

Brazilian´s Families of Preterm Child: Experiences in the Transition Period from NICU to Home

Claudia Silveira Viera¹; Barbara Medoff-Cooper²; Débora Falleiros de Mello³; Luciana Mara Monti Fonseca⁴; Rosane Munhoz da Silva⁵; Beatriz Rosana Gonçalves de Oliveira Toso⁶; Letícia Pancieri⁷

Abstract

Objective: Describing the experience of Brazilian´s families of preterm child during the transition period from NICU to home and analyze the extension in which the guidelines of the National Humanization Policy were present in the support experienced by those families. Method: Sixteen family members took part of this qualitative and descriptive study and were heard four times, through semi-structured recorded interviews throughout the first month at home. Two thematic categories described it: 'family's stress post discharge' and 'management of daily care'. Results: Parents have never mentioned special attention and support by nurses or health professionals, especially from the Primary Health Care. The transition period from NICU to home requires earlier and continued follow-up assistance. Conclusion: In the reality of this study do not have support in the transition period provided by health staff, so, the guidelines of the National Humanization Policy are underused.

Keywords: Home, parents, preterm infant, transition period.

Introduction

Technological advances and improvement of health care, especially in the Neonatal Intensive Care Unit (NICU), determine the increase of survival of preterm (PT) and/or low birth weight babies.^{1, 2} so; those children and their families become an important issue for health care system and care providers, in all levels of health assistance. The PT birth context, NICU stay, discharge period and home care of the PT impose several demands for parents, with potential to increase their stress and affect parents' role.³ The maternal sensitivity and responsiveness for the infant can be compromised as, for example, in feeding practices, more specifically breastfeeding; sleeping routines and well-child visits, vaccinations and safety practices.⁴ It is recommended that the discharge process begin in the NICU's admission and keep on afterwards aiming to improve parents' competence in the PT care at home to decrease their anxiety.^{5, 6} The home transition process must promote comprehension and abilities for the PT infant care at home and transcend the mother's care, including other family members.⁷

¹ State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

² State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

³ State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

⁴ State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

⁵ State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

⁶ State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

⁷ State University of Parana Western – Unioeste. 2069 Universitaria Street, Cascavel, Brazil. Zipcode: 858119110.

Both of them need an adequate support from the health services to develop skills to care the PT, as well as, empowering them to understand the PT necessities and health demands at home. Brazil has a government-funded health care system and also a system of private health insurance. Approximately 70% of the population uses the health public service, called "Sistema Único de Saúde - SUS." The health system is divided into primary, secondary, and tertiary levels; this last level includes the NICU. There are 7,854 NICU's beds around the country, but we have observed regional differences in the distribution of beds per thousand births live, as follows: North and Northeast 1.7; Midwest 2.7; South 3.1, and Southeast 3.9.⁸

After NICU discharge, infants who have required low complex care receive follow-up in basic health units, and those who required highly complex care are referred to the hospital follow-up ambulatory clinic. However, it should be noted that this routine is not common for whole Brazil, in small cities there are neither NICU nor follow up outpatients.⁹ Thereby, in this context, both the low and high risk preterm are attended in the basic health unit and difficulties and vulnerabilities faced by discharged premature families at the NICU have been described in the south of Brazil. In this region was evidenced the need for continued care beyond the period of hospitalization to provide follow-up with greater interfaces among specialized and primary care services. There is a necessity to strengthen the health system in Brazil to provide more systematic follow-up and integration of care after NICU discharge.¹⁰

Adequate neonatal care goes beyond the objective of ensuring survival of premature infants until discharge, as well as, an appropriate follow-up and support for children discharged from NICU and their families are still enormous challenges in our country. Interventions in specific clinical features of this group, including higher risk of post discharge readmission and timely multidisciplinary care for deviations of development and growth are lacks observed in the necessary coverage. This situation is strongly recommended to understand the family dynamics in environments where the primary care giver is the mother, due to implications related to stress and lack of self-efficacy, with long term consequences,³ besides recognizing the health service should be a supporting service for families after discharge. The partnership among parents, families and the health team is important to improve the child's care at home.

Currently, the Brazilian Unified Health System (SUS) adopts the National Humanization Policy (NHP) as a strategy to strengthen the public health system, which values autonomy, solidarity and participation of all people involved in the process of promoting health. The proposal of this policy is being effective in the concrete experiences of health services daily routine. Based on the human experiences, this 'concept' is sustained from the understanding that is necessary to promote universal and equitable access to services, good quality health and comprehensive care.¹¹

Thus, considering this policy, the health services should work with the new paradigm, the human care to the child, the mother, and the family, respecting their characteristics and individualities. The humanization is expressed in the practice of health services. So, to promote a humanized and qualified attention in the context of providing care for a PT infant must involve the family since the admission of the neonate in the NICU and throughout the follow up process. In the NHP regulation, all services have to support those families, trying to decrease insecurities and lack of confidence in caring for those children and promoting a healthy growth and development. The health team could contribute for the mother's skills developed from the follow up care in the Primary Health Attention guided for the NHP policy. In this sense, trying to contribute with nursing and health care practice to those families, the aim of the present study was to describe the experience of family members in caring for the PT child during the transition period. In addition, to analyze the extension in which the guidelines of the National Humanization Policy were presented in the health service support experienced by families.

Method

Qualitative study based on hermeneutic dialectic perspective was undertaken, which intends to understand the meaning for mothers' PT care experience and the NHP implementation after discharge. Thus, we aimed to interpret different interests and values presented in a special interaction that creates new possibilities for a redefinition and reconstruction of knowledge and practice.¹² this study was carried out in southern Brazil, in an urban area, after its approval by the Research Ethics Committee of the State University of Western Parana.

Mothers were recruited during visiting their babies at the NICU by one researcher. The inclusion criteria were: having a PT hospitalized in the NICU regardless of its prematurity degree; being a mother of a PT who did not have a congenital anomaly; being the one prospected to stay with the infant at home for most of the time. After this step, the mother was contacted at the NICU and the research proposal was explained and they were invited to take part in the study.

Data collection

The interviews were applied not only to parents, but to any other member of the extended families. Therefore, during this first interview, other family members, named by the mother as relevant for the experience of caring for the child, were located and included in the study when they agreed with it. Throughout the family member description, the researcher presented questions in order to explore and understand how the care changed or developed overtime, so the content of the interviews was for example, 'Who participated in that care?', 'What feelings and beliefs have you experienced while caring your baby at home?'. 'How the health professional has helped you in this period?' In addition, observational field notes were written after each interview with the aim of capturing aspects of the interaction between the mother and infant as well with other family members.

After each interview the data were transcribed and analyzed, thus a new family was recruited for the study until occur the data saturation and the aim of the study was answered. Therefore, sixteen family members (Figure 1) took part of this study and were heard four times, through semi-structured interviews, after the NICU discharge of the child and throughout the first month after it. All interviews were recorded and were applied by means of four domiciliary visits for each family was realized by of the same interviewer, one per week after hospital discharge. The first contact occurred in the NICU and the genogram was started to build with the mother for to know the demographics data of the families. After this first contact when the PT was discharged, the first visit was scheduled for one week later. The family members chose their names and they are fictitious.

Data analysis

The empirical data (text transcription of the interviews and field notes) were treated in a comprehensive way, seeking to reveal what could be behind the manifested content.⁽¹⁶⁾ The speeches of the family members were shown in the studies through of pseudonymous chosen by each family member, as for example Melissa. The data produced from the interviews were transcribed by one of the researchers and checked by the second researcher. Parents had the opportunity to review their transcripts at the last (fourth) visit at home and they validated their speeches. Afterward, the researchers read the transcribed interviews, and placed all data concerning a family into a family file. The next step was to classifying and indexing the data. Finally, the researchers developed a category scheme and then to code data according to the categories. Thus, an interpretative reading was done and central meanings were identified. Subsequently, data were reexamined following the steps recommended by the thematic content analysis by two researchers, that is, pre-analysis, analysis of the expressed and latent meanings and final analysis.¹³ then, data were organized and structured in parts to identify aspects which were repeated and emphasized by the families in terms of their caring experience at home. The core variable identified was the parents experience during the first month at home. So, two thematic categories described it: 'family's stress post discharge' and 'management of daily care'. The participation of the health professionals in the first month at home was analyzed from the comprehension of the NHP.

Results

The demographic data of the families showed that half of parents and their baby were living with their relatives; almost of the parents had completed the high school, excepted for two couples who attended elementary school. The family income was less then U\$ 500.00 for four families, for another family was of U\$850.00, and the other one survive a month with U\$ 150.00. The PT average gestational age was 30 weeks and the average of the birth weight was 1.180,00 g.

Family's stress post discharge

During the first month after hospital discharge, parents described changes in the family routine, as they adapted their lives to the PT life, as showed:

Beth, maternal Gaby's grandmother: "[...] when she [the mother] had gone to the hospital, we panicked because the baby was not fully formed. We got very anxious. It was very hard when we saw her there, by herself in the maternity ward, without the baby, among other women who had their infants. She seemed to be in shock, because she hadn't cried yet [...]. These memories are so close [...]"

Marcos, Malu's father: "At first I was afraid. Then, they [health professionals] said she [baby] was stable and I got calmer, kind of losing my fear, and each day she improved a little, I got happier, but I was looking forward to seeing an end to all that and finally have her with us [...]"

Once the PT went home, families characterized their experiences through ambiguous feelings: joy and security but, at the same time, concern, and anguish.

George, Camily's father: "[...] it's very different from when she [baby] was at the hospital, we got calmer for having her at home. I felt very uneasy when she was at the hospital, we were so distressed, didn't know if she'd survive. We're still a little worried, afraid something happens to her, but even so, it's so good to have her here".

Another feeling reported by families is connected to their fear of providing daily care for their babies and also protecting them at home, as illustrated by the following reports:

Brenda Camily's mother: "[...] I was afraid of taking care of her, she is so small, and I thought I wouldn't be able to bath her by myself, taking care of her by myself scared me. I was afraid of not having milk, she drowned during sleep or breastfeeding and I wouldn't know what to do, nobody told me about it".

Melissa, Malu's mother: "While taking care, as changing the diaper, bathing, breast-feeding, I was afraid. I was scared to hold her on my lap, because she seemed so feeble, in the hospital was different there were always people around to help us.

Thus, concerns about providing daily care at home emerged since usual aspects of baby's care to highly technical issues, which caused an impact in the mothering role, as follows:

Melissa, Malu's mother: "[...] Malu [PT] still has her nose stuffed-up, especially in the morning and at night, though everything else got better, cramps are gone [...]. I put medicine in her nose, check if she doesn't have a fever. I also have to watch what I eat, you know, she is not having cramps because I pay attention to that and she is taking the medicine [for flatulence]"

The potential adverse responses in PT such as showed above may increase the mother concern about the baby care, consequently, may increase the mother stress, with impacts on family dynamics.

Management of daily care

For these families, changes in families' routine were also reported:

Cynthia, Gaby's mother: "[...] when we got home from the hospital I was pretty tired and sad. It's difficult to leave my baby there and come back home by myself and still find energy to cook, iron, and clean the house. I only wanted to take a shower and go to bed, looking forward to the next day so I could stay with her [PT]."

Judy, Keith's aunt: "Now, we must take care not to speak loud, take care with the sound, these are some things we have to change. We need to help taking care of her".

Families reported that caring for the baby at home comprised the following activities: breastfeeding, keeping the baby warm, giving affection, taking the infant to the doctor for growth and development follow-up, and keeping hygiene and the house clean.

Korn, Gabriela's father: "I became very picky because I don't want her [PT] to get cold air, be exposed to dust, or people getting her on their lap, and I think it makes a difference. What makes the difference is the super care you have with the baby, because I think it's pretty easy for the baby to get anything, airborne stuff, so I guess if you overprotect, at least at the beginning, it makes the difference".

Another point that emerged in the interviews were comments about the health care services, the families used the basic health unit during the first month after the baby's discharge from the NICU for checking weight and height, immunizations and visiting the pediatrician in case of intermittent problems with the baby.

Eda, Malu's grandmother: "She was not feeling well, then we did not know where we could take her, then we took her to the doctor, in the health center. [...] the doctor examined the baby carefully and he said that her belly was bloated and gave her a medicine".

Xandi, Keith's father: "She [mother] leads the baby to the health center every week [...], in the follow up program, she takes the baby to weigh and verify if she is well, whether she's growing, also to give her the vaccines".

Once at home, family members revealed issues that had potential to impact the family: how can we care our baby? What does he/she needs? How can I discover the right way to care for him/her? What is our responsibility with the baby future? Despite their desire to have their babies at home, they were afraid of caring for them out of the hospital and all families' members are involved in the PT care at home, the relatives are sharing the care with the parents mainly because most of the parents were living at the same home of their relatives.

Understanding the parents' experiences within the context of their infant's transition from the NICU to home is necessary for improved health outcomes for both the parent and infant. Therefore, the health professionals of the Primary Health Care (PHC) beyond of the follow up service, should be close the families and their babies to provide support during this period. However, the health professional in this study did not appear as a participant in the PT care at home. Thereby, the data showed a gap of primary health service in the first month at home for PT and family, once the parents, and relatives did not mention a strong bond with the professional of the PHC.

Discussion

The initial period with the baby at home requires an adaptation of the family to a new lifestyle and to deal at the same time with their fear of loss triggered by the experience with a PT baby who had been hospitalized just recently. This context revealed that the first month at home with a PT infant is recognized as a period of transition between the NICU and home.¹⁴The fear that something could happen existed among family members. They felt insecure and concerned about potential complications that were not embraced by the health professionals. To dialogue about concerns is an intervention that should be more widely used in care in order to provide a humanized care.

Parents desire more information than is provided, particularly about infants' health, care, coping, and what they can do to face adverse responses of the PT at home. However, the health providers do not give enough information about PT needs and care for these parents. In the NHP, the health services need to provide care based on the human experience and human context to offer a universal access based on the comprehensiveness care. Thereby, the study data showed that during the transition period from NICU to home, the families experienced a lonely care to the PT. The family looked for the health services only to give a punctual care to the baby as a vaccination. It reflects the fragmentation of care received after discharge and it could represent the inability of the health system to absorb the special needs of this babies.¹⁵

The health team in the NICU and in the PHC should be the main source of support and help for parents in understanding and adapting to their baby. It is very important for health care providers to inform parents about infants' treatment plan, procedures, actively listen to parents' fears and expectations, and assist parents in understanding infants' responses to hospitalization and other effective nursing interventions to help meet the needs of the NICU infants' parents.^{16, 17} Especially in the first month at home and, the interaction between those professional and family members is the key element to reach recommendations of the NHP. In the interviews, parents have never mentioned special attention and support by nurses or health professionals, especially from the PHC services that are now responsible to support them. The services that they did receive were basic care for the PT infant, such as vaccines or control the baby's growth. This shows a fragile relationship between the family and PHC services. Thus, it seems that in the reality of these families do not have support in the transition period from NICU to home provided by health staff and, the guidelines of the National Humanization Policy are underused.

Implications for Practice

The period of transition to home is permeated by the responsibility to take care and protect the infant and the family. In this study the fragile access, comprehensiveness care, responsible care, and bond contributed to the lack of emotional support necessary to the maternal identification with the baby's health needs. It is evident that the relationship between the assistance of secondary and tertiary healthcare with primary care needs to be integrated to avoid the hospital readmission of children with special needs. For professional support to be effective, it is necessary to understand the family as a unit of care, taking into consideration its routines, vulnerabilities, and the resources used to cope with stressful situations. Health professionals can decrease mothers' and families' experiences of exclusion increase their feelings of participation and understanding, as recommended by the NHP. It is necessary to improve the PT care in the NICU and continuing after discharge in the PHC, as the hospitalization period is central to the development of meanings about PT infants and their care. Supporting parents in the transition period contributes to the reduction of parental stress and development of their parental role, increased confidence, and security in caring for the PT baby after discharge, as well as, to reduce the baby's rehospitalization and increase it development and growth.¹⁸

Analyzing the dynamics of management and operation of the PT care in this study, it is possible to find distance between the program standards and the reality of the Brazilian health system. As presented before the NHP provide a guideline to offer the PT and families care, but the data could not show the implementation of this regulation in the PT follow up. Even though there is a theoretical knowledge about the NHP, the health professional have not yet applied this guidelines in their daily clinical practice. Under this circumstance, we observed that the health professional not recognize the whole neonatal care and, it needs to improve to offer better access and comprehensiveness care to the PT and their family after discharge.

References

- Ministry of Health (Ministério da Saúde). Secretaria de Atenção à Saúde. Departamento de Ações Programáticas e Estratégicas. Atenção à Saúde do recém-nascido: guia para os profissionais de saúde. Brasília: Ministério da Saúde, 2011.
- Silveira MF, Santos IS, Barros AJ, Matijasevich A, Barros FC, Victora CG. Increase in preterm births in Brazil: Review of population-based studies. *Revista de Saude Publica* 2008; **42**(5):957-64.
- Olshain-Mann O, Auslander GK. Parents of preterm infants two months after discharge from the hospital: are they still at (parental) risk? *Health & Social Work* 2008; **33**(4):299-308.
- Field T. Postpartum depression effects on early interactions, parenting, and safety practices: a review. *Infant Behavior & Development* 2010; **33**(1):1-6. doi: 10.1016/j.infbeh.2009.10.005; 10.1016/j.infbeh.2009.10.005
- Lopez LG, Anderson KH, Feutchinger J. Transition of premature infants from hospital to home life. *Neonatal Network: NN* 2012; **31**(4): 207-14.
- Schlittenhart JM, Smart D, Miller K, Severtson B. Preparing parents for NICU discharge: An evidence-based teaching tool. *Nursing for Women's Health* 2011; **15**(6): 484-94. doi: 10.1111/j.1751-486X.2011.01676.x; 10.1111/j.1751-486X.2011.01676.x
- Couto FF, Praça NS. Preterm newborn: Recém-nascido prematuro: maternal support at home for care. *Rev Bras Enferm* 2012; **65** (1):19-26. Doi: dx.doi.org/10.1590/S0034-71672012000100003

- Ministry of Health. Datasus. Cadastro Nacional de Estabelecimentos de Saúde 2013; Available: <http://www.cnes.datasus.gov.br>.
- Wilson L, Bodin MM, Fernandez, P, Godoy G, Sambuceti C, Squarre R, et al., Neonatal Intensive Care: a Global Perspective of Similarities and Differences in Selected Neonatal Intensive Care Units in Brazil, Chile, the United States, and Zambia. *Newborn&InfantNursingReviews* Jun 2011; **2**(2): 61-8.
- Viera CS, Mello DF. Seguimento da saúde da criança pré-termo e de baixo peso egressa da terapia intensiva neonatal. *Tex to Context to Enfermagem* 2009; **18**:74-82.
- Ministry of Health. National Humanization Policy: humanization as the guiding for the center line of practices care and management at all instances of Universal Health System. Brasília: Ministry of Health; 2004.
- Ayres JRCM. Hermeneutic and humanization health's care. *Ciencia Saúde Coletiva* 2005; **10**(3): 549-60.
- Streubert HJ, Carpenter DR. Phenomenology as method. In H. J. Streubert, & D. R. Carpenter (Eds.), *Qualitative research in nursing: Advancing the humanistic imperative*. [null] (5th ed., pp. 72-95) Lippincott Williams & Wilkins; 2010.
- Boykova M, Kenner C. Transition from hospital to home for parents of preterm infants. *The Journal of Perinatal & Neonatal Nursing* 2012; **26**(1): 81-7. doi: 10.1097/JPN.0b013e318243e948; 10.1097/JPN.0b013e318243e948.
- Vidal M. Discharge and rehospitalization of preterm infants: a reflection on access to health services. *Mental* 2011; **9**(17): 537-58.
- Reis MD, Rempel GR, Scott SD, Brady-Fryer BA, Van Aerde J. Developing nurse/parent relationships in the NICU through negotiated partnership. *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 2010; **39**(6): 675-83. doi: 10.1111/j.1552-6909.2010.01189.x; 10.1111/j.1552-6909.2010.01189.x
- Lee TY, Lin HR, Huang TH, Hsu CH, Bartlett R. Assuring the integrity of the family: Being the father of a very low birth weight infant. *Journal of Clinical Nursing* 2009; **18**(4): 512-19. doi: 10.1111/j.1365-2702.2008.02487.x.
- Melnyk BM, Crean HF, Feinstein NF, Fairbanks E. Maternal anxiety and depression after a premature infant's discharge from the neonatal intensive care unit: Explanatory effects of the creating opportunities for parent empowerment program. *Nursing Research* 2008; **57**(6): 383-94. doi: 10.1097/NNR.0b013e3181906f59; 10.1097/NNR.0b013e3181906f59.

Family	PT character	Family members	Name of the family members	Family members in the study
Gabriela's family	31GA, 3,24lb, Apgar 7/8, length of stay in the hospital: 36 days	03	Gabriela (PT) Korn (father) Cintia (mother)	Korn (father) Cintia (mother) Beth (grandmother)
Keity's family	30GA, 2,49lb, Apgar de 5/9, length of stay in the hospital: 47 days	08	Keity (PT) John (father) Sheila (mother) Téo (PT's brother) Tuty (grandmother) Mey (aunt) Anne (cousin) Judy (aunt)	John (father) Sheila (mother) Judy (aunt)
Wagner's family	33GA, 4,29lb, APGAR 6/8, length of stay in the hospital: 15 days	11	Wagner (PT) Lola, Lili, Julia (daughters of the PT) Shandi (father) Iris (mother) Ana (friend) Fernanda, Ana Carolina, Joel (Ana's children)	Iris (mother) Ana (friend)
Leticia's family	33GA, 3,83lb, Apgar 5/8, length of stay in the hospital: 61 days	03	Larissa (PT) Antonio (father) Manoela (mother)	Antonio (father) Manoela (mother)
Camilly's family	28GA, 2,27lb, Apgar 8/9, length of stay in the hospital: 57 days	03	Camilly (PT) George (father) Brenda (mother)	George (father) Brenda (mother)
Malu's family	28GA, 2,75lb, Apgar 0/7, length of stay in the hospital: 49 days	06	Malu (PT) Marcos (father) Melissa (mother) Eda (grandmother) Pablo (grandfather) Marina (aunt)	Marcos (father) Melissa (mother) Eda (grandmother) Pablo (grandfather)

Figure 1: Family member's participants in the study.