

Perception of premature infants' mothers on home visits before and after hospital discharge

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Objective. To understand the meaning of home visits by neonatal nurses for mothers of premature babies. **Methodology.** A qualitative study was conducted with 21 mothers of families participating in a project that supported families of premature infants, born at a university hospital in the city of Londrina, Brazil. Data collection was conducted through semi-structured individual interviews, using a form with the identification data of mothers and an interview script. **Results.** Three themes were revealed: the home visit as a support to the family, individualized home care, feeling cared for and supported in performing the baby's care. **Conclusion.** The home visit from the perspective of longitudinal care was a powerful resource that promoted the link between families and nurses, decreasing doubts, fears and anxieties of the mother. In addition, home care was provided and adherence to care and treatment was encouraged.

Key words: home visit; family; infant, premature; patient discharge.

Percepción de las madres de los bebés prematuros sobre las visitas domiciliarias antes y después del alta

Objetivo. Comprender el significado que tiene para las madres de bebés prematuros las visitas domiciliarias realizadas por enfermeras neonatales. **Metodología.** Estudio cualitativo realizado con 21 madres de familia, quienes participaron en un proyecto que apoyaba a las familias de los bebés prematuros nacidos en un hospital universitario en la ciudad de Londrina, Brasil. La recolección de datos se llevó a cabo mediante entrevistas individuales semiestructuradas, utilizando un formulario con los datos de identificación de las madres y guión de la entrevista. **Resultados.** Se identificaron tres temáticas: primera, la visita como un apoyo a las familias en el hogar; segunda, individualización de la atención domiciliaria; y, tercera, sintiéndose cuidadas y apoyadas para cuidar. **Conclusión.** La visita domiciliaria, desde la perspectiva de la atención longitudinal, es un recurso poderoso que favorece, por un lado, el vínculo entre las familias y las

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enfermeras, y, por otro, disminuye las dudas, miedos y ansiedades de la madre. Además, se proporcionan cuidados en el hogar y se fomenta la adherencia a los cuidados y tratamientos.

Palabras clave: visita domiciliaria; familia; prematuro; alta del paciente.

Percepção das mães dos bebês prematuros sobre as visitas domiciliares antes e depois da alta

Objetivo. Compreender o significado que tem para as mães de bebês prematuros as visitas domiciliares realizadas por enfermeiras neonatais. **Metodologia.** Estudo qualitativo realizado com 21 mães de famílias que participam num projeto que apoiava às famílias dos bebês prematuros nascidos num hospital universitário na cidade de Londrina, Brasil. A recolha de dados se levou a cabo através de entrevistas individuais semiestruturadas, utilizando um formulário com os dados de identificação das mães e roteiro da entrevista. **Resultados.** Foram identificadas três temáticas: a visita como um apoio às famílias no lar, individualização do atendimento domiciliário, sentindo-se cuidadas e apoiadas para cuidar. **Conclusão.** A visita domiciliar desde a perspectiva do atendimento longitudinal é um recurso poderoso que favorece o vínculo entre as famílias e as enfermeiras, diminui as dúvidas, medos e ansiedades da mãe. Além de que se proporcionam cuidados no lar e se fomenta a aderência aos cuidados e tratamentos.

Palavras chaves: visita domiciliar; família; prematuro; alta do paciente.

Introduction

The home visit (HV), is defined as the displacement of the professional to the user's home, with the purposes of health care, education or research; it consists of a rich moment in which qualified listening, bonding and receptivity are established, favoring family groups by enabling them to become more independent in producing their own health and facilitating adherence to treatment. Additionally, the visit is established locally, permeating the daily living place, the world in which they live, according to their view of the world.¹ The complexity of this strategy requires a workforce able to articulate the purpose of understanding the sociocultural context of the clients, and to develop a dialogue that covers their social representations.² This process should also be considered as a instrument for health education, helping to change some behaviors, promoting the premature infant's quality of life, preventing risk situations for possible readmissions, and promoting the bond between the family and the new child. Therefore, the HV allows educational activities to be consolidated

through the possibility of knowing the individuals for whom health actions are intended, including their culture, beliefs, habits and roles, and the conditions under which they live.³

The project "A support network for the premature infant's family", developed by faculty, residents, graduate students and a multidisciplinary team at a university hospital in Londrina, aims to support families of premature infants through a follow-up that begins with admission of the newborn (NB) in the Neonatal Intensive Care Unit (NICU), and which is performed throughout the period of hospitalization, the discharge process, and continues up to one year of age with outpatient care.⁴ This follow-up is done by a health staff that includes physicians, nurses, psychologists and social workers with the participation of parents. The project seeks to respect the individuality and needs of each family, and is developed in several steps, including the home visits. During the period of hospitalization, parents participate in the preparation process for discharge, when they are

also trained to perform general care, including: administering medications, tube feeding and breastfeeding the preterm infant, hygiene care, sleep and rest. As part of this process, two home visits are conducted near to hospital discharge. The first, when the premature infant is still hospitalized, is called the pre-discharge visit; and the second is the post-discharge visit, preferably held within seven days after discharge, in order to assist parents in the adjustment period during the baby's arrival home, which is characterized by several uncertainties.

The meeting with the families at home during visits has great value, especially for bringing important subsidies for baby care according to the reality of each family. After explaining the purpose of the visits, and before they were performed, it was noticed that for some families it seemed to signify greater care for their baby, expressing gratitude to the staff and / or anxiety and desire to receive the visits. However, others manifested feelings of distrust and apprehension because they felt supervised, since the first visit was performed when the baby was still hospitalized. Thus, the need to investigate the meaning of HV for mothers who had experienced them was observed. The goal of this research was to understand the mothers' perceptions about the HV performed. It was hoped that this study would provide support for the health team to improve its process of acting and assisting families at home, ensuring quality and appreciation of the family and the health team.

Methodology

This was a descriptive, qualitative study using a phenomenological approach, aimed at the understanding of a lived experience. This approach was selected so that one could work with the universe of expectations, meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships, processes and phenomena that cannot be reduced to the operationalization of variables.⁵ The study

subjects were 21 mothers of preterm infants, born before 32 weeks of pregnancy and / or weighing less than 1500g, admitted to the NICU of the University Hospital of Londrina (HUL), who were up to six months of chronological age, and who participated in the project "A support network for the premature infant's family", developed by the neonatal health team at the State University of Londrina (UEL).⁴ The data collection was conducted over a period of nine months at the UEL University Hospital ambulatory clinic, where follow-up of these premature infants who were hospitalized in the NICU was performed. Mothers were approached by female graduate students previously trained for interviews. Female graduate students were selected to conduct the interviews for the bond between mothers and staff, especially resident nurses, established during the entire period of hospitalization, so as not to interfere in the responses.

The technique of semi-structured individual interviews was used, based on a script composed of two parts: socioeconomic data of the mothers (age, education, place of residence, occupation, marital status and number of children) and the guiding research questions (part: II): How did you feel when resident nurses approached you to participate in the project? Were you informed about the motives for the two visits that you would receive in your home? How did you feel when you learned about the two visits in your home? For you, what business was more important? Why? After the acceptance and signing of the Terms of Free and Informed Consent form, to participate in the interview, we proceeded to record the interview. This study was approved by the Ethics Committee at UEL Research Board, under process 046/10 and CAAE 0047.0.268.000-10. To preserve the identity of the participants and not identifying the statements, we attributed flower names to the mothers, and the recordings were destroyed.

To systematize the data we used content analysis, of the thematic modality: a set of communication analysis techniques that aimed, through systematic and objective procedures, to describe the content of the messages, obtain

indicators, qualitative or not, that allowed the inference of knowledge concerning the conditions of production / reception of these messages.⁶ Data analysis was based on the perspective of family-centered care, proposed by Shelton et al., in 1987, and Johnson in 1990⁷, based on eight principles: 1) Recognize the strength of the family as a constant in the child's life, while services and professionals vary; 2) Facilitate collaboration between families and professionals at all levels of health care; 3) Share complete and unbiased information between families and professionals in a welcoming manner at all times; 4) Respect and value cultural, racial, ethnic and socioeconomic diversity in each family; 5) Recognize the strengths and individuality of the family, respecting different methods of coping; 6) Encourage and facilitate family and network support; 7) Make sure that the services of the hospital, home and community for children needing specialized health care and their families are flexible, accessible and comprehensive to meet the diversity of needs identified; and 8) Enjoy / consider families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions and aspirations, beyond their need for support and specialized health services.⁷

Results

Of the 21 mothers interviewed, maternal age ranged from 14 to 42 years, 50% of mothers were married, four participated in formal work outside the home, and 60% had more than one child and had less than eight years of education. Three themes were revealed from the analysis of the interviewed mothers' statements: the visit as a support for families at home, the individualization of care at home, and feeling cared for and encouraged to care.

Home visit as a support for families

This child that remained hospitalized for so much time, when he arrived home, required specific care that differed from the demands of a healthy

term baby. Although technical preparation for the discharge was accomplished through ongoing monitoring of information and training of these parents and family, they often experienced feelings of insecurity and powerlessness, because they were far from the care of hospital staff, which gave them confidence. The discourses about the visit after discharge, mostly performed by resident nurses, achieved the goal of minimizing feelings of helplessness, loneliness and insecurity that some mothers may have experienced when they came home and did not have the necessary help to care for their child. In the statements of the mothers, the need for support was observed in expressions by these women, so that they can gain independence and trust in caring for their children: *They gave me a lot of strength ... so they guided me in everything, how to proceed, how to be careful with him ... and it was not for me getting so scared ... I was going to nail it... and I'm achieving all that they went through with me* (Rose); *So, yeah, I would like them to visit me, because then I would be learning even more with them, I would not be alone ...* (Blossom); *There were a few days that I was worried because the baby was already at home, and I called the women there and they treated me very well* (Lily).

Individualized care at home

It was very important to clarify for families that the visit, especially before discharge, aimed to support them in the organization of the house for the baby's arrival; to provide, within the family's reality and budget, what was missing; and it was a moment of individualized attention that was necessary to strengthen the orientations given in the hospital environment; and it was also a particular time to discuss specific issues, according to each situation. The possibility of individualization of care allowed by HVs was highlighted by mothers' statements on the contribution offered to address the specific demands of care, sometimes complemented by a referral of the situation to social workers or psychologists. But beyond clarification, the posture of understanding, respect and consideration of the context of individual families by the staff was expressed in mothers' statements: *(During the*

visit) they give more attention, explain things in details, there in the hospital we end up doing the bathing, changing, giving medicines... during the visit they give more attention to us because at the hospital they did not have time, everything was in such a rush, at home they are more attentive, they explain better (Lily); At home you talk more freely, you're there in your own place, the person will help you, he/she will see how your home and your life is... I think I would pick a thousand times only home rather than the hospital because at the hospital there are always a lot of people, everything is always very busy, you know? You can not keep asking things, there's no way that the person can stop caring for all children to pay attention to you. At home it is the opposite, they stop, they will be there just to talk to you, to see how the baby is... I think this is excellent, I think you could not take it from us (Violet). Even for women who had previously experienced motherhood, the individualized care of the HV was received as important learning and sharing of experience, demonstrated as a new mother experience: *All they did at home, is what I have to do. Although I already have many sons, I have enough experience, but she is quite tiny, you know, I do not have much experience yet, but I'll try ... I really am ...* (Pansy).

Feeling cared for and supported in performing care

The existence of the previously established bond between these professionals and the family is the foundation of this feature, since nurses in the NICU who had experienced and accompanied the whole process of hospitalization performed these HVs. The failure of accepting the visit was a rarity in our practice, i.e., instead of families feeling monitored or frightened by the visit, they felt cared for. The moment of the visit was also seen as an opportunity to demonstrate and validate the learning acquired during the hospitalization period by adapting care being performed. This was evidenced in the following narrative: *It helped; helped a lot because when they were at home...I don't know... It was so different because they could see that I was doing it right,*

the way they taught, not that I had to, it was my obligation to do it the way they taught, you know, it was a way, a suggestion that they gave, now they wanted to know if I was following (Daisy); ah well ... I thought it was pretty important, a way for them to show that they worry about people, seeing if indeed you will take good care of your baby... (Bromeliad); Then ... it was OK because I seek to leave everything in order, everything just right, not to have anything out of the box, so no one comes in to tell me that something is wrong, do you know? So, I do it right (Chrysanthemum); I was thinking: will they think that's right or not? But I do not know what they found, this is what I tried to do, but I enjoyed the visit (Sunflower); they come to see how the house is, how the room of the baby is, if it is well ventilated (Violet); this service they provide is important, they come in the house, they see everything how it is (Bromeliad).

Discussion

The discharge of premature infants occurs independent of housing conditions and competence of parents, but home visits around the time of discharge should serve to verify the actual conditions in which the family lives, their potential, and enable the best conditions and moment for the discharge. The development of the bond between the project team and the family, through to the performance of the visits, was carefully assessed in the context of care experienced by families throughout the hospitalization period, so that they could understand and receive the visit as another strategy of the family support network for receiving technical and social support to take their premature child home.

The HV becomes essential according to the perspective of continuity of hospital care to home care. The relationship with the premature and low birth weight infants and their families in health services requires dialogue and interaction, which enables the knowing of the social, cultural, economic contexts and interests of individuals,

allowing approximations of decisions and mechanisms used by these subjects to face the situations experienced in life.⁸ A study⁹ that quantified the major problems observed in visits to families of premature infants found that the HV proved useful in identifying difficulties in providing care for newborns and problems related to the environment and the home in poor conditions, since many times these individuals would not be sufficiently identified except by hospital conviviality; in addition to being a strategy to develop a bond and facilitate the adherence of the families of premature births for follow-up programs.

Particularly in this study, the bond was established during the period of hospitalization, and reinforced by the HV, allowing the team to continue as a reference even after discharge, in a period of transition between hospital and home care. We highlight the importance and the difference for families when the HV is done by the same health team that attended them at the hospital, ensuring continuity of care supported by a safe and trusting relationship between families and staff, facilitating the professional performance and implementing more individualized and coherent interventions.⁹ Moreover, the bond and accountability are identified as key strategies for successful monitoring and reducing the chance of dropout among children in follow-up programs.¹⁰ According to a study conducted on the follow-up of premature and very low birth weight from the NICU, the responsibility of entering the service was generally only that of the family, since the active pursuit from the Basic Health Unit (BHU) does not occur. This weakness can be understood as the absence of reference from the hospital to the BHU.⁸

In this study, a way to contribute to the guarantee of adequate and comprehensive care, and to realize the referral from hospital to BHU, a visit was made to the BHU at the time of the after discharge HV, for the delivery of a report of the main data regarding the birth, hospital stay, diagnoses, care to be maintained at home, medications, food, among others. Assessment

data and preparation of the home environment to receive the baby were important for the continued assistance of the BHU team, helping to determine the level of care demanded and to identify potential problems that may interfere with care.¹¹ Furthermore, this systematic and formalized transfer to the BHU also helps them to feel responsible and involved in the follow-up of preterm infants and their families in primary care, regardless of the follow-up at outpatient services.⁹

The following categories refer to the principles of family-centered care: “make sure that the services of the hospital, home and community for children needing specialized health care and their families are flexible, accessible and comprehensive to meet the diversity of needs identified “; and also: “facilitate collaboration between families and professionals at all levels of health care”:⁷ hospital, home and community. The development of nursing actions for mothers and families of premature babies in the home setting, including home visits and the availability of the nurse to clarify doubts and protocols is one of the possible strategies for appropriate assistance for the preterm child.¹² We found that the HV provided this kind of approach when it allowed the understanding and incorporation of the real needs into the health plans to be developed with the family by the different levels of health care.

The home assessment made by nurses can provide insight to the family health clinics or specialist health teams, who will continue the health assistance, in relation to the expectations of families regarding home care, the emotional needs of the family, and close support systems available in the home. The social context and the family support should be considered for care planning. Therefore, the guidelines made during HV were based on the most common needs presented by families, especially on questions and problems exhibited by each family during hospitalization and during visits.⁹ For the family of the premature infant, the discharge is a moment marked by contradictory feelings of celebrating the overcoming of obstacles during hospitalization of the baby, while expressing insecurity and

anxiety related to the increased responsibilities for the family and the end of the support provided by hospital staff.^{13,14} This may announce a new crisis, as the family will have to face the challenge of providing complete assistance by itself, without the sustained support of the health team.⁴

This experience becomes difficult when parents do not have a group of family, friends and health professionals with whom they can share this experience, and who can help to provide the care required by the child when he is discharged home.¹⁵ Moreover, the context of each family, considering the difficulty of access to health services, restricted financial conditions, lack of public policies that support the monitoring of premature infants, result in, if nonexistent, ineffective monitoring, which exposes these premature infants to an increased risk of morbidity / mortality.¹² Thus, the HV becomes an important strategy of care that mobilizes family participation and generates advancement of knowledge, especially for meeting the individual needs of each family, which is important for mothers to feel empowered to care. Care is improved as this family realizes that it is their own responsibility to provide care, but that care can be shared with the health service, which happens to be a support network and is no longer primarily responsible for the growth and development of their son/daughter. In this context of NICU discharge care management; nurses are recognized as facilitators for the development of the family autonomy in the care of premature infant development after hospital discharge.¹⁰

This collaboration between professionals and family is the essence of family-centered care, demonstrating a respectful way to humanize care and improve outcomes.⁷ according to the categories represented here. The discharge home of the premature infant implies changes in the family dynamics. For parents of premature babies, the concern after birth and during hospitalization focuses on survival, and after discharge this is replaced by the maintenance of health. This is due to the perception and realization that there are still risks to the baby's health, and even when

clinical stability is achieved, premature infants can have complications.¹² The HV can signify a feeling among families that they are being "watched" in care, which therefore requires the establishment of a relationship fundamentally oriented through dialogue and ethics.¹⁶ The way the health care professional performs the construction of this practice with families needs to be managed very carefully, so as not to generate negative processes for effective interaction, which may result in a contact and relationship permeated by technical knowledge and not by the horizontality of dialogue.⁸

An approach based on comprehensive care and in the interaction between individuals, families and healthcare professionals is necessary, mediated by a relationship of trust and the establishment of a participative therapeutic process.⁸ The living and hygiene conditions, the socioeconomic level approach that we found during these visits, served as a guide in the search for appropriate social networks that this family will need when this premature infant comes home, with no judgment of right or wrong, but considering the practical realities. On the other hand, the act of receptivity does not restrict the other actions to the investigation of health needs, it only amplifies the production of care arising from curative procedures and the assistance requirements of the family.²

From the perspective of family-centered care, this open attitude toward reality brings us to the principle of incorporation into policy and practice the recognition and respect for cultural diversity, the strengths and individuality within and around each family, including ethnic, racial, spiritual, social, economic, educational and geographic diversity.⁷ It is important that the family perceives this attitude in the professional, as expressed in the final analysis category, since, in general, parents are accustomed to being judged, charged and repressed in health services. Therefore, among all the results, we found that the HV was a way to maintain the bond between families and professionals, reducing doubts, fears and anxieties, assisting in home care and encouraging

mothers to care, and the adherence to the proposed treatments. Also, the HV constitutes a link with services that will provide continuity for this care.

We concluded that the HV was a strategy that contributed to improving the quality of home care, when supported by the framework that considered the family as the center of such care and an irreplaceable partner in the daily work, adopting a professional attitude perceived as supporting and strengthening for families. This posture should be devoid of preconceptions and prejudices, and include unconditional respect for the family and its diversity portrayed by recognizing the individualization of care. The HV needs to be strengthened at all levels of care, allowing the aggregation of formal and informal care, forming social support networks, aimed at better assisting and developing autonomy and security for the families of preterm infants after hospital discharge, contributing to their healthy growth and development.

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