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CONTINUITY OF CARE FOR PRETERM NEWBORN DISCHARGE FROM THE NEONATAL UNIT: FAMILY EXPERIENCES

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ABSTRACT

Objective: to investigate the continuity of care of preterm newborns discharged from the neonatal unit from the perspective of family members.
Method: qualitative exploratory study, based on the conceptual perspective of continuity of care, developed with 16 relatives of preterm newborns discharged from a neonatal unit of a university hospital in the state capital of Mato Grosso, Brazil. Data collection occurred from August to November 2019, through semi-structured interviews conducted in the participants' homes and subsequently submitted to the content analysis technique.
Results: the 16 family members reported their perspectives on the continuity of care for preterm newborns who graduated from the neonatal unit, revealing informational fragility in the scope of primary care and other health services; a satisfactory relationship through the link with the service in which the child was born, which is materialized by the access to the follow-up outpatient clinic; and difficulty access to care, lack of articulation and communication between the different levels of care, compromising the implementation of the reference and counter-reference between the services.
Conclusion: the continuity of care after discharge is brokered by the family itself, due to its protagonism and autonomy when caring for the child in the neonatal unit. Regardless of whether health services act in an articulated way, families seek health spaces, information and sources of support to support care.

DESCRIPTORS: Premature newborn. Family. Continuity of patient care. Care of the child. Transitional care. Neonatal nursing.

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CONTINUIDADE DO CUIDADO AO RECÉM-NASCIDO PRÉ-TERMO EGRESSO DA UNIDADE NEONATAL: VIVÊNCIAS DE FAMILIARES

RESUMO

Objetivo: investigar a continuidade do cuidado de recém-nascidos pré-termos egressos da unidade neonatal na perspectiva dos familiares.
Método: estudo exploratório qualitativo, fundamentado na perspectiva conceitual da continuidade do cuidado, desenvolvido com 16 familiares de recém-nascidos pré-termo egressos de unidade neonatal de um hospital universitário da capital do estado de Mato Grosso, Brasil. A coleta dos dados ocorreu de agosto a novembro de 2019, por meio de entrevistas semiestruturadas realizadas nas residências dos participantes e, posteriormente, submetidas à técnica de análise de conteúdo.
Resultados: os 16 familiares relataram suas perspectivas sobre a continuidade do cuidado de recém-nascidos pré-termos egressos da unidade neonatal, revelando fragilidade informacional no âmbito da atenção básica e outros serviços de saúde; relação satisfatória por meio do vínculo com o serviço em que ocorreu o nascimento da criança, que se materializa pela adesão ao ambulatório de seguimento; e dificuldade de acesso a atendimentos, ausência de articulação e comunicação entre os diferentes níveis de atenção, comprometendo a efetivação da referência e contrarreferência entre os serviços.
Conclusão: a continuidade do cuidado após a alta é agenciada pela própria família, pelo seu protagonismo e autonomia ao cuidarem da criança egressa da unidade neonatal. Independentemente de os serviços de saúde atuarem de forma articulada, as famílias buscam espaços de saúde, informações e fontes de apoio para subsidiar o cuidado.

DESCRITORES: Recém-nascido prematuro. Família. Continuidade da assistência ao paciente. Cuidado da criança. Cuidado transicional. Enfermagem neonatal.

CONTINUIDAD DE LA ATENCIÓN AL RECIÉN NACIDO PRETÉRMINO DE LA UNIDAD NEONATAL: EXPERIENCIAS FAMILIARES

RESUMEN

Objetivo: investigar la continuidad de la atención a los recién nacidos prematuros dados de alta de la unidad neonatal en la perspectiva de los familiares.
Método: estudio cualitativo exploratorio, basado en la perspectiva conceptual de la continuidad del cuidado, desarrollado con 16 familiares de recién nacidos prematuros dados de alta de la unidad neonatal de un hospital universitario de la capital del estado de Mato Grosso, Brasil. La recolección de datos ocurrió de agosto a noviembre de 2019, a través de entrevistas semiestructuradas realizadas en los domicilios de los participantes y posteriormente sometidas a la técnica de análisis de contenido.
Resultados: los 16 familiares relataron sus perspectivas sobre la continuidad de la atención a los recién nacidos prematuros dados de alta de la unidad neonatal, revelando fragilidad de la información en el ámbito de la atención primaria y otros servicios de salud; relación satisfactoria a través del vínculo con el servicio donde nació el niño, que se materializa a través de la adhesión a la clínica de seguimiento; y dificultad de acceso a la atención, falta de articulación y comunicación entre los diferentes niveles de atención, comprometiendo la efectividad de la referencia y contrarreferencia entre servicios.
Conclusión: la continuidad del cuidado después del alta es gestionada por la propia familia, debido a su protagonismo y autonomía en el cuidado del niño dado de alta de la unidad neonatal. Independientemente de que los servicios de salud funcionen de manera articulada, las familias buscan espacios de salud, información y fuentes de apoyo para subsidiar la atención.

DESCRIPTORES: Recién nacido prematuro. Familia. Continuidad de la atención al paciente. Cuidado de los niños. Cuidado de transición. Enfermería neonatal.

INTRODUCTION

Discharge from the Neonatal Intensive Care Unit (NICU) and the transition of care to the premature newborn (PTNB) to the home is a critical period of adaptation and reorganization of the family's daily life to meet the child's needs[1]. This requires multiprofessional monitoring and differentiated and sometimes complex care, especially when there is a chronic condition or dependence on technology resulting from prematurity[2]. It is common for the family to experience a constant search for care and a pilgrimage through the different levels of health care in order to ensure the continuity of care[3].

Technological advances in intensive care environments, especially with the use of modern therapeutic equipment, have resulted in progress in the care of newborns, contributing to the reduction of neonatal mortality and improvement of the quality of care. On the other hand, the prevalence of neonatal morbidities has increased significantly, making follow-up after hospital discharge an extension of the care provided in the NICU[4].This care should be implemented through specialized follow-up programs (neonatal follow-up) and involve: discharge plan; continuous evaluation, detection and early intervention in clinical complications and/or developmental changes; support and information for the family; and professional training. These programs are considered essential and capable of providing high quality care with positive results[5]. However, they are still poorly implemented and in small numbers in low- and middle-income countries.

Continuity concerns the quality of care over time, represented by two perspectives: of the patient and his/her family; and the professional. Continuity of care is idealized in the patient/family experience as a "continuous care relationship" with a reference health professional. For professionals, the ideal is the delivery of a "continuous service" through the integration, coordination and sharing of information between the different levels of health care[6].

Continuity, therefore, is the degree to which health care events are experienced as coherent, connected and consistent with the needs and personal context of the patient and his/her family. In this sense, it is distinguished from other attributes of care by two central elements: care over time and care centered on the individual and family[7].

Considering that health care needs can rarely be met by a single professional, multidimensional constructs of continuity have been developed. In this sense, there are three types of continuity: informational, management and relational. Information continuity refers to the use of information about past events and personal circumstances to make current care appropriate for each individual/family. Continuity of management is about a consistent and coherent approach to managing a health condition that responds to the changing needs of a patient/family. Relational continuity represents a continuous therapeutic relationship between a patient/family and one or more professionals. The emphasis on each component of continuity differs, depending on the type and configuration of care (disease-centered or person-centered)[7].

Despite all the advances, the Brazilian health system is still characterized by a fragmented and deficient network of services, accessed unequally by the population/users[8]. The families of PTNB discharged from experienced failures in the orientations received in preparation for discharge, disarticulation between the services in which the child is attended, lack of family and social support, difficulties in accessing services with regard to distance from home to health units and the time spent with this displacement, and difficulty in scheduling for the necessary care, evidencing weaknesses in the continuity of care[9]. Moreover, the dependence on technologies by these children and the professional´s lack of knowledge regarding risk factors for non-follow-up are associated with the discontinuity of outpatient follow-up[10].

In this sense, offering support to the family of PTNBs is a challenge, and it is the responsibility of health services and professionals to promote actions and strategies that help the adaptation of PTNBs at home and in the family to meet their needs[11], since the care received after discharge, whether at home or in health services, is crucial for the child's future health condition, highlighting the importance of comprehensive care and adequate follow-up[2].

Results of several studies suggest a strong relationship between parental experiences and continuity of follow-up in health services, as well as the quality of bonding and care offered at home[12,13]. Follow-up programs that use early interventions focused on increasing mothers' confidence in their parental abilities can promote maternal bonding and attachment as well as the quality of life of families of PTNB children[12].

In view of this context, the following question emerges: how does the continuity of care occur for the family that takes care of a PTNB discharged from the NICU? Considering the role of the family in the care directed to PTNBs, this study aimed to investigate the continuity of care for PTNBs discharged from the neonatal unit from the perspective of family members.

METHOD

This is an exploratory study, with a qualitative approach, based on the conceptual perspective of continuity of care[7].

The following selection criteria were adopted to participate in the study: being family, over 18 years of age, a child who was born with gestational age equal to or less than 32 weeks and who was hospitalized in the NICU from January 2018 to July 2019. The choice of this gestational age is justified by the greater complexity and particularities of care resulting from the condition of prematurity, which includes a longer hospitalization time as a consequence. Families of newborns who died after discharge from the NICU and those whose address was not located by the researcher were excluded.

Regarding the location of participants, a survey was carried out in the NICU admissions book from January 2018 to July 2019 at a university hospital in Cuiabá, Mato Grosso and in the records of newborns. A total of 38 PTNBs with potential to participate in the research were located; and then the first contact was made via telephone with the family members, when the research objectives were presented and the family member's interest in participating in the study was verified. Upon acceptance, the researcher went to the family's residence to bring the Free and Informed Consent Term (FICT), which was read and signed in two copies. There were 27 refusals to participate in the investigation, justified by the family member's lack of time for the interview. Five family members were excluded, three because they could not be found at the address provided for the interview and two due to the child's death shortly after discharge.

Thus, the study participants were 16 relatives, six were preterm newborns, six mothers, three fathers, three grandparents, two sisters and two aunts, representing six family systems. In this study, we considered family all people who reported collaborating with preterm home care.

Data collection was guided by a semi-structured instrument containing the following guided questions: tell me about your experience of caring for a prematurely born child after discharge from the NICU? Tell me what were the main care needs for the child after discharge from the NICU and what did you do to meet the demands of such care? What places (health services and other spaces of care and support) have you sought to meet the demands of child care? The instrument was validated in the first interview and there was no need to adjust the questions.

The interviews were conducted by the principal researcher, who is close to the theme studied and understands the guiding principles of the interview technique in order to obtain data. In addition, the researcher was accompanied by the social worker throughout the fieldwork. It is emphasized that the interviewer did not have any kind of connection with the research participants.

Data collection was performed in person and individually, in the households of the six families, from August to November 2019, with an average duration of 80 minutes, recorded using a smartphone device on offline mode, with a digital recorder application. Thus, the recruitment was terminated when the researcher observed that the information began to repeat itself and the reach of the information power was sufficient to understand the phenomenon studied and respond to the proposed objective[14]. Finally, the material wasfully transcribed in a Microsoft Office Word 2016 document®, forming the corpus of analysis.

The reports were edited during the transcription process, taking care to correct colloquial terms, gibberish, grammatical errors and language defects. Indicative signs were also standardized in the sentences: quotation marks and ellipsis in parentheses, used at the beginning and end of sentences to indicate interruption in the report; mid-sentence ellipsis indicating a pause during the participant's report; and report in square brackets, to signal the researcher's comment.

The empirical data were submitted to thematic content analysis, anchored in three stages: pre-analysis; exploitation of the material and treatment of the results; and interpretation[15]. For this purpose, the corpus of analysis was read, and the findings pertinent to the objectives of this investigation were highlighted and systematically organized.

To preserve the identity of the participants, the reports were identified by means of a code composed of 2 letters and 1 number, the first letter corresponds to the identification of the family member, for example, letter M the word mother, P - father, I - Sister, V- grandmother and T - Aunt, followed by the letter F of family and the number assigned to the family, based on the order in which the participants were interviewed, for example: MF3 - mother of the third family interviewed.

This investigation respected the ethical principles of research involving human beings in accordance with Resolution 466/2012 of the National Health Council. The writing of this article followed the recommendations of the consolidated criteria for reporting a qualitative research (COREQ).

RESULTS

The participating family members were characterized according to the family unit, presented below:

Family 1: composed of: mother; father; 2 sisters, grandmother and aunt. The mother has completed higher education, a father who has a complete high school education, two sisters, who have incomplete higher education, a grandmother who has incomplete elementary school and an aunt who has a complete high school education; child with GA of 26w and 2d, birth weight of 855g, hydrocephalus diagnosis.

Family 2: composed of a mother and father who has a complete high school education and a mother who has a complete high school education; child with GA of 30w and 6d and birth weight of 1,130g.

Family 3: composed of grandmother and mother, the latter has complete higher education, and grandmother who has completed high school; child with GA of 29w and 3d and birth weight of 980g, diagnosis of hearing loss.

Family 4: composed of a grandmother and mother who has a complete high school education, and an aunt who declared himself illiterate; child with GA of 30w and birth weight of 1,050g, diagnosis of metabolic bone disease.

Family 5: composed of a mother and father who has completed higher education, and a mother who has incomplete higher education; 28w GA and birth weight of 950g.

Family 6: composed of mother and grandmother, both with complete high school; 32w GA and birth weight of 1,250g.

The qualitative analysis allowed the construction of three thematic axes presented in this section and later discussed in the light of the construct of continuity of care[7].

Informational continuity: family protagonism and the assistance of NICU health professionals

The elements related to the informational dimension of continuity of care refer to the exchange of information and communication between families and health professionals in the different spaces focused on child health care. However, although this study focused on the continuity of care after hospital discharge, the interviewed families mainly portrayed the situations that occurred during the hospitalization of the PTNB in the NICU.

During hospitalization in the NICU, communication between nursing and family occurs mainly through guidance for care.

[...] *the nurse always talked about how to do it, because she choked a few times there* [NICU] *with me right, then the nurse, there was a nurse who sat with me and taught me* (IF1).

[...] *we went through a little meeting that they* [nurses] *do before discharge (* MF1).

However, some maternal statements reveal difficulties in communicating with the professionals of the neonatal unit.

[...] *she* [NICU doctor] did *not pass me any support, like we asked and she was so very cold, she was always very distant and so no, she never gave us much attention, and she is like that with everyone inside the ICU, with it was very, very difficult* (MF5).

[...] *there are some nurses who were just like that, that we do not understand right, that we are afraid to ask* [...] *she has a kind of direct way of talking to us, I even cried* (MF3).

To address the family's difficulties regarding information and support after discharge, in particular about the child's health condition or care demanded by the child, or about care in health units, the families use digital resources, such as internet groups with mothers who had their children hospitalized in the NICU.

[...] *we have this group to answer all doubts* [...] *we have this group and one gives strength to another, they help when we have doubts, because like this, there are mothers who have had other children, but there are girls who had the first child and they have many doubts right* (MF1).

[...] *it's a WhatsApp group for the* NICU group*, when one has consultation the other already warns, you have and such, how is your baby? And it's like this, the baby's having a fever, or you went to the hospital, your baby's okay? what do I give?* (MF2).

[...] *we set up a* group [*WhatsApp group*] *of moms who have the little children who have already been discharged, I liked feeling welcomed* (MF4).

The reports clearly show that informational continuity is established in the NICU, but at no time do families portray how it occurs after discharge from the unit, which can denote informational fragility in the scope of primary care and other health services.

Relational Continuity: humanization and bonding as fundamental elements for its effectiveness

Relational continuity concerns the establishment of continuous relationships of users with different professionals, which can favor both current and future care.

The aspects of the relational dimension of continuity of care were evidenced from the relationship between the families of the PTNB and the health professionals, such as the perception of support and humanization in the care received.

[...] *they treat us like people there, at least me and my family, so we have nothing to complain about, the care was wonderful, from the time we entered to the time we were discharged from this hospital* (PF5).

[...] *I can't complain about the care. There* [NICU] *they investigate everything. Everything you ask they answer. Of course there are some people who do not answer right, but there is always one who listens and comes to help you, doctor, nurse too, many people helped me, especially the second time his case was more serious* (MF3).

[...] *I have nothing to complain about, from the moment we arrived to the time we left, they do all the exams right, they are very helpful* (MF6).

It is also observed that family members' satisfaction with health care is related to the bond established with the NICU team.

[...] *from the nurse, to the cleaning team we talked to and made friends, to the head of the sector, so I am very grateful to this same team, they were very good to us* (PF5).

[...] *oh! It was good, as I said to you, they were very attentive right* [hospital professionals], *they helped me a lot with all the doubts I had, they helped me a lot* (MF1).

It is observed that most reports refer to the hospitalization of PTNBs in the NICU, which may indicate that the families interviewed have little interaction and a fragile bond with primary care professionals. In addition, it was evident that families maintain a bond with the service where the child was born and hospitalized, which is materialized through adherence to the outpatient follow-up clinic for at-risk newborns in the hospital and by seeking outpatient care in the face of complications and health needs perceived by the family after discharge.

[...] *there* [hospital] does *tests, tests, tests, they look at everything.* [...] *so it was very good, at least for me, the team I got was very good, from the nurses to the girls who do internship* (MF6).

[...] *we always got quality care, so much so that we decided to keep the follow-up* [Hospital], *both her doctor there who accompanied her, we liked the care very much, and the nurses who took care of us there* (PF1).

[...] *I went to several consultations* [outpatient] *they guided* [NICU professionals] *to be taking the health center and is doing the follow-up, then I take it right, I take him there when he is a little sick, and for the vaccines, only* (MF2).

The predictability in care, an aspect present in the relational dimension, can be evidenced in the statements as the feeling of guarantee of care and resolution. This aspect of the relational dimension was identified in this study as indispensable for the family to continue follow-up in the follow-up outpatient clinic after hospital discharge.

Continuity of Management: the disarticulation between services and the paths taken by the family in the search for care

The continuity of management refers to the management of care offered by different professionals, with the possibility of acting with shared objectives.

The elements related to the continuity of management identified by the family members are associated with the assistance in different health services and the coherence of the care offered by them in response to the needs of the PTNB.

[...] *they made an appointment* there [PSF] *and there was an error, because there was no doctor, then it was postponed, then they booked for another month, then I do not know what happened there and they postponed again, I know it was delayed right, then came her consultation there in the hospital, we did not even go to the health clinic because we already had the consultation* (AF6).

[...] *I went to several of her consultations* [follow-up outpatient]*, then the doctor even said, Monday to Friday, anything, anything, you bring her here, you do not go elsewhere, only if it is the weekend* (AF1).

[...] *I did not choose because* [primary care] *I could do the follow-up there as they will ask for examination, all the exams they ask for there in the outpatient clinic* [follow-up outpatient clinic] *they do them right there, here no, here it seems that the place is far away* (MF4).

Based on the narratives, the disarticulation between the services offered at the different levels of health care and the professionals' difficulty in establishing the reference and counter-reference in the care directed to PTNBs and their families after discharge can be observed. There is no communication between the levels of health care responsible for monitoring preterm infants discharged from the NICU, so the family needs to access them based on the guidelines, emphasizing that the continuity of care depends mainly on the family.

Commonly, families experience the discontinuity of care after discharge from the PTNB of the NICU, which happens not only due to weaknesses in the different dimensions of continuity, but also because of the difficulty of access to specialized services, leading families to seek public and private spaces to meet the child's health needs.

[...] *because the SUS* [physiotherapy service] *has not been called yet, the girls there said that sometimes it takes up to two years to be called, and as her development was already behind, that's where we took it went after, until the girls of the service had spoken, if you can do private, as it is urgent, it is easier for you to go private and monitor her development instead of waiting* (MF1).

[...] *as we get there* [Hospital] early *in the morning and the consultation there is only twenty-five people, then we have to go very early right, sometimes we cannot* (MF4).

Based on the narratives of family members, it is possible to notice weaknesses referring to the continuity of management. We observed the difficulty of access to care, lack of articulation and communication between the different levels of care, which compromises the implementation of the reference and counter-reference between the services, impairing the continuity of care to the PTNB after discharge from the NICU.

DISCUSSION

The informational dimension of continuity of care begins during the hospitalization period in the NICU, so that the information offered by professionals will influence the care that the preterm will receive after discharge. It is emphasized that this information is indispensable for the family to be able to continue to meet the needs of the child in health services, as well as at home, and so that other health services can also continue to meet the needs of the child and the family itself. Going home after the hospitalization of the child in the NICU is a paradoxical moment, in which mothers experience positive feelings for hospital discharge, and fear and insecurity because they no longer have the professional support of the NICU[16].

In the place under study, the preparation for discharge was, according to the participants' reports, punctual, directed to the transfer of information that the team considered necessary for the parents to exercise care at home. Another relevant finding is that the need for family members to use groups of instant messaging applications to exchange with other parents shows a weakness in communication with professionals, who do not meet all the family's needs, leading to the interpretation that the guidelines for discharge are not made in a systematic way by the health team of place under study.

The literature shows that the non-systematization of discharge preparation, even if professionals use several tools that can help in the individual planning of discharge of PTNBs – such as the measurement of stress, self-efficacy for care and breastfeeding, the knowledge of parents' beliefs, the care check list practiced by parents in the NICU, in addition to the social aspects involved in the family context – these focused on general information and without focus on the needs of each family and its PTNB[17].

The use of technological resources, such as the Internet and groups in instant messaging applications to obtain information about the care of the PTNB, was also reported in another research, in which data from the Internet were used by families in situations that the guidance received from professionals was considered fragile or insufficient. Internet access was mainly used as a source of knowledge, clarification of doubts and to communicate with health professionals[18].

It is reiterated that information continuity in the NICU has taken place through guidance offered to families. Thus, the continuity of care in different health services depends on the family's understanding of the need for monitoring and its role in sharing information about the child's health with other family members.

It is noteworthy that the research on the transition of PTNBs from the NICU to the home, in the last 15 years, focused on research on professional support and guidance for families, during hospitalization and after discharge[16]. However, it is still possible to observe how fragile some of these guidelines can be, due to the difficulty of family members to communicate with NICU professionals, as reported by one of the mothers in this research.

In the present research, one of the mothers reports difficulty in communicating with the professionals of the neonatal unit, in this context, the speech gave emphasis to the medical professional. However, research carried out in the southern region of Brazil showed that this professional is a source of confidence for families of PTNBs in post-discharge care[19]. Professional communication is among the different strategies that facilitate the discharge process from the NICU, as well as the inclusion and involvement of parents in the care of the child, so that the needs of both are met[20].

In turn, nurses have been cited as important sources of emotional and informational support for parents, demonstrating a satisfactory interaction with the family, through the establishment of bonds and empathy[21]. In addition, results from another research reinforce the importance of the nurse's role in providing adequate guidelines to support family care at home after discharge[22], as observed in this study, whose role of nurses in the process of preparing for discharge was mentioned as a source of information and support for family care.

The nurse, as a member of the health team, competently performs the assessment of which aspects of care the preterm mother needs more, support and guidance from health services, because this reinforcement can improve the confidence and autonomy of mothers regarding the care of the child at home[23]. Even so, the inadequate number of nurses in the NICU and the bureaucratic and management actions of the unit that fall on these professionals reduce the time needed to be with families and carry out the discharge orientations[21].

It is up to the nurse to promote actions that favor the continuity of care from the period of hospitalization until the arrival of the preterm child at home, considering that these professionals care for the child and their family at different points of the health care network, especially in the NICU and in primary care, and have the competence to intervene in their health needs[2].

However, the programmatic vulnerability of health services is evident in which counter-referrals are weakened and there is no effective articulation between the points of care that the PTNB and their family may integrate with. It is up to family members to trace their itinerary in search of support. A study showed that informational support in the NICU and in the follow-up after discharge still has gaps, compromising the potential for parental care and the families' understanding of the health condition and needs of preterm children[10].

With regard to relational continuity, in the present research, humanization appears in the speeches of the family members related to the bond and the perception of reception and attention in the care received from the health professionals of the NICU and the outpatient clinic. Humanization is also highlighted in the participants' reports as an essential element for adherence and permanence in the follow-up, strengthening the continuity of care after discharge.

The humanization of neonatal care is linked to the implementation of care models, with an impact on improving the quality of care and survival of PTNBs. Research showed that the humanization of neonatal care is directly related to welcoming, empathy, respect and establishment of a bond between professionals, PTNBs and their families[24].

From this perspective of humanization, the Kangaroo Method (KM) is highlighted, which consists of a care model aimed at humanization and qualification of neonatal care and provides for the monitoring of the PTNB in a shared way between the hospital and primary care. In this care model, the articulation of the neonatal unit and Primary Health Care (PHC) should be initiated during hospitalization, with the aim of knowing the clinical conditions of the NB and ensuring continuity of care after discharge from the neonatal unit[25]. However, a study suggests that there is little knowledge of PHC professionals regarding the Kangaroo Method, and that many professionals in this area of health care do not receive information from the hospital about woman in the post-partum period and her child being discharged from the NICU, which can lead to the absence of the these professionals in the homes of these families[26].

A study carried out in the Family Health Units (FHU) belonging to the five Health Districts of João Pessoa, in the municipality of Paraíba, and in the homes of mothers, whose objective was to understand the continuity of the third stage of the Kangaroo Method from the perspective of mothers and health professionals, portrayed the poor knowledge about the Kangaroo Method, both of health professionals and mothers, and the role of PHC in continuity of care. Thus, it was noticed that this problem is one of the reasons that weaken the care of the mother-child binomial, evidencing gaps in care after discharge[26].

As for the articulation of neonatal units and primary health care, the Ministry of Health recommends that this should be initiated during hospitalization, in order to know the clinical conditions of the newborn and ensure continuity of care after discharge from the neonatal unit[25].

It can be inferred that the relational dimension of continuity of care is associated with the bond established between health professionals and the family, also highlighted in another study as an element that enhances continuity of care, and, in short, is built through continuous, welcoming and resolute care[4]. When health service professionals are welcoming and work in networks, they have the potential to effect continuity of care and meet the needs and particularities of preterm infants and their families[11].

Management continuity is established when services are offered in a complementary and timely manner, seeking to meet the objectives and facilitate individuals' access to health services, in addition to considering flexibility and adaptation in the care offered in the long term[7]. Despite the importance of continuous contact with a professional or health service, it is worth emphasizing that the continuity of management has a multiprofessional character[27]. When it comes to a PTNB, it is known that the conditions of birth and subsequent hospitalization in the NICU can lead to sequelae or health conditions that determine the need for complex care and specialized monitoring with several professionals.

A study conducted with health team professionals from basic units in the north of the state of Santa Catarina revealed that there is difficulty in communication between professionals of different services, which contributes to a deficient counter-reference, making care poorly cohesive and disjointed. Thus, it is common for this role of sharing information to be performed by the child's relatives, who assume this responsibility, in addition to experiencing a pilgrimage through the health system to accompany the child through primary care health units[8]. It is worth noting that through the flow of information, it is possible to articulate the health professionals and the management of care that is coherent with the demands of individuals[27].

A similar finding was evidenced in another study carried out with mothers who were extreme preterm caregivers in Minas Gerais, whose participants faced difficulties in accessing specialized health services, resorting to the use of private health services to make up for the weaknesses in care[3]. The families participating in this study also underwent follow-up at the neonatology outpatient clinic of the university hospital, a place that has already been considered a reference for family members of preterm infants in situations of acute and chronic conditions, and is where the medical professional, reported in another investigation as the only professional family trust in some situations[19]. The certainty of the physician's presence, not always found in PHC, evokes the idea that the family´s network is connected with greater participation in secondary and tertiary care services, to the detriment of greater and possible participation of the primary.

Thus, for the effectiveness and continuity of care for PTNBs after discharge, there is a need for improvements in access to services and better support from health professionals[28]. Another study showed the PHC as a reference for care for acute cases, but not for follow-up after the discharge of premature babies, evidencing the lack of articulation between the hospital services of the NICU and the PHC units[19].

What drew attention in the present research was the little emphasis given by families to the care provided to PTNBs by primary care units, this finding may reaffirm the non-integration of hospitals that provide care to these children and primary care health units, as recommended by the third stage of the Kangaroo Method. The results also suggest that, in terms of continuity of care, the services provided by the neonatal hospital unit are more relevant in the experiences of these families, as they centrally occupy the narrative about the experience of continuity of care.

Thus, it is essential that hospital teams, especially PTNB follow-up programs and primary care, work together and provide adequate preterm follow-up after hospital discharge, through breastfeeding support, observation of weight gain, treatment of complications and evaluation of rehospitalizations[20].

We emphasize that the results of this study are related to the experience of 16 family members of preterm newborns who were discharged from a single NICU service and linked to the same follow-up outpatient clinic, so it is necessary to conduct future studies on different social realities that add more knowledge about the phenomenon studied.

New research is suggested, perhaps with the use of therapeutic itineraries in the search for care for PTNBs discharged from the NICU, as they will be able to collect data that demonstrate the articulation between the services sought by families to meet their needs. Many researches in the area focus on the informational aspect for preterm discharge and going home care. Thus, further investigations could diversify and focus more on the relational aspect and on the continuity of management, deepening the analysis of the potential and challenges of supporting families with their preterm children. Furthermore, reflections and recommendations are suggested for the incorporation of the families' experiences, in the continuity of PTNB care, in the care process (continuous care plan/project for PTNBs).

This study made it possible to understand, from the perspective of families, some dimensions of their experience in caring for PTNBs after discharge from the neonatal unit, and can support discussions about the responsibility of health services and the effects of their organization for these families. It contributes to the professional practice in pointing out some weaknesses in the informational, relational and care management aspects for this population, favoring actions and strategies that help families in the challenge of adapting and caring for the PTNB at home.

The research has limitations regarding the data being from families of different preterm gestational age and discharged from a single hospital service, which makes it necessary to carry out future studies that present other realities, in order to add more knowledge and new findings to the phenomenon under study.

CONCLUSION

It was evident that the effectiveness of continuity of care depends on several aspects, which include the preparation of the family for the preterm discharge, the behavior of professionals, the organization of care at different levels and the active participation of the family, which assumes the responsibility and decision on the care of the PTNB from its arrival at home.

The continuity of care after discharge occurs with different care flows, with the family being the protagonist and essential element for its effectiveness. With regard to health services, there are still gaps in the informational, relational and management dimensions, which weaken care for preterm children discharged from the NICU and reiterate the need to implement actions and strategies that enhance the continuity of care and consider the family as the central part in this process.

Finally, it reaffirms the importance of understanding the experience of families regarding the continuity of care for PTNBs discharged from neonatal units in order to direct the planning of health actions, with a view to continuity and improving the quality of care offered to this public. This understanding of the families' experiences can also contribute to a professional performance that is more sensitive to the needs of these children and their families.

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NOTES

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Study design: Bernardino FBS; Gaíva MAM, EFL Silva.
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