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The vulnerabilities of premature children: home and institutional contexts

Vulnerabilidades para a criança prematura: contextos domiciliar e institucional

Vulnerabilidad para niño prematuro: contextos domiciliares e institucional

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ABSTRACT

Objective: To analyze situations in which premature children are vulnerable in home care, in the first six months after hospital discharge. **Method**: Qualitative study, from the perspective of philosophical hermeneutics, carried out in a Brazilian city on the border. In-depth interviews were conducted, with a data analysis considering the method of interpretation of meanings. 18 mothers of premature children discharged from a hospital unit participated. 25 home visits and 56 calls were made. **Results:** The reports from the mothers express situations of vulnerability, concerns, needs for care, singularities of the development of the premature baby, and repercussions of institutional routines in home care. **Final considerations:** There are vulnerable circumstances in prematurity that reaffirm interconnected individual, social, and institutional dimensions. It is important to highlight that the institutional dimension involves the responsibility of health professionals not to increase individual and social vulnerabilities, but to promote care and seek to reduce situations that generate risks, uncertainties, concerns, and damages.

Descriptors: Infant, Premature; Health Promotion; Health Vulnerability; Child Care; Mother-Child Relations.

RESUMO

Objetivo: Analisar situações vulneráveis para crianças prematuras em cuidado domiciliar nos primeiros seis meses após a alta. **Método**: Estudo qualitativo, na perspectiva da hermenêutica filosófica, realizado em um município brasileiro em região de fronteira. Foram conduzidas entrevistas em profundidade, com análise de dados pela interpretação de sentidos, com 18 mães de crianças prematuras egressas de unidade hospitalar, perfazendo 25 visitas domiciliares e 56 contatos telefônicos. **Resultados:** Relatos maternos expressam situações de relações vulneráveis, movimentos de preocupações e necessidades de cuidados, singularidades do desenvolvimento do bebê prematuro, e repercussões das rotinas institucionais no cuidado em domicílio. **Considerações finais:** Há circunstâncias vulneráveis da prematuridade que reafirmam dimensões individuais, sociais e institucionais interligadas. Importante destacar que a dimensão institucional envolve a responsabilidade dos profissionais de saúde em não ampliar as vulnerabilidades individuais e sociais, e sim promover o cuidado e buscar reduzir situações que geram ameaças, incertezas, preocupações e danos.

Descritores: Recém-Nascido Prematuro; Promoção da Saúde; Vulnerabilidade em Saúde; Cuidado da Criança; Relações Mãe-Filho.

RESUMEN

Objetivo: Analizar situaciones vulnerables para niños prematuros en cuidado domiciliar en los primeros seis meses después de la alta. **Método**: Estudio cualitativo, en la perspectiva de la hermenéutica filosófica, realizado en un municipio brasileño en región de frontera. Han sido conducidas entrevistas en profundidad, con análisis de datos por la interpretación de sentidos, con 18 madres de niños prematuros egresas de unidad hospitalaria, un total de 25 visitas domiciliares y 56 contactos telefónicos. **Resultados:** Relatos maternos expresan situaciones de relaciones vulnerables, movimientos de preocupaciones y necesidades de cuidados, singularidades del desarrollo del bebé prematuro, y repercusiones de las rutinas institucionales en el cuidado en domicilio. **Consideraciones finales:** Hay circunstancias vulnerables de la prematuridad que reafirman dimensiones individuales, sociales e institucionales interrelacionadas. Importante destacar que la dimensión institucional envuelve la responsabilidad de los profesionales de salud en no ampliar las vulnerabilidades individuales y sociales, y sí promover el cuidado y buscar reducir situaciones que generan amenazas, incertidumbres, preocupaciones y daños.

Descriptores: Recién Nacido Prematuro; Promoción de la Salud; Vulnerabilidad en Salud; Cuidado del Niño; Relaciones Madre-Hijo.

INTRODUCTION

A premature child is considered vulnerable by birth itself, due to complications from prematurity, prolonged hospitalization, and factors related to difficulties intrinsic to each family context, which are permeated by biological problems and psychological, social, economic and family aspects[1]. In this context, preterm infants require greater attention regarding their protection and the promotion of their health for a good development[1].

The experience of prematurity, hospitalization, and transitions home can break expectations built during pregnancy by the family, which can generate suffering and difficulties[2]. The family's responsibility for home care is very important, and the role of health professionals with parental caregivers in a situation of prematurity is fundamental in the face of everyday challenges[3].

The influences of family dynamics, home and community environments, and, mainly, of parental care practices in this process, can contribute or impair the development of the premature child[4-5]. Thus, the need to systematically monitor the families of premature babies is justified in order to provide interventions that promote positive parenting and quality of life for the child[4-6]. Parents should be considered partners in the health care of premature children, especially for the promotion of child development. The family environment and the community are spaces in which the child spends most of their time, and their proper insertion there will contribute to long-term development[7].

Considering the importance of safe practices at home, the concern with the quality of care and the environment where the child lives, and the impact they had on the progress of the child[8], it is relevant to investigate the vulnerable situations in home care, considering the need to give people a voice to identify aspects related to meeting the needs for growth and development in childhood.

OBJECTIVE

To analyze vulnerable situations for premature children in home care in the first six months after hospital discharge.

METHODS

Ethical aspects

The research project was approved by the Research Ethics Committee of the Ribeirão Preto School of Nursing at the University of the São Paulo, in compliance with research standards involving human beings.

To maintain anonymity, participants were identified by the letter P, followed by a number indicating the order of the interview (P1, P2, up to P18). The moment when the interview was conducted was described by the acronym HV (home visit, 15 days after discharge), Phone call I (30 days after HV) and Phone call II (when the child had 6 months of age).

Theoretical-methodological framework and type of study

This is a qualitative study, from the perspective of philosophical hermeneutics[9], based on the conceptual framework of vulnerability and health care[10-11].

The construction of the conceptual framework of vulnerability in the health field is related to the understanding of preventive practices and the possibilities to move beyond practices based strictly on biomedical knowledge[10]. People face different situations of vulnerability, individually or collectively, and situations of health problems can be divided into three interconnected dimensions: individual, social, and programmatic or institutional[10]. Individual, social and institutional situations cannot be analyzed in isolation. Their singularities need to be identified, based on the following practical questions: "Whose vulnerability? Vulnerability to what? Vulnerability under what circumstances or conditions?" People are not vulnerable *themselves*, but can *be* vulnerable to some problems and not to others, under certain conditions, at different times in their lives[12]. In this study, the issues of premature baby care involve sociocultural, individual, structural and institutional aspects. This study is also supported by the conceptual framework of health care[11], with an emphasis on health care with a dialogical method, that is, sustained by the knowledge and values of the different subjects involved and sensitive to the meanings and senses in the face of demands and interventions in the health field.

Study setting

The research was carried out in a Brazilian municipality in a triple border region. The inclusion criteria in the present investigation included mothers over 18 years of age, with children born with a gestational age below 37 weeks, hospitalized in a neonatal intensive care unit (NICU) or intermediate neonatal care unit (INCU) for at least five days, and who lived in Foz do Iguaçu-PR, Brazil. The exclusion criteria were: mothers diagnosed with mental health problems registered in their medical records; communication difficulties related to the ethnic diversity in the municipality; and impossibility of carrying out the home visit (HV) due to the lack of an address and/or the absence of the mother at the address after three attempts.

The NICU considered has a high technological density and is the only one intended for the care of high-risk newborns for the municipalities belonging to the Foz do Iguaçu health region. It often provides care to the newborns of tourists visiting the city and foreigners residing in neighboring countries (Paraguay and Argentina).

Data source

Of the 33 mothers of premature children hospitalized in the period of the study, who lived in Foz do Iguaçu, three did not participate in the research because they were under 18; three did not speak Portuguese; one did not accept to participate in the research, considering that her other son (twin) was still hospitalized in a grave state; one mother had her child transferred to another hospital; and it was not possible to establish contact with seven of them during the period of data collection, because the parents did not had free access to the NICU and/or the INCU, since the policy of the institution restricts visiting hours. Therefore, 18 mothers participated in this investigation.

The searching and inclusion of participants ended when the results produced meanings capable that allowed for an understanding of the phenomena in depth, with richness and complexity[13].

Data collection and organization

Data collection took place between July 2017 and April 2018, through HV and calls conducted by the first author, who has professional training in neonatal nursing. At the hospital, in a private location, the first contact with each participant was established when the child was still hospitalized, with the presentation of the research objectives and the Informed Consent Form. The interview was conducted during the HV, 15 days after the baby was discharged. Calls or instant text messages were made 30 days after HV and after the children were 6 months old. The semi-structured interview was chosen as the technique for data collection. Interviews were recorded in audio at the HV and transcribed in full. By telephone, the contacts were registered directly by the researcher and then read for the participant's consent. The interview started from the following guiding instruction: "Tell me how your daily care with your child has been". During the research, 25 HVs and 25 phone calls were made, and 31 text messages were sent.

Data analysis

Data analysis was based in the interpretation of meanings, which seeks to describe, understand, and contextualize information based on the data collected, culminating in themes that translate significant parts of the data. Repeated readings of the empirical material were carried out, considering the statements in full and their particularities, seeking to understand the meanings and reinterpreting them to generate explanations[14].

The results were grouped into the following thematic units: Vulnerable interaction relationships; Concerns and needs for physical care; Singularities of premature babies and their development; and Repercussions of institutional routines in home care.

RESULTS

The maternal narratives reflected the main aspects of the vulnerability of children born prematurely regarding the care provided by the mothers in the home environment.

Vulnerable interaction relationships

The participants' statements express moments of interaction with the premature child at home and expose difficulties in dealing with the baby.

> *When she cries, I don't know what to do.* (P2, HV)

> *I just keep thinking that the situation would be quite different if she were born at the right time, you know? But, I also learned a lot from her and the premature birth. The whole process when I needed something, I talked to my husband, we needed that time too, to grow as a family, as parents.* (P5, HV)

> *If he mumbles, I'm already there to see if he's not drowning with something, but I think that's because he's the first child.* (P6, HV)

The situations show that adults are not always prepared to care for their children, and parenting needs to be learned over time.

The difficulties expressed by mothers is based on the fear of stimulating and caring for a delicate baby, and this fact is perceived as harmful to the interactional process.

> *I didn't hold her in the first minute after birth, she was shown to me taken away* [by the health team]. *I touched her the next day, but it's not the same as holding her, smelling her, she feeling my warmth and me feeling hers. That was on the seventh day, when she came out of the tubes. I was afraid to even touch her, that I would get anything out of place.* (P18, HV)

Other vulnerable aspects were identified in the maternal reports, showing that they are likely to compromise care and interaction with the premature infant at home.

> *Since the first month of pregnancy, I have been nervous. They tried to kill my husband in front of me, I was afraid. After he went to prison, they came to tell what he really had done, because I didn't know. So, it was a lot of news, one on top of the other.* [...]. *I was afraid, I went to live near my mother-in-law. And I wondered what I was going to do with three children.* (P7, HV)

> *Her birth was a moment in my life when he* [the father] *was not present, I missed him very much. When I was in the hospital, I didn't even like watching men enter the rooms, just remembering it makes me sad. It is something that I always wanted to have. During birth, none of the three were there* [parents of the other children]. (P7, HV)

The damaging effects of vulnerable interactions between premature babies and their family members can be determinant in disorganizing their behavior and personality traits. They can also manifest themselves and influence the entire process of child development.

Concerns and needs of physical care

The reports of the mothers pointed out aspects inherent to concerns about physical and protective care for premature children at home. The most emphasized concerns involve the practice of feeding, regarding the uncertainty as to whether they are being able to exercise care properly.

> *My worry about her drowning is when I'm giving her a bottle, because when breastfeeding she is there, she controls, she sucks, stops, and breathes. And when it comes to giving the bottle, no ... you give the bottle, if I don't take it out she aspirates it, that's what I'm afraid of.* (P1, HV)

> *I think, will he be satisfied with my milk, will I be able to take good care of him. That mother's insecurity. Am I giving 100%, am I doing it right? Am I managing to fulfill my role 100%?* (P13, HV)

Intertwined with the care with feeding, the concern with weight gain was also mentioned by the mothers.

> *The concern is only for her to put on weight soon. It's about growing up, putting on weight soon to be like a normal baby.* (P2, HV)

> *The concern is for her to lose weight. I'm afraid, that's my concern.* (P7, HV)

When considering the premature child as fragile, mothers also reported concerns about their health, and their susceptibility to acquire diseases and the need for further hospitalization.

> *I think that, because he is premature, I worry a little more, I imagine that maybe his immunity will need more time to develop, it will take him a little longer to be well. I would have been careful if he had been born in the right time, but my biggest concern is that he is premature.* (P12, HV)

> *My biggest concern is for him to return to the hospital. Another concern that I saw a lot at the hospital is bronchitis, bronchiolitis. This is what concerns me the most.* (P13, HV)

Thus, at home, mothers are vigilant with any different signs or reactions that the child may have, and, in particular, they are attentive to their breathing. They cite the child's hospitalization due to experiences with episodes of breathing difficulties during hospitalization, and the concern about losing their child is still strong for some of them.

> *I always keep an eye on her. If she is breathing, if she is well, if she is awake.* (P5, HV)

> *In the first few nights, whatever happens you think they will die. You think they are going to die during sleep. I wake up a lot at night to see if he's breathing.* (P17, HV)

The perspective that their premature children are at risk of falling ill is constantly present in maternal reports, demanding a large part of their care time in order to protect the children. Thus, the return to work and the organization to leave the children under the care of another person also become an important concern for the mothers.

> *I think I'm starting to worry more, as I'm going to have to get back to work later* [laughs]. *I still have two months, but I'm already worried. I already think: "With whom am I going to leave the baby, I cannot leave my baby with anyone."* (P6, HV)

> *My concern is when I get back to work* […]. *I don't know what I'm going to do, if I'm suddenly going to hire a nanny, to be with him, I don't know what is safer, I don't know if it is because he was born premature, I end up having more concerns, you know?* (P12, HV)

Feelings of uncertainty and perceptions that your child will not be safe and with all the care he/she needs influence the mother's daily life, suggesting situations of suffering and attitudes that can affect the development of trust and autonomy.

Singularities of premature babies and their development

Maternal perceptions regarding the care for a premature child are different, since they consider the baby more fragile and delicate. Maternal reports indicate that these differences are related to a greater zeal since the child is smaller.

> *It is different just because it is small, more delicate.* (P7, HV)

> *This is the difference, because the other children cry, she cries when she is dirty, sometimes when she is hungry, but it is very rare.* [...]. *If you wait for the premature child to cry to breastfeed, she won´t.* (P8, HV)

> *A lot of difference, mainly because he was born premature.* (P13, HV)

> *Because he is underweight, premature, care is different in relation to schedules.* (P17, HV)

The daily routine of the premature child at home was pointed out by the mothers as deserving greater attention and surveillance. Maternal statements showed concerns and fears for the child's future development, especially regarding the sequelae resulting from complications presented during the hospitalization period and premature birth.

> *I fear, mainly, how the future will be. Like… one of my children* [twins] *had a respiratory arrest. When he was born, he forgot to breathe. So, because of that, he was intubated, with medical devices. I am more concerned with him in relation to this, of him having sequela due to this period.* (P3, HV)

> *I'm afraid of what the future will bring. I hope that everything goes well, that she grows well, that she learns well, that she doesn't have any problems. She even had a transfontanellar ultrasound because she was not waking up* [...]. *The fear was, was there any sequelae? I had this doubt, to know if there was really lack of oxygen in her brain or not. I don't know if it will affect her future.* (P18, HV)

The reports express fears related to individual and biological vulnerabilities due to prematurity, and, although they have concerns, mothers do not always believe there is a need for stimuli, and others do not know how to do it.

> *I think she needs little stimulus, because she is very smart.* (P8, Phone Call II)

> *I think she needs very little. I play, I talk, you know, but my daughter is developing very well.* (P11, Phone Call II)

> *I do very little. She is great, she's developing very well.* (P14, Phone Call II)

> *I'm still not sure how to stimulate my daughter.* (P15, Phone Call I)

It is important to highlight that both the excess of concern and the perception that it needs little stimulus can prejudice the development of the child.

Repercussions of institutional routines in home care

Maternal reports suggest the existence of gaps and impediments for mothers to become stronger in their role as caregivers and learn to care for their children, which can generate insecurity in the home environment.

> *Coming and going* [pause]*, the nights were very long, and, the moment I went to stay with her at the kangaroo unit, it was even more difficult. When she was there, I stayed with her all day, when*

> *it was time to go home, it was much more difficult to leave her there.* (P5, HV)

> *I think that, if I could sleep there, I would have stayed, because the worst thing is not staying there, to leave him. It is inhuman to leave him there, it seems that he is abandoned.* (P17, HV)

The setting presented refers to the visitation routine of the hospital, which restricts the parents' possibility of staying with the child, so that even breastfeeding times are programmed.

Regarding the hospital structure to receive the mothers, the participants described difficulties, considering that there were problems in offering an appropriate place for them to be with the child.

> *It was tiring, I was there all day, from 9 am to 11 pm. I stayed at the reception, outside, there was no place to stay inside.* (P11, HV)

> *It was difficult, very difficult, very tiring. Because you don't have a place to stay. I, to tell you the truth, walked around the hospital. Because I had to get out between breastfeeding moments. I stayed at the private health sector reception, the sofa was more comfortable* [...] (P13, HV)

> *Food was provided by the hospital, but I discovered this only on the second or third day. No one told me this.* (P13, HV)

In addition to the lack of structure for mothers to stay at the hospital, another important aspect related to the reality studied involves teaching strategies during hospitalization, with the purpose of preparing them to care for the baby at home.

> *At the hospital, they didn't teach me how to bathe them* [twins] *... I had to learn on my own, I did it myself. I'm bathing them the way I know, the way I used to do it with my nephew, but they are very tiny* [laughs]. (P4, HV)

> *Since she came home, I have been alone; and at the hospital, I had no guidance. When I arrived to breastfeed her, the nursing technician had already bathed her. And then at home, the first bath was complicated.* (P18, HV)

In hospital care, not all mothers received guidance or had space to talk when their children were hospitalized. Some did not even experience the process of taking care of their premature child before hospital discharge. Thus, shortcomings or nonexistence of routines to prepare the mothers for care, as well as for planning hospital discharge, means that they do not feel prepared to take care of their child at home. This can even lead them to miss important steps for the follow-up of the child after hospital discharge.

> *If you had the assistance of a professional before, let's say, the day before discharge, you would spend the whole day taking care alone, it would be quite different.* (P13, HV)

> *I was only told something when she went to deliver my son's document and said: "Now you have to go to social services to get the referral to the Nutritional Service." I was thinking that in the euphoria of leaving, I will not take the boy, go to the reception, talk to the social worker.* (P13, HV)

Monitoring the child's health after hospital discharge is seen as important to the health of the premature baby, since they require specialized attention and trained health professionals. In the present study, mothers mentioned that health professionals from Basic Health Units (BHU) and Family Health Units (FHU), in their opinion, are not prepared for the specific health care of children born prematurely.

> *I thought that they* [the FHU team] *were not prepared to care for a premature child, for me it was very offensive to say that she was very small. She is my daughter you know? They could say something else, it wasn't good.* (P5, HV)

> *The other time I went to the health unit* [BHU]*, it was chaos, I couldn't even weigh him. They told me: "You can go in that little room, if there is no one, you can weigh him yourself."* (P6, HV)

> *I don't think I'm going to take him there* [FHU]*, I'm going to go to the hospital, to the pediatrician. Because it's no use, I go there just to weigh and measure him. She* [nurse] *doesn't say anything, doesn't teach anything, doesn't explain anything. I will expose him only once.* (P17, HV)

The statements show aspects of the context of the mothers with regard to situations of institutional or programmatic vulnerability for the follow-up of premature infants. In this sense, aspects inherent to accountability and the quality of health care in situations of prematurity are inserted in the experiences reported by the participants, suggesting reflexes in the management of care and monitoring of practices and programs within the scope of health promotion and disease prevention.

DISCUSSION

The present study shows that premature birth and hospitalization can trigger vulnerabilities that interfere in the relationship between parent caregivers and their children. The fragility may increase the risk of problems in child development and behavior, especially in the cognitive and expressive language fields, as well as impair the progress of maternal skills to care for the child at home[15].

In addition, premature babies are less active and responsive, which can weaken parental involvement in interactive processes[3]. The vulnerability of premature infants in the interactional process becomes a concern regarding the development of the child[7].

The harmful effects of vulnerable interactions can be minimized when health professionals support and facilitate the progressive approximation between mother and child while in the hospital, contributing to a better interactive processes[16]. It is necessary to create opportunities for long and supportive interactions[7].

Another important issue refers to the experience of a healthy pregnancy: this means that pregnant women could not be exposed to iatrogenic environments or situations, as shown in the present investigation. Such circumstances can favor premature birth, weaken the mothering process and have negative consequences on the development of children[17]. In the presence of these situations, the health team needs to contribute to carefully evaluate, monitor and intervene at home and in the care, as such problems may trigger maternal exhaustion and symptoms of postpartum mental disorders[18-19].

Considering the home care routine, mothers believe that their maternal role will be successful if they can breastfeed, as they recognize the benefits that breast milk offers to premature children, especially for their recovery and healthy growth. Faced with the inability to feed their child, feelings of guilt and shame can appear[3]. Maternal concerns about eating problems and, consequently, weight loss at home represent for mothers predictive factors of returns to the hospital. And considering that, during the hospitalization period, premature children present complications that directly influence their gain or loss of weight, it can prevent them from being discharged[20].

For this reason, it is necessary to rethink professional attitudes with mothers in delicate moments, because it is necessary to have true conversations, open for dialogue, giving them the opportunity to talk about their fears and difficulties regarding breastfeeding and weight gain. It is necessary for the professional to be attentive to the singularities of each mother and child, clarifying that breastfeeding is not the only way to provide care[21].

The biological vulnerability of the premature baby, highlighted by the mothers' narratives, corroborates other studies carried out in the South of Brazil, which followed the clinical evolution of premature children in the first year of life and identified that about 40% of these children required hospitalization, being respiratory problems the main cause for hospital returns[22].

It is worth mentioning that fear due to the clinical condition presented by the child while in the NICU is a feeling that remains in the memory of the mothers[23]. As a result, even though they are at home, mothers are vigilant about any different signs or reactions that the child may have; and when they need to be away, particularly due to the need to work, the feelings and perceptions that their child will not be safe become more intense.

In the process of caring for the premature child, both the excess of concern and the view that the child needs little stimulation and care can impair child development. It is important to mention the relevance of health professionals in providing assistance to encourage mothers, fathers and families regarding positive opportunities for development during the child's daily care. A Dutch study, which considered children regarding the relationship between the development of the preterm infant and the levels of maternal care, showed that the stimuli offered by the mother must be mediated, considering that both its excess and its absence can cause negative effects in the development of the child[24]. Family experiences should provide adequate and pleasurable opportunities for child development[7], particularly for those with parents, siblings, and other relatives.

The maternal statements also showed that returning home without the baby is not an easy situation, as it is marked by much suffering. Allowing parents to be present at the NICU will, in addition to allowing them to be with the child day and night, ensure that they build a relationship. It is important to highlight that, in the hospitalization process, the whole family routine is transformed, meaning that its members stay most of the time in the hospital. In this context, it is important to embrace families, especially the mother, who was found to be the most present caregiver, especially due to the needs of breastfeeding and being a company for the child.

The lack of a structure to provide comfort for the mother who needs to stay in the hospital, the intensity of noise from institutional technological devices, added to physical tiredness, emotional problems and the lack of time for self-care, are aspects that interfere in the hospitalization process of premature children. Such aspects can intensify the frailty of mothers who accompany the child, generating physical and mental health problems[25]. In this context, the investment of health institutions in resources to build and adapt spaces in order to improve care for hospitalized children and their families is relevant[25].

It is worth considering that as much as it is not possible to minimize the family's suffering caused by the child's health condition, it is essential that professionals and institutions strive to alleviate other sources of suffering. Thus, health practices based on elements such as attentive listening, dialogue, and communication are essential to support and strengthen people in vulnerable situations — such as the parents of premature infants, who need to acquire skills to care for their child at home[26-27].

In addition, performing basic care under the supervision of professionals still in the hospital and valuing the practical knowledge of the mothers guarantee mothers more confidence in their actions[27]. For example, bathing the premature baby, described as a difficulty at home, can be practiced by mothers before hospital discharge, which would improve their abilities and confidence at performing this care at home.

Considering this situation, hospital discharges require careful programming and cannot be notified to the family suddenly, as was pointed out by this investigation; it should be planned and participative[2,28]. Scientific literature indicates that discharge planning must be individualized, with clear and secure information for the proper understanding of caregivers and, preferably, with the health team that already created a bond with the patient and the family[28-29]. Resorting to alternatives such as educational materials can enhance the health education process, as it simplifies routines and benefits caregivers with instructions that can improve their performance. The use of images is a valuable strategy, since it transforms the information in visual language, stimulating and facilitating the understanding of guidelines[30].

Teaching how to care for premature children at home, according to previous plans way and valuing family experiences, can allow caregivers to develop their sense of responsibility and, consequently, reduce stress and new hospitalizations, as well as instigate the search for resources in the community to supply the child's needs after discharge[30]. In this context, it is also worth pointing out the importance of community responsibility[7], as the care for the most vulnerable children and families can be positively benefited when there is a supportive community.

Regarding the maternal reports of situations of institutional or programmatic vulnerability for the follow-up of premature babies, the literature shows many problems in Primary Care services, such as incomplete surveillance of neuropsychomotor development; precarious knowledge of development goals; vulnerable and detached interactive processes; difficulties in accessing and scheduling appointments; the lack of pediatricians in some services; constant changes of professionals in the units; delay in referrals for exams and specialized consultations[1]. The follow-up of a premature baby after discharge still seems to be a challenge for the Primary Health Care. It is a situation permeated by concerns, doubts, and insecurities, where professionals

are not always able to identify the needs of the premature child and to perform the care demanded by them and their families[31].

The permanent education of health professionals is recommended for the continuous work of health units in order to enable professional updating based on the gaps present in daily routines, especially considering the need for training the health team for the care of premature babies. For professionals to work with a collective and integral approach, it is necessary to highlight technical training and include a social support network, which should be conceived as a strategic action aimed at promoting health and reducing damages to child development[1,7].

Situations of vulnerability, in the individual and family spheres, and those found in the interface with health services found in this study, involve the individual, social, and institutional dimensions[10]. These results highlight the circumstances experienced by mothers after discharge, expressing that they are *not* vulnerable themselves, but may *be momentarily* vulnerable under certain conditions and at different times[12].

The setting under study is a municipality at the border, and it is worth noting that mother and child care become weaker as health financing is influenced by population mobility between countries, and the financial support only takes into account the population who lives in the city. However, health care is provided to the entire floating population, which leads to overload of health services and problems with investments in the sector[32]. Also, situations of this nature suggest shortcomings in health promotion, compromising attention to more vulnerable segments such as the child born prematurely, and impacting infant morbidity and mortality in these regions.

Study limitations

This study focused on the first six months after hospital discharge of the baby from the NICU, and points out to the need to accompany mothers with premature children after 6 months of age, considering that new vulnerabilities may surface at home — families need support from professionals and from the community to exercise care safely and autonomously, thus guaranteeing the safe and healthy development of their premature child. In this context, the object under study is complex, meaning that it is important to expand it to other investigations, having as a background the observation of care and interventions to reduce vulnerabilities in the home.

Contributions to the field of Nursing, Health, or Public Policy

The study contributes to the strengthening of good practices in the hospital environment regarding the insertion of mothers in care, aiming to enhance the promotion of their skills for when they arrive at home, and leading them to acquire autonomy and security to recognize and meet the health needs of the premature child. In addition, the present research also contributes to the design of strategies that guide improvements in the quality of the follow-up to premature infants in primary care services, especially in border regions, considering the shortcomings in the cooperation between countries to guarantee access to public health services.

FINAL CONSIDERATIONS

The present investigation made it possible to identify vulnerabilities regarding the exercise of maternal care at home for children born prematurely, namely: weaknesses in moments of interaction; fear and insecurity for taking care of a fragile child; lack of institutional motivation to exercise the maternal role; insecurity in practices regarding nutrition; perception of the possibility of illness in the child and of returns to the hospital; differences in the premature child that can compromise their health condition; long-term development concerns; thinking that there is no need to stimulate children at home; lack of interactive processes in the hospital; fragility in the preparation for home care; absence of hospital discharge planning; and discontinuity of follow-up of premature infants in primary care services.

In the analysis of such vulnerable situations for the premature child, it was found, through dialogs with the participating mothers, that there are circumstances regarding prematurity that reiterate the interconnected individual, social, and institutional dimensions. Thus, it is important to highlight that the institutional dimension, in view of the great responsibility of health professionals, must not increase individual and social vulnerabilities, but promote care and seek to reduce situations that generate risks, uncertainties, concerns and damages.

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