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Individual, Social and Institutional Vulnerabilities in the Premature Infant Care at Home

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Abstract

The prematurity carries some difficulties for families during the preterm infant hospitalization, as well as, after hospital discharge. In this context, is required a specific knowledge about the preterm biological characteristics, family's life conditions, health care, and social context. This study aims to analyze parent's experiences on daily home care for preterm infants focusing on individual, social and institutional vulnerabilities. Descriptive qualitative study was developed through the hermeneutic perspective approach, in South of Brazil with six families, who had babies discharged from Neonatal Intensive Care Unit. Non-structured interviews were recorded in the home visit with 12 participants (parents) and genogram and ecomap were applied. Emerged as core theme: Parents' feelings related to preterm care at home and their interaction with health services. During the first month after discharge, parents were emotionally vulnerable. There is a lack of connection between parents and Primary Health Care, what increases institutional vulnerability. After discharge, parents have experienced an individual, social, and institutional vulnerability. To minimize their institutional vulnerability, the health services need to be organized in a network offering qualified follow-up. Applying the Health Policy to care for premature infant, consequently, reducing the individual vulnerability and recognize social vulnerabilities related to premature infant care.

Keywords

parents, preterm infant, vulnerability, primary health care, descriptive qualitative study

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Individual, Social and Institutional Vulnerabilities in the Premature Infant Care at Home

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The prematurity carries some difficulties for families during the preterm infant hospitalization, as well as, after hospital discharge. In this context, is required a specific knowledge about the preterm biological characteristics, family's life conditions, health care, and social context. This study aims to analyze parent's experiences on daily home care for preterm infants focusing on individual, social and institutional vulnerabilities. Descriptive qualitative study was developed through the hermeneutic perspective approach, in South of Brazil with six families, who had babies discharged from Neonatal Intensive Care Unit. Non-structured interviews were recorded in the home visit with 12 participants (parents) and genogram and ecomap were applied. Emerged as core theme: Parents' feelings related to preterm care at home and their interaction with health services. During the first month after discharge, parents were emotionally vulnerable. There is a lack of connection between parents and Primary Health Care, what increases institutional vulnerability. After discharge, parents have experienced an individual, social, and institutional vulnerability. To minimize their institutional vulnerability, the health services need to be organized in a network offering qualified follow-up. Applying the Health Policy to care for premature infant, consequently, reducing the individual vulnerability and recognize social vulnerabilities related to premature infant care.

Keywords: parents, preterm infant, vulnerability, primary health care, descriptive qualitative study

Significance

Preterm infants have survived being hospitalized, however, when they are discharged, there are several difficulties that the parents need to face, for example, adapting to a new routine and learning how to care for their preterm infants. This care includes health and basic care, as well as their own social conditions and the services offered by the health system. Recognizing vulnerabilities involved in the preterm infant's follow-up contributes to minimizing the stressful situation experienced after discharge. In addition, it can promote greater maternal competence to care for the child at home with support from primary health care (Silva et al., 2020).

Introduction

The preterm infants (PT), and their families are considered vulnerable for itself face to the complications from prematurity, prolonged hospitalization, and factors related biological and psychological problems, social, economic, and family aspects (Silva et al., 2020). Then, based in this context and the vulnerability comprehension, this study aims to identify the Brazilian parents' experiences on the PT infant's daily home care and analyze then focusing on individual, social and institutional vulnerabilities. To apprehend this complex context requires a deep understanding and interpretation, for this, the view to the vulnerabilities in the prematurity context was the hermeneutic approach (Gadamer, 2008). Due to, the process of understanding is present in the entire process of life experience in which written, spoken or symbolic language show aspects of human reality.

In addition, interactions with health professionals and existing standards and protocols could present some vulnerabilities and compromise maternal recognition and autonomy. Thus, in the prematurity context, becoming a parent of a PT infant can bring feelings of uncertainty and anxiety related to the PT surveillance and about their self-confidence to caring the infant (Boykova, 2016). These feelings during the hospitalization at the Neonatal Intensive Care Unit (NICU) and the context around the parents and their PT infant should be consider for the health professional team during the preparation to discharge and to care the baby at home.

After the NICU discharge, a transition period starts, when the primary health care (PHC) staff must develop adequate skills, to ensure a positive transition from hospital to home, and to offer parent's conditions to develop their healthy parenthood (Fleming et al., 2016). The health staff should contemplate in their planning care, the possible traumatic stress situation caused by the hospitalization, including the parents and PT infant's relationship, as well as their familiar, cultural, biological, and psychosocial contexts (Fernandes et al., 2016; Sanders & Hall, 2018).

There have been criticisms about the traditional model of health care follow-up, especially after discharge, such as the PT care is centered in the illness and not in the development and family. In this sense, the follow-up care should be regarded as an extended approach that recognizes and encourages the family participation in the identification of infants' vulnerabilities (Utzuml et al., 2018). The prematurity is a condition of vulnerability due to the biological and psychological repercussions that expose the PT infants and their family (Patel et al., 2017). Therefore, our study contributes to this conception since the vulnerabilities involved in the prematurity context after NICU discharge are presented.

The concept of vulnerability is evidenced as an important element should be considered in the PT infant follow-up. Vulnerability has three components, individual, social, and institutional, which are interrelated, and implied with an increased susceptibility to illness and concomitantly, with a greater or lesser availability of health protection resources (Ayres et al., 2009).

The "individual vulnerability" is concerning mainly about the cognitive aspects, that involve the quantity and quality of information people have received, and their ability to work with it, and the behavioral aspects which is the capability and interest to transform these concerns into protector and protective actions (Ayres et al., 2009). The "social vulnerability" involves access to information, the possibilities to understand it, and to incorporate it into their routine. This information is directly associated with the access to material resources and social institutions, such as schools, health services, and the probability to confront cultural barriers. The "institutional vulnerability" is linked with the person and social vulnerabilities. It combines commitments to level and quality of life, availability of resources to the management of national, regional, or local monitoring programs related to prevention and health care (Ayres et al., 2009), as well as relevant aspects on PT infants are responsible for high rates of re-

hospitalization. This could mean that home care offered may not be adequately addressing the needs of infants and their families. It is important to know how parents deal with PT infants at home and how vulnerabilities are identified for them.

Considering the increasing rates of preterm birth around the world and the prematurity repercussion in the PT infant and their family lives, it is relevant to investigate the vulnerable situations in home care. In addition, to give voice for the parents for them explain about their perception of this vulnerabilities, to facilitate the professional's comprehension of this context and to contribute to family and PT care from NICU to home. So, what are the parents' experiences after hospital discharge in concern of the vulnerabilities involved in the prematurity context?

The team involved in this investigation are composed by registered nurse, as well as advanced nurse and all of them are PhD and professors at university. Their main topic of work is neonatology. The first author, since 1995 have been searching about the PT infant care and the family context from NICU to home. Therefore, demonstrating her interest in investigations about this subject. In the last 10 years, this researcher coordinates the investigation project named "Repercussion of prematurity: From birth to adolescence." In this sense, the results presented in this manuscript are part of this main project. So, along this period different results are published about the prematurity repercussion such as: assessment of the stress level of PT infant mothers' (Fernandes et al., 2016); validation of the Parental Stress Index to Brazilian Portuguese (Pereira et al., 2016); preterm growth failure after discharge (Rover et al., 2016), growth and biochemical markers of preterm newborns up to six months of corrected age (Barreto et al., 2018), educative activity for PT infant mothers as a support to care (Bugs et al., 2018), educative activity and maternal stress: a clinical trial (Viera et al., 2019), metabolic parameters from birth to six months among full term and PT infants' diet and metabolic changes (Favil et al., 2020), among others.

In this way, the results presented in this manuscript also refer to the repercussions of prematurity. In this case, in relation to the vulnerabilities that the PT and his family might face after the NICU discharge.

Method

This is a qualitative study based on hermeneutic perspective approach and analysis, which was chosen based on the possibilities to understand the meaning and interpretation of different interests and values presented in a special interaction. Creating new possibilities for redefinition and reconstruction of knowledge and practice (Minayo, 2015). The hermeneutic approach associated with the content analysis is a method that brings together joining the principles of content analysis as coding, categorization, systematization, and interpretation with understanding and reflection.

The study follows these steps: researchers doubt and questioning about the PT infant care at home and the vulnerabilities involved; elaborate the project investigation and send it to the ethical commitment; selection of participants; contact with the participants and schedule the home visits after NICU discharge; interview the participants during the home visit; transcribe and validate the interviews; organize data for analyses; establish the codes; interpretation of data; write the results.

Study Place

The study was carried out at the NICU of a school hospital, in Paraná, Brazil. This unit has a traditional model of care, where families may visit their babies along the day. Mothers could not sleep over in the hospital due to the lack of physical structured conditions.

Participants

Family's members, who PT infant was hospitalized at the NICU, composed the study participant's sample. The inclusion criteria were as follow: parents who had a PT infant hospitalized at NICU, regardless gestational age and time of hospitalization; living in the same city at hospital localization, and PT infant without congenital anomalies. Family's members, who have experienced another PT birth were excluded of the sample.

Parents were asked about their interest to participate in the study and received information about the research objective, which is to analyze the parents' experiences on daily home care for PT infants and discuss about their vulnerabilities in this process. Six families, whose members agreed to participate, totalizing twelve participants. The researcher listened to other family's members, not only the mother, as it allows them to understand the role of each one within the family dynamics, as their interactions, interconnections, and mutual influences.

The number of respondents was defined during the process of data collection centered on the power of information from the interviews' reports. This process consisted in all interviews for each visit were analyzed together and apprehend the content each one shows. This comparison occurred from the first interview during the home visit until the last. Based on this, the researcher identified the necessity to include more participants or not. Greater the power of information, obtained in qualitative research, the number of people participating in the study will be lower (Malterud et al., 2016).

Data Collection and Analysis

From the participant's enrolment in the study, the researcher scheduled the home visits, each family received one home visit after the hospital discharge, one each two weeks, during the first month at home. In the first visit, the research built the genogram and ecomap with the family. From these tools, the deep interview was started in the subsequent **visit**.

The same researcher carried out the data collection trough unstructured interviews, guided by the following question: How has PT infant care been developed at home? During the interview, attempts were made to comprehend parents' narrative, to know about their experiences, concerns, needs, vulnerabilities, and the decisions they have made on PT infants' healthcare.

The empirical data were transcribed and organized into individual files for the first research. Another researcher checked the transcripts to confirm the interview data. It is of extreme importance each individual experience should be taken into consideration, as the individuality is a manifestation of a series of experiences that the individual goes through that mold their perception of life. However, even though these experiences are individual perceptions of reality, it is essential that each statement of the interviewees should be placed together. So, it is possible to comprehend the totality of it all. It is the representativeness of the hermeneutic circle, which shows hermeneutic as art of interpretation of understanding a text happening in a circular movement that involves both subjective and objective sides going through the part to whole and vice versa (Gadamer, 2008).

Henceforth, an ideal qualitative sample is the one that reflects, in quantity and intensity, the multiple dimensions of a given phenomenon and seeks the quality of actions and interactions throughout the process. Consequently, it allows the deepening, comprehensiveness, and diversity in understanding the process that the studied group goes through, inserting these different aspects in the theories that the study is based (Malterud et al., 2016).

Data analysis followed the thematic content analysis, this method requires researcher to focus on selected aspects of meaning, that is, aspects relate to the general question of research

(Minayo, 2015). The steps to the thematic content analysis followed the Minayo's description: pre-analysis (reading the empirical material seeking to map the meanings attributed by the participants in the interviews); analysis of the expressed and latent meanings (identifying units of meaning) and final analysis (themes discussion). In sense to demonstrate the data representativity, the data analysis considered the coherent essence of a predetermined text (participant speeches), and, on the other hand, the objectivity of author. After this step, the researches followed instructions in order to help in interpretation of text such as, study the text sentence-by-sentence, impression after impression; so, to perform the explanation of contradictions at least; read the text again as a whole; bring some reflections from general text; create a sketch for all text; make a draft for each part of text, as private formulation of explanation and, finally read again the text (Vieira & Queiroz, 2017).

The content analysis requires assigning segments of the material to the categories of the coding frame; this step is the data codification that was carried in double coding, at least for parts of the material. Representing a test of the quality of the category definitions, which should be so clear and unambiguous that the second coding yields results are very similar to those of the first coding. The categories were certified if they in fact match the data – or the coding frame provides a valid description of the material (Vieira & Queiroz, 2017).

The aspects were highlighted to discuss relevant ideas and organize axis of reports with facts, values, and feelings related to parents' experiences on PT infant health care. The interpretative trajectory was supported on the analytic categories: social, individual, and institutional vulnerabilities (Ayres et al., 2009), which do not present themselves isolated, but connected to each other and they indicate the presence of multiple dimensions. Based on this information, the thematic categories were Parent's feelings: caring of PT infant at home and Parents and their relationships with health services. This research was approved by the Research Ethics Committee.

Results and Discussion

Parent's Feelings: Caring of Premature Infant at Home

Parental experiences of caring for PT infant at home have been previously researched that might be synthesized in the Adama et al. (2015) meta-synthesis. The authors mentioned the health care support improves the parents' caring confidence, as well as it is a process that involve the parents' deals with challenges of caring for PT infant at home and the overprotective parenting creates difficulties with the baby care. Therefore, prematurity is a condition of vulnerability for infants and their family, then, high-risk infants transitioning from the NICU to home represent a vulnerable situation, given its complex care requirements (Patel et al., 2017).

In this situation, parents may feel insecure and ambiguous feelings which become them emotionally fragile. The NICU discharge and the initial experienced moments at home cause tension and worries for the family (Utzuml et al., 2018). However, despite of fear and exhaustion feelings, researchers checked that the mothers are also determined, grateful, and are capable to do whatever is necessary to ensure the best outcome for their babies at home (Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014). In our study, this perception appears when the family members arrived at home with the PT infant and, they start to experience controversial feelings such as, joy and tranquility, but the worry is still present. As show in their speeches:

I was afraid of changing the diaper, bathing, breastfeeding, especially when my milk was little. I was afraid of not being able to breastfeed. Also, I was worried

because she was so weak. I was afraid even to hold her on my lap, she seemed so fragile, it could hurt her... (E5)

I was afraid of her getting a cold or infection, having some trouble, a worsening, and here [home], we do not have the device to measure her oxygen. We got too scared that her breath dropped, and it could do away with her. (E2)

When she got home, I thought it had to be the same. The room was nice and warm ... So, it seemed to be the best for her, we did not open the window, because we were afraid of getting dirt from the street. I was afraid she got some disease, some flu or something would happen to her and then, she would have to go back to the hospital. (E6)

In addition, parents had doubts about PT infant care at home, as evidenced in other studies (Fleming et al., 2016; Veronez et al., 2017). They also tend to reproduce the assistance that was developed at NICU during their first moments at home, and especially mothers face several challenges by experiencing a PT infant care (Arzani et al., 2015). Thus, our study shows these aspects because they demonstrated with the PT infant at home sets the opportunity for them to discover the baby's needs. Parents start doing actions they believe will prevent infections (cleaning up their home and preparing the infant's belongings). Even as, they compared the care at home with the ones at NICU; closed bedroom seems to be as safe as the incubator's environment. In this sense, they tried to reproduce a hospital atmosphere at home, because this gives the PT infant more security when safe daily care will be offered. These situations can create individual vulnerability, in which the parents need to elaborate and obtain information for a PT infant's daily care.

After being at home for some weeks, their fear decrease. Parents feel strengthen and show to be more confident as they pointed in their speeches:

Now [first month after discharge] it's very different from the hospitalization period, we got more relaxed and little by little we got used with the idea of her being at home. It is very nice to have her at home; it is much more than that. (E2)

Now, I am used to care for her, I am not so afraid anymore ... Now [first month after discharge] she's growing a lot and I know what she wants. (E3)

Familiarity with the infant at home builds autonomy and understanding about the process of care of a NICU egress PT infant every day.

Parents and Their Relationships with Health Services

Considering the gradual increasing in the PT infant survival, the continuity of care after discharge is an important factor for the infant health. The survival rate in the United States is nearly 50% among infants aged 24 weeks, 80% to 90% in infants aged 28 weeks and 95% in those aged 32 weeks (University of Utah Health, n.d.). Nevertheless, faced the limitations in human and financial resources and difficulties in health service accessibility, it is not easy to provide health related interventions for PT infants and their families after hospital discharge (Kang & Cho, 2021). This aspect was observed in our study when the PT infant parent's relation with health care services pointed some weaknesses in the infant follow-up. Families can feel loneliness in taking care of their PT infant during the transitional period from hospital

to home. Parents present doubts about the infant's health follow-up, and they demonstrated dependency on the NICU staff. As they trust them more, because the NICU team **contributes** to the PT infant survival:

I don't know if we will continue to take her to the public health unit, because there, at the hospital, I think it is better for her, the health staff knows her, they know what she has suffered. (E5)

They [public health professionals] will only know that my child was born, and she is already at home if we go to the health unit. I think, if they came here, I would feel safer, especially now with the baby at home. Sometimes, we are afraid of something happening or we do not know what to do, then we have nowhere to go. (E1)

Worries also appear around the continuity of care by health services, either the public or the private ones:

To the public health unit, I will take her to have the vaccines. The infant care, we will do in the private health service, because the public one takes a long time to get an appointment and still, the doctors do not know about her. (E7)

We take the baby to have the vaccines there [public health unit], however, we must wait for the assistance. In addition, they do not have experience with premature babies. So, E3 [mother] and I [father] have been going the public health unit. Moreover, we pay for the baby's health insurance. (E4)

She [mother] takes the baby to the public health unit, her weight is checked; also, the vaccines are given (E10)

When we have some doubts, she (mother) calls the nurse at the NICU because there they have more information about the baby ... in the Primary Health Care (PHC), the team do not have the same information. (E5)

Parents see infant's follow-up, on PHC, as restricted to vaccination and anthropometry. For a PT infant clinical follow-up, private services are used but showing a fragmented assistance. In addition, for parents, there is a poor knowledge from the professionals on PHC about the PT infants' care, what becomes clear that there is a lack of confidence. The absence of a connection with the PHC team does not give the family a recognition of that local as a possibility to be asked, when necessary, what increases institutional vulnerability. The gap in the connection with the PHC team avoid the family recognized the PHC as a service to be asked, when necessary, what increases institutional vulnerability.

In this context, after NICU discharge, parents were faced a precarity of safe connection with the health assistance network. Therefore, they appreciated the actions of nurse professionals at their home visit highlighting the care that PT infant needs, not only to be offered during hospitalization, but also at home together with health care network in the PHC.

The Brazilian health system (SUS) preconizes as one of their guidelines, the universal health care access, as well as an equalitarian and organized health services, in a regional hierarchized network according to the technological density (Department of Health, 2011). Concerning the PT care, within the Brazilian health system, there is a public policy named Humanized care for low weight newborns: Kangaroo Method. It was instituted to reorganize

the way of caring this group, looking for a humanized attention and minimize the institutional and social vulnerability (Klossowski et al., 2016). Even though these policies exist, the Brazilian population, as well as the PT infant and their families are faced with difficulties and fragmentation on continuity of health assistance. Improving the delivery of PT care and health promotion from the community setting are very important and may result in benefits for growth, health, and development of PT infant, even as, reduction of post-NICU discharge costs with rehospitalizations (Voie et al., 2018).

In general, PT infant's parents cited in their speeches, PHC professionals do not seem to be prepared to take care their infants. Contradictions between professional practices and public policy are identified once the practice in the PHC do not follow the regimentations pointed out in the public policy for the PT follow-up. Indicating that professionals are unaware of what it advocates, and value hospital care. Thus, contributing to non-compliance with the policy, as indicated (Klossowski et al., 2016). The PT infant follow-up is broken down with health interventions that are put apart, duplicated and without communication among the levels of health attention. The PT infant follow-up shows some vulnerabilities due to it is offered by a fragmented care. The health interventions for this group are developed put apart, duplicated and without communication among the levels of health attention.

The participants' speeches also point the necessity of home visits for parents' support, as a great linking between health professionals and families. The proximity between parents and PHC unit is important, and the presence of a nurse at home grants security for the family to evaluate the infant and do the follow-up:

She is throwing up quite often, I am giving her the medicine, but sometimes she does it a lot, and then the hiccup starts. As soon as she finishes being fed, the hiccup starts, and it does not stop so fast. These things, I would like to ask somebody about what they mean. (E5)

They [professionals of the public health unit] came here twice, as soon as, the baby was discharged from hospital. They came here, the nurse and two assistants, to evaluate and to exam her, so they asked if she was ok. These visits were good for us, we felt safer. (E9)

According to Kang and Cho (2021), the main follow-up care after NICU discharge include elements as growth/developmental monitoring and support, continuity of care, parent- and family-centered elements, and a multidisciplinary approach. Following these elements, some intervention methods could be developed such as home visits, phone calls, video calls, and applications.

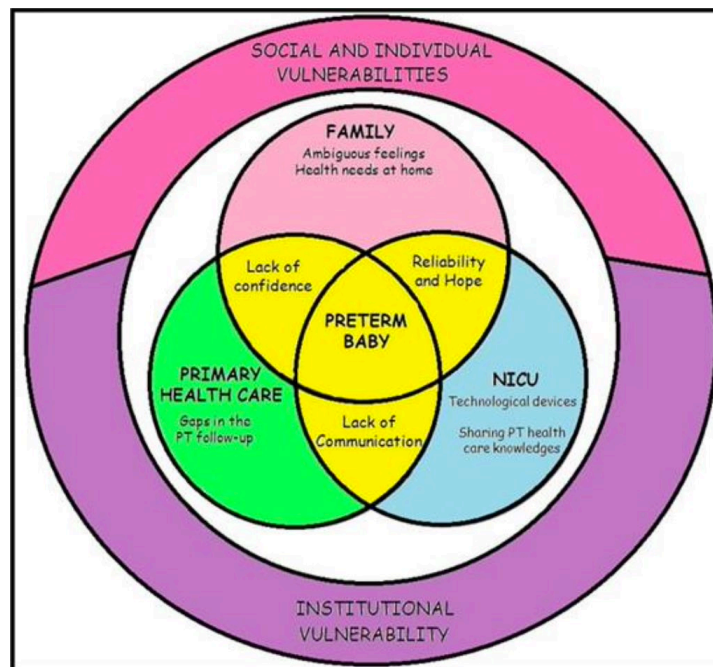
The social vulnerability emerged in our study, when the parents showed they are insecure about the information on the PT infant care at the PHC. Thus, they must decide if they need to continue the PT infant follow-up at this service.

Parents feel there are differences between the health institutions (PHC and NICU). Unfortunately, neither of them has a closer families' monitoring, suggesting institutional vulnerabilities. This context pointed the necessity of health service's reorganization to provide conditions to the family in the sense of empowering them to understand and identify the PT infant necessities. The integration between family and health team from the PHC and NICU are essential to PT infant care after the hospital discharge. The interrelation among individual, social and institutional vulnerability components is important to understand parents' lived experiences at home. Premature infant's daily tasks at home must be part of infant's health care, and it must be required to enter the PHC and special care programs, linking institutions and families, because this link among health services will provide an expanded and effective

follow-up. A compilation of the data focusing PT infant care vulnerabilities is evident in Figure 1.

Figure 1

Complexity of PT Follow-Up at PHC and its Vulnerability. Brazil, 2019



Going home happens within an exhausting emotional context, although there is a relief to have their child with them (Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014). Often these infants are discharged from the NICU requiring a lot of health specialists (ophthalmologist, physiotherapist, neurologist, among others) appointments, as well as, medications, specialized feeding, home medical equipment (Mills et al., 2018; Toly et al., 2016). The families have the necessity of carrying out this complex and dynamic care after hospital discharge. They equally have an increased need for support to stimulate their self-confidence in the PT infant care at home. The PHC health team should provide this support throughout the home visitation along with efficient communication (Patel et al., 2017). This strategy contributes to the reduction of the social and individual vulnerabilities.

The data results revealed that the family of PT infant is fragile and vulnerable; thus, it is important to offer a technical and social support for parents to know how to take care of the PT infant at home. It is essential to develop family capacity aiming to identify the infant's needs and to stimulate the parents' abilities that will help them to identify the infant vulnerability at home.

People can cope with different situations of vulnerability, individually or collectively. As for the individual vulnerability scope, harm is related to behaviors that cause sufferings and difficulties (Ayres et al., 2009). Some of them are not perceived as an immediate result of voluntary action but can be related to both individual and environmental conditions, including social, cultural aspects and the level of consciousness that people have about the behavior (Ayres et al., 2009; Kuo et al., 2017; Voie et al., 2018).

Individual vulnerabilities that PT infants' parents have presented, in this paper, are much connected to social vulnerabilities. It is relevant that families could have access to information, as well as the possibility of understanding and incorporating it in their life routine to deal with fears, concerns, and difficult situations. These conditions are directly associated

with educational level, family income and opportunities to overcome cultural barriers (Klossowski et al., 2016). These conditions need to be understood by health professionals and they should be able to expand health care at home.

If PHC professionals do not know about families' lives and their health conditions, they become far from them, involving institutional vulnerability. It's important to emphasize the health professionals should perform interventions to reduce vulnerabilities, to avoid parents' traumatic situations and its consequences. There should be an appropriate discharge plan referred to the PT infants and their family in the PHC. There is a need of clear guidelines about the discharge process from the NICU (Lemyre et al., 2018). In order, to facilitate this process, the AAP indicated guidelines for discharge of the high-risk neonate in which defining when discharge is appropriate, as well, the specific needs for follow-up care, and the process of detailed discharge planning are addressed. Recommendations are given to ensure that all necessary care will be available and well-coordinated after discharge (AAP, 2008). The health team from PHC should start the follow-up of this PT infant 24 to 72 hours after NICU discharge (Taleghani et al., 2019).

For some parents, in this study, there were no advisement and home visiting during daily care at home, what led families to look for available services of PHC, set as low-skilled and that would not be able to provide adequate care for PT infant after NICU discharge. Therefore, they put this level of health attention in a low priority as, in their opinions; those care practices in PHC are ineffective, generating uncertainty about the quality of health actions in these services. Institutional vulnerability was present in this study, once the care is fragmented with specific actions, not articulated to other levels of health care and without continuity. Thus, linking with families is fragile, increasing the distance between PT infants' parents and health services.

This paper portrays the quality of commitments and the resources that PHC professionals do not offer to PT infants' parents in the sense to identify the needs of infants and their families. It is important to highlight that there are yet situations in health services which are either creating vulnerability or failing to reduce vulnerability in families.

Parent's experience on daily care after NICU discharge in a Brazilian reality is characterized as an adaptation period for parents and PT infants. In this process, a mix of feelings emerged, and they are faced an individual, social, and institutional vulnerabilities.

Despite of the Brazilian health public policy exclusive for high-risk infants, the study identified the three components of the vulnerability in the parents' experiences after NICU discharge, that is the individual, social and institutional. Daily care at home is an important task that brings out vulnerable situations, in this context, PHC professionals should provide health care with continuity, enabling the creation of a bond, seeking for new common horizons, looking for preventive actions to reduce harm and the individual, social and institutional vulnerabilities. With a continuous expansion of NICU and consequently an increase on survival rate of infants and children with special health care needs, there are challenges to implement the PT care after discharge, to contribute for a successful transition hospital-home and daily care at home.

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