Rev Saúde Pública 2007;41(5)

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Maternal perception of premature birth and the experience of pre-eclampsia pregnancy

ABSTRACT

OBJECTIVE: To analyze maternal experiences of preeclampsia pregnancy with premature birth at a neonatal intensive care unit.

METHODS: A qualitative study using the focus group technique was conducted with 28 women in a facility specialized in high-risk pregnancies in the state of Rio Grande do Norte, Northeastern Brazil, in 2004. Mothers included had had preeclampsia during pregnancy and a preterm delivery with consequent hospitalization of their baby at a neonatal intensive care unit. The data were analyzed using thematic content analysis of three thematic nuclei subjects: information about preeclampsia during prenatal care; experiences with the preterm newborn, and their perception of neonatal intensive care unit professionals' attitudes.

RESULTS: Maternal reports showed subjects' lack of knowledge with regard to preeclampsia and its association with prematurity. Difficulties inherent to the maternal role of caring for the child in the neonatal intensive care unit were identified, accentuated by communication flaws between health professionals and users.

CONCLUSIONS: Some difficulties experienced by the mothers, in the context of preeclampsia and prematurity, were aggravated by lack or inadequacy of information provided to the users.

KEY WORDS: Pre-eclampsia, psychology. Obstetric labor, Premature, psychology. Obstetric labor complications, psychology. Health knowledge, attitudes, practice. Qualitative research.

INTRODUCTION

Periodic prenatal care is essential for the healthy evolution of a pregnancy. It should include fundamental aspects such as: treating pregnant women and their family with dignity, providing relevant information and adopting behaviors and procedures conducive to the healthy development of the pregnancy, delivery and birth.*

Thus, the basic care for women in the pregnancy-puerperal cycle includes measures of prevention and health promotion, in addition to the early detection and treatment of clinical events that negatively affect the mother or the fetus.

* Ministério da Saúde (BR). Secretaria de Assistência á Saúde. Programa de humanização do pré-natal e nascimento. Brasília (DF);2001.

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Received: 7/24/2006
Reviewed: 4/6/2007
Approved: 5/28/2007

Among these events are preeclampsia, whose onset is slow and insidious in the second half of the pregnancy, with an incidence between 5% and 8% of pregnancies.[15] It is characterized by the development of hypertension with proteinuria or edema, or both,[3] with the following predisposing factors: early and late pregnancies (younger than 15 and older than 35 years), Black racial group, first degree relatives who had preeclampsia, chronic hypertension, maternal age, and low socioeconomic status. In addition, some pregnant women may show an association between psychological alterations and hypertension.[3,18,*]

Authors point out a number of maternal impacts of preeclampsia such as increased number of cesarean sections, kidney failure and liver failure or rupture[1]. Fetal impacts are intrauterine growth retardation, placental infarction, early placenta displacement, prematurity and its consequences.[12,19]

In addition to that, it is believed that delivery may be preceded by a period of increased anxiety, aggravated by early maternal hospitalization and pregnancy interruption.[10] This event changes the natural birth rhythm, provoking maternal feelings of despair, fear and anxiety.*

Thus, psychological and emotional support should be part of women health care, especially those prone to pregnancy complications, in particular, newborns weighing less than 2,500 grams[6] and consequent hospitalizations in neonatal intensive care units (NICU).

In this context, it is considered that the advent of technology has caused a significant increase in premature newborn survival rates in NICUs. However, it is important that the focus of professional attention be directed not only to attending babies' biological needs, but also their parents' psychological and emotional needs, especially the mothers who face NICU routine.

In this perspective, the present study was motivated by the aspect of humanized care and by the practical experience of fragmented care. The objective was to analyze maternal experiences of preeclampsia pregnancy and newborn care in the NICU.

METHODS

This is a qualitative study using the focus group technique,[4] whose objective was to obtain data by means of discussions, in which subjects expressed opinions and attitudes about a certain matter in an informal and spontaneous way.[9]

The study was conducted in a state facility specialized in high-risk pregnancies. Data were collected between September 2004 and March 2005.

The study sample comprised 28 women with preeclampsia, confirmed by their medical records, who had preterm delivery and consequent hospitalization of their child in the NICU. Researchers were allocated to three groups, averaging nine subjects each.

Inclusion criteria required a minimum of six and maximum of ten women for a group to be formed. The study was carried out in the postpartum period. While the baby was hospitalized, women were enrolled in mother-attendant programs, which prolonged their stay in a hospital setting.

They took part in meetings with a moderator (the researcher), who conducted interviews with open questions whose responses were not induced and who stimulated the participation of all the mothers, thus avoiding discussions to get monopolized by a few of them. One observer was responsible for recording each response, in addition to registering facial expressions and reactions to the questions, for future identification of the discourse transcription of each woman.

The meetings lasted 90 minutes on average. There were occasional interruptions due to the crying of some interviewees; two emotionally upset women, one from the first group and the other from the third, were referred for counseling by professionals from the institution itself.

The following thematic nuclei were approached: information about preeclampsia during prenatal care, experiences with the preterm newborn in the NICU and mothers' perception of NICU professionals' attitudes.

Subjects' responses were assessed using the categorical thematic content analysis proposed by Bardin[2] (1995).

The identity of subjects was preserved; they were represented by flower names corresponding to their hospital beds. The study was approved by the Research Ethics Committee-UFRN, approval No. 90/04 and an informed consent form was signed by all study participants.

RESULTS

Interviewees' age varied between 18 and 35 years; 82.1% had elementary and secondary schooling, while 17.9% had university education. Monthly family income was less than US$ 520.00.

Obstetric and perinatal data showed that 71.4% of the women had four prenatal consultations. From gestation week 24, elevated blood pressure on more than one

* Ministério da Saúde. Gestação de alto risco. Brasília (DF);2001.

Table. Analysis of puerperal women reports, distributed into categories, subcategories and thematic nuclei analysis units. Natal, Northeastern Brazil, 2005.

Thematic nucleus/Category	Subcategory	Analysis unit
1. Information on preeclampsia during prenatal care		
Awareness level of preeclampsia	Awareness	6
	Unawareness	20
Association to prematurity	Preeclampsia	4
	Other factors	20
Situations experienced at confirmation of high-risk pregnancy	Fear of dying	26
	Fear of the child dying	24
2. Experience with their child in the NICU		
Feelings experienced	Shock	20
	Sadness	14
	Insecurity	12
	Despair	13
	Joy	10
	Agitation	12
	Happiness	8
Prolonged hospital stay	Family and social distancing	26
	Lack of leisure activities	22
3. Patient perception of NICU professionals' attitudes		
Relationships with health professionals	Conflicts	6
	Doubts	16
Access to information on the child's clinical condition	Insufficient	10
	Technical language	12
Encouragement to maternal involvement with child care	Dissatisfaction	14
	Impatience	2
Technical capacity of the team	Reliable	15
	Doubtful	6

NICU: Neonatal intensive care unit

occasion over a 30-day period was found on prenatal charts of 60% of the subjects. Most (57%) were in their second pregnancy; 80% had cesarean delivery, owing to the seriousness of their gestation; and baby's birth weight varied between 1,200 g and 1,500 g.

Significant differences in group homogeneity ($p < 0.002$) were found only between groups I and II in terms of subjects' age. The similarities between the remaining variables allowed the use of the same procedure for data analysis.

Interpretation of the reports was based on theoretical reference since the purpose of the study was not to measure the factors studied but rather understand women's perceptions of them. The Table shows the three thematic nuclei that gave rise to nine categories, 23 subcategories and 318 analysis units. The relevant points will be discussed.

Information on preeclampsia during prenatal care

It was focused on the time at which subjects should have been informed about preeclampsia. Twenty analysis units showed they were unaware of this condition during prenatal care. They only became aware after hospitalization or by the imminent premature delivery, as illustrated in the following discourses:

"I didn't know. During prenatal care the doctor told me to rest and not to eat salt but she didn't say my pregnancy was high-risk." (Jonquil)

"I realized when I got here. My blood pressure started to go up before seven months but the doctor thought it would go down. I came to all prenatal visits and she only told me to lie down. I didn't know that high blood pressure was bad." (Sunflower)

In the same context it was assessed the level of maternal awareness of factors related to prematurity. Only

four reports showed an association with gestational hypertension; factors linked to religion, diet and family problems predominated.

"I think God wanted it this way." (Violet)

"I think it was because I was angry and didn't cry." (Gardenia)

The ideas that emerged from the interviews show women were unaware of their preeclampsia, which may have contributed to deficient preventive care and even to early hospitalization caused by the severity of their condition.

Early hospitalization and imminent preterm delivery triggered in the women a fear of death or of losing their child, situations found in 26 and 24 analysis units, respectively. This feeling was aggravated by the fact that some of these children did not cry at birth and were taken immediately to the NICU. Recalling these experiences in the group made women pause or weep, as can be seen in the following discourses:

"This is what I thought […] because when they are born they usually cry, and then the doctor puts the baby on top of us. I waited but it didn't happen." (Marvel of Peru)

"[…] I didn't see him, I waited for him to cry but nothing happened. I thought that my son was very sick, he didn't even cry. That was when the doctor told me he had been born, but he was in a serious condition and had been taken to the ICU. For me the ICU means it's very serious, it's the end [weeping]." (Poppy)

Experiences with a child in the NICU

Maternal experiences with their newborn in the NICU were categorized into aspects related to feelings according to their frequency in the reports, associating them to situations that the mothers considered as the hardest moments and those that were acceptable to the group.

Initially, it was investigated the mothers' first visit to the NICU, the first postpartum contact between mother and child. On this occasion, a thorough analysis allowed to understand the emotional load expressed by pauses, weeping and words such as shock, sadness and despair, illustrated as follows:

"When I got there I was in shock. […] When I saw my baby inside there I stopped and started to cry [weeping]." (Lobelia)

"The fact that he's there in that place full of machines, wires, the little thing pierced all over is a shock. […] It's sad to see him and not be able to hold him in my arms. It's horrible." (Poppy)

In NICU daily routine, the difficulties reported were attributed to different reasons such as not being able to hold their child (in their arms), seeing their child being pierced, fear of feeding their child with a tube and seeing their baby in phototherapy. From the maternal point of view, some equipment and care procedures were seen as causing suffering, although the mothers were aware of their need to improve the baby's clinical condition and their likelihood of survival.

"I knew that she was in the incubator. I was kind of sad because I couldn't hold her in my arms but I understood that she had to stay." (Carnation)

*"It's sad to see him crying, without being able to hold him, and pierced all over. I wish I could be in his place." (*Marvel of Peru)

The mothers also talked about other feelings arousing from the interaction with their child (joy, emotion and happiness), experienced when they held their babies in their arms for the first time, when they heard them cry and when phototherapy and IV tubes were removed.

"When I heard him cry for the first time, I was so happy because if he was crying it was because he had the strength to cry." (Chrysanthemum)

"Everything that shows he's getting better makes us happy. Even when he gains only 5 grams, it seems like he gained a kilo; we are so happy and it makes our day." (Lobelia)

It can be noted in the following report that being a mother-attendant causes distancing of the mothers from their family and social environment, and difficulties arising from the conflict between the importance of staying with their baby and not being able to engage in routine family activities.

"*I miss my home and I dream of the day when I can go home. Time drags and we don't have much to do."* (Flowers)

"I know that I have to stay because of my baby but it's very hard being in a hospital for such a long time." (Poppy)

This process was aggravated by the fact that the institution did not regularly provide leisure activities or programs that would favor healthy activities to reduce stress and promote maternal socialization.

Thus, it was found that support derived from the families, the interaction between mothers experiencing similar problems, comforting words of some professionals and religious faith.

Mothers' perception of NICU professional attitudes

Professionals' attitudes toward women with their children in the NICU revealed that the relationships between health professionals and patients generate conflicts and doubts. Although there is no obstacle to maternal involvement in the care of their child, it was perceived an inability to interact affectively, showing that NICU team is not aware of the difficulties faced by mothers when caring for their children. The professionals offer formal support, providing insufficient information using technical language that induces mothers to create a distorted reality.

"When I asked a doctor about my baby she would say she wasn't the one taking care of her but doctor such and such. This doctor would say the same. I know very little or almost nothing of what went on in the ICU. They only told me her condition was very serious but why serious? I don't know why she was hooked up to so many machines, I only found out why she was tube fed." (Mountain Rose)

"When I would get there to give her milk through the tube, I didn't know how. I was afraid and it took me a long time to learn. Some were understanding and helped me but others [...] and sometimes I was so sad when I went back to my room. I thought: "My God I don't know how to do it and they're going to make me do it all alone". (Carnation)

In this thematic nucleus two different statements were found. First, women pointed out the flaws in the communication process between NICU team and the mothers; second, they expressed satisfaction with the care provided to meet their child's biophysical needs (e.g., team's technical ability, easy access to complementary tests and therapeutic and technological resources), even though their doubts and anxieties were not attended to. These women are probably unaware that these two realities complement one another in an integrated health care system.

DISCUSSION

The study did not allow to associating the occurrence of preeclampsia and/or prematurity to the frequency of prenatal consultations since these data were not corrected by the gestation duration. Because of their shorter gestation, mothers of premature babies have fewer consultations. Some studies show no significant differences between the number of prenatal consultations and perinatal outcomes.[11,16] On the other hand, Coimbra et al[5] (2003) point out that inadequate prenatal care is closely related with social inequalities.

The episodes of elevated blood pressure experienced by some subjects in this study during prenatal care should have alerted professionals to the need for a shorter interval between consultations and thorough investigation. Or, according to the Brazilian Ministry of Health guidelines,* women should have been referred to high-risk prenatal care.

It is during prenatal care that health team has the opportunity of identifying factors, either social or biological, that may negatively affect the course of gestation Among these factors is early detection of gestational hypertension, which can be identified by the simple, low-cost technique of measuring arterial pressure.[14]

It was noted that the quality of information provided to the women about pregnancy with preeclampsia during prenatal care was inadequate or not appropriate to their level of understanding. This may have contributed to not having both prevention measures and better care for more serious conditions.* This finding is corroborated by Harrison et al.[7] (2003) who argued that women's involvement with their own health care in high-risk pregnancies makes them feel responsible for themselves and their baby's health.

The fear of dying or losing their child may be caused by lack of information during prenatal care and unpreparedness for adversities caused by preeclampsia during pregnancy.

It is known that unfavorable perinatal outcomes, associated to gestational hypertension, pose significant risks for prematurity and consequent hospitalization in the NICU.[19] As a result, mothers and family members experience emotional overload[8,17] due to mixed feelings about the need for therapeutic resources and their frustration of not being able to affectively interact with the child. In this way, the distancing from family and social life caused by maternal hospital stay is conflicting. Although mothers are allowed to leave the hospital, financial constrictions and the distance from their home make it not feasible. However, this situation could be minimized by the adoption of recreational and occupational activities that could reduce the idleness detected.[13]

The gaps seen in the relationship between health professionals and mothers suggest a need for changes in psychological and emotional care of women stressing on their involvement as indispensable for newborn recovery in the NICU. Above all, there should be provided better quality of information. This is corroborated by Scochi et al[13] (2004) who found that NICU team, although in favor of maternal involvement in child care, are clearly unprepared to facilitate it. However, one should bear in mind factors such as professional turnover, excess work demand on the institution and constant overcrowding that cause team overwork and make them to adopt a technicist approach. But to change this process, the reasons that make some professionals adopt such posture need to be thoroughly investigated.

The implementation of humanized health care is currently under way. These professionals' reality is far from the proposed integrated health actions since they are not able to identify or understand the emotionally fragile condition of premature babies' mothers, especially when they are psychologically exhausted by high-risk pregnancies.

Thus, the study findings show that the difficulties experienced by women in the context of preeclampsia and prematurity were aggravated by little or no information. This lack of communication was seen during prenatal care, hospitalization, and mostly in NICU team-mother relationship. This hampered maternal understanding of their child's clinical conditions and rendered the mother-attendant process exhausting, causing considerable emotional impact and sometimes reflected in the mother-child bond.

In conclusion, the study indicates a need for a reorganization of perinatal care, not only in hospital units but also in basic prenatal care services. It is suggested the integration of health actions for women in the pregnancy-puerperal cycle, especially when pregnancy poses maternal/fetus risks. Certain aspects of maternal involvement in caring for their child in the NICU should be reconsidered and measures implemented that support and define the real maternal role in caring for their child.

REFERENCES

1. American College of Obstetricians and Gynecologists Committee on Practice Bulletins-Obstetrics. ACOG practice bulletin. Diagnosis and management of preeclampsia and eclampsia. Number 33, January 2002. *Obstet Gynecol.* 2002;99(1):159-67.
2. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 1995.
3. Beckmann CRB, Ling FW, Herbert WNP, Laube DW, Smith RP, Barzansky BM. Hypertension in pregnancy. In: Obstetrics and gynecology. Baltimore: Williamns & Wilkins; 1998. p. 237-46.
4. Carlini-Cotrim B. Potencialidades da técnica qualitativa grupo focal em investigações sobre abuso de substancias. *Rev Saude Publica.* 1996;30(3) 285-93.
5. Coimbra LC, Silva AA, Mochel EG, Alves MT, Ribeiro VS, Aragão VM, et al. Fatores associados à inadequação do uso da assistência pré-natal. *Rev Saude Publica.* 2003;37(4):456-62.
6. Enkin M, Keirse MJNC, Neilson J, Crowther C, Duley L, Hodnett E, et al. Guia para atenção efetiva na gravidez e no parto. Rio de Janeiro: Guanabara Koogan; 2005. p.11-3.
7. Harrison MJ, Kushner KE, Benzies K, Rempel G, Kimac C. Women's satisfaction with their involvement in health care decisions during a high-risk pregnancy. *Birth.* 2003;30(2):109-15.
8. Holditch-Davis D. Bartlett TR, Blickman Al, Miles MS. Posttraumatic stress symptoms in mothers of premature infants. *J Obstet Gynecol Neonatal Nurs.* 2003;32(2):161-71.
9. Kruerger RA. Focus groups: a practical guide for applied research. Newbury Park : Sage Publications; 1988.
10. Leichrentritt RD, Blumenthal N, Elyassi A, Rotmensch S. Higt-risk pregnancy and hospitalization: the women's voices. *Health Soc Work.* 2005; 30(1):39-47.
11. Munjanja SP, Lindmark G, Nyström L. Randomised controlld trial of a reduced-visits programme of antenatal are in Harare, Zimbabwe. *Lancet.* 1996;348(9024):364-9.
12. Rades E, Bittar RE, Zugaib M. Determinantes diretos do parto prematuro eletivo e os resultados neonatais. *Rev Bras Ginecol Obstet.* 2004;26(8):655-62.
13. Scochi CGS, Brunherotti MR, Fonseca LMM, Nogueira FSN, Vasconcelos MGL, Leite AM. Lazer para mães de bebês de risco hospitalizados: análise da experiência na perspectiva dessas mulheres. *Rev Latino-Am Enfermagem.*2004;12(5):727-35.
14. Serruya SJ, Lago TG, Cecatti JG. Avaliação preliminar do programa de humanização no pré-natal e nascimento no Brasil. *Rev Bras Ginecol Obstet.* 2004;26(7):517-25.
15. Sibai BM. Diagnosis and management of gestational hypertension and preeclampsia. *Obstet Gynecol.* 2003;102(1):181-92.
16. Sikorski J, Wilson J, Clemet SS, Das S, Smeeton N. A randomized controlled trial comparing two schedules of antenatal visits: the antenatal care project. *BMJ.*1996;312(7030):546-53.
17. Sittner BJ, DeFrain J, Hudson DB. Effects of right-risk pregnancies on families. *MCN Am J Matern Child Nurs.*2005;30(2):121-6.
18. Smith RA, Baker PN. Risk factors, prevention and treatment of hypertension in pregnancy. *Minerva Ginecol.* 2005;57(4):379-88.
19. Oliveira CA, Lins CP, Sá RAM, Chaves Netto H, Bornia RG, Silva NR, et al. Síndromes hipertensivas da gestação e repercussões perinatais. *Rev Bras Saude Matern Infant.*2006;6(1):93-8.

Article based on the master's dissertation of NL Souza, presented at the Graduate Program in Health Sciences of the Universidade Federal do Rio Grande do Norte, in 2005.