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Monitoring high-risk neonates from the perspective of professionals, managers and mothers

Seguimento do neonato de risco na perspectiva de profissionais, gestores e mães

Seguimiento de neonatos de riesgo desde la perspectiva de profesionales, directivos y madres

ABSTRACT

Objective: To analyze the follow-up of newborns at risk from the perspective of health professionals, managers and mothers, identifying the challenges and strategies adopted to improve continued care. **Method:** Descriptive study with a qualitative approach carried out in a teaching hospital through interviews with two managers, two health professionals and nine mothers of at-risk newborns, who were subjected to the content analysis technique. **Results:** Participants recognize the importance of a well-organized follow-up service for at-risk newborns in the hospital. However, the service faces operational and human resource barriers that result in discontinuity of care, such as disorganization and difficulties in meeting demand. **Final considerations:** The follow-up of newborns at risk in the analyzed outpatient clinic requires the organization and implementation of flows to organize care and meet demand, in addition to articulation with the services of the health care network.

Descriptors: Infant: Newborn; Ambulatory care; Continuity of patient care.

RESUMO

Objetivo: Analisar o seguimento do recém-nascido de risco na perspectiva de profissionais de saúde, gestores e mães, identificando os desafios e as estratégias adotadas para melhorar a assistência continuada. **Método:** Estudo descritivo de abordagem qualitativa desenvolvido em um hospital de ensino por meio de entrevistas com dois gestores, dois profissionais de saúde e nove mães de neonatos de risco, que foram submetidas à técnica de análise de conteúdo. **Resultados:** Os participantes reconhecem a importância de um serviço de seguimento bem organizado para os recém-nascidos de risco no hospital; no entanto, este enfrenta barreiras operacionais e de recursos humanos que resultam na descontinuidade do cuidado, como a desorganização e as dificuldades para atender à demanda. **Considerações finais:** O seguimento do recém-nascido de risco no ambulatório analisado necessita de organização e implementação de fluxos para o ordenamento da atenção e atendimento da demanda, além da articulação com os serviços da rede de atenção à saúde.

Descritores: Recém-nascido; Assistência ambulatorial; Continuidade da assistência ao paciente.

RESUMEN

Objetivo: Analizar el seguimiento de los recién nacidos en riesgo desde la perspectiva de profesionales de la salud, gestores y madres, identificando los desafíos y estrategias adoptadas para mejorar la atención continuada. **Método:** Estudio descriptivo con enfoque cualitativo, desarrollado en un hospital universitario, a través de entrevistas a dos directivos, dos profesionales de la salud y nueve madres de recién nacidos en riesgo, a quienes se les aplicó la técnica de análisis de contenido. **Resultados:** Los participantes reconocen la importancia de un servicio de seguimiento bien organizado para recién nacidos en riesgo en el hospital. Sin embargo, el servicio enfrenta barreras operativas y de recursos humanos que resultan en la discontinuidad de la atención, como la desorganización del servicio y dificultades para satisfacer la demanda. **Consideraciones finales:** El seguimiento de los recién nacidos en riesgo en el ambulatorio analizado requiere la organización e implementación de flujos para organizar la atención y atender la demanda, además de la articulación con los servicios de la red de atención de salud.

Descriptores: Recién nacido; Atención ambulatoria; Continuidad de la atención al paciente.

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INTRODUCTION

In the last decade, the premature birth rate has remained high around the world. In Brazil, between 2010 and 2020, these rates fell by only 5%, representing a decrease of 0.5% per year(1). In addition, technological advances have increased the neonate survival rate at increasingly earlier gestational ages, raising concerns about the quality of life of preterm newborns (PTNBs) and low birth weight newborns (LWNBs) after hospital discharge, since they are considered high-risk children(2).

Children considered to be at normal risk are those with risks inherent to the life cycle itself; those at intermediate risk have factors related to health conditions in the first week and month of life, nutrition, care, socio-family situations, the environment and diseases specific to the period; those at high risk include those with perinatal conditions (prematurity, low weight, small or large for gestational age), perinatal and neonatal conditions, complications of prematurity, maternal factors, evolutionary factors and special conditions (weight less than 2. 000 g, gestational age of less than 34 weeks, congenital malformations and two or more hospitalizations in a year)(3).

PTNBs have a higher risk of complications and infections during the first year of life, so their care should not end after they are discharged from the neonatal unit(4). In recent years, the survival of critically ill newborns (NBs) hospitalized in neonatal units has demanded that these babies be linked to follow-up programs after discharge, contributing to the early detection of delays in child development and the referral of eligible cases to intervention services(5).

For LWNBs, the Brazilian version of the Kangaroo Method (KC) guarantees, in its third stage, that the NB and his/her family will receive care shared between the teams of the Basic Health Unit (BHU) and the birth hospital, including consultations, home visits, observation and guidance. When the NB reaches 2,500 g, it will be discharged from the KC and will be taken care of by Primary Health Care (PHC) professionals and, in some situations, by specialized outpatient clinics (follow-up or clinical specialty clinics)(6).

After discharge from the neonatal unit, it is recommended that the at-risk neonate and his/her family follow a schedule of appointments, both at the BHU and at the outpatient clinic of the hospital of origin(6). Although the continuity of care after hospital discharge is considered fundamental for the quality of life of children at risk, the effectiveness of this assistance still has structural and procedural weaknesses in the context of child health care in the country(7).

In view of these weaknesses, the following questions arise: how do health professionals, managers and families perceive and experience the follow-up of at-risk NBs leaving the neonatal unit? What are the main challenges and strategies implemented to ensure continuity of care in this context? Thus, this study aims to analyze the follow-up of at-risk NB from the perspective of health professionals, managers and mothers, identifying the challenges faced and the strategies adopted to improve ongoing care.

METHODOLOGY

This is a descriptive study with a qualitative approach. This type of study was chosen because it allows for a better understanding and knowledge of how continuity of care for at-risk NBs occurs in a health service. The research was guided and structured according to the Consolidated Criteria for Reporting Qualitative Research (Coreq), with the aim of providing greater reliability, in order to contribute to compliance with methodological rigor in qualitative research(8).

The research was carried out at the Pediatrics outpatient clinic of a teaching hospital in the city of Campo Grande, Mato Grosso do Sul (MS), where at-risk newborns are cared for. The hospital has been part of the Brazilian Hospital Services Company (Empresa Brasileira de Serviços Hospitalares, EBSERH) since December 2013 and is linked to a federal university with specific characteristics such as: it serves patients from the Unified Health System (Sistema Único de Saúde, SUS) and, above all, supports the training of health professionals and the development of research.

Outpatient care at the hospital takes place in the general outpatient clinic, which shares space between various care units and medical and multi-professional specialties. The Care Regulation Unit (Unidade de Regulação Assistencial, URA) coordinates actions between services, manages agendas and receptions, as well as maintaining a constant dialog with unit heads and the Care Management Division. More than 68 specialties are offered, with appointments scheduled via the Municipal Regulation System (Sisreg), including patients from other municipalities in the state. The clinic has 80 consulting rooms and carries out a mean of 9,000 consultations a month. Undergraduate students and residents from health courses carry out care activities accompanied by preceptors.

The Pediatric Outpatient Clinic, which has several rooms equipped for consultations and procedures, is a specialized unit that is part of the hospital complex and offers pediatric care for children of all ages, to provide high quality health care. The team includes pediatricians, nurses, psychologists, nutritionists, social workers and other health professionals. Routine consultations are offered for regular monitoring of children's growth and development, as well as pediatric specialties such as Cardiology, Nephrology, Endocrinology, among others. It should be noted that the follow-up of at-risk NBs takes place in the physical space of the aforementioned outpatient clinic.

Participants included the hospital manager, the manager of the neonatal unit and the follow-up outpatient clinic and the health professionals who work in the outpatient clinic, as well as the mothers of the children who were being monitored in the outpatient clinic at the time of data collection, which took place between May and August 2022. The inclusion criteria for managers were to have been in management for at least six months and the exclusion criteria were to be on sick leave. The inclusion criteria for professionals to take part in the study were having a minimum of six months' experience at the institution and working in the outpatient care of high-risk NBs, and the exclusion criteria were being a temporary professional with no ties to the service. The inclusion criteria for family members were to be the father, mother or legal guardian of the child at risk being monitored at the hospital's outpatient clinic and to be aged 18 or over.

Exclusion criteria were fathers, mothers or legal guardians of neonates who only had their first outpatient appointment at the service.

The initial approach to the participants was through personal contact, when the researchers presented the objectives and justifications of the study. Only one interview was conducted with each participant, all of which were recorded on digital media and lasted a mean of ten minutes. The number of participants was considered sufficient once the data reflected, in intensity and depth, the multiple dimensions of the phenomenon under study, in order to flesh out the research and make it defensible(9). In addition, this number of interviews generated recurring data and complementary information, meeting the proposed objectives.

Data was collected through interviews based on semi-structured scripts. The script for the interview with the professionals consisted of questions related to professional characterization (degree, specialty, length of training, age, gender and length of time working in the outpatient clinic) and open-ended questions about the functioning of the service, the care of neonates, the difficulties and facilities experienced in the service and suggestions for improvement. The interview with the managers also included questions about the professional characterization and structure of the program, the operational strategy and the link with primary care and other services. The family member interview script contained closed questions about family composition (family members, age, schooling), family address, BHU near the home, birth data (type of birth and medical diagnosis) and the age of the children at the time of the interview. The open-ended questions dealt with the child's health care at the follow-up clinic, difficulties and facilities encountered by families, professionals involved in the care, guidance received, care provided by other services and suggestions for improvement.

The interviews were carried out in the hospital's pediatric outpatient clinic, on the days of appointments, and only the mothers took part, since they were the ones accompanying their children during the data collection period. The professionals and managers were interviewed at previously scheduled times so as not to interfere with their work activities. The interviews, conducted by the researcher responsible for the study, who was a nurse in the hospital's neonatal unit and a master's student, were recorded with the consent of the participants and transcribed in full. The research was guided and supervised by a researcher with experience in qualitative studies, and the data was organized and submitted to the content analysis technique, according to the following stages: choice of document, floating reading and preparation of material, coding, categorization and inference and results interpretation(9). The data was organized into descriptive categories and subcategories.

The study complied with the recommendations of Resolutions No. 466/2012 and No. 510/2016 of the National Health Council, which regulate research with human beings in the country, and the favorable opinion of the Research Ethics Committee was registered under No. 5,243,612. To guarantee the anonymity of the participants, we used the letter "P", which stands for "Professional", the letter "G", to identify the managers, and "M", for Mother, followed by an Arabic number, according to the chronological order in which the interviews took place (P1, G1 and M1, for example).

RESULTS

The first section presents a brief characterization of the participants in the study and a description of how the service works, followed by a description of the organization of care for at-risk NBs from the perspective of the service's managers and professionals and, finally, the mothers' perception of the care received by their child.

Characterization of the participants

Two managers took part in the study, one with a degree in Administration and one in Medicine, the latter being the manager of the neonatal unit and the follow-up clinic; and two health professionals, a doctor and a nurse. The mean age of the managers was 53.5 years and they had been trained for 30.5 years. In relation to the professionals, the mean age was 40.5 years, the mean length of training was 17 years and the mean length of time working in the outpatient clinic was two years. Nine mothers were interviewed, with a mean age of 29.7 years, predominantly having completed high school, five of whom lived in the capital and the others in cities in the interior of the state.

Of the participating mothers, one had a twin birth, so there were ten children in outpatient care, more than half of whom were born by cesarean section and were on mean 10 months old at the time of the intervention. The most common medical diagnoses of these children were prematurity, neonatal meningitis, neonatal sepsis, respiratory distress syndrome, congenital syphilis and bronchodysplasia.

Operation of the service for at-risk newborns

The follow-up of at-risk NBs after discharge from the neonatal unit takes place in two rooms in the hospital's Pediatrics outpatient clinic. The professional team that cares for these children is made up of a pediatrician, two pediatric residents, a nurse and two receptionists. The medical coordinator of the follow-up clinic works in the neonatal unit and is responsible for referring children at risk to follow-up appointments and specialties, as well as supervising the service.

The criteria for including at-risk newborns in the follow-up service are: prematurity, low birth weight, Apgar score of less than seven in the fifth minute of life and newborns who had any complications during their hospitalization in the neonatal unit. The first visit to the outpatient clinic takes place in the first few days after discharge, with a referral from the hospital's neonatal unit doctor.

The outpatient clinic treats at-risk NBs once a week, in the morning, and a mean of six children are scheduled for medical consultations, depending on the availability of vacancies in the service. Before the appointment, the children are weighed by the nurse or resident doctors. As the service does not have a multi-professional team, when children need to be assessed by another professional, they are referred to a specialized service via the municipality's vacancy regulation system.

It is noteworthy that the service does not have a formalized program for monitoring the health conditions of high-risk NB after discharge from the neonatal unit, as well as a schedule of appointments/flow of care, an approach protocol and support for the family in caring for the NB at home. It should be noted that from the moment the child is admitted to hospital, the family is instructed to go to the nearest BHU if the child has any health problems after discharge, as well as to start the vaccination schedule.

Perspectives of managers and health professionals on the organization of care for newborns at risk

The perspective of managers and health professionals regarding the organization of care and the continuity of care offered to at-risk NBs was described under the category Discontinuity of care for at-risk NBs, made up of subcategories: Disorganization of the service and difficulties in meeting demand.

Discontinuity of care for high-risk NBs

Both managers and health professionals recognize the importance of the hospital having an organized and functioning follow-up service for newborns at risk. In addition, they make efforts to meet structuring needs and overcome challenges to meet demand, operationalize continuity of care and offer support to the families of these neonates; however, the service is faced with operational and human resource barriers that culminate in the discontinuity of care for at-risk newborns.

The disorganization of the service

For managers and professionals, the disorganization of the service and the lack of a flow to guide the care and continuity of care for at-risk NBs are worrying. According to reports, the service does not have a flowchart or protocol for caring for this population - after the NB is discharged from hospital and the first pediatric appointment is made, the family is instructed to proceed with the appointments directly at the hospital's Pediatrics outpatient clinic.

The disorganization of the service becomes clear when the professionals report that they only know that the children are being monitored, but are unaware of how this monitoring takes place in practice:

"I know that they are monitored, but I don't know how many appointments they receive, how many of them remain and how they are progressing" (G2's report).

"Look, there's nothing written, there's no program flowchart or anything like that. In practice, after the children are discharged, the parents are told to come to the outpatient clinic to make an appointment, they go through childcare" (P2's report).

For the professionals interviewed, the lack of a flowchart for conducting care, in order to standardize their actions, as well as the absence of institutional protocols and regulations, hinder the implementation and operationalization of the follow-up of at-risk NBs and the continuity of care by the professional team:

"[...] I've never seen a written flow of this program, I'm not aware of it, I even think that if it had it would make everyone's life a lot easier, things would be clearer, more objective, maybe we'd be able to optimize the service more" (P2's report).

The interviewees mentioned that there is no link between the service and the municipal health care network, and this information was part of the narrative of both managers and professionals:

"[...] at first, I don't know if there is a link with the basic care network, I don't know if he [NB] is referred directly to the BHU" (P1's report).

"[...] I'm not aware of it and no one has told me, but there would have to be a written flow of this program and the articulations, continuing and permanent education, for everyone who is part of it" (G2's report).

As it is a teaching hospital, the professionals point out that there could be more organization and participation by health students, as well as a multi-professional team working together, in order to concentrate the care and monitoring of neonates in the service itself:

"I think the biggest challenges are that we can't have all the professionals in the same space, in the same place, because these patients are seen here by doctors, and in other places by physios [physiotherapists], they are often in several places, instead of being followed up in the same place for continuity of treatment" (P1's report).

Disorganization is also evident when professionals report not knowing the number of children registered and how many are currently being monitored at the service:

"Actually, I have no idea how many children are registered at the outpatient clinic, but all the children who need this care are booked here" (G2's report).

Professionals are unaware of the existence of support for families in the service for the management and continuity of NB care at home. When they feel it's necessary, they call on the hospital's social services to help the family with any specific needs:

"I don't know about family support, sometimes we get in touch with the social services and they bridge the gap between the hospital and the family, but there's no direct help" (P1's report).

Difficulties in meeting demand

The service's lack of structure makes it difficult to meet the current demand from patients, perhaps due to the fact that appointments are only made once a week, with the absence of a multi-professional team and a reduced number of consultations:

"Actually, this program exists, but because of the number of patients we have at the moment, it may not yet be fully adequate, so the patient is discharged today and sometimes doesn't have as close an appointment as we would like. Because we don't have the capacity to see so many patients on just one day of the week" (G2's report).

"At the follow-up clinic, we schedule six patients and they are seen every Thursday. Around 24 children are seen each month [...] the ideal would be to see children up to six months old and for them to be seen monthly, but unfortunately we don't have enough places to see children that often" (P1's report).

Due to the insufficient number of places, the child's first visit to the outpatient clinic often takes place two or three months after discharge, which has an impact on continuity of care:

"As we don't have enough vacancies, these consultations are often held with a very long waiting time, two to three months after the patient has been discharged" (P1's report).

The professionals suggest strategies to minimize the service's difficulties, including the inclusion of health academics in the outpatient clinic:

"We don't have the capacity to treat so many patients, maybe if we improve the structure and have more professionals, students and residents" (G2's report).

Mothers' perspective on the care received by their child

Next, we present the perspective of the families, represented here by the mothers, regarding the care offered to the NB after discharge from hospital, through the category Perceptions and expectations with care, which can be translated in the mothers' speeches by the fact that the child is being monitored in a referral service, which brings them relief and security, in addition to some mothers being satisfied with the care and attention given by the professionals. However, there are mothers who expose their difficulties in carrying out this follow-up, as well as their dissatisfaction with the service. This category was broken down into two subcategories: Valuing medical care, since mothers take the doctor's appointment as a reference for monitoring their newborn; and Facilities and difficulties for monitoring the NB in the service, which concerns accessibility and challenges for attending appointments and continuing the child's care.

Valuing medical care

Although the NB is cared for by professionals from the medical team and, occasionally, by the nurse, the mothers value the doctor's work and are satisfied with his consultations:

"The [medical] team that attends to L. is sufficient, thank God she is well looked after" (M1's report).

"[...] I'm satisfied, she's being monitored every 3/3 months, her progress is great, I don't have any problems and the doctor monitors her very well" (M3's report).

The mothers consider that the technical skills of the medical team are compatible with excellent care, as the child is assisted in their needs to monitor development and prevent health problems:

"When they [the medical team] analyze her, do the tests, we feel calmer, because we know she's fine" (M4's account).

"She's well assisted, they monitor her development, make sure everything is all right, because they understand better. It's not like private care, it's much better here" (M9).

Although the nurse participates in the pre-consultation and, occasionally, the social worker, the mothers perceive the nurse's role as non-essential, since her participation is only in weighing the child:

"[...] the pediatrician attends, the nurse helps with screening, she just weighs" (M1's report).

"[...] His pediatrician does the appointments, the nurse helps with the triage" (M2's report).

Facilities and difficulties for monitoring at-risk newborns in the service

The mothers consider themselves privileged to be able to see a pediatrician. When asked about the existence of a multidisciplinary team, they say that the doctor meets the child's needs and demands, as he monitors their growth and development:

"Thank God I'm being taken care of, L. is being well monitored, her evolution is getting better and better every day. She's developing" (M1's report).

However, mothers who live far from the hospital, as well as those who live in cities in the interior of the state, report financial difficulties in attending, as they have to pay for fuel, accommodation and transportation, as well as the tiring commute:

"I don't have any facilities, I find it difficult to come because I can't always do it, because I spend 25 reais to come and 25 reais to go back by Uber and I don't always have that kind of money" (M5's account).

"It's not easy, I have difficulties because I live in a farm and I spend a lot on fuel to come" (M6).

In addition, for some mothers, going to see their child at the clinic means organizing the family dynamic and making adjustments at work:

"It's in relation to work, in relation to the timetable, because I need to organize things at home and at work" (M3's report).

The mothers also report that it is difficult to contact the outpatient service by phone and that they travel from another city to see their child, without confirmation:

"Another difficulty is that it's hard for them to answer the phone, and for those who live abroad, they're worried about confirming it, so they don't come for nothing, because coming, spending on gas, hotels and not getting an appointment is bad" (M4's report).

Although mothers describe satisfaction with the care their child receives at the clinic, they report that they need to seek complementary care at other services. Cities don't always have the specialized treatment needed, which puts an even greater burden on the family, who have to seek out these assistance resources in the capital:

"[...] she needs to go to Apae [Association of Parents and Friends of the Exceptional] as well, there she does physio and OT [occupational therapy], here she doesn't have this service" (M1's report).

"We do some appointments at Apae and when I need them or have doubts I make a private appointment, because here at the outpatient clinic they're only every three months. (M3's report).

The participating mothers strive to provide their children with the best possible care, within their means. They demonstrate a deep commitment to their children's well-being by stimulating their NBs and carrying out the exercises, following the instructions they receive:

"She does physiotherapy, I do the exercises with her, I put music on for her, I dance with her, I sing and I do kangaroo" (M1's report).

However, one mother reports needing more information/guidance, which is not always provided:

"I'd like more information and guidance on breastfeeding, because I only breastfeed, I don't supplement" (M4's report).

DISCUSSION

The research was carried out in a teaching hospital that provides care for at-risk NBs coming out of the neonatal unit, but which so far does not have a structured follow-up program. These children are cared for in the Pediatrics outpatient clinic, and there is no schedule of appointments, protocols or defined care flows.

A study carried out in the Midwest region of the country with the aim of characterizing the follow-up programs in the state of Mato Grosso (MT) and the Distrito Federal (DF) showed that most of the outpatient clinics studied, except those that carry out the third stage of the MC, do not have a pre-established schedule of appointments and organize their care according to the demand of each neonate and the pathology presented(10).

In the service studied, post-discharge care has been limited, as there is no multi-professional team to attend to children who require special health care, which is at odds with the recommendations in the literature(3).

A study of 111 participants representing 60 long-term care institutions for critically ill children after discharge from hospital in the United States, Canada, Australia and the United Kingdom found that most services focus on neurocritical care and the medical professional, with few services offering multidisciplinary care(11). This pattern was also observed in this investigation, in which children are only seen by doctors.

In addition, the service studied has no flowchart or documented protocol for the follow-up of at-risk NBs. The lack of these documents and institutional regulations hinders the implementation and operation of the program and, consequently, the continuity of care by the team. The protocols can be used as guiding instruments in institutions, allowing for better guidance in the conduct adopted by professionals. In addition, they can be implemented to organize services, systematizing care, contributing to greater professional adherence and linkage to the care process(3).

From the perspective of the families, represented here by the mothers, they say they are satisfied with the care received by their children because the child is being monitored in a referral service, which brings relief and security. The emphasis on medical care is justified, as the model centered on medical care is still seen as the reference for families to follow up their children. However, as this is a teaching hospital with several health courses, the involvement of the multi-professional team in the follow-up would be a gain for both the children/families and the undergraduate and postgraduate students.

The difficulties pointed out by mothers in continuing to care for at-risk NBs are related to accessibility and the challenges they face in attending appointments, such as: traveling to the service, due to the distance from home and the long time it takes, the insufficiency of the public transport system, financial limitations to pay for tickets and per diems, the fragility of the support network and the impossibility of taking time off work. These factors favor evasion from follow-up, as has already been shown in the literature(12,13).

The difficulties reported by the mothers were also observed in the hospitals that have implemented the KC, since these neonatal units are also located in the capitals, which leads the mothers of PT-NBs who live in other municipalities to seek accommodation in relatives' homes until they are discharged from the third stage of the KC(14).

Accessibility to the outpatient clinic, flexibility of appointments, communication and professional interaction, support and guidance to meet the needs of children and families all help them to remain in follow-up. Furthermore, telephone support is an additional strategy to meet the family's needs after discharge from the neonatal unit, as it improves the accessibility and efficiency of health care(15). The mothers who took part in this study found it difficult to confirm scheduled appointments by telephone.

Parents of PTNBs know that the sooner they start interventions with the help of the multi-professional team, the better their child's prognosis will be. A study aimed at identifying the experiences of parents of children at risk of neurodevelopmental delay showed that they want to receive honest information through face-to-face consultations, as well as information about their child's diagnosis and prognosis, with consistent follow-up and with a professional leading the whole process(16).

A survey of RNBP mothers who took part in a follow-up program that started the multi-professional team's interventions early, with an emphasis on the mother's participation and home visits, demonstrated their desire to obtain early information about the long-term prognosis for their children, as well as the importance of their participation in the activities developed by the professionals for their children(17).

Each health professional involved in monitoring children at risk plays an important role and the exchange of information between them and the family contributes to continuity of care(5). Although there is occasional participation by the outpatient clinic nurse in the monitoring of at-risk NBs, the mothers perceive the professional as non-essential, as her participation is only in the pre-consultation of the children. The nurse, as part of the professional team, must develop strategies aimed at meeting the patient's health needs in order to avoid interruptions in their follow-up(18). In addition, the nurse's assistance tends to improve maternal care, as well as supporting the process of child growth and development(19,20).

Research carried out in another hospital in Campo Grande, MS, revealed that parents who received nursing and medical consultations in the third stage of the KC valued the importance of these follow-ups and also their children's achievements in the follow-up consultations with the physiotherapist and occupational therapist. This demonstrates the importance of the participation of the multi-professional team and nurses in monitoring NBs and their families after discharge from the neonatal unit(14).

The participants' speeches showed a lack of communication and coordination between the outpatient clinic for high-risk NBs and PHC, hindering the shared follow-up of these children. Integration between the two levels of care can facilitate and speed up the scheduling of appointments, exams or specialized procedures that the preterm child needs (6).

The link between the hospital and PHC should be configured as a range of care, starting with prenatal care, identifying the risks of pregnancy, continuing with the hospitalization of the mother and newborn and the continuous monitoring of the binomial in different places of care(6). However, in practice, health services are organized and structured in a uniprofessional, fragmented and disjointed way, which makes it impossible to provide networked care for children and their families(21).

In view of the above, it is up to family members to trace the route in search of support, due to the programmatic vulnerability of health services, since counter-referral is weakened and there is no effective articulation between the points of care that the PTNB and his family will integrate(22). Parents feel helpless due to the fragmented care and unpreparedness of health professionals with regard to the complexity of the relationships involved in caring for PTNBs and their families, both individually and collectively(12).

Thus, including municipal and state managers in the Child Health, Women's Health and Stork Network is one of the strategies for tackling the conditions that interfere with and restrict the continuity of care for PTNBs, since the main demands can be met if there is an adequate and high-quality supply of services and professionals(23), since it is known that there is a need to improve access to services and to have more support from health professionals for network care in the face of the various care conditions required by PTNBs(24).

The study showed that the existing weaknesses in the care of at-risk NBs involve the managerial dimension, marked by the inefficiency of referral and counter-referral, as well as the lack of materials for care and the difficulty of access by families. There is also a need to sensitize institutional managers to the implementation of good practices in the care of newborns at risk, with the aim of improving the quality of care provided, training the professionals involved and offering appropriate conditions for the effective care of newborns and their families(25), as in this investigation.

In this context, it is important that managers take an active role in promoting structural and operational changes, prioritizing the allocation of resources needed to ensure the availability of adequate materials and facilitate families' access to services. In addition, they must foster an environment of continuous training for health professionals, promoting regular training that incorporates best practices and innovations in the care of at-risk NBs. In this way, they will be making a significant contribution to improving the quality of care and strengthening the support network for families.

A limitation of the study is that it only analyzed the reality of one of the state's outpatient services for high-risk neonates. Thus, we recognize the need to deepen the continuity of care for at-risk NBs, considering the specificities of the different levels of care and other institutions; however, the results of this study may contribute to the effectiveness of the nursing role in this institution's follow-up clinic, given the importance of nurses as part of the multi-professional team and in monitoring the growth and development of at-risk NBs.

FINAL CONSIDERATIONS

Although the aim of the study was to analyze the follow-up of at-risk NBs from the perspective of health professionals, managers and mothers, identifying the challenges faced and the strategies adopted to improve ongoing care, no specific strategies were identified during the research. This absence highlights the need to develop and document effective practices that can be implemented in the context of at-risk NB care. It is crucial that future studies and interventions focus on creating, testing and disseminating practical strategies that can directly address the weaknesses identified, thus ensuring more integrated and efficient care for these NBs and their families.

Both health professionals, managers and the mothers interviewed recognize the importance of providing the hospital's outpatient service with follow-up care for at-risk newborns, especially through a structured and organized follow-up program. However, they face operational, human resource and structural barriers. The current organization of the service prevents adequate monitoring of all at-risk NBs leaving the neonatal unit, as well as referral and counter-referral with other services to which these NBs are referred.

The follow-up of high-risk NBs in the service analyzed requires organization and the implementation of flows that order care and meet demand, guaranteeing continuity of care. In addition, follow-up could also be carried out by nurses, who currently only help with screening. This manuscript reinforces the importance of making nurses aware of their role in the multi-professional team, highlighting the importance of their active participation in the follow-up of at-risk NBs.

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