue of great concern to nursing as the treated in this paper. Thus, for practitioners to get closer to the experience will help them to assess the high risk pregnancies women's and their families needs, from prenatal care, and hospitalization during childbirth and postpartum. This, from a holistic view of women, which take into account the socioeconomic and cultural context.

Thus, phenomenological research has realized the need to investigate other areas other than the clinic, as the feelings that generate alteration and mixed and ambivalent emotions experienced by women and their families, the objective and subjective needs of pregnant women, the perception and experience of the relationship with professionals in the health care received, the harsh experiences during hospitalization and the impact on the family and the role it plays, among others. The knowledge of the above would improve the quality of nursing care and help alleviate feelings of fear, despair and uncertainty and acceptance of gestation in order to get changes in attitudes and health habits.²⁵

In this sense, the knowledge obtained will help to improve the Nursing "job" and also will create a concern for "being" of the experience of women, bringing new elements to the discipline. Knowing how women live this unique experience could be considered an improvement, but it will be enriched by the identification of attributes of the categories, which vary according to the characteristics of the phenomenon, its cultural and socio-economic scenario. These findings are required to evidence and be used in care interventions consistent with the reality of pregnant women. This is also a way to enhance the discipline and specially to improve the quality of care to women in this situation.

From the social part, understood as the interaction of women with family and group, this approach will help to get closer the practice of nursing and the reality faced by pregnant women, and the links that develop or want to develop. This advance can provide feedback to health teams and intervene to prevent this type of health situations, and thus improve care.

All this will enable the achievement of a critical exercise which will contribute significantly to the nurse thought, taking in consideration that to understand the daily reality of this exercise, the nurse should be immersed in subjectivity and the essence of the human subject of care, making it understanding the reality that women is living. Furthermore, this research tradition also becomes a reflection strategy, that explores the experience of women during a high-risk pregnancy and allows to interact directly with her, and designs processes of care that get closer to meet the needs of the patient, allowing the practice of quality care.

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