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RESEARCH

FAMILY DEMANDS AND RESOURCES IN ADAPTING TO HOME CARE FOR PRETERM BABIES FROM THE MATERNAL PERSPECTIVE*

*DEMANDAS E RECURSOS FAMILIARES NA ADAPTAÇÃO PARA O CUIDADO DOMICILIAR AO PREMATURO NA PERSPECTIVA MATERNA**

*DEMANDAS Y RECURSOS FAMILIARES EN LA ADAPTACIÓN AL CUIDADO DOMICILIARIO DEL PREMATURO DESDE LA PERSPECTIVA MATERNA**

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ABSTRACT

Objective: to examine family demands and resources in adapting to care for preterm babies at home from the maternal perspective. **Method**: qualitative, descriptive, exploratory study guided by the theoretical framework of Resilience, Stress, Adjustment and Family Adaptation. Twenty-two mothers of children whose gestational age at birth was less than 32 weeks were interviewed. The mothers acted as informants on the daily dynamics of the family for the care of preterm babies. The MAXQDA© software was used to support the thematic analysis. **Results**: from the maternal perspective, the family demands identified were increased household chores, constant dedication and care for the child, greater availability of time to attend health care appointments, less social contact and purchase of products for child care. To meet the demands, the family used its own resources, such as spirituality, financial resources and reorganization of the routine, as well as external resources, such as access to health services and the support network, represented by the family and its members individually. **Conclusion**: demands require effort to be met, indicating that they can contribute to increased family tension and changes in daily life; however, the families' own and external resources contributed to coping with the situations experienced. In practice, nurses' recognition of demands allows them to direct actions to identify and use family resources seeking their adaptation.
Keywords: Infant, Premature; Patient Discharge; Nursing; Qualitative Research; Child Care.

RESUMO

Objetivo*: examinar as demandas e os recursos familiares na adaptação para o cuidado à criança nascida prematura no domicílio na perspectiva materna.* ***Método****: estudo qualitativo, descritivo exploratório, guiado pelo referencial teórico de Resiliência, Estresse, Ajustamento e Adaptação Familiar. Foram entrevistadas 22 mães de crianças cuja idade gestacional de nascimento foi menor que 32 semanas. As mães se configuram como informantes da dinâmica cotidiana da família para o cuidado ao prematuro. O software MAXQDA© foi utilizado para apoio à análise temática.* ***Resultados****: sob a perspectiva materna, as demandas familiares identificadas foram aumento de afazeres domésticos, dedicação e cuidados constantes com a criança, maior disponibilidade de tempo para comparecer aos atendimentos de saúde, menor contato social e aquisição de produtos para o cuidado à criança. Para atender às demandas a família utilizou de recursos próprios, como espiritualidade, recursos financeiros e reorganização da rotina, bem como de recursos externos, como acesso a serviços de saúde e a rede de apoio, representada pela família e seus membros individualmente.* ***Conclusão****: as demandas exigem um esforço para que sejam atendidas sinalizando que podem contribuir para o aumento da tensão familiar e para mudanças no cotidiano, contudo os recursos próprios e externos às famílias contribuíram para o enfrentamento das situações vividas. Na prática, o reconhecimento das demandas pelos enfermeiros permite-lhes direcionar ações para identificar e utilizar os recursos familiares buscando a sua adaptação.*
Palavras-chave: *Recém-Nascido Prematuro; Alta do Paciente; Enfermagem; Pesquisa Qualitativa; Cuidado da Criança.*

RESUMEN

Objetivo*: examinar las demandas y los recursos familiares en la adaptación al cuidado del niño nacido prematuro en el hogar desde la perspectiva materna.* ***Método****: estudio cualitativo, descriptivo exploratorio, guiado por el marco teórico de Resiliencia, Estrés, Ajuste y Adaptación Familiar. Se entrevistó a 22 madres de niños cuya edad gestacional al nacer fue menor de 32 semanas. Las madres se consideran informantes de la dinámica diaria de la familia para el cuidado del prematuro. Se utilizó el software MAXQDA© para apoyar el análisis temático.* ***Resultados****: desde la perspectiva materna, las demandas familiares identificadas fueron el aumento de las tareas domésticas, la dedicación y los cuidados constantes del niño, más disponibilidad de tiempo para asistir a las citas médicas, menor contacto social y adquisición de productos para el cuidado del niño. Para hacer frente a estas demandas, la familia utilizó recursos propios, como la espiritualidad, los recursos financieros y la reorganización de la rutina, así como recursos externos, como el acceso a servicios de salud y la red de apoyo, representada por la familia y sus miembros individualmente.* ***Conclusión****: estas demandas requieren un esfuerzo para ser atendidas, lo que puede contribuir a aumentar la tensión familiar y provocar cambios en la vida diaria. Sin embargo, los recursos propios y externos de las familias contribuyeron a hacer frente a las situaciones vividas. En la práctica, el reconocimiento de estas demandas por parte de los enfermeros les permite dirigir acciones para identificar y utilizar los recursos familiares en busca de su adaptación.*
Palabras clave: *Recién Nacido Prematuro; Alta del Paciente; Enfermería; Investigación Cualitativa; Cuidado del Niño.*

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INTRODUCTION

A Prematurity is a global problem, and estimates show that the prevalence of premature birth is high in both developed and developing countries. Furthermore, there has been a tendency for this prevalence to increase over the years[1]. There is a directly proportional relationship between the risk of morbidity and mortality in the first year of life and the lowest gestational age at birth, even with all the technological advances in perinatal care[2,3]. This fact emphasizes the importance of continuous care for children born prematurely and their families[2,3].

Preterm babies require ongoing care, varying in duration and complexity, after hospital discharge. These demands include: greater need for health services[4], frequent use of medications[5], access to rehabilitation therapies[5], special requirements regarding food, including the route of administration, form of supply, type of food and its consistency[6], in addition to the need for monitoring body temperature, cleaning the home environment and extra care when visiting poorly ventilated places or places with large crowds[7]. Furthermore, preterm babies have a high risk of readmissions[5] and a greater likelihood of developing chronic conditions[4].

Evidence indicates significant changes in the daily lives of families due to the health condition of preterm babies, affecting the work and social life of parents[3,7]. The family plays a central role in the care of preterm babies at home[8]. However, it is mostly mothers who face the greatest challenges, taking on full responsibility for care after hospital discharge[8]. In this study, the concept of family was adopted as a social group formed by people related biologically or through long-lasting commitments, encompassing different generations and genders, playing roles that involve socialization, upbringing and emotional bonds[9].

The insertion of a preterm baby into the home environment implies changes in the family routine, requiring adaptation to this new reality[5]. Adaptation is a process of changes in family functioning in the face of new events[10], in this case, characterized by caring for the premature child at home after hospital discharge. Changes that meet the needs of all family members indicate successful family adaptation[10].

In this study, family adaptation is seen as an event that encompasses multiple facets, whose elements interact to determine family functioning[10]. Such elements include: family perception, vulnerabilities, coping and problem-solving strategies, social support, family dynamics, family demands and resources[10], the last two being the focus of this study.

Family demands refer to situations experienced by families that can cause stress and lead to an accumulation of tensions, which in turn increases the fragility of the family system and makes the process of adapting to a new stressful situation difficult[10]. In this study, such a situation is represented by the home care of a preterm baby after hospital discharge. Family resources, on the other hand, refer to the potential that the family or its members have to face the crisis[10]. This potential can be mobilized in the face of the multiple demands of caring for a preterm baby at home, encompassing financial, spiritual and social resources.

It is assumed that the arrival of a preterm baby at home causes changes in family functioning, resulting from their care needs, which may be more or less met by the family. The way in which the family manages these demands, making use of the available resources, is crucial. An imbalance between the demands and the family's resources can generate tensions and conflicts, affect the family's adaptation and the satisfaction of the child's needs, leading to dysfunctions in the management of the experiences lived.

Therefore, recognizing the importance of family demands in incorporating care for their prematurely born children at home, as well as the need to identify resources to meet these demands and the relationship between available resources and family demands for adaptation to care, the following objective was established: To examine the demands and family resources involved in adapting to care for prematurely born children at home from the maternal perspective.

METHOD

Type of Study

This study has a qualitative approach and descriptive-exploratory character, guided by the theoretical model of Resilience, Stress, Adjustment and Family Adaptation of McCubbin and McCubbin[10]. The recommendations established by the Consolidated Criteria for Reporting Qualitative Research (COREQ) were adopted[11].

This work is a segment of a more comprehensive research, entitled “Family adaptation to the situation of premature birth during hospitalization in the Neonatal Intensive Care Unit (NICU) in the 1st, 3rd, 6th, 9th and 12th month after hospital discharge: a longitudinal and mixed-methods study”. The main objective of this study

was to investigate the process of adaptation of families to premature birth during the stay in the NICU, as well as in the 1st, 3rd, 6th, 9th and 12th months following discharge[12].

Participants

Twenty-two mothers of preterm babies who had been discharged from the NICU (Neonatal Intensive Care Unit) of a philanthropic hospital located in a capital city in the Southeast region of Brazil participated in the study. It is important to note that the research focused on the main caregivers of these children, who were, without exception, the mothers. They are essential informants on the daily dynamics of home care for prematurely born children. Considering the family as the primary environment for the child's growth and development, data provided by an individual family member constitute a valuable and appropriate source of analysis[13]. Therefore, the participating mothers represent their families in this study, offering information about family functioning, including available resources and needs in preterm baby care.

The choice of the setting is due to the fact that it constitutes a reference maternity hospital in humanized care for women, children and newborns, both in Brazil and in Minas Gerais. This institution stands out for its multidisciplinary approach and adoption of humanization strategies, including accommodations so that women can remain with their children during their stay in the NICU and ICU (Intermediate Care Unit), encouraging paternal presence, support for breastfeeding, “kangaroo mother and/or father” care, family engagement and outpatient monitoring of high-risk newborns after discharge.

The data used in this study come from a broad survey, whose convenience sample included 181 fathers or mothers of children who met the inclusion criteria. The criteria defined were being the main caregiver of a preterm baby born with a gestational age of less than 32 weeks and who required hospitalization in the NICU. The selection of gestational age was based on the high risk for chronic health conditions, changes in growth patterns and delays in neuropsychomotor development, requiring systematic monitoring after hospital discharge[14]. Caregivers who had communication difficulties or cognitive impairment, conditions that could affect their responses to the instruments, were excluded. These criteria were verified based on records of care provided to the family by the multidisciplinary team during the child's hospitalization.

Of the 181 participants eligible for the broad survey, 83 agreed to participate in the data collection phase during their NICU stay. Of these, they were selected for follow-up after hospital discharge. In the first month after discharge, of the 83 families included during hospitalization, 12 deaths were recorded, 46 failed telephone contact, two withdrawals from the study and one transfer of the child to another institution before discharge, totaling 22 subjects for this research.

Data Collection

Data collection was carried out using a questionnaire to characterize the sociodemographic featueres of families and children, and a semi-structured interview based on the theoretical frameworks of Resilience, Stress, Adjustment and Family Adaptation by McCubbin and McCubbin[10]. The sociodemographic questionnaire included questions about maternal age, marital status, parity, prenatal consultations, place of residence, education, ethnicity and religion. The interviews sought to explore the caregivers' perception of family adaptation to caring for preterm babies at home, as detailed in Figure 1.

In the first phase of the study, from September 2018 to September 2019, interviews were conducted in person with families during the preterm baby’sinteraction in the NICU. The second phase of the research, corresponding to the data presented in this article, took place from October 2018 to October 2019 and was conducted one month after the child's hospital discharge, through telephone contact.

At the time of the call, the researcher provided information about the second phase of data collection and

Figure 1 – Semi-structured interview script.

1. Describe to me a typical day in your child's life.
2. How would you describe your child's day compared to other children his/her age??
3. Tell me about some of your child’s needs that you feel you meet well. Are there any needs of your child that you are unable to meet? If so, which ones? If you were to hire someone to meet your child’s daily needs, how many hours per week would that person work? What would their job description be? What would they need to know or learn?
4. What are the biggest challenges you and your family face in caring for your child? What types of things help you deal with these challenges? How would you describe the impact of having a preterm baby on your family’s day-to-day life??

Source: Elaborated by the authors

confirmed with the participant about her interest and availability to remain in the study, guiding her on the need for a safe and private place for the interview. Then, the interview was conducted by telephone on the same day or, depending on the participant's wishes, a date and time was scheduled for the interview. In total, 13 interviews were conducted by telephone contact. In situations where telephone contact was difficult, it was decided to collect data when the child returned to the institution's outpatient clinic, during the third stage of the Kangaroo Method. The face-to-face interview with nine participants was conducted individually, in a quiet and private environment, maintaining the participant's confidentiality.

Data analysis and processing

The interviews lasted an average of ten minutes and six seconds, ranging from five minutes to twenty minutes and thirty-five seconds. They were conducted by a group of nurse researchers with experience in the topic, including the first two authors of this study, who did not know or have any previous contact with the participants. The interviews were audio-recorded and later transcribed in full by the first author of this study. After transcription, the interviews were submitted to deductive thematic analysis[15], from the perspective of the Family Resilience, Stress, Adjustment and Adaptation Model[10].

To organize and code the data, verify agreement between coders and support the analysis, the MAXQDA© software, version 20.2.1was used[16]. In order to ensure the anonymity of the participants, the interviews were identified according to the degree of kinship with the child, with "M" for "mother", followed by the order number of the interview, for example: M24. The term "my son" was standardized to anonymize the names of the children mentioned during the interviews.

Initially, codes were defined based on six components of the theoretical framework: family demands and family resources, family appreciation, social support, vulnerabilities, coping strategies and problem solving[10]. For this article, the codes used referred to Family Demands and Resources, defined according to the theoretical framework and the objective of the investigation. Demands were understood as situations experienced by families that can cause stress and accumulate tension, increasing the fragility of the family system and making it difficult for the family to adapt and cope with these moments[10]. Resources refer to the family's ability to face the stressful event and deal with its demands, and may be internal to the caregivers or external to them[10].

Two researchers, a researcher with experience in the topic, coded three interviews simultaneously, selecting the text fragments relevant to the previously defined codes. The codings were subsequently compared by the coders, together with another author of the study, to verify the need for refinement of the codes and alignment in the application. After this stage, a new round of independent coding was conducted, resulting in a Kappa index of 0.83 for intercoder agreement. The remaining interviews were coded exclusively by main researcher, and the doubts were discussed to reach a final consensus.

Ethical Aspects

The research followed the regulations established by Resolutions 466/2012 and 580/2018 of the National Health Council[17,18], and was only carried out after receiving approval from the Research Ethics Committee of the proposing institution, in accordance with opinion report number CAAE: 37059020300005149.

RESULTS

Features of the Participants

The age of the participants ranged from 16 to 40 years, with a median of 29 years. Of the participants, 16 (72.7%) did not live in the city where the child was hospitalized. Regarding marital status, 13 (59.0%) lived with a partner, eight in a stable union, five married and nine (41%) were single. Most participants had between 11 and 13 years of school education (54.5%), followed by those with eight to ten years of school education (22.7%), 15 years or more of school education (18.1%) and, lastly, one to seven years of school education (4.5%). Regarding monthly family income, three participants reported not knowing what their family income was, five said they had an income of one minimum wage and the others declared having a family income above one minimum wage, with the highest declared income being four minimum wages. A total of 21 participants followed a religion (95.45%).

Gestational age at birth ranged from 26 weeks to 31 weeks and four days. The mother was identified as the child's primary caregiver in 20 (90.9%) of the cases; in two families, participants considered both the mother and the father to be the primary caregivers (9.09%). All children were being monitored by some health service at the time of the interview.

Analytical Categories

Data analysis to meet the objective of this research was performed under two categories: Care demands of preterm babies after hospital discharge; Family resources for care of preterm babies after hospital discharge[1,2]. It is important to note that the experiences lived by families, which make up the categories, are interconnected by a complex process of interaction. These categories are correlated, demonstrating the family organization for adaptation to home care of a premature child.

Care demands of preterm babies after hospital discharge

The demands presented by children born prematurely after hospital discharge are determined by their risk condition and, thus, are related to situations that aim to maintain their health and well-being. Participants reported demands for care in the home environment and reduced social interaction to minimize the risk of illness, constant surveillance to prevent problems such as choking and pulmonary aspiration, the need for continuous care to ensure that comfort, safety and food needs are met, availability of time for health consultations and the acquisition of specific products for care.

Although the demands presented by preterm babies are similar to those with no risk, the participants' statements allow us to identify distinctions between these two situations. The intensity of the demands was highlighted by the use of expressions such as "very careful" (M63), "having someone near her at all times" (M20), "there are more doctors" (M63). Furthermore, the demands also differ according to the repercussions of the hospitalization experience and the severity of the child's condition at birth. This is evidenced by statements such as "we are very afraid of her going back to the hospital" (M63) and "we are worried" (M20). Figure 2 presents the information that makes up the category and selected fragments of speeches to illustrate them.

Family resources for care of preterm babies after hospital discharge

This category presents the resources that assisted the family in managing the care of a preterm baby at home. The resources identified are based on both the caregivers' own capabilities and external supports, and are recognized by their presence or absence.

Among the caregivers' own resources, the following were identified: spirituality, the ability to reorganize the routine for child care, and financial resources. On the other hand, external resources include the support of the family and its individual members, as well as monitoring carried out by health institutions. In addition, access to health services, similar to financial resources, was highlighted by its absence in the reality of some families.

It is observed that these resources contributed to increasing maternal safety in care by allowing, for example, through spirituality, the mother to believe that her strength is not internal, but divine (M118). The extended family and its members represented a source of practical support, both in direct child care and in other household tasks. This helped women feel empowered to care, as illustrated in the reports: “she [my sister-in-law] is even at home today helping me, cleaning the house and my mother helps me with the laundry” (M112), “my mother was showing me how to do it” (M168), “He [partner] cleans the bag when I don’t” (M63).

Mothers’ ability to reorganize their routines emerged as a crucial resource, enabling them to remain the primary caregivers. To achieve this, women changed their eating, sleeping and household chores habits, some even leaving their jobs to adapt to the new routine, highlighting the depth of the changes required in this caregiving context. When mentioned by participants, financial resources were highlighted as lacking to meet the demands of childcare. These resources are essential for families to be able to purchase childcare products and maintain recommended health monitoring.

Regarding health services, the statements highlight access, difficulty in accessing and lack of access to this essential resource. It is important to highlight that, although not all participants mentioned access to health services as a resource, the family's sociodemographic data indicate that all children had some type of care, with 10 being followed up in specialized outpatient clinics and primary care, 7 only in primary care and 11 exclusively in specialized outpatient clinics. However, it was the lack of access that stood out in the maternal discourses. Figure 3 presents the information that makes up the category, along with fragments of discourses selected for exemplification.

Figure 4 presents a schematic summary of the information that underpinned the formation of the categories. conformação das categorias.

DISCUSSION

This study made it possible to examine the demands and resources used by families of preterm babies for home

Figure 2 – Category – Care demands of premature babies after hospital discharge

Demands of preterm babies on families	Examples of Statements
Hygiene care in the home environment	*We are very afraid of her catching an infection, having a bactéria infection again, so we are very careful with that. With the hygiene of the house, cleaning, everything so that she doesn't get sick, because we are very afraid of her going back to the hospital, being admitted (M63).*
Constant monitoring to prevent situations such as choking and pulmonary aspirations	*Eu estava tranquila até ela começar a engasgar, né? Então a gente fica preocupado e tem que toda hora ter alguém perto dela (M20). Primeiro eu não consigo dar ela sozinha, preciso de alguém, tem que ser de duas pessoas (...) e é com uma colherzinha, que uma pessoa segura a colher e a outra vai com uma seringa colocando aos poucos, mas no mais as outras vitaminas é só colocar na seringa (...) e dar na boquinha, essa daí é mais difícil que ela é mais viscosa e ela cospe (...) ela toda, ou pode acontecer dela engasgar (M16).*
Availability of time to attend health care appointments	*The impact... I think the care itself, which demands a lot, and the routine, right? Doctor, hospital, health center, outpatient clinic, because preterm babies have to see more doctors, demands more follow-ups, right? There is follow-up over almost everything, so I think it demands more of our time, right? I think that's in our daily routine (M63).* *[The health service] is far from home, so it takes a long time to get there (M16).*
Need for ongoing care	*I came home and I had to take care of her, I didn't have time to sleep, I didn't have time for anything, so I wasn't going to have peace and a quiet time, because I was sleeping too much, that, that rush of everyday life to take care of her, so I didn't have milk, I didn't breastfeed, which I know she needs (M151).* *[...] sometimes you have to wake up quite often, then you end up being a zoombie, and the baby requires you to breastfeed, breastfeed, breastfeed (laughs) (M168).* *Sometimes, When "my son" doesn't sleep I just can't have something to eat, no time to have lunch (M112).*
Less social contact	*So the biggest impact was the care, right? That many people don't understand, the fact of not being able to receive a large number of visitors, of not being able to leave the house with the baby to go anywhere (M116).* *The fact that the pediatrician asked her to stay at home as much as possible and she has to stay inside the house and I also have to stay with her, but there are days when we have to go out to resolve something, that's the biggest difficulty for me and for my family in general, is having to stay safe at home (M151).*
Increased expenses and acquisition of care products	*All because having a child is good, but it's a lot of expense, there are diapers and wet wipes, there are so many things and when they start to run out, the mother's head starts going crazy, oh, we're going to run out of this, we're going to run out of that (M118).*

Figure 3 – Category – Resources used by the family in the care of premature babies

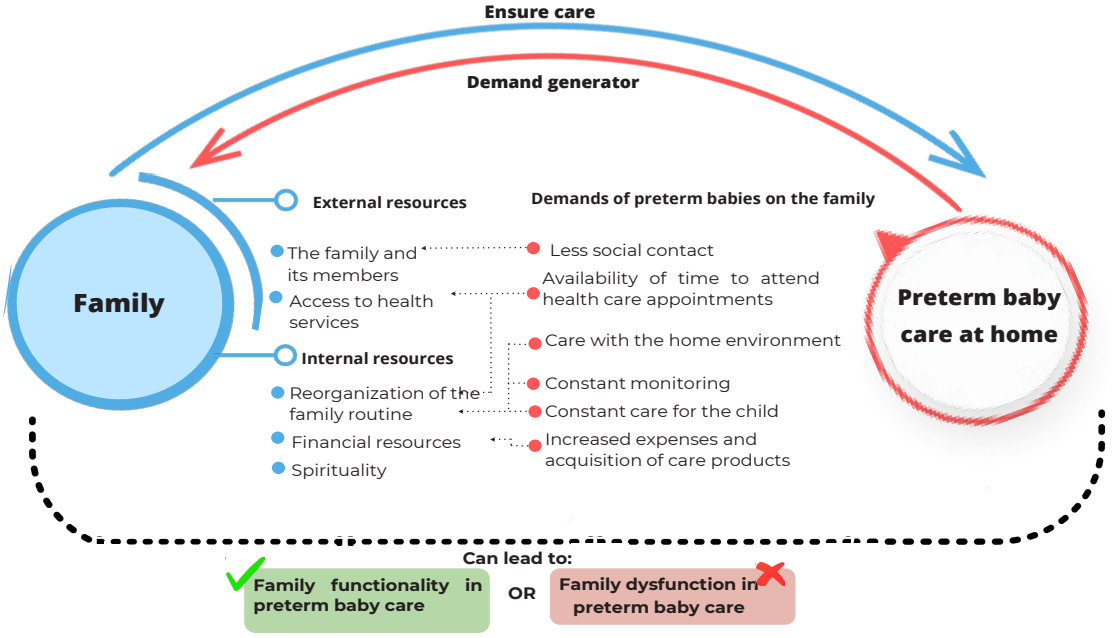
Recursos utilizados pela família	Exemplos de Enunciados
Spirituality	*The first impact is a frustration that leaves that romantic pregnancy behind. Once the frustration has passed, there is fear, fear of losing your baby, and then you start talking, praying, asking God in a non-stop mode, you feed your faith a lot, because only God can reverse this situation (M63).* *I learned that we are strong, yes, for going through any situation, even if we think we are not capable, that we will not succeed, yes we are strong, that strength does not come from us, strength comes from God (...) And I learned to have more faith in God, because when we are with our child in the hospital, if we lose faith we cannot stay, faith has to be the main thing (M118).* *Everyone in my family is praying, giving strength, thank God, she was born very small, but now thank God she has grown well, they say she has developed a lot (M149).*
Reorganization of the family routine	*Because they have their own waking time and if I wake up at the same time as them, there's no time to do the housework, you know, I have to get up earlier to do the housework so that when they wake up, the time is theirs, right? That's how it is (M184).* *Right now, I'm dedicated to "my daughter". My maternity leave is already over, but I've already resolved it at the company, right? I've already resigned, so I can dedicate myself to her because I know she needs me in these first months of her life, maybe even the first year of her life. She, you know, demands more care, right? Yeah, but nowadays, everything has a schedule (M63).* *(...) I stopped working as soon as I was admitted, I was working here at home, but I'm not going back now, I'm going to take care of him for a while longer (M160).*
Financial	*The challenge is that I wanted to be working to buy everything he needs, (...) especially when we are looking for a job and can't find one, sometimes my head gets full because of this, when I see his things running out and I'm not working, it's just my father and he earns little (M118).* *The father of "my son" didn't want to help with anything, you know? So sometimes he didn't even ask about him or anything, but now things are working out. Thank God, he said he'll help, deposit the money for "my son", (...) it's hard to have to wait all this time, because the boy's things run out, right? (M118).*
The family and its members individually	*Not here in the city, but my sister-in-law came to help me, I told you, right? She's even at home today helping me, cleaning the house and my mother helps me with the laundry. She helps me a lot (M112).* *It's okay, I was a bit scared the first few days, but I'm more confident now. My family helps me a lot and that makes a difference (M25).* *Oh no it's just us, my husband, my daughter and I, you know? Sometimes if we need to go out, you know, then the aunts come in, or grandma stays with one when she can't take it with her, you know, right? (M184).* *I looked for my mother, my mother showed me how to do it, then I started to notice my mother bathing her, then I saw the way my mother held her, then I said, "Mom, now I'm going to bathe her, I'm going to try to bathe her today", then I picked her up properly and bathed her, then my mother said, "Wow", then I said, "We learn by watching" (laughs) (M168).* *When I need to go out, sometimes I arrange it with her father, and her father look after her. (...) we understand each other, we divide the tasks well, because he is very dedicated, he changes the bag, right? He cleans the bag when I don't, so it's well shared (M63).*
Access, difficulty or lack of health services	*IShe is being well monitored, both in the hospital and at the clinic (...) They teach us how to deal with her, how to proceed and take care of her. The information helps a lot (M116).* *Yes, I have access to the health center, they give guidance, they ask if you need anything, and when you need it, you can look for it (...) that's the help we have (M184).* *Because in that case I would have to see a doctor, a neurologist, but for now there is no way, he is so small thus it is complicated and there is no such thing in my city, I have to go to another city. And sleep, you know, it accumulates and then it hurts, then my head and stomach hurt (M112).* *At [the health institution] it's difficult. Even though it has a car, they don't come to pick me up. It's far from home, it's close to my work, so it takes a long time to get there (M16).*

Source: Research data.

care, from the maternal perspective, and confirmed the assumption that, with the arrival of the child at home, changes occur in family functioning to make care viable. A close relationship was identified between the demands required for care and the types of resources mobilized by the family. Different resources were presented, both internal and external, which are essential for managing the demands arising from the preterm baby and necessary to ensure care after hospital discharge. Situations considered stressful, such as home care for a preterm baby, require the family to deal with and organize themselves in the face of new demands. The existence of resources to deal with the stressful situation allows families to experience less suffering and a more positive family adjustment[10].

The data from this research indicate that the main demands highlighted by mothers are constant surveillance and the need for continuous care for the preterm baby. This perception may arise from the assessment that the family makes of the child in the first month after hospital discharge, a period in which they still place greater emphasis on fragility and the need for constant care. These data reinforce the importance of considering the family as the protagonist of care from admission to the Neonatal ICU, offering support so that they can deal with

Figure 4. Demands and resources for home care of preterm babies



Source: Elaboraded by the authors.

fears and insecurities and develop skills to carry out care at home after hospital discharge[19,20].

It is clear that there is a demand for care for preterm babies and that it requires greater dedication, attention and time from caregivers. The availability of time is mentioned in the statements as a demand to attend multiple health care appointments to monitor the child's growth and development or some specific health condition. Most families did not live in the city where the child was hospitalized and, to receive follow-up care in specialized outpatient clinics, mothers needed to travel between cities, which required time and reorganization of the family routine to make it possible for the child to be present in these health monitoring spaces. Evidence points to continuous maternal efforts, involving time and reorganization of the routine, aiming at continuity of care for the child[12,21].

In addition to time, the literature points to the need for financial resources to displace to health services[22], whether for transportation or food. This study did not highlight the need for these resources for transportation, which can be explained by the provision of transportation by municipal health departments, thus avoiding the family from absorbing this cost. The increase in economic demand related to the social cost of treatment and recovery of preterm baby is an issue that deserves attention from health professionals, who must identify early on the life contexts that put the care of premature children at risk by their families, perceiving this identification as a trigger for the mobilization of other resources external to the family[20].

Additionally to the care demands directly directed at the child, there is the demand for care with the hygiene of the home environment, given the susceptibility of preterm babies to illness. Therefore, mothers need to reorganize their family routine to also incorporate care for the environments in which the child lives. Household chores, combined with the demands of caring for a preterm baby and caring for other children[23], in addition to health care[22], contribute to maternal overload[24]. To deal with this overload, mothers can resort to resources, whether internal or external. In the present investigation, internal resources, that is, those related to the participants themselves, were mentioned by them. Spirituality is an example of these internal resources that, for the mothers in this study, provided hope and generated strength to meet the needs of their preterm baby. Similar to other studies, this resource was used by women as a source of comfort[24], and internal control over their feelings, allowing them to better face the crisis situation[25].

Regarding external resources for caring for preterm babies, family members stood out, with the main sources of support mentioned by participants being people with whom they have strong ties, including the maternal grandmother and partner[22,26]. It is worth noting again that most mothers did not live in the city where the child was hospitalized, which may compromise the mobilization of their support network during the child's hospitalization. With the return home and the reduction of social contact to protect the child, the support network tends to distance itself, limited to people who live in the same household, which may explain the preference for less social contact expressed in maternal statements.

Access to health services was identified as an important resource for care, especially as it is a source of relevant information for continuing care at home. The prolonged hospitalization of the premature baby strengthened the participants' bond with the multidisciplinary team at the maternity hospital. However, the same was not observed in relation to the team at the follow-up outpatient clinic, possibly because data collection was performed in the first month after the child's discharge.

In the data analysis, family resources related to access to health services were identified mainly through the lack of access, as reported by the participants, and not through their availability. This perception appears to be a result of the first month after hospital discharge, a period in which families focus on practical issues of daily care. Considering that, for most of the families studied, access to the service was already established through the follow-up clinic of the institution where the child was born, this aspect may have been mentioned by participants concerned about the risk of losing this access. The reasons for the compromised access to health services are associated with the fragility of the public network in providing the necessary care.

Studies highlight numerous challenges for the follow-up of care for preterm babies in primary health care, mainly related to the lack of transition programs from hospital to home, which plan in advance the flow of care for the child and family within the health care network[27,28]. Furthermore, the lack of communication between high and low complexity sectors results in gaps in care, which is not thought of in a comprehensive and integrated way[27]. In the home environment, it is essential that there is a well-established health care flow for preterm babies, in order to favor the early recognition of risk situations and the management of possible health problems[27].

Healthcare professionals, especially nurses, should encourage maternal presence and participation in child care from the moment the child is admitted to hospital, as this impacts home care[29]. Nurses should be able to help families identify members of their support network, recognize risk situations, conduct active listening consultations, and provide guidance. In addition, it is essential to demonstrate and teach child care according to the family's concerns. After hospital discharge, nurses can implement actions that promote family adaptation to caring for premature children, such as creating practical and emotional support, providing guidance on home care demands, helping to identify available resources and finding unavailable resources, and addressing family concerns.

The results of this study show correlations between the demands identified by the participants and the resources used to meet them. Examples include the demand for continuous care, made possible by family participation and reorganization of care, and the demand for health care, facilitated or compromised by the condition of access to health services. The demands for which it was not possible to guarantee care through the available resources are largely determined by the living conditions of the participants, as evidenced by their socioeconomic situation.

The data reinforce the assertion that establishing home care for a preterm baby requires family adaptation, demonstrated by the reorganization of the routine and the mobilization of family members in the care. Changes are part of the family adaptation process, whether in the environment, in daily life or in family relationships. In order for the family to adapt to these changes, it is necessary to balance family demands and resources[10]. Imbalances

between these dimensions indicate possible dysfunctions in family organization and can compromise child care in the home environment. This information highlights the importance of healthcare professionals recognizing and enhancing available resources in order to meet the multiple demands of the preterm baby, favoring family adaptation and functioning in the new context of care.

CONCLUSION

Family demands require substantial efforts to be met, which can increase family tension and lead to changes in daily life. However, the use of resources, both internal and external to families, plays a crucial role in coping with these circumstances. In practice, recognition of these demands by professionals facilitates the guidance of actions aimed at identifying and using family resources, aiming at family adaptation.

Therefore, it is recommended that nurses encourage and support families of children born prematurely in identifying their support networks, offer clear and objective information about the necessary care for the child, carry out qualified listening to better understand the needs of caregivers, prepare caregivers to manage care in the home environment and, when necessary, for more effective monitoring and support for the family, mobilize the health care network.

A limitation of this study is the lack of participation of other family members, who could offer complementary perspectives. Future research should include other family members and the healthcare team in order to enrich the understanding of the topic.

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