Nursing actions in homecare to extremely low birth weight infant

Ações de enfermagem na assistência domiciliar ao recém-nascido de muito baixo peso

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Abstract

Objective: To describe nursing actions implemented in a home context for the needs presented by the families of extremely low birth weight newborns.
Methods: This convergent care research was carried out with nine families who were visited in their home. For data collection we used semi-structured informal interviews and observation of participants during the first six months after hospital discharge. Data were analyzed using the thematic modality.
Results: Care needs of families during daily home care were related mainly to doubts and insecurities specific to extremely low birth weight premature babies and the care and guidance required for follow-up of newborns in general.
Conclusion: Nursing actions in a home context involve child evaluation, guidance, demonstrations, clarifications, referrals, and stimulation for puericulture follow-up with specialists. These actions also include facilitating family empowerment and gradual autonomy of care.

Resumo

Objetivo: Descrever as ações de Enfermagem implementadas no contexto domiciliar, a partir das necessidades apresentadas pelas famílias de bebês nascidos muito baixo peso.
Métodos: Pesquisa convergente-assistencial realizada com nove famílias, por meio de visitas domiciliares, entrevistas informais, semiestruturadas e observação participante, durante os 6 primeiros meses após a alta hospitalar. Os dados foram submetidos à análise de conteúdo, modalidade temática.
Resultados: As necessidades assistenciais das famílias durante o cuidado cotidiano no domicílio estiveram relacionadas principalmente a dúvidas e inseguranças advindas da prematuridade e do muito baixo peso, aos cuidados específicos e à orientação quanto ao seguimento dos bebês.
Conclusão: As ações de Enfermagem no contexto domiciliar envolveram avaliação da criança, orientações, demonstrações, esclarecimentos, encaminhamentos e estímulo para o acompanhamento de puericultura e com especialistas, além de uma abordagem que facilitou o empoderamento familiar e a autonomia gradativa para o cuidar.

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Introduction

Premature infants with extremely low birth weight (≤1500g) are becoming more frequent. Worldwide, almost 14 million children are born prematurely every year, meaning that more than 1 in 10 births are pre-term.[1] This is mainly due to improvements in obstetric care and the increase in multiple gestations stemming from more access to and use of assisted reproduction.[2]

The health of these babies becomes compromised soon after birth. They are exposed to a variety of risks related to their weight and gestational birth age; they require intensive care, as well as systematic follow-up of growth and development for long periods. This follow-up helps improve their prognosis in the face of increased vulnerability due to chronic conditions from childhood to adolescence.[3,4]

Although technological advances in neonatal care have helped improve survival of even smaller and more immature babies, follow-up of these children after discharge is indispensable. [5] However, in Brazil, this follow-up is limited and little is known about how often it occurs; in addition, few studies have addressed the interventions implemented for these babies and their families at home.[6]

The importance of hospital care for these children, care in daily life, daily duties at home, and regular, multidisciplinary follow-up after hospital discharge are critical for satisfactory growth and development, despite the limitations that might exist.

For this reason, it is fundamental that health professionals identify the needs of low birth weight children, state goals for their care, and support mothers and families with demands of home care. [7] In the home context, nurses have an important role for providing guidance and support to the family, particularly the mother, for daily life care, and these professionals must ensure individualized, continuing care that is adapted to the family's specific needs.

Because care after hospital discharge is fundamental for maintenance of the baby's health, this study sought to describe nursing actions implemented in the homes of families of extremely low birth weight newborns.

Methods

This descriptive study with a qualitative approach used a convergent care research method.[8] Participants were nine families of extremely low birth weight newborns from the surveillance program of Baby at Risk in May to October 2010. The study was conducted in the city of Maringá, state of Paraná, in the southern region of Brazil. We included babies whose birth weight was ≤1.500g.

Data were collected from June 2010 to August 2011 by informal interviews and observation of participants during home visits in the first 6 months after hospital discharge that were scheduled according to care plan or at least once a month. The first contacts with families occurred during babies' hospitalization, over the phone, at a hospital visit, or at home. Visits were previously scheduled according to the established care plan or at least one a month.

Follow-up and nursing care were done in person, over the phone, and electronically and was based on needs that emerged during each contact. Activities covered included guidance, clarification of doubts, management of breastfeeding, demonstration of care and procedures, physical exams, and assessment of child's growth and development.

Perceptions concerning the doubts and needs of families and nursing management observed in the families' presence were recorded in a field diary and were submitted to content analysis (thematic modality). Some of notes in the diary are used here to represent inferences from data analysis. Development of this study followed all national and international ethical and legal aspects of research on human subjects.

Results

The 10 babies in this study were born via cesarean deliver, weighed 655g to 1,479g, and were maintained in a neonatal intensive care unit for 15 to 109 days. All mothers were allowed to assume the care of their babies with regard to feeding and hygiene during hospitalization.

Content analysis of nursing care records identified the category "Clarifying doubts, supporting families in daily life care". Families of extremely low birth weight babies shared the same idea: that the child, because of the birth conditions and long term hospital stay, must receive care that differs from that given to other children in the family in order to protect them and address their special needs for attention and care.

In the first days after discharge, families were concerned about continuing the care that the baby received during hospitalization, protecting the baby from infections, and identifying possible intercurrences early (italicized text was obtained from the nurses' field notes; the identified theme is also listed).

Because of the fragility of babies and intercurrences that had already occurred, mothers were insecure and afraid of not perceiving whether the child was not well. They did their best to be awake during night and to be constantly alert. (Family strength and carefulness, first days after discharge).

For the anxiety showed by families, guidance was offered to prevent harms and promote health. In addition, for the doubts and experience faced by the families, we created and distributed explanatory pamphlets to help them identify possible signs and symptoms of harms to the baby's health. Although each family had a specific doubt, pamphlets were produced and distributed to all families participating in the study in order to be provide equal benefit with guidance.

Families were concerned about protecting the child from disease through vaccination. Therefore, during all visits, the brochure about child health was verified and parents were guided on the disease prevented by each vaccine, possible vaccine reactions, and eventual side effects. Vaccine reactions, such as fever, reduced appetite, pain and irritation at the injection site, and apathy, were common in the babies, and parents requested help from the nurses regarding what actions they should take to prevent or attenuate such reactions:

The mother asked if the second dose of the vaccine would cause more reactions and what she must do if they appeared. (Family carefulness, 3 months and 22 days after discharge).

The stimulus to obtain follow up of the baby with a specialist was also a main focus of nursing homecare. The nurses informed the families about the importance of these follow-up and puericulture visits in a basic health unit for late diagnosis, treatment, and prevention of dysfunction associated with the extremely low birth weight and high-complexity therapy used during hospitalization:

Although the mother already had the referral for ophthalmology consultation, she still had not scheduled the medical visit. She did not know the risks of retinopathy in prematurity. (Family carefulness, 23 days after discharge).

In addition, it was often necessary to guide families to help them to overcome barriers to scheduling medical follow-ups due to difficulty accessing the service and lack of training of professionals that provide support in basic care units:

The mother went to the basic health unit to schedule ophthalmoscopy [...] but the nurse thought that the mother was requesting the red reflex test. (Family friendship, 19 days after discharge).

After medical visits, parents felt they needed more clarification concerning information on their babies' clinical conditions or the exams conducted:

The mother was concerned because on skull ultrasonography a ventricular cyst appeared. [...] *She wants to understand what that meant.* (Family carefulness, 1 month and 14 days after discharge).

In addition, when mothers returned home with a prescription for a new medicine, they did not understand the importance of correctly following the treatment and requested explanations about its effects:

The baby was receiving an inhaled medication six times a day [...] *The mother perceived improvement and decided by herself to reduce administration to four times a day. Soon the child returned presenting effort with breathing* [...] *After that, the mother asked about the reason for those medicines.* (Family friendship, 4 months and 20 days after discharge).

In the case of the theme of family love, nursing follow-up at home enabled detection of shortcomings in the treatment prescribed for the baby be-

cause an important medicine, prescribed at hospital discharge, was not being administered:

[...] *I found that in some papers of the baby a prescription of phenobarbital – administer 17 drops once a day. I asked why that medicine was not being administered and the mother reported that when she brought the prescription to the health unit pharmacy they said the medicine was to control her anxiety, and she thought it was not necessary because she was feeling well.* (Family love, 4 days after discharge).

Mothers' doubts were present at all follow-up periods, and these doubts were related to issues concerning hygiene/comfort and signs and symptoms presented by the babies. During physical exam and anthropometric measurement of babies conducted at home, mothers, parents and relatives took the opportunity to clarify doubts that emerged during the child's care. They asked about such issues as fontanelle and sutures, the structure and development of the ears, and changes in the skin:

The mother observed that some parts of the child' skull were softer [...]. *I explained that sutures and fontanelle were still not totally calcified and asked her to touch them in order to understand this better.* (Family carefulness, 1 month and 17 days after discharge).

Homecare also served to address families' requests for support during intercurrences, for evaluations of the babies, for guidance, and for referral for needs detected:

The mother, concerned, called and requested me to go to her house. The baby was vomiting and refused to breastfeed [...] *The diaper had little mucous and small blood spots.* [...] *I explained to her that something can be affecting her bowel mucus.*[...] *I instructed her to keep ad libitum breastfeeding and to visit the pediatrician and to continue the observation. The next day, the mother called saying that the pediatrician confirmed all the information I gave her and prescribed only analgesics and observation.* (Family affection, two months and eight days after discharge).

On the previous day, the child had apnea, cyanosis and hypotonia during a bath and the mother was very scared [...] *I realized that she wanted me to follow up the baby's bath, and she waited to give a bath to the baby during the home visit.* (Family friendship, 21 days after hospital discharge).

Discussion

Limitations of this study are related to the methodological approach and small number of participants. For this reason, the results cannot be extrapolated to other populations.

However, the use of convergent care research, besides constituting a differential approach, enabled us to enhance the comprehension of needs for professional care presented by families of extremely low birth weight infants and possible actions to be developed in the home context. Therefore, our study contributed to nursing practice because it evidenced the need for improvement in nursing actions provided to the follow-up of these infants and their families at home.

The study data showed that mothers and other family members associated extremely low birth weight to a more fragile condition and an increased probability of severe disease even after hospital discharge. This association was the main reason for anxiety, apprehension, and insecurity, which affected families for long periods, and also caused doubts concerning the delivery of care to the babies at home. Hence, in the first day at home after discharge of the baby, families were worried about meeting the needs of the child, especially given what they experienced during hospitalization; these fears facilitated care but did not prevent anxiety related to their baby's fragility.

Adequate preparation of families for discharge, stimulation and reinforcing the parents' trust in their ability to take care of the child at home is extremely important.[9-11] However, it is imperative that the baby's clinical picture is stable, that parents have adequate physical and emotional reserves, and that parents have access to a service network that can be easily reached in case of any intercurrence and that offers support for the family to implement home care.[12]

Families' doubts in relation to signs and symptoms presented by the baby, the baby's characteristics, and risks and weakness were related to daily care at home. This home care required that families make continuous decisions that previously were guided by hospital staff. Many parents perceived

that, even after discharge, the baby had health risks and that, despite the advanced clinical stability, the threats of intercurrences and harms persisted[13].

In addition, even facing a long period of experience in the hospital environment before the discharge, we believe that the mother had gone through enough care situations to guide her in taking care of the child, but the reality at home is quite different. In the hospital the mother has the constant support of professionals, whereas at home she is often alone. Even mothers with other children associate prematurity with fragility of the baby, which triggers the need for specific and differentiated care; such care is possible by the extension of professional support at home.[14]

To reduce these situations, guidance on particularities of extremely low birth weight babies was given. The assistance might be provided in a conventional manner that respected the context of the baby's family and cultural practices. Homecare may favor promotion and protection of physical care and development of these children, who, without a doubt, had higher risks of changes related to birth weight.[15]

A study that sought to identify difficulties perceived by mothers with regard to care of low birth weight infants and resources used to address health intercurrences showed that situations interpreted by mothers as "dangerous" were associated with great fear and, for this reason, constituted a reason to seek professional support.[7] In this context, the planned discharge along with family and home visits of nurses helped reduce anxiety and fear.[16]

Home care is based on interaction among health professionals, patients and their relatives, and it seeks to improve the autonomy and highlight skills of individuals by using educational actions, demonstration and/or execution of procedures in the families environment – their homes.[17,18] In patients' home, the professionals can understand the reality of the supported individuals, recognize their problems and needs[17] and, in this way, adapt the knowledge and technical procedures to home care.

In case of extremely low birth weight babies, the constant contact with the family at home enables the nurse to be closer to the family,[19] so that the professional can plan assistance that is based on the real needs of each family and is consonant with the context in which the child and family live. It can also strengthen the bond between parents and baby.[20] Our study results highlighted that nurse actions to support, guide, and assist families at home reduced the insecurity and fear that are common within the first months after discharge. As a result, the nurses strengthened the families to provide the specific care that these babies need.

Reports in the literature emphasize that families felt more prepared and more secure in taking care of premature baby when they receive adequate support of a multidisciplinary team.[21] Indeed, home care enabled the creation of strong bonds and mutual trust between professionals and families, thereby reducing suffering and increasing support of the family,[21] offering strength and support for care,[13] and helping reduce the morbidity and mortality of extremely low birth weight infants.

A randomized study in families of premature babies that conducted home visits during the first year of life showed long-term benefits of professional care at home related to lower risk of anxiety among caregivers when children already had reached preschool age; in addition, the intervention showed positive effects on the behavior and mental status of children.[22]

Nursing homecare in the studied context enabled families to feel secure and trust the care delivery by nurses. The bond enabled mothers to feel free to request professional support. When mothers felt supported to face problems that appeared while caring for the baby at home, families experienced a new opportunity of learning that probably would be not possible at outpatient unit visit.

In our study, we found that nurses who availed themselves of information obtained from families during medical visits used a more accessible posture and language, answered questions that emerged, and enabled parents to better comprehend what was occurring with the baby. When mothers became calmer and better informed as a result of the nurses' approach, they were able to be more attentive to identifying any specific care need.

Nurse's sensibility and listening were important to identify families' anguish. The availability of time to share care at home between nurse and family and the valorization of anxieties, doubts, and uncertainty enabled nurses to better understand the meaning of the experience according to the family's point of view. In addition, it allowed nurses to plan actions with families, reduce their anguish, and eliminate difficulties found during care after the baby's hospital discharge. Therefore, nursing homecare constitutes a key component for intervention for those taking care of extremely low birth weight babies.[10]

This support is extremely important because families of extremely low birth weight babies, as a unit responsible for care, need to feel supported and protected after leaving the hospital environment in order to transition from the institutional environment to home environment, and from professional care to family care. Such transition must be done in a safe and calm manner, moderated by the presence and action of nurses in this new context of life and care.

Conclusion

Nursing actions in the home context involved the assessment of the child, guidance, demonstrations, clarifications, referrals, and stimulation for puericulture follow-up and consultation with specialists. They also involve an approach that facilitates empowering the family and gradual autonomy in delivery of care.

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Collaborations

Sassa AH declare that contributed to the project design, executing the research and drafting the manuscript. Gaíva MAM and Higarashi IH contributed to critical revision of important intellectual content. Marcon SS participated in project design, executing the research, critical revision of important intellectual content and final approval of the version to be published.

References

1. Blencove H, Cousens S, Oestergaard MZ, Chou D, Moller AB, Narwal R, et al. National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. Lancet. 2012; 379(9832):2162-72.
2. Beck S, Wojdyla D, Say L, Betran AP, Merialdi M, Requejo JH, et al. The worldwide incidence of preterm birth: a systematic reviem of maternal mortality and morbidity. Bull World Health Organ. 2010; 88(1):31-8.
3. Barreto MS, Silva RL, Marcon SS. [Morbidity in children of less than one year of age in risky conditions: a prospective study]. Braz J Nurs. 2013; 12(1):5-18. Portuguese.
4. Farooqi A, Hägglöf B, Sedin G, Serenius F. Impact at age 11 years of major neonatal morbidities in children born extremely preterm. Pediatrics. 2011; 127(5):1247-57.
5. Hwang SS, Barfield WD, Smith RA, Morrow B, Shapiro-Mendoza CK, Prince CB, et al. Discharge timing, outpatient follow-up, and home care of late-preterm and early-term infants. Pediatrics. 2013; 132(1):101-8.
6. Vieira CS, Mello DF. [The health follow up of premature and low birth weight children discharged from the neonatal intensive care unit]. Texto & Contexto Enferm. 2009; 18(1):74-82. Portuguese.
7. Fonseca EL, Marcon SS. [Mother's perception about homecare delivered to her low-weight infant]. Rev Bras Enferm. 2011; 64(1):11-7. Portuguese.
8. Rocha PK, Prado ML, Silva DM. [Convergent Care Research: use in developing models of nursing care]. Rev Bras Enferm. 2012; 65(6):1019-25. Portuguese.
9. Jefferies AL, Canadian Paediatric Society, Fetus and Newborn Committee. Going home: facilitating discharge of the preterm infant. Paediatr Child Health; 2014; 19(1):31-42.
10. Lopez GL, Anderson KH, Feutchinger J. Transition of premature infants from hospital to home life. Neonatal Netw. 2012; 31(4):207-14.
11. Soares DC, Cecagno D, Milbrath V, Oliveira N, Cecagno S, Siqueira HC. [Faces of care given to the extremely premature infants at home]. Cienc Cuid Saude. 2010; 9(2):238-45. Portuguese.
12. Boykova M, Kenner C. Transition from hospital to home for parents of preterm infants. J Perinat Neonatal Nurs. 2012;26(1):81-7.
13. Morais AC, Quirino MD, Almeida MS. [Home care of the premature baby]. Acta Paul Enferm. 2009; 22(1):24-30. Portuguese.
14. Schmidt KT, Terassi M, Marcon SS, Higarashi IH. [Practices of nursing staff in the process of preterm baby hospital discharge]. Rev Bras Enferm. 2013; 66(6):833-9. Portuguese.
15. Salas J, Xaverius PK, Chang JJ. Does a medical home influence the effect of low birthweight on health outcomes?. Matern Child Health J. 2012; 16 Suppl 1:S143-50.

16. Frota MA, Silva PF, Moraes SR, Martins EM, Chaves EM, Silva CA. [Hospital and care of the premature newborn at home: maternal experiences]. Esc Anna Nery Rev Enferm. 2013; 17(2):277-83. Portuguese.

17. Couto FF, Praça NS.[Premature newborn: maternal support at home for care]. Rev Bras Enferm. 2012; 65(1):19-26. Portuguese.

18. Favero L, Mazza VA, Lacerda MR. [Home care nurse's experiencing transpersonal care to a family of a neonate discharged from an intensive care unit: case study]. Braz J Nurs. 2010; 9(1). Portuguese.

19. Sassa AH, Rosa TC, Souza SN, Rosseto EJ. [Home visits in the health care to the very-low-birth-weight infants and their families]. Cienc Cuid Saude. 2011;10(4):713-21. Portuguese.

20. Goyal NK, Teerters A, Ammerman RT. Home visiting and outcomes of preterm infants: a systematic review. Pediactrics. 2013; 132(3):502-16.

21. Bengozi TM, Souza SN, Rossetto EG, Radigonda B, Hayakawa LM, Ramalho DP. [A network of support to the family of the premature baby]. Cienc Cuid Saude. 2010;9(1):155-60. Portuguese.

22. Spencer-Smith MM, Spittle AJ, Doyle LW, Lee KJ, Lorefice L, Suetin A, et al. Long-term benefits of home-based preventive care for preterm infants: a randomizad trial. Pediactrics. 2012; 130(6):1094-101.