

Home care of the premature baby*

O cuidado da criança prematura no domicílio

El cuidado del niño prematuro en el domicilio

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ABSTRACT

Objectives: To characterize and describe home care to the premature baby provided by mothers or other caretakers. **Methods:** A descriptive qualitative study was used. Seven caretakers were interviewed in their homes. The data were collected through semi-structured interview and analyzed using content analysis. **Results:** The emerged categories were: caring for the premature baby at home; living and interacting with the premature baby; and, the importance of social support in caring for the premature baby. **Conclusions:** The mothers, as caretakers, provided proper care to the premature baby, expressed concerns regarding the baby's development and growth, and voiced the need of support to deliver proper care.

Keywords: Infant premature; Infant care; Caregivers; Mother-child relations

RESUMO

Objetivos: Identificar o cuidado domiciliar prestado pela mãe e/ou responsáveis pelo cuidado da criança prematura; descrever o cuidado prestado ao prematuro no domicílio e os aspectos que interferem neste processo. **Métodos:** Estudo descritivo, qualitativo. Foram entrevistadas sete cuidadoras de prematuros nos seus domicílios. Os dados foram coletados por meio de entrevista semi-estruturada e observação descritiva, analisados pela técnica de análise de conteúdo. **Resultados:** As categorias foram: o cuidar da criança prematura no domicílio; preocupações que emergiram convivendo com o prematuro; a importância do suporte social para o cuidar do prematuro. **Conclusões:** As mães, cuidadoras, desempenhavam adequadamente o cuidado; explicitaram preocupações com crescimento e desenvolvimento do filho, com as intercorrências apresentadas e, também, a necessidade de suporte para este cuidar.

Descritores: Prematuro; Cuidado do lactente; Cuidadores; Relações mãe-filho

RESUMEN

Objetivos: Identificar el cuidado domiciliario prestado por la madre y/o responsable del cuidado del niño prematuro; describir el cuidado prestado al prematuro en el domicilio y los aspectos que interfieren en este proceso. **Métodos:** Estudio descriptivo, cualitativo. Fueron entrevistadas siete cuidadoras de prematuros en sus domicilios. Los datos recolectados por medio de una entrevista semi-estructurada y observación descriptiva, se analizaron por la técnica del análisis de contenido. **Resultados:** Las categorías fueron: el cuidar del niño prematuro en el domicilio; preocupaciones que emergieron conviviendo con el prematuro; la importancia del soporte social para el cuidar del prematuro. **Conclusiones:** Las madres, cuidadoras, desempeñaban adecuadamente el cuidado; explicitaron preocupaciones con el crecimiento y desarrollo del hijo, con las ocurrencias presentadas y, también, la necesidad de soporte para este cuidar.

Descriptores: Prematuro; Cuidado del lactante; Asistencia domiciliaria; Cuidadores; Relaciones madre-hijo

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INTRODUCTION

Neonatal care has substantially advanced in the last decades, with the introduction of more efficient therapeutic resources, more modern technological resources and more specialized human resources.

These technical-scientific advances cause biopsychosocial care to have a less important role and, at times, key aspects not to be performed during care as well, such as the presence of the family, individualized care or valuing individual socio-cultural characteristics.

Given this context, the need for more humane hospital care for the premature newborn* and family members stand out, valuing the biopsychosocial well-being during the child's health recovery and rehabilitation, the formation and maintenance of the mother-child emotional bond, and care that continues at home.

Following parents during the period of hospitalization, observing if contact with their children is maintained and how it is made, is a way to support child recovery. This follow-up is important for them to know their child, identify its needs and learn how to care for it when it's discharged, or even before that, while yet in the hospital⁽¹⁾.

Hospital discharge of the premature child leads to special care, due to its higher organic and emotional vulnerability. Both the parents and the child have their share of participation and responsibility in this process of care, where each mother-child bond is unique in its dynamics and history⁽²⁻³⁾. Thus, when planning to discharge a premature newborn, it is essential to balance its well-being and stability with the family's ability to care for it and the availability of support services in the community, enabling the maintenance of care for the premature child at home.

The responsibilities of the family are associated with the support they can provide the newborn, their ability to care, their understanding about the child's satisfaction responses, and the social, financial, and cultural issues that influence how well the newborn is understood and accepted by them.

Based on these reflections, the following problem was formulated: how is the premature child cared for at home?

OBJECTIVE

This study aimed to: identify home care provided by the mother and/or those responsible for care of the premature child; describe care given to the premature child at home; and describe aspects that interfere with the premature child care process.

Theoretical Framework

This study was based on human being care, with an emphasis on premature child care and the Kangaroo Mother Care as a strategy to care for low-weight children.

This care consists in transpersonal efforts from one human being to another human being, in the sense of protecting, promoting and preserving humanity, helping people to find meaning in a situation involving disease, suffering and pain, as well as in existence. Care helps the other person to obtain self-knowledge, control and self-healing⁽⁴⁾.

Premature child care, due to its peculiarities, requires knowledge and the establishment of assistance aimed at its needs, covering specific care during hospitalization and its maintenance after hospital discharge.

The premature newborn is an infant at risk, susceptible to several problems resulting from the immaturity of the central nervous, immunological, cardiovascular, respiratory, digestive and renal systems⁽⁵⁾. Another relevant aspect is the fact that the child's early birth and hospitalization in the Neonatal Intensive Care Unit (NICU) can cause parents to feel incomplete and unprepared to fulfill their roles. This is because there is a psychological preparation during pregnancy, associated with the woman's stages of body changes, so that, at the end of nine months, she experiences a feeling of readiness to meet all the infant's needs: feeding, hygiene, affection and caring⁽⁶⁻⁷⁾.

In this way, parental assistance and their participation in child care have been prioritized by neonatal units. The infant's long period of hospitalization and lack of affection and care increase maternal and family stress, which can harm the maintenance of a bond and attachment⁽⁸⁾.

The mother-child bond is the most solid relationship existing among human beings, and in this relationship there is something unique, guaranteed during pregnancy and after birth. The mother guarantees her child's survival, as it continues to be dependent on her during a relatively long period⁽⁷⁾.

In this sense, the nurse in the neonatal unit must facilitate the early contact between parents and premature infants, aiming to maintain the bond and attachment, considering this to be a gradual process, which may take more time than the first days or weeks of a full-term infant's postnatal period⁽⁸⁾. The support and safety premature children's parents are given by the nurse are essential for them to understand the situation of risk the infant is exposed to and also to learn how to care for it at home⁽⁹⁾.

Among the strategies that enable parents to understand this, the Kangaroo Mother Care (KMC) should be emphasized, as it consists in early skin-to-skin contact between the mother and her newborn, thus promoting breastfeeding, temperature control, sensory stimulation and emotional bond strengthening⁽¹⁰⁾. KMC enables the

* In this study, the terms "premature newborn", "premature infant", and "premature child" will be used as synonyms.

family, child and health care team to come closer together, as well as the development of humane-oriented care.

METHODS

This study was descriptive, with a qualitative approach, and it was performed between May and August 2007. The homes of children who had been hospitalized in the Inácia Pinto dos Santos Hospital (HIPS), located in the city of Feira de Santana, were the study location.

Research was performed in accordance with the Resolution n° 196/96. Confidentiality and privacy were guaranteed by participants' identification code. This research project was approved by the Feira de Santana State University Research Ethics Committee, under Process n.° 087/2007.

A total of seven mothers of premature infants participated in this study. Criteria for inclusion were as follows: to have a hospitalized premature child receiving KMC at the HIPS, between April and June 2007; to live in the city of Feira de Santana; and to have already received discharge from hospital. Initially, the number of interviewees was not restricted, based on the supposition that interviews would be carried out until they became repetitive and/or met the research objective.

Data were obtained using the Descriptive Direct Observation and Semi-Structured Interview techniques. This observation was performed in a completely free manner, even though the field investigator must always be focused on what constitutes the object of study⁽¹⁾. In this study, the observation focused on the following aspects: Home space; Caregiver-child relationship; Care provided during investigator's visit; Family participation as support for caregiver; and Home access to/distance from health services. In addition, other aspects that appeared spontaneously in each context were recorded in a Field Journal.

This Field Journal was designed from observations made by the researcher during visits to the children's homes. They were recorded spontaneously, lacking theoretical rigor, but involving notes that were relevant to understand the object of study. These notes were recorded after each visit, in the researcher's home.

Semi-structured interviews were used to enable greater interaction between researcher and the individual under study, in addition to enabling perception of feelings, emotions and values. Guiding questions were the following: How do you take care of this premature child at home? What is it like to care for this child? What aspects interfere with this care?

Data collection occurred at the home of seven caregiver-child pairs and, coincidentally, caregivers were the mothers, as they were the ones caring for the premature children full time.

Home visits of each caregiver-child pair occurred in two moments: the first between eight and 14 days after hospital discharge, and the second between eight and 10 days after the first one. A total of two visits were made, aiming to reach the objectives proposed by the study. Each visit lasted one hour on average. These visits were booked during researcher's contact with individuals in the hospital, after an Informed Consent Form was signed, while the second visit was booked during the first one.

After data collection, Thematic Content Analysis⁽²⁾ was employed to find out the mothers' subjectivity in the premature child care process at home.

Data analysis was performed with the codification of interviewees' speech, associating them with observation data and theoretical foundation. Codes were grouped according to similarities of meaning into specific categories.

RESULTS

Analysis of premature child care at home enabled this study to: know what the mother (caregiver) and family experienced in this context; know how these children were cared for; and identify what aspects were involved in this process, as well as the concerns that arise when living with the premature newborn.

The categories found were as follows: Caring for the premature child at home; Concerns arising from living with the premature child; The importance of social support to care for the premature child.

Caring for the premature child at home

The thematic universe of premature child care is revealed through general aspects of caring for the premature infant, the way the caregiver perceives the premature infant, and how this infant is given care.

Mothers considered the premature child as fragile and susceptible to complications due to its size, as expressed by the following statements:

"He's so tiny it seems he's going to fall from my hand" (Dália, Int.1).

"As she was born early, [...] she's more vulnerable" (Hortência, Int.1).

"She's too fragile... to catch such bad flu, she's too fragile to resist" (Azaléia, Int.2).

By perceiving the premature child's body as delicate and small, subtle in its size, mothers may feel unprepared and incapable of caring, or develop a distorted perception of their child, focusing more on the deficiencies and vulnerabilities, rather than on the existing positive resources. As a result, they begin to overprotect their child⁽³⁾.

The mother shows apprehension about not knowing

how to meet her child's requirements or about exposing it to risky situations, as reported below:

"I always look at him carefully... because he was premature... The nurses always said that we had to give him special care, you know... always keep an eye on him, not leave him alone for long" (Camélia, Int.1.).

"Because of his size and the fact that he's premature. For this reason, I think care is more personalized and intense" (Rosa, Int.1.).

"But I know that care is much (emphatic) greater than that given to a full-term child" (Hortência, Int.1.).

The following speech reveals how mothers meet their child's basic needs (feeding, hygiene, sleep and rest, among others), including emotional support (affection and playfulness):

"I give him a bath... always at the right time, I give him milk, I do all the usual things [...] I give him a bath and affection, I do a lot of things there" (Dália, Int.1.).

"I give him a bath, always at the same time, everyday, [...] then, I breastfeed him, and put him to sleep. [...] We play, laugh, oh, it's so good (laughs)" (Amarilis, Int.1.).

"I take care of him with all my love and care [...] I wake up, breastfeed him, give him a bath at the right time, and the medicine at the right time as well" (Rosa, Int.1.).

It was possible to describe and observe how mothers perform care for feeding, hygiene, warming and infection prevention.

In terms of feeding, mothers prioritize exclusive breastfeeding. Mother's milk is valued and they can identify the necessary changes of breastfeeding frequency and amount. Though incipient, concerns about the moment of weaning arise, especially in terms of what the infant should be offered:

"To only give mother's milk until the sixth month, then introduce other foods." (Camélia, Int.1.).

"I breastfeed him at the right time, burp him, and then he goes to sleep. When he wakes up... he wants to have milk again... So, I go give it to him." (Dália, Int.1.).

"Then, it's so relative for me to describe the times, she doesn't follow diet times as she did in the hospital. She... sometimes it's every three hours, sometimes two and a half, sometimes three and a half." (Hortência, Int.1.).

Human milk is a basic recommendation in the premature child's diet, as the milk produced by its mother during the first month after birth has higher levels of proteins, sodium and chloride than the milk of the mother of a full-term newborn, thus constituting the best food for these children⁽¹⁴⁾.

To keep the infant warm, mothers reproduce what

they learned during the KMC program, such as the use of the kangaroo mother position, wrapping this infant with cotton and blankets, and the use of a thermometer to control the temperature.

"I always carry him so he stays quiet... but I don't have the kangaroo pouch here (laughs) I use a blanket with him here in the bedroom" (Camélia, Int.1.).

"I'm always using the thermometer to see if her temperature's good, 'cause I'm always warming her, I use cotton in her hands and feet" (Jasmim, Int.1.).

By recognizing the susceptibility of the premature infant from its immunological system's vulnerability, mothers prevent infections with visit restriction, utensil care and vaccination.

"Nobody can come in before he weighs three kilograms [...] we're very careful. And we boil the bottle every day" (Amarilis, Int.1.).

"Visits are a real problem [...] I say he can't get visits, then I say he was born premature. And that he can't have much contact with people." (Hortência, Int.2.).

"I think it'd bring bacteria from the streets, this is the information I got, I think it'd bring something from the streets, I certainly wouldn't let anybody pick him up, everyone who comes here wants to pick him up [...] then, I try to avoid this." (Hortência, Int.2.).

Visit restriction is a measure that contributes to prevent infections. Thus, parents must prevent their child from coming into contact with people with a cold or the flu. Moreover, they must explain to visitors that they will have plenty of time to visit the child as it is staying at home, so they do not need to gather together⁽¹⁵⁾.

Other protective measures used were: hand washing; bottle and pacifier boiling, perfume and air current restriction. These home measures were mentioned by Balbino⁽⁶⁾, showing that premature infants' parents prevent home infection with hygiene habits at home, general cleaning, and care for the newborn, such as hand washing to change the infant's clothing and hygiene during food preparation.

Vaccination constitutes one efficient strategy to prevent contagious infectious diseases, which are very severe when afflicting small premature children. For this reason, probably, mothers become concerned, as they recognize that their children need to be vaccinated. However, some of them revealed that vaccines are too strong to be administered or that they were discouraged by basic health unit professionals, who showed different practices to vaccinate babies and used, as a reference point, the infant's age or weight.

"I haven't got around to the vaccine, nor did I look for it. Only

after the child weighs more than three kilograms. (Amarilis, Int.1.)

"Then, due to this shot in the leg being very strong, [...] because she had one today, then, in two days, she'll turn two months old, and there's another vaccine she's got to be given at two months. So, not to be given two shots in such short period, and because her weight's two kilos and two hundred, they told me to give her this shot when she turns two and a half months and has gained some weight" (Jasmim, Int.1.).

Concerns arising from living with the premature child

In this study, maternal concerns arose about the child's growth and development and also about the complications that occurred to them.

Apprehension about these complications includes exacerbation of some pre-existing disease, the appearance of other diseases and adequacy of behavior when symptoms are present.

Concern about the child's growth was associated with the increase in height and especially in weight. For the mothers, the only significant reference point is whether the child is gaining weight, regardless of this gain being what was expected.

Another concern found was about the child's development. Aspects that mothers adopted to assess this development arose, with the observation of movements the child can perform standing out.

"She's already staying in the car by herself" (Jasmim, Int.2.).

"She used to stay quiet in bed. Now, she doesn't stay quiet in bed. She already leaves her place, she's already moving, she raises her head" (Hortência, Int.2.).

Caring for this child implies three challenges: to guarantee its immediate prognosis, i.e. its survival; to minimize its morbidity; and to provide a good late prognosis. For parents of a premature child, the main concern after birth and during hospitalization is about its survival, whereas, after discharge from hospital, it becomes about health maintenance. This is due to the perception and observation that health risks to the child still exist, and also that the premature newborn can have complications, even when clinical stability is reached.

"The only thing that worries me now is the reflux" (Hortência, Int.2.).

"She was the kind of child who'd been through many things, she's already... already got cyanosis, you know, out of the blue, then... we'd be frightened if this ever happened again" (Jasmim, Int.1.).

"He's got heart problems, [...] he's also got reflux, and his pressure is high as well" (Amarilis, Int.1.).

Care for the complications the child had was based

on the guidance received during the Kangaroo Mother Care program.

The importance of social support to care for the premature child

In this study, social support covers the support network the caregiver has for the home care/caring process. It includes the support provided to the family or other people who are willing to help this caregiver; and the service organization that offers assistance to the individual and health, social, educational and spiritual support.

The mother was found to be the one who cares for the premature infant, reaffirming the woman's cultural responsibility for the task of child care, particularly when it comes to a premature child who requires special care⁽⁵⁾. It should be emphasized that grandmothers and parents help the caregiver, though in an indirect way, with support actions.

The mother's training to care for the infant at home takes place during the premature child's hospitalization, seeking to develop abilities and pass on specific knowledge. The literature emphasizes the importance of preparing mothers for hospital discharge, reducing maternal anxiety and increasing self-confidence in home care. In this way, family's adaptation to the child, after discharge from hospital, is facilitated⁽¹⁵⁾.

The following accounts confirm how KMC contributed to the home care learning process:

"Help from some people who were there as well, and who've encouraged us... some professionals [...]. In the Kangaroo, they always guided us" (Rosa, Int.1.).

"Cause in the Kangaroo we experience how we're gonna care at home, you know, 'cause I spent one week there, taking care of him almost all by myself. On the first day the nurse helped me, but on the other days I was alone, doing as I was expected to do at home [...] That was practice already... 'cause I gained more experience to care for him" (Camélia, Int.2.).

Associated with the KMC routine and practice, caregivers received information that guided them as to how to care in the social space of a home. In addition to this support, follow-up of this child is essential.

This follow-up must be conducted until the child reaches school age and must be periodic as well, with the first visit taking place about one week after hospital discharge to assess the premature child's adaptation to the home. Subsequent visits must be made every two months in the first semester, and every three months until the 18th month. From two to four years of age, visits can be made every six months, provided the child is progressing well, and, once a year, subsequently⁽¹⁶⁾.

However, among the children, only one had a follow-up close to what was expected, including visits and exams

in a private health service, as reported below:

"For the time being I'm not having a follow-up" (Azaléia, Int.1.).

"Here at the health center there's no pediatrician, you know...so it's been hard" (Hortência, Int.1.).

"I haven't made any appointments for him yet [...] so, I wanna see a pediatrician, I'm gonna do the child care guidance and make all appointments this week" (Rosa, Int.1.).

"I've done the ultrasound, [...] the ear test [...] For now, I'm going to a private clinic" (Hortência, Int.2.).

DISCUSSION

To care for a premature infant, mothers compare it to a full-term infant and recognize that the former has peculiarities that require greater attention and dedication. This special care and the mother's concern about constantly watching the premature child are justified by its birth condition, which demanded complex care.

Observations made showed that adequate care is provided to the child for its hygiene, feeding, and infection prevention. As regards the child complications cared for (apnea, gastroesophageic reflux, cyanosis), mothers expressed concerns, insecurity and fear during interview.

Comments about the premature infant ranged from fearful aspects to excessive care, which may influence parents' ability to care for this child well or cause them to be afraid or insecure to provide care. Feelings of apprehension, restlessness and fear are more evident in this care, as parents never prepare themselves to care for a premature child, they do not expect their child to be born early⁽¹⁷⁻¹⁸⁾.

In terms of child hygiene (bath, diaper changing, body cleaning), literature recommendations are practically followed, except for the lateral rotation to handle the infant during its hygiene, as the position used is exclusively dorsal decubitus.

In caring for a premature newborn, apprehension about complications arise, because they see it as a fragile and vulnerable being, more likely to become ill than a full-term child. By living with a premature child at home, families are found to be concerned not only about caring for its vulnerable body, but also about the fear of the child becoming ill or having serious complications. This leads to such insecurity that it interferes with the habits and routine of all family members⁽¹⁹⁾.

Each family's context, considering the difficulty of

access to health services, restricted financial condition, interruption of the KMC program's third stage, and lack of public policies that help premature children to be followed, results in inefficient or even inexistent follow-up, exposing the premature newborn to a higher morbimortality risk.

In this sense, perinatal care involves: countless difficulties, instead of guaranteed access; inequality, where there should be equality; disorganization and fragmentation, instead of system hierarchy and regionalization; as well as frequent and concerning technical-scientific inadequacies. These, as a result, represent challenges for public management of this type of care⁽²⁰⁾.

FINAL CONSIDERATIONS

Situations experienced by the mothers and family members, involved in the premature child care process at home, could be found by this study.

Observations made showed that adequate care is provided to the child for its hygiene, feeding, and infection prevention. As regards the child complications cared for (apnea, gastroesophageic reflux, cyanosis), mothers expressed concerns, insecurity and fear during interview.

These aspects emphasize the importance of providing the information previously mentioned, as well as information about complications to caregivers of premature children, during their stay in the KMC program.

As a result, the professional responsible for the act of caring must allow the needs felt by mothers to surface, rather than determining them. They must perform child care actions with the mothers, instead of for the mothers, giving them the opportunity to speak about their fears, anxiety, and insecurity when caring for the child.

It is believed that this is the first step for the premature infant to be given care that is adequate for its needs. The next step consists in creating a nursing practice protocol for mothers and family members of premature children in the KMC program and in their homes, including a home visit and nurse availability to clarify questions both in the KMC program and at home.

Finally, it should also be emphasized the importance of encouraging public authorities to implement the KMC program's third stage – the follow-up outpatient clinic – to follow child growth and development, in accordance with the KMC program's own recommendations.

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