



REVISIONES

Experiences and feelings endured during a high-risk pregnancy: a documental study 2005-2011

Experiencias y sentimientos vividos durante una gestación de alto riesgo: un estudio documental 2005-2011

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Keywords: High-risk pregnancy; experience; documental study; qualitative research

Palabras clave: Embarazo de alto riesgo; experiencias; vivencias; estudio documental; investigación cualitativa.

ABSTRACT

Objective: To explore the experiences endured by women while in a high-risk pregnancy, reported in the scientific literature during 2005-2011.

Methods: Qualitative documental study. Analysis units were the scientific papers published worldwide in Spanish, English and Portuguese during 2005 to 2011. Data were treated by contents analysis.

Results: Bibliographic search rendered twenty papers dealing with the study objective. All of them had qualitative focus, fourteen of them were papers published in the so-called underdeveloped world; most frequent publication occurred around 2010. From the analysis emerged two main topics: the women's experiences while in a high-risk pregnancy from a pathologic condition, and those product of a pregnancy in early or late reproductive age.

Conclusion: The role of the pregnant support networks is underlined: family, other women sharing their condition and health professionals; also were of note the difficulties during hospitalization and the technical jargon used by those professionals. Nursing care should focus to reinforce the networks and to procure better environment for the inpatients. The experiences endured by pregnant women living

with HIV or by those women older than 35-year are still matter of pending research based upon qualitative focus.

RESUMEN

Objetivo: Acercase a las experiencias vividas por las mujeres frente a una gestación de alto riesgo, reportadas en la literatura científica durante el período de 2005 a 2011.

Materiales y métodos: Estudio documental de corte cualitativo. Las unidades de análisis fueron los artículos científicos de todas las nacionalidades en idioma español, inglés y portugués en el período 2005-2011. Los datos se trataron mediante el análisis de contenido.

Resultados: La búsqueda bibliográfica dio como resultado veinte artículos que respondían al objetivo del estudio. Todos tenían un enfoque cualitativo, 14 de ellos fueron trabajos realizados en el mundo en desarrollo y el año de mayor publicación fue 2010. Del análisis emergieron dos grandes temas: las experiencias de las mujeres frente a un embarazo de alto riesgo producto de una condición patológica y las que fueron producto de una gestación en una edad reproductiva temprana o tardía.

Conclusiones: Se resalta el papel que juegan las redes de apoyo para las gestantes: la familia, otras mujeres en igual condición y los profesionales de la salud; las dificultades durante la hospitalización y el manejo de un lenguaje cargado de tecnicismos por parte de los profesionales. El cuidado de enfermería debe encaminarse a reforzar las redes de apoyo y procurar mejores ambientes de hospitalización. Las experiencias de las gestantes conviviendo con VIH y de las mujeres que tienen un embarazo después de los 35 años, son necesidades aún pendientes por la investigación. El enfoque cualitativo es válido para el abordaje de este tema

INTRODUCTION

In Colombia, maternal mortality is the third cause of death on young adult women; maternal mortality ratio in 2008 was 71,6 per 100.000 newborns¹ showing only a minor reduction when compared to 2007. In spite of maternal deaths' relevance, also it is the morbidity during pregnancy, which includes different degrees of severity and points out the need to better know those problems related with pregnancy, delivery and puerperium not resulting in death but causing suffering and leaving lasting effects on women². Extreme or severe maternal morbidity due to a high-risk pregnancy has been defined as a severe obstetric complication which needs urgent medical intervention in order to prevent maternal death³.

High-risk pregnancy occurs when mother, fetus and/or neonate have greater probability to suffer disease, death or sequels before or after delivery⁴. Risk of such a pregnancy is higher when pathologic conditions, short interpregnancy intervals, high parity or extreme early/late reproductive age⁵.

Cordero & Gonzalez (2011)⁶ draw attention about extreme early/late reproductive after 35 year-old for it implies additional risk on delivery and maternal mortality; besides, it is especially important in developing countries, where aged women often have many children: this is one of the key elements used to define maternal high-risk. Other predictive factors of morbidity are non-white race, social exclusion, previous history of postpartum hemorrhage, hypertension, diabetes mellitus, emergency cesarean section and anemia⁷.

On the other hand, adolescent pregnancy is a high-risk condition because this is stage of human growth & development with quite particular features, in turn due to physiological, psychological and social changes affecting this subpopulation. So,

pregnancy at this life stage is a risk condition due to possible medical, obstetrical and perinatal complications that may happen; the younger the adolescent woman, the greater significance of those complications⁸.

Apart from the approach to the medical aspects of high-risk pregnancies, key elements are the women's experiences who lived these events. Experience, according to Husserl (1980)⁹ is an active and evaluative conduct rather than a cognitive, judgmental one. At the sphere of experiences, the world is always the substrate that underlies whether to begin knowledge or to energize praxis. Experiences have an actual character, strictly speaking, but in this actuality are marked somehow by past ones, structurally stuck to those of both present and future¹⁰.

So, besides evaluation and treatment of women's health problems in high-risk pregnancy, it is equally important to evaluate their experiences and future emotional impact in order to get knowledge and comprehension of those ones. Souza *et al* (2009)¹¹ proposed the need to take into account the voices of those women who lived and survived a high-risk pregnancy since they may offer testimony on what, how, when and why facts occurred in such a way. Identification of post-traumatic stress disorder and acute stress syndrome may play an important role in the understanding on the development of long-term sequels and to help reducing the global burden of severe maternal morbidity.

However, Vecino¹² retorts this saying that in Colombia available information is scarce and has poor or no relevance about what pregnant women think and feel about pregnancy risk, antenatal control, medical attention or hospital delivery, among other issues.

Set the state of the art about experiences versus high-risk pregnancy turns into a need to account for evidences and knowledge obtained in other contexts, given that scarcity of studies made in Colombia. In this way, documentary research turns into an important instrument since its results offer a panoramic view of today's knowledge on the issue, giving account of cumulated information at certain historical moment and about an specific area of research. As such, it is far beyond a finished product, but paves the way to new fields of research, which in turn multiply others in the previously explored area¹³.

Likewise, results may allow to identify knowledge gaps and new research problems to be investigated; they will be vital input for future endeavors and for establishing a research line on the issue. Given these reasons, the objective of this study was to explore the experiences endured by women during a high-risk pregnancy, as reported in scientific literature during 2005 to 2011.

MATERIALS & METHODS

A qualitative, documentary research was made based upon proposal by Hoyos¹³, selected study design as a way to give an account about research that has been made on a central matter. To this purpose, original scientific papers from any nationality, written in Spanish, English or Portuguese and published in journals of Health, Social or Human Sciences from 2005 to 2011 were included. They had to be indexed in any of the following databases: EBSCO, Academic Edition, MedicLatina, Medline, Journal

Medline, Dynamic, Pubmed, Ovid, Ovid Nursing, Scielo, Cantarida, Lilacs, or ScienceDirect (Elsevier, Pergamon, Excerpta-Medica and North Holland).

MeSH, DeCS descriptors were used in Spanish, English or Portuguese: pregnancy, gestation, perception, high-risk, extreme maternal morbidity, experiences, nursing qualitative investigation. Advanced Search option was used, keeping in mind period restriction, study objective and Boolean connector AND.

To collect the data, an instructive form was made, based upon that proposed by Hoyos¹³, which included these topics: formal aspects, research matter, context framework, purpose, methodology and results.

Data processing was made through analysis of content, which stands for a group of methods and documentary analytic procedures with emphasis in the meaning of text¹⁴. Data collection and analyses were made simultaneously using a matrix to include the information from each unit of analysis, making the initial data reduction.

Later, reduction and synthesis of information was made to define initial categories, ending with two major topics with their respective categories.

RESULTS

- Formal issues of the papers

Bibliometric search initially rendered 150 papers; of them, 20 answered the objective of this study. As for the formal issues of the analyses units, it is of note that nine of them were published in Portuguese, six in English and the rest in Spanish. All the studies were made with a qualitative research focus; Phenomenology and Grounded Theory were the dominant traditions (three each). However, nine of the papers did not specify nor design neither epistemologic tradition.

Table 1. Distribution of consulted publications according to tradition and/or research design used to make the study. Bogota, 2012

| Type of study | Freq. |
|---------------------------------|-----------|
| Unspecified tradition or design | 9 |
| Grounded theory | 3 |
| Phenomenologic | 3 |
| Descriptive | 2 |
| Hermeneutic-interpretative | 2 |
| Oral story | 1 |
| Total | 20 |

Source: The authors, 2012

The greatest number of studies, fourteen, were made in developing countries, which matches the weight of maternal morbimortality and occurrence of high-risk pregnancies in these contexts.

Table 2. Distribution of consulted publications by country of origin. Bogota, 2012

| Place of study | Freq. |
|-----------------------|--------------|
| Brazil | 9 |
| Colombia | 3 |
| Sweden | 2 |
| México | 1 |
| Australia | 1 |
| United Kingdom | 1 |
| Thailand | 1 |
| Taiwan | 1 |
| Israel | 1 |
| Total | 20 |

Source: The authors, 2012

Most frequent year of publication was 2010; showing increase of interest at this research field, in spite of its novelty. There were no publications in 2011.

Table 3. Distribution of consulted papers by year of publication. Bogota, 2012

| Year of publication | Freq |
|----------------------------|-------------|
| 2010 | 6 |
| 2009 | 5 |
| 2008 | 3 |
| 2007 | 2 |
| 2006 | 2 |
| 2005 | 2 |
| Total | 20 |

Source: The authors, 2012

It is interesting that 17 of the papers were written by Nursing professionals.

- Topics and resulting categories

Results were pooled around two major topics: a) women´s experiences about high-risk pregnancy due to a pathologic condition or health disorder, or b) those product of a pregnancy at extremely early or late reproductive age.

Table 4. Distribution of consulted publications according to pooled results and publication topics. Bogota, 2012.

| Resulting topics | Causes for high-risk pregnancy examined in the studies | Freq |
|--|---|-------------|
| Women´s experiences about a high-risk pregnancy due to pathologic condition. | Different pathologic conditions studied. | 4 |
| | Pregnancy hypertensive syndrome | 3 |
| | Diabetes mellitus | 2 |
| | Gestational diabetes | |
| | Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome | 2 |
| | Premature rupture of membranes | 1 |

| | | |
|---|----------------------|-----------|
| | Multifetal pregnancy | 2 |
| Women's experiences product of a pregnancy at extremely early or late reproductive age. | Adolescent pregnancy | 5 |
| | Late-age pregnancy | 1 |
| Total | | 20 |

Source: The authors, 2012

In the first group, a variety of discussed issues was observed, although there area some still considered to be studied by scientific production; the number of studies about endured experiences during a pregnancy with pre-eclampsia is noticeable, also visible on papers dealing with different pathological conditions of the pregnant women under study.

Interest for experiences of those women who suffered this disease arouse because in 2009 more than half a million women died during pregnancy, delivery and puerperium due to occurrence of hypertensive events at pregnancy and related causes, and 99% of these deaths occurred in developing countries¹⁵. Hypertensive disease of the pregnancy (HDP) persist as the main cause of maternal death at poor countries, being responsible for 63.000 annual deaths and maternal mortality caused by pre-eclampsia is between 0% and 13,2%¹⁶. The latter affects 5% to 8% of the ¹⁷. Also, it may cause permanent sequels on women, such as neurological, hepatic, renal or hematologic ones¹⁸.

In the second group, emergence of different experiences during adolescent pregnancy is no less than evidence about the phenomenon's reality at the developing world and this investigation's answer to this situation. Given its steady increase, ECLAC ¹⁹ explains that this situation happens in countries with different levels of economic development, education and poverty incidence, which reveals its complexity and multiplicity of factors involved in their evolution. Frecuencies of maternal mortality and adolescent pregnancy are higher among women in the poorest sectors, who have less access to education, information and sexual & reproductive health.

Here, the topics and categories giving account of endured experiences who suffered a high risk-pregnancy are described:

Topic 1. Women's experiences about a high-risk pregnancy due to pathologic condition.

This topic encompasses different categories who behave as opposites and inform about experiences and feelings endured by pregnant women during their elapse in high risk. However, these cathegories not only inform about the women's experiences but also about their families and the relations established with the health professionals and with other women in the same situation.

1. Perception about disease and its causality

Only in three papers who dealt with pregnant women's experiences were there issues about percepton and causality of the disease. So, pathologic conditions leading to a high-risk pregnancy were perceived as frightening, severe, life-threatening for both their lives and their children's; especially a death-risk for the latter. Adding to this, the sudden, unexpected disease onset.

Even when some women identified the signs of alarm, they ignore their meaning and importance.

Causality about high-risk pregnancy was unclear and attributed to stress and problems at home and with the couple. Others were heritage, emotional and psychological factors and lack of good food during pregnancy. Divine punishment was a big-weight factor on the etiologic perception of the disease.

2. Negative experiences endured along the disease

This category is considered, altogether with that of negative feelings caused by disease, the biggest in weight and importance. Here are their constitutive elements.

Hospitalization. In eight studies, pregnant women told about the experience of being hospitalized as disturbing, causing rage, frustration and loneliness due to the meager visit time and the low physical active allowed to them.

Souza *et al*²⁰, reported in their research that some women did not accepted hospitalization because they had no symptom or sign, whilst for others to look their children at the Neonatal Intensive Care Unit meant only sadness and despair.

Deficient support by primary relief networks. Four of the papers reported that, whenever a pregnancy alteration happened, families were against a stressful, exhausting situation, causing deep alterations in family dynamics and prolonged with baby's hospitalization.

As for the gestational diabetes (GD), Persson *et al*²¹ reported that women felt constantly under diet control to keep on check adequate blood glucose levels. For the part of pregnant women living with HIV, Araujo *et al*²² wrote that women receive no family support and engaged much suffering, making their social interaction difficult.

Deficient relationship with health professionals. In four studies, women questioned health professionals about their lack of clarity in their information their health status and that of their child, since it was full of inintelligible "technicisms". The same occurred with procedures of interventions, increasing their anxiety and distress.

3. Negative feelings caused by disease.

In thirteen of the studies, pregnant women referred fear, sadness, concern, unsteadiness and distress about the complications they suffered and consequences for mother-fetus lives.

Likewise, Persson *et al*²¹ documented feelings of guilt in the pregnant women when diagnosed with GD, since they considered themselves responsible for the disease's causes. Quite related to guilt, there were lack of control, impotence, shame and doubt, all of these related to women's fight to resist persistent temptations and low adjustments made to the prescribed medical recommendations.

Uncertainty during delivery was high since they represented the maternal and fetal results, hoping that GD would not affected baby's health and they would cure of the disease and avoid its sequels.

Guilt also accompanied women who lived with HIV, as evident in the study by Ross *et al*²³; but also they found participants had feelings of shame and anger when they received news of the diagnosis, with their spouses, family and friends. Loneliness accompanied them during the best part of their pregnancies as they had no one to share with the situation.

Feelings of ambivalence were expressed by women who had long periods of hospitalization, as it was the case for pregnant women who suffered GD and premature rupture of membranes, since the hospitalization offered safety for their babies but at the same time they had the urge to deal with tasks at home and their other children's care.

4. Positive experiences about the disease

Positive experiences of pregnant women during their illness emerged in seventeen of the reviewed investigations, their sources being very diverse. Generally speaking, those appeared when there was either adaptation or resolution of the situation by women, or when the relief networks were evident.

Hospitalization. In two studies about experiences of women with pre-eclampsia²⁰⁻²⁴, hospitalization was seen by women as the place where they found social and emotional help by health personnel and by other pregnant women. Besides, Ross *et al*²³ reported in their paper about HIV and pregnancy that women participated in meetings and antiretroviral programs, helping endure the disease.

Primary relief networks. In seven studies, pregnant women spoke of feeling peacefulness when they met their relatives. These accompanied women during their pregnancy, since they felt the need to be listened up, to receive an encouraging voice to comfort their minds.

Araujo *et al*²² reported in their paper about HIV that pregnant women who had relatives' help understood their illness, its cause and treatment better, causing a better compliance.

Another social support were the other pregnant women. Barlow *et al*²⁴, in their study about hypertension in pregnancy, reported that women felt hopeful when listening to the testimony of pregnant women who also suffered pre-eclampsia, and the final results were satisfactory.

Satisfactory relationship with health professionals. In five of the studies there was high concern and dedication from the health professionals about pregnant women's compliance; counseling was mainly focused to reduce emotional problems derived from the diagnosis itself. Thanks to their help and persistence distress was reduced and good mood increased.

Spirituality and religious practices. Belief in God caused in pregnant women a positive experience to relieve their disease's burden and to feel improvement of their situation. Faith and religious practices turned into source of hope and confidence to lead the pregnancy to a happy end.

5. Positive feelings caused by disease

In five of the cases, pregnant women expressed feelings assumed as positive when there was acceptance, solutions or resolution of their situation.

Women who lived with GD expressed acceptance, adaptation and control when they reconciled with their own situation, accepted the disease and adapted to imposed routines and treatment. This was possible thanks to a development of a responsibility to take care of themselves to offer their babies a healthy birth and to overcome several obstacles, which improved their self-confidence to deal with the disease. This feature was also present in the pregnant women who lived with HIV, before the hope of reducing virus transmission to their children thanks to the antiretroviral treatment.

As for the women who had a multifetal pregnancy, emerging positive feelings were adaptation, to feel a normal pregnancy situation after embrionary reduction; and to accept their self-image as caring mother of their children.

Topic 2. Women´s experiences product of a pregnancy at extremely early or late reproductive age.

1. Negative experiences about pregnancy

Deficient support by primary relief networks. In four of the studies, adolescents spoke of disapproval by both parents and mates; besides, Hoga²⁵ reported there was a relationship of inferiority, since several adolescents got pregnant just to satisfy their mates.

Relationship pregnant-studies-labor market. Three works reported that because of adolescent pregnancy there was school dropout, making their access to labor market quite difficult. Besides, to halt their studies meant some dreams of their lives were over.

2. Positive experiences about pregnancy

Primary relief networks. In a study, pregnancy during adolescence was assumed as a positive experience because it made possible to formalize adolescent´s relationship with their mates. In the case of the study about pregnancy after 35 year-old, women spoke of their mate´s participation during all the stages of pregnancy and delivery was essential for their healthy development, allowing to keep rutinary activities.

Possibility to grow up. This sub-category speaks about one study in which pregnancy meant for adolescent women to assume a new role as mothers and to leave behind drugs addiction, alcoholism and smoking. Also, pregnancy was a “solution” to problems inside their families and possibilities for better personal and family life conditions.

Relationship pregnant-studies-labor market. Moreira *et al*²⁶ reported that some adolescents who participated in their research came back to studies believing that by means of better education they could get work and better economical conditions.

Spirituality. In two studies, belief in God appeared as a support along the process of adolescent pregnancy. Thus, the origin of pregnancy was attributed to a “Divine Wish”

and, when contemplating abortion, they expressed that only God had the power to make their babies live or die.

3. Negative feelings due to pregnancy.

In five papers reviewed, pregnancy during adolescence caused feelings which might be interpreted as negative, such as fear, unsteadiness, concern and uncertainty, while considering to confront their parents with news of pregnancy; repentance because of the wish to abort and resignation given the new situation caused by the new son-to-be-expected.

On the other hand, in the study by Parada & Tonete²⁷ on the experience of pregnancy in women older than 35 year, feelings emerged as conflict when pregnancy was not desired or expected by poor women.

CONCLUSIONS

In relation with the first topic, in spite of the differences in the causes behind high-risk pregnancies due to pathologies, analysis of reported categories in scientific papers are very similar between them. One exception is about pregnant women living with HIV, where feelings and experiences offer account of a different, more complex phenomenon. In this sense, it is necessary to go deeper while closing in, even more when this topic has turned into a chronic one, targeting the women at reproductive age.

About the second topic, analysis show no new issues on research in adolescent pregnancy: new life option, lack of relief networks during the event and academic dropout, among others. On the other side, a new and underexplored issue is the experience of women 35+ year-old, the "aged" ones who get pregnant then. This is an increasingly frequent event in the developing world, given present feminine interests and roles.

On a daily practice in Nursing, it is necessary to stress the role of relief networks for those women who endure a high-risk pregnancy, as a tool to help them in these critical moments, while highlighting its value and role during the disease.

In spite of contextual differences of the analyzed studies, it is of outmost importance to review hospital environments, and leisure & entertainment conditions for pregnant women during their hospitalization, as well as possibilities to interact with their families. Also, it is necessary to adapt professional jargon, judged as too technical for women's comprehension.

This study showed that research in this field still has much to render, confirming doubts about research work against a problem successfully dealt from the biomedical perspective, but not from that of the comprehension of human being subjectivity. In this sense, qualitative research has shown usefulness to bring about women's voices who suffered a high-risk pregnancy; however, its scope must be widened whilst thinking of the advantages of techniques and participants' triangulation; according to Minayo²⁸, instead of focusing on a single data source, it is possible to multiply possibilities for approaching.

Given this logic, it is essential to stress on the inclusion of women's perspective and that of their families while enduring a high-risk pregnancy, useful both in the training of the next generation of nurses and in the making of nursery health care plans.

Finally, it is confirmed that a high-risk pregnancy is a complex, subjective event, impossible to encompass as a biological event alone: it implies physiological, psychological, social, economical, cultural and spiritual changes affecting both mother and baby directly; nursing health care should be seen from this perspective.

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Annex 1. List of consulted papers

| Nr. | Authors | Title | Year | Source |
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