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Domestic maternal experience with preterm newborn children

Vivência materna domiciliar com recém-nascido prematuro

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RESUMO

Objetivo Explorar as vivências maternas no cuidar de um recém-nascido prematuro em casa e analisar as dificuldades na assistência materno-infantil, após a alta hospitalar dos prematuros.
Métodos Estudo descritivo de natureza qualitativa com utilização do grupo focal com 24 mulheres que tiveram partos pré-termos em uma Maternidade escola, referência estadual para gestação de alto risco no nordeste brasileiro, no período junho a outubro de 2005. As mulheres retornaram ao serviço no período mínimo de 30 dias após a alta do neonato para relatar suas experiências de como cuidavam do recém-nascido prematuro em casa.
Resultados Os conteúdos das entrevistas foram divididos em quatro núcleos temáticos: A alta hospitalar; o preparo da família para a alta; cuidando de um bebê prematuro no domicílio materno e, mudanças na vida impostas pelo nascimento prematuro. As maiores dificuldades apresentados pelas mães no cuidado com o filho prematuro em casa dizem respeito à alimentação e resultaram das falhas da equipe de saúde no preparo dessas famílias para os cuidados domiciliares com o prematuro. Surgiram ainda sentimentos de insegurança e medo, revelando a necessidade de uma rede de apoio com seguimento ambulatorial e de pronto atendimento para oferecer suporte às famílias de bebês prematuros após a alta.
Conclusões No cuidado materno com o filho prematuro no domicílio predominaram sentimentos negativos que impuseram mudanças no cotidiano familiar, no trabalho e na própria vida social, revelando a necessidade de apoio aos pais na transição da vida hospitalar para domiciliar em situação de prematuridade.

Palavras-chaves: Nascimento prematuro, comportamento materno, relações mãe-filho (*fonte: DeCS, BIREME*).

ABSTRACT

Objective Exploring maternal experience with premature newborn children in a domestic environment.

Methods The study was qualitative and used focus group interviews with 24 women who had had preterm deliveries in a public maternity hospital located in Northeast Brazil during June and October 2005. The mothers returned to the hospital facility at least 30 days after the newborn were discharged to share their experiences in caring for a premature infant at home.
Results Interview data was analysed for content, four thematic nuclei being identified: hospital discharge, preparing the family for discharge, caring for a premature baby at home and life changes arising from the premature birth. The greatest difficulties reported by the mothers in caring for their premature children at home were related to feeding and feelings of insecurity and fear were expressed which showed the need for a support network for the families following discharge.
Conclusions The mothers' care of premature infants at home represented changes for parents in everyday family life, work and social life, thus showing the need for a support network for them during the transition from hospital to home when considering premature children.

Key Words: Premature birth, maternal behavior, mother-child relationship (*source: MeSH, NLM*).

RESUMEN
Experiencias maternas en el hogar con recién nacidos prematuros

Objetivo Explorar las experiencias maternas con recién nacidos prematuros en el entorno domiciliario.
Métodos Estudio cualitativo que utilizó un grupo focal con 24 mujeres que tuvieron partos prematuros entre junio y octubre de 2005 en una maternidad pública en el noreste de Brasil. Las madres regresaron a la instalación al menos 30 días después del alta del parto para compartir sus experiencias en el cuidado de un recién nacido prematuro en el hogar.
Resultados Cuatro núcleos temáticos fueron identificados: el alta hospitalaria, la preparación de la familia para la aprobación de la gestión, el cuidado de un bebé prematuro en el hogar y los cambios en la vida como resultado del nacimiento prematuro. Las mayores dificultades señaladas por las madres en el cuidado de sus niños prematuros en el hogar estaban relacionados con la alimentación y se expresaron sentimientos de inseguridad y temor, lo que demuestra la necesidad de una red de apoyo a las familias después del alta.
Conclusión El cuidado de la madre del recién nacido prematuro en el hogar representa para los padres cambios diarios en la familia, el trabajo y la vida social, mostrando la necesidad de una red de apoyo para ellos durante la transición del hospital a la casa en una situación de prematuridad.

Palabras Clave: Nacimiento prematuro, conduducta materna, relaciones madre-hijo (*fuente: DeCS, BIREME*).

The transition to motherhood, as with many types of transitions, is depicted as being a normal process that causes changes in a woman's life (1). Greater difficulties may be encountered in the case of a mother having a premature child (2) because such births are often associated with fear, disappointment and anxiety. Such emotional stress occurs as a result of the uncertainties experienced by the mother and the family regarding a child's survival whilst being hospitalised in a neonatal intensive care unit (NICU) (3). Such lack of equilibrium understandably exacerbates the insecurities surrounding future motherhood which must be overcome if a mother is to achieve mastery in caring for her premature infant (1). The mother's reaction during this transition period is therefore an important element in the home-care process and the baby's growth and development, as well as in mother-child-family bonding.

A premature baby is an infant who is born having undergone less than 37 weeks gestation and is therefore more vulnerable to morbidity during the neonatal period as a result of interrupted gestational development. Around 10 % of births in Brazil are premature and they account for 75 % of neonatal deaths (4). These babies are usually cared for in an NICU; in some institutions they take part in a programme known as the Kangaroo method that aims to promote a baby's weight gain; this is done by encouraging kangaroo-type bodily contact between mother and baby during the hospital stay (5).

The birth of a premature baby represents anxiety for mother-child health because of its relationship with child morbidity and mortality indices and with the effects it can have on family life. Amongst other problems, premature newborns are at risk of suffering alterations in cognitive, motor and respiratory development (6,7) and require special care after hospital discharge, given their susceptibility to sickness and death. However, the discharge of a premature child, although greatly desired by the parents, does not mean the resolution of these problems. Discharge is thus usually conditional on the availability of specialised out-patient follow-up and specific domiciliary care, requiring greater family contact during the treatment of these babies.

Few studies have assessed the difficulties faced by parents when caring for a premature child after hospital discharge. Some studies have pointed out the parents' importance in caring for their babies during hospitalisation, primarily because of the strict relationship identified between a mother's experience during the child's hospitalisation in an NICU and success in providing domiciliary care upon discharge (8,9). Other events such as traumatic maternal experiences during the pregnancy and puerperal period have been found to have

harmful effects on parents' interaction with their babies eighteen months after delivery (10). The special care required to help mothers adapt to the new reality of a premature birth point to the need for early weaning of preterm newborns, a situation which should be managed during hospitalisation and guaranteed by the institutions involved (11,12).

Other factors' influence on maternal adaptation to prematurity should be highlighted when considering domiciliary care being provided by parents. These would include the parents' educational level, psycho-social factors and family preparation for discharge by the NICU team (13).

It is thus crucial that the healthcare team (especially the nurse) develop procedures involving the family in the care of premature children during newborns' hospitalisation (8,14). These could include emotional, psychological and social strategies which could help in acquiring security and increasing family competence to successfully care for their premature infants at home.

Some countries have attempted to influence maternal adjustment to prematurity. For example, mothers are encouraged to maintain skin-to-skin contact with their premature babies for 24 hours when implementing the Kangaroo method in Colombia. The Kangaroo method has been widely accepted in Brazil and the Ministry of Health has promoted the continuation of this practice after hospital discharge (5). Such transfer to the home environment suggests a new sense of responsibility that could cause greater emotional tension for the mothers of premature children (9,10).

The difficulties faced by mothers and families in caring for premature infants after discharge must thus be understood, especially in countries having high prematurity rates, to ensure good child development and reduce neonatal mortality rates, especially in developing countries where this is an area of concern.

This study was thus aimed at exploring mothers' experience of caring for a premature newborn at home and analysing the difficulties that these mothers encounter in maternal-child care following hospital discharge.

METHODS

This was a qualitative descriptive study using focus group method (15). The study was conducted in a public maternity teaching hospital located in North-

east Brazil during June and October 2005. The participants were 24 women who met the eligibility criteria of having had a preterm delivery and whose newborn were hospitalised in the NCIU. The women were invited to participate in the study during their stay in the institution and at that time were provided with full information about their participation in the study. Those who agreed to participate signed the informed consent agreement form. They were then assigned flower names to preserve their anonymity.

Two research instruments were used. A questionnaire was designed to obtain socioeconomic, obstetric and neonatal data from the participants and semi-structured guidelines were constructed for directing the interview during the focus group meetings. The guidelines contained the following question, "Describe what it was like to take care of your premature baby at home."

The study was approved by the Research Ethics Committee of the Universidade Federal do Rio Grande do Norte (UFRN) protocol 90/04. An informed consent form was signed by all study participants.

The selected women were contacted seven days after discharge; they were invited to come to a group meeting at the hospital on a specific date to discuss their experiences regarding caring for their premature newborn children at home. Three focus groups were formed, ranging in composition from 6 to 10 women.

Three gatherings were held 30 days after the discharge of the last premature newborn (i.e. one for each group). A 30-day period for holding the meeting was determined, given that greater adaptation occurs after this period, thereby diverging from the study's aims of understanding the first days with the newborn in a domestic environment. The lead researcher and an observer conducted the group interview. The lead researcher posed the guiding question to the group, without inducing responses and seeking the participation of everyone whilst avoiding monopolising the discussion.

The participants authorised the observer to record the interview and to record the beginning of each discourse, in addition to their expressions and reactions to the question. This procedure enabled the subsequent matching of the women (fictitious names) with the discourse transcription made by the researcher.

The meetings lasted an average of ninety minutes. The meetings occasionally had to be interrupted because some women became upset as they narrated their experiences. The meetings resumed as soon as the women could compose themselves and were willing to proceed. Professional psychological support from the institution was made available to the participants, but they did not require it.

The study group's socioeconomic, obstetric and neonatal data were analysed using SPSS software (version 14.0) for descriptive statistics. The women's discourses were transcribed verbatim and were then qualitatively analysed based on the thematic content analysis procedure proposed by Bardin (16). All printed responses were read by two investigators. These themes were confirmed by two additional readers in an attempt to establish trustworthiness and to ensure credibility (one was a study participant and the other a nurse from the institution).

FINDINGS

The women's mean age was 26 (±4.02). The participants had reached primary and secondary school levels (82 1 %). 71 4 % of the women reported monthly family income of up to three times the minimum salary (≈US$ 400). Obstetric and perinatal data showed that 42 9 % of the women were nulliparous prior to the birth of the preterm baby. 57 1 % of the women's newborns weighed between 500 g and 1 500g.

The coding system and discourse analysis led to four main themes: hospital discharge experience, preparing the family for discharge, caring for a premature baby at home and life changes resulting from the premature birth.

Theme 1: hospital discharge experience

This theme assessed the mothers' expectations on the days preceding discharge. This was only evaluated at the first group meeting, owing to the different discharge dates.

The moment was characterised by a range of mixed feelings. The mothers celebrated overcoming the obstacles they had experienced during the babies' hospitalisation, welcoming the opportunity to take their babies home. Yet, they also expressed their insecurity and anxiety related to the increased responsibilities demanded of them and the end of the support provided by the hospital team. This conflict of feelings was expressed as follows.

It was awful. I dreamt about it and in the week that she was supposed to be discharged, I was scared to take her home. (Jasmine)

We think he's safe here; there are trained people to save him. (Petunia)

Theme 2: Preparing the family for discharge

This theme assessed the NICU team's support for the family aimed at introducing a premature baby into an extended-hospital environment. The findings suggested that this situation was experienced individually while the mother was being familiarised with daily NICU routine. The mothers' participation was often limited to basic care (diaper changing, bathing and other simple procedures). The fathers' participation was also limited to visiting hours, making it impossible for them to understand this new reality and establish their real role in caring for the children.

Information concerning domiciliary follow-up which the health professionals provided the family with described the preparation for the discharge which they received as being unsatisfactory, relying on an excessive use of technical language. This type of approach resulted in inadequate communication, especially for parents having had little schooling. They stated that,

think we need more orientation meetings like these, for us and the family, so that we can talk about our insecurities and get advice. (Jasmine)

Ithink they should be more detailed so that we can understand better. (Carnation)

Theme 3: Caring for a premature baby at home

This represented the main focus of our study. It reported the difficulties faced by the mothers in the day-to-day care of infants at home. Although the women were gratified to be at home with their babies, they felt the weight of the responsibility of taking care of such frail babies without the hospital team's support. The mixed feelings expressed (some gratifying, others unsatisfactory) enabled subcategories to be divided into negative and positive aspects for clearer understanding of this situation.

Negative aspects

Negative feelings were present during discharge and at the onset of social and family life. This moment was described as being of concern and fear of not knowing how to care for a baby, difficulties in feeding them and uncertainties about their functional stability. The following discourses illustrated this.

It wore me out; I couldn't sleep and every few minutes I'd put my hands on him to see if he was breathing. (Petunia)
One day I comforted the sheet. Because he was crying, and I was sleeping; I was so sleepy, so tired, and when I woke up, I was rocking the sheets. (Jasmine)

The mothers had to deal with curiosity visits from friends and neighbours on a daily basis, also with the comments that normally arise when people see an unusually small baby. These situations reflected the obstacles the mothers faced in forming the concept of a "child's normality." The discourses that follow exemplified such concept.

Every day the neighbours asked me if he ate, I felt like saying - he's not dead; he's alive. (Carnation)
People would look and say - Ah he's got no nails, ah he's got no fingers! When they'd leave, I was sad. (Tulip)

The lack of specialised and prompt care available to the mothers at home whilst attending to prematurity-related problems produced maternal stress, given the frequent respiratory and metabolic instabilities caused by prematurity. The following statements demonstrated that need.

We're insecure because if anything happens to him there's no ICU nearby, like there is in the hospital. (Jasmine)
When I got home, the insecurity hit me. I knew I couldn't take him back there. I had to take him to the general emergency hospital, but do they know how to take care of such a small baby? (Rose)

One of the negative aspects reported by the mothers was related to the continuation of the Kangaroo method; only four mothers maintained skin-to-skin contact with their children, albeit for short periods daily. The remainder stated that responsibilities and exhaustive routines at home prevented them from continuing with this method. Similarly, difficulties inherent to the feeding of premature babies revealed numerous problems involving continued breastfeeding or alternative food regimens.

The practice of exclusive breastfeeding until six months of age is encouraged by the Ministry of Health in Brazil; however, when newborns are premature, the mothers need further encouragement by the neonatal team to prevent early weaning due to these children's greater vulnerability to morbidity and neonatal mortality.

To better understand this situation, the continuity of post-discharge breastfeeding was investigated, finding that only 25 % of the women inter-

viewed had managed to maintain exclusive breastfeeding. Their discourses demonstrated their lack of available information about breastfeeding.

It was hard for me to breastfeed; I didn't have much milk, so I bought milk and gave it well diluted. (Rose)
I don't breastfeed. I haven't breastfed since I left here. My milk dried up while I was still here. (Four o'clock)

This shows the mothers' concern and confirms that the problem of early weaning originated in the institution itself when exclusive breastfeeding was not enforced as a condition for discharge. Additionally, relactation was not explained as being a possibility in cases of prolonged enteral and parenteral feeding.

Positive aspects

Adapting to the new daily routine brought positive aspects related to mother-family and baby triad. This, in turn, reinforced the child's physical and cognitive development.

Assigning roles to each family member indicated the sharing of responsibilities and the emotion shown when faced with difficulties arising from prematurity.

We're fulfilled when we see him at home crying. It's a sign of life, a sign that he won. It's marvellous. (Mountain Rose)
I think his crying is beautiful because he didn't cry when he was born and here he only moaned, but now he cries loud and hard and it makes me very happy. (Chinese Hibiscus)

It is worth pointing out that pleasure at hearing a baby cry was widely reported by the participants and may have been associated with the fact that some of these women, given their children's clinical severity, did not hear their babies cry at birth.

Theme 4: Life changes resulting from the premature birth

The mothers were overwhelmed by the life changes brought about by having a premature child. Their responses showed overprotection due to their image of a fragile baby and the likely difficulty in never perceiving him/her as being normal. This fact caused the mothers to dedicate themselves entirely to caring for the baby to the point of neglecting their own appearances, as suggested by the following discourses.

Life changed a lot because the baby needed special care. I have twice as much responsibility. (Rose).
Only after three months did I have my hair cut and start to use lipstick again. The first months were totally for him; I didn't care if I was ugly or pretty. I just wanted to see him well. (Petunia)

Although faced with difficulty, the women described being the mothers of premature children as an experience which had brought maturity, triumph and faith. Despite the trauma of having experienced such a difficult situation, they felt compensated for having their children at home and being able to enjoy the role of motherhood.

DISCUSSION

Using the focus groups led to finding that premature babies' discharge from hospital triggered insecurity and concern within the study group. This was represented by a combination of stress, anxiety and gratification. It is a situation where the mothers experienced the responsibility of caring for their children without the support of the hospital team.

It was observed that the intensity of the problems so identified was related to the professionals' lack of preparing the mothers during their stay in the NICU. A number of authors have suggested that psycho-emotional support must be provided for a family during this period if they are to overcome the trauma caused by premature birth (17). The gaps left by the health team in stabilising the family during the transition period between hospitalisation and discharge may have generated conflict and overload during their adaptation to life at home (18).

Premature newborns run potential risks related to feeding disorders. Seeing children eating normally and gaining weight satisfactorily therefore brings great satisfaction to parents and reduces their anxiety about caring for such children at home. Part of the difficulty experienced by the mothers regarding prematurity was aggravated by the absence of information or lack of understanding (19). It is thus essential that they be provided with support and guidance so that they can adopt feeding strategies for their children during the transition phase from hospitalisation to discharge (20).

This was observed in the present study when the mothers alluded to feeding difficulties that resulted in early weaning, a worrisome situation given the importance of maternal milk in premature newborn development. Studies on premature newborn feeding have shown that health professionals' support and

knowledge about maternal peculiarities during breastfeeding are indispensable (12). Regarding early weaning, it has been suggested that the early onset of breast sucking be implemented and that exclusive breastfeeding and gradual weight gain be conditions for discharge, thereby ensuring out-patient follow-up and post-discharge orientation (11).

The Kangaroo method instituted in Brazil in 2000 consists of three stages, the first being developed in an NICU, the second in shared lodging where a family is prepared for t discharge and the third during domiciliary follow-up until the newborn weighs more than 2,500g. This method is also credited with breastfeeding success in premature children (5). This method's phases were not being adequately followed at the institution where the study took place, this being a situation which might have been contributing towards the difficulties reported by the mothers.

The study should alert neonatal professionals (especially nurses) to the need for a more systematic approach to delivering educational programmes directed at parents during their premature babies' hospitalisation. The aim should be to reduce anxiety regarding discharge and make mothers more confident when caring for their babies at home. The study also showed the need for a support network having out-patient follow-up and prompt treatment of problems which could compromise the premature newborn's healthy development.

The study presented here has thus shown that feelings of insecurity and fear predominate in the care of premature children at home. Such negative feelings cause changes in daily family life, at work and in social life resulting from deficiencies in the healthcare team preparing the parents for the transition from hospital to life at home. It is as if the experience could be divided into two moments, before and after premature birth. This shows the close association between the difficulties encountered on a daily basis regarding a premature baby, the quality of information provided by the team during a child's hospitalisation in an NICU and the family's inadequate preparation for discharge, especially that of the mother.

This study was limited by the formation of focus groups to obtain at least eight women who met the criteria established in the research and also by the fact that some lived far from the study area and had financial difficulties preventing their attendance at the study site within the times scheduled. However, the data collected and the type of methodology used showed that the study objectives were fully met.

Further studies should be performed for a better understanding of Kangaroo method functioning and its relationship to the problems faced by parents during and after premature newborn hospitalisation ♣

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