Esc Anna Nery 2019;23(2):e20180248

RESEARCH | PESQUISA

www.scielo.br/EAN

Discontinuity of outpatient follow-up of risk children: perspective of mothers

Descontinuidade do seguimento ambulatorial de crianças de risco: perspectiva das mães

Descontinuidad del seguimiento ambulatorial de niños de riesgo: perspectiva de las madres

Ieda Aparecida Diniz[1]
Bárbara Radieddine Guimarães[1]
Juliana Barony da Silva[1]
Tatiana Silva Tavares[1]
Elysângela Dittz Duarte[1]

1. Universidade Federal de Minas Gerais. Belo Horizonte, MG, Brasil

Abstract

Objective: to identify aspects that contribute to the discontinuation of outpatient follow-up of newborns from Neonatal Intensive Care Units (NICU) from the perspective of mothers. **Method:** exploratory, qualitative study, whose theoretical framework was Symbolic Interactionism. Fifteen mothers of children with NICU who discontinued outpatient follow-up in Belo Horizonte-MG were included in a semi-structured interview. Data were analyzed based on the proposal of Hsieh and Shannon. **Results:** distance from the health service, absence of family support, difficulty in leaving work, maternal health status, organization of the health service itself and deficiency of public transportation were predisposing factors for outpatient abandonment. Mothers understand that their children do not need differentiated care of children at usual risk. **Conclusion:** service organization, socioeconomic status of the family and social support perceived by mothers were related with the lack of compliance with outpatient follow-up.

Keywords: Continuity of Patient Care; Neonatal Intensive Care Units; Ambulatory Care; Symbolic Interactionism.

Resumo

Objetivo: identificar aspectos que contribuem para a descontinuidade do seguimento ambulatorial de crianças egressas de Unidades de Terapia Intensiva Neonatal (UTIN), sob a perspectiva materna. **Método:** estudo exploratório, qualitativo, cujo referencial teórico foi o Interacionismo Simbólico. Incluiu-se, por meio de entrevista semiestruturada, 15 mães de crianças egressas de UTIN que descontinuaram o seguimento ambulatorial em Belo Horizonte-MG. Os dados foram analisados baseados na proposta de Hsieh e Shannon. **Resultados:** a distância do serviço de saúde, ausência de apoio familiar, dificuldade de se ausentar do trabalho, condição de saúde materna, organização do próprio serviço de saúde e deficiência do transporte público foram aspectos predisponentes para o abandono ambulatorial. As mães entendem que seus filhos não precisam de cuidados diferenciados de crianças de risco habitual. **Conclusão:** a organização do serviço, a condição socioeconômica da família e apoio social percebido pelas mães esteve relacionado à falta de adesão ao seguimento ambulatorial.

Palavras-chave: Continuidade da Assistência ao aciente; Unidades de Terapia Intensiva Neonatal; Assistência Ambulatorial; Interacionismo Simbólico.

Resumen

Objetivo: identificar aspectos que contribuyen a la discontinuidad del seguimiento ambulatorio de niños egresados de Unidades de Terapia Intensiva Neonatal (UTIN) bajo la perspectiva materna. **Método:** estudio exploratorio, cualitativo, cuyo referencial teórico fue el Interaccionismo Simbólico. Se incluyó, por medio de una entrevista semiestructurada, 15 madres de niños egresados de UTIN que discontinuaron el seguimiento ambulatorial en la ciudad de Belo Horizonte, estado de Minas Gerais. Los datos fueron analizados basados en la propuesta de Hsieh y Shannon. **Resultados:** la distancia del servicio de salud, ausencia de apoyo familiar, dificultad para ausentarse del trabajo, condición de salud materna, organización del propio servicio de salud y deficiencia del transporte público fueron aspectos predisponentes para el abandono ambulatorial. Las madres entienden que sus hijos no necesitan los cuidados diferenciados de niños de riesgo habitual. **Conclusión:** la organización del servicio, la condición socioeconómica de la familia y el apoyo social percibido por las madres estuvieron conexo a la falta de adhesión al seguimiento ambulatorial.

Palabras clave: Continuidad de la Asistencia al Paciente; Unidades de Terapia Intensiva Neonatal; Asistencia Ambulatoria; Interaccionismo Simbólico.

Corresponding author:
Elysângela Dittz Duarte.
E-mail: elysangeladittz@gmail.com.

Submitted on 08/19/2018.
Accepted on 01/18/2019.

DOI: 10.1590/2177-9465-EAN-2018-0248

INTRODUCTION

Specialized outpatient follow-up service is intended for children at increased risk of morbidities due to premature birth and hospitalization in Intensive Care Units. This type of service enables a monitoring of growth and development, identifying early changes that need interventions and referrals to other services. It is also one of its purposes orientation and support for family members for the accomplishment of care for newborns[1].

Families that comply with outpatient follow-up, when compared to those who do not do it, have lower rates of disability and higher cognitive ability. Not compliance with outpatient follow-up results in the risk of worse long-term prognosis[2], since these children may have important repercussions regarding their growth, development[3] and family interaction[2]. In addition, it may compromise the health needs of children and their families[4].

Although the benefits of follow-up are known, non-compliance or avoidance rates are high. A study with mothers of children attending a referral outpatient clinic in the treatment of congenital syphilis in the state of Paraná identified 63.8% of outpatient drop-outs[5] higher than the rates found in international studies with mothers of preterm children, ranging from 33%[6] to 46%[2].

It was found that factors related to discontinuation of outpatient follow-up need to be deepened, considering the complex reality of the discontinuity of care for risk children[4,6].

They have been identified as predisposing factors for the non-outpatient follow-up relationship between professional--family, barriers faced to reach the service, lack of social support and time available[2,6]. A study in Canada showed that discontinuous families sought care only in the emergency room when the child's health needs were visible[6].

In order to ensure comprehensive and humanized care for the newborn at risk, in 2015, in Brazil, *Política Nacional de Atenção Integral à Saúde da Criança* (PNAISC - National Policy for Comprehensive Care for Children's Health) was introduced. Among the proposed actions, it is recommended that care for newborns egressed from the NICU be performed by PHC and also by a specialized follow-up clinic. This model of shared care aims at the quality of care offered to the newborn and the family at all levels of care[7]. Although the bond between health services sought to favor a continuous and humanized action, this was still a challenge that lacked effective solutions for the exchange of clinical information between services[8].

Mothers and family members play a major role in decisions about what is necessary or not for their children. Beliefs and values that permeate parental care practices represent organized sets of ideas that are implicit in the daily activities of these family members, acting in judgments, choices and decision making. These different ways of acting and perceiving the world around them may vary according to experiences, cultural and socioeconomic settings[9].

Therefore, it is assumed that the maternal assessment of the need for outpatient follow-up comes from her individual experiences acquired from gestation, as well as the contact with professionals in health services, which delineate the mother's perception, their behaviors, expectations and the sense that she attributes to the care provided to her child. In this context, mother or family creates meanings about the need for continuity of care.

In this sense, the present study aimed to identify aspects that contribute to the discontinuity of outpatient follow-up of newborns from NICUs from the perspective of mothers.

METHODS

It is an exploratory study of qualitative nature whose theoretical framework was Symbolic Interactionism. This approach allows the study of social behavior from their individual experience, considering that people build their world based on their interactions with the environment[10]. It contributes, therefore, to the knowledge about maternal opinions, behaviors and expectations that enabled them to interpret the need for outpatient follow-up of their children.

Data collection took place from July to October 2015, and the setting was the outpatient clinics for follow-up of high-risk child of a Philanthropic Maternity Hospital (A) reference in the implementation of the Stork Network (*Rede Cegonha*)'s strategy and a University Hospital (B), both from the city of Belo Horizonte.

The study included caregivers residing in the metropolitan area of Belo Horizonte, whose children were enrolled in NICUs, aged 0-2 years, and who discontinued outpatient follow-up.

Fifty-five children from NICUs who were discharged to outpatient follow-up were discharged at the time of discharge and discontinued follow-up. Discontinuation was considered as the absence of any outpatient appointment after hospital discharge or non-attendance in three or more consecutive visits.

Identification of risk children at outpatient follow-up was carried out in different ways according to the reality of each service. In the follow-up clinic linked to service A, consultations absence from the medical record was identified. Subsequently, confirmation was made with the health team. The follow-up clinic linked to service B has a database in Excel spreadsheet that lists the child's absences. This document was consulted to identify those in care discontinuity.

After the identification of children, their mothers were contacted through telephone and were informed about the research and invited to participate. Through the acceptance, the interview was scheduled in their homes. It is noteworthy that for 18 of the children identified, it was not possible to schedule the interview for several reasons, of which 06 were due to a telephone number that did not exist or belonged to other people who were not family members; 08 due to moving out of the metropolitan region of Belo Horizonte; 01 refusal in the telephone contact; 02 not attending at home; and 01 death of the mother resulting in the child moving out of Belo Horizonte.

For data collection, a semi-structured interview was used, consisting of the following questions: Does your child need special care compared to children at the same age? Why? Give your opinion regarding the contribution that the follow-up (outpatient

follow-up) has or does not have for the health of your child and explain why. What facilities and difficulties do you find for follow-up (outpatient follow-up)? Tell a bit about them. Is there an event that caused you to interrupt the child's outpatient follow-up? Which one? This script was previously tested for compliance with the objectives of the study, requiring no modifications. Interviews were conducted by one of the researchers at the place and time of the participant's choice.

Participants were previously informed of the anonymity and use of voice recorder. At the end of interviews, mothers listened to the recordings for confirmation that they had expressed themselves as they would like by their lines. None of the mothers asked for the exclusion or modification of their speech.

Interviews had an average duration of 19 min and 59 seconds and were transcribed within 48 hours after their completion. Interviews were later read by two researchers and a researcher from outside, in order to certify the adequate conduction of the interview, verify data adequacy to meet the objectives and define about the interruption of data collection.

Data collection was interrupted when the researchers verified that participants' speeches were repeated continuously with no new information to be recorded, which characterized data saturation. After this, three more interviews were performed to confirm that data were sufficient to respond to the study objective. At the end, the study was carried out with 15 mothers and 19 children.

For anonymity assurance, after transcription, names of mothers have been replaced by the letter M and followed by a number representing the sequence of the interview (E.g., M3).

After data collection, data were organized and analyzed using the content analysis proposed by Hsieh and Shannon[11]. For this, the researcher carried out the reading of interviews with the identification of central themes. These themes were grouped by similarity, constituting the categories and subcategories which are: *Understanding of mothers about child care needs*; *Socioeconomic conditions and aspects of everyday life that interfere with the maintenance of outpatient follow-up*; and *Aspects related to follow-up services and discontinuation of care in follow-up clinics* (Chart 1).

Chart 1. Description of the categories and themes constructed from empirical data

Categories	Themes that made up the categories
Understanding of mothers about child care needs	Understanding that children do not need different care
	Uncertainty about changes in development and differentiated care needs
	Recognition of the need for care with complex clinical conditions
	Assessment of the condition of the child, comparing it with other children of the same age
Socioeconomic conditions and aspects of everyday life that interfere with the maintenance of outpatient follow-up	Outpatient clinic far from home
	Disability in public transport and cost above family financial conditions
	Lack of support from the family and social network
	Difficulty in leaving work
	Demands of everyday life
	Maternal health condition
	Hospitalizações das crianças
Aspects related to follow-up services and discontinuation of care in follow-up clinics	Unavailability of schedules for consultations
	Need to wait for care with patients from other clinics
	Mothers do not have the understanding about the service offered
	Service with the participation of students delays and fragments

Source: chart drawn by the authors themselves;

The research was approved by the Research Ethics Committee, under Opinion 1,096,677.

RESULTS

Fifteen family members responsible for care participated in the study. Four of the participating mothers had twin children, totaling 19 risk children at outpatient follow-up discontinuation. Among the 15 participants, 14 were mothers of the children and one grandmother who had taken care of the newborn, so it was decided to refer to participants as mothers.

The mean maternal age was 31.4 years (SD 10.02). Only one family had more than one minimum wage per capita. Regarding marital status, 10 mothers lived with their partner, 8 being married and 2 in stable marriage. Three of the mothers were single and two were widows.

In relation to schooling, 8 mothers had 11 years of schooling. In this study, mothers presented an average of 10 years of education (SD 1.97). This is higher than the average number of years studied in Brazil (7.7 years) 12 and in the state of Minas Gerais (7.2 years)[13].

Of the 19 children who discontinued follow-up, 9 were from the outpatient clinic of hospital A and 10 from hospital B. The mean duration of discontinuation of follow-up up to the time of data collection was 12.1 months (SD of 4.65 months). Regarding the gestational age of birth in the outpatient clinic of hospital A, 6 of the children were born premature and in the follow-up clinic of

hospital B all the children of the families interviewed were born premature. In both outpatient clinics, all children discontinuing follow-up presented low birth weight. Mothers reported that 11 children had no health problems, 6 had bronchitis or asthma, 1 had Moebius Syndrome and 1 had hydrocephalus.

Understanding of mothers about child care needs

It is understood through the mothers' speech that they have an understanding that their children do not need care other than those offered to children at usual risk, and therefore do not need outpatient follow-up. Although the risk of developmental changes was reported by professionals, it was not effective for mothers to consider follow-up as necessary for their children.

> *Just as she* [the health professional] *said they would take longer to do things because they were premature. But, because of their age, I think they are almost on their way now, doing everything the boys their age are doing, even though they said they would be late, I do not think they stayed. That's why I do not think they need* [of follow-up] (M 16).

Of the 19 children, 13 were followed up by professionals from the Health Center. When asked if their children presented development expected for the age or if they presented some need for differentiated care, mothers did not know how to respond safely. Participants only highlighted the need for differentiated care in cases where children had more complex clinical conditions, physical changes, and developmental impairment that were visible to them.

> *No, I do not think* [needs differentiated care] *because I clear my doubts by my sister's* (...).*There is also follow-up that I do with him at the Health Center. The doctors tell me this. They say that his weight, size and development is being of a child his age* (...) (M 09)

> *Only G3* [needs special care]*, because he has hydrocephalus, now for G4 there is no need. He* [G4] *is smarter than my other 4-year-old; he does everything, talks too much, jumps, rises in things, curses you, he puts video on YouTube of "Lottie Dottie Chicken". He does everything you can imagine, he is awesome* (M 08).

Socioeconomic conditions and aspects of everyday life that interfere with the maintenance of outpatient follow-up

It was identified, in the participants' speeches, aspects that made it difficult to go to the outpatient clinic. Among them, the distance from the follow-up clinic, the insufficiency of public transport, the financial conditions for transportation, the lack of support from the family and social network, and the difficulty of being absent from work.

Regarding the distance from the follow-up clinics, it was verified that families lived on average 16.2 kilometers away. Mothers report that in addition to the distance from the outpatient clinic to the home, the time spent on the trip is a difficulty for the maintenance of follow-up. It was also mentioned the need to use more than one bus for each stretch and the limited financial resources for the payment of tickets.

> *The thing is, I live here in the neighborhood. To get a bus there, I'd have to get a three, four bus to get to the clinic. I live on the border of the two municipalities, so there it would be complicated to commute* (...). (M 10)

> *Another difficulty is the ticket, because the ticket from here to there is expensive, not every time we have money for it, only difficulty* (M 03).

In addition to transportation issues, M04 also reported on the influence of her health condition and difficulty to accept the child's birth as contributing factors for non-attendance.

> *I had to take a bus and I was not well, just like I told you I gave the postpartum depression, when I had it I did not want to have it, I did not like it, you know* (...). *So I did not care much for her, I did not go to the hospital, to follow, I did not care* (...) (M 04)

Absence of family and social support has also influenced the discontinuation of outpatient follow-up, due to the lack of helpers to take the children to the care and difficulty to leave work more often.

> *It's just hard for me to go because, sometimes, just as I would label them the same day, sometimes I do not find a person to go with me, understand?* (…) (M 16)

> (...) *sometimes, they call and book the appointment of one, then three days to another, sometimes four days, it's difficult because I work, to take one from there three days leads to another, there to interfere in the company, does not release me, It's kind of complicated.* (...) (M 01)

Children hospitalization was also reported as a reason for discontinuation of follow-up.

> *The problem was the issue of having coincided, the issue of him having fallen ill, of having missed the date because he was hospitalized.* (...) *I think it got in the way the hospital did not give me a return to come back* (...) (M 09)

Aspects related to follow-up services and discontinuation of care in follow-up clinics

This category was built from the fragments of the speeches that approached the aspects of the services that the mothers identified as difficulties for attendance. It is emphasized that it is not intended to evaluate the service, but rather to identify how aspects in the organization of the service, practices of the professionals and infrastructure can interfere in the choices about their use. Therefore, it was decided not to specify the outpatient clinic to which the mothers referred.

One aspect mentioned by the mothers concerns the unavailability of scheduling schedules, making it difficult to schedule appointments.

> *So, it's because the neurologist's agenda is busy, many boys, wow. And she and they are great, but it's a lot of kids.* (...) *The third* [appointment] *you have to try book an appointment, the neurologist, it is difficult to book* (M 07).

In one setting, the flow of access to the outpatient building is one aspect of the service that generated dissatisfaction. According to 3 participants, the entrance occurs through a queue and the mothers had to wait with the child for a long time at the entrance of the building. In addition, all children are scheduled for 1:00 a.m., so, after they are allowed to enter the service, the mothers had to wait to be answered in first-come basis.

> (...) *we have to stand in that line under the sun, rain, cold, whatever, back there, wait until we get up the fourth floor. This is the only bad thing* (...). *Sometimes you're scheduled to be taken in at 1:00 a.m. and 1:30 p.m. You're down there waiting* (...) (M 07)

In addition to the aspects related to waiting for care, the speech of M08 expresses that there is no recognition of what is done in the outpatient clinic, as a necessary and specialized care. It is inferred that there was no sharing with the mother of the evaluation of the professional and the meaning of the activities developed with the child.

> (...) *they leave the G3 joking, understand? They put some toys there so he can play. So, I think, if I go to him and do it, I'll put him down on the floor so he can play, understand? It's something I can do in my house, so I go there, in quotes, for nothing.* (...) (M 08)

Mothers' speech is dissatisfied with the performance of students, considering that they delay attendance and they fragment the care, turning attendance into tiring for the child and for the mother.

> *In relation to the pediatrician, I do not like not, because it is not always she who attends. How can I say? They are students and they do not know anything, the worst is that they do not know the boys, they ask all the time* (...). *Every day you have to repeat the same thing, every month. There every hour is one, you have to stay there, the other goes there and reads everything again.* (...) *it is very annoying the service in relation to this* (M 08).

It was evidenced an understanding of M10 and M05 that children would only need to return to the service if there were any changes. According to the participants, this was the orientation received from professionals, who recommended that they be kept in the Basic Health Unit. From this perspective, from the perspective of these mothers, there was no discontinuity of follow-up.

> *Yeah, and she* [the physiotherapy] *said that at 6 months I would come back if I needed it, if he was okay, if he had not opened his little hands, that up to four months he had to open his little hands. I was watching and it was where I observed and I saw that it was normal development there and I did not come back* (M 10).

> *No, there was no* [discontinuation of follow-up], [the follow-up] *is no longer in the hospital, at the Health Center, she said that when I observed that everything was normal, I did not have to go any more* (M 05).

DISCUSSION

Speeches allowed exploring the mothers' understanding of the health needs of their children and of the aspects that interfere in the continuity of follow-up in a specialized outpatient clinic. The data made it possible to grasp what has supported their choices about child care, how health professionals can support them for decisions that foster children's growth and development, and also how services can be organized to facilitate adhesion to follow-up.

Maternal understanding of adequate growth and development and the possibility of changes in the health status of premature infants is based on the absence of disease and how healthy their children are[14]. This understanding was observed in the speech of M10, when evaluating the good general condition of the child due to their ability to open their little hands up to six months, and in the speech of M05, which considers the child "normal" and therefore without need of follow-up. However, prematurity influences the child's development over time and, although there is a risk of developmental impairment, potential delays are sometimes imperceptible for mothers[15-16].

Maternal perception of the need for outpatient follow-up for her child is influenced by the biological condition and socio-cultural context that permeates family life[15]. In this sense, culture encompasses a diversity of community resources, material, technical and cognitive[10,17] that influence the meaning that the mother attributes to the need or not of specific health care for her children.

Another factor that interferes with maternal perception regarding the care needs of their children is the orientation provided by

professionals. However, it is observed that the relationship built between professionals and mothers did not allow the sharing of knowledge and practices for the studied population. Although follow-up clinic professionals may have informed about the risks of harm to the development of premature newborns and the importance of interventions performed in the service, the guidelines were not effective for maternal understanding of the need for follow-up, corroborating the findings of others studies[17-18].

When they did not perceive visible changes in the development of their children and did not understand the actions developed at the clinic, the mothers took on the role of defining the absence of follow-up. It is considered that knowledge and practices need to be shared between professionals and families, recognizing their differences and contributions to meeting the needs of children[19]. This difficulty in sharing the knowledge and practices of the health professional may have compromised the mothers' understanding of the specific outpatient care. In the mothers' report, this incomprehension led to the replacement of follow-up in the Basic Health Units.

A survey of 31 Primary Care professionals in Belo Horizonte showed that preterm or low birth weight newborns follow-up is still unknown to these professionals. Opinions diverged when asked whether a preterm child needed differentiated care or not, and whether they could be compared to a full-term newborn[18].

Data from this study allow us to affirm that the socioeconomic conditions and aspects of daily family life also interfere in the continuity of specialized outpatient follow-up, such as maternal health condition, difficulties to move to the hospital and child hospitalization.

Regarding the displacement, the mothers participating in this research mentioned the distance from the domicile to the service; the long time spent; the insufficiency of the public transport system; the financial limitation to pay for the tickets; the fragility of the support network; and the impossibility to leave work.

Corroborating with the findings of this study, regarding the contributory aspects to the outpatient follow-up discontinuation, distance has also been mentioned in other studies[6,18]. In Canada, an average of 48 kilometers was reported as a predictive factor for discontinuation of follow-up[20]. In both studies, transport realities are different from those found in Brazil, requiring caution in the use of these results, especially in the establishment of distance parameters.

Distance may have been perceived by the mothers with greater relevance due to the time spent on the trip to the follow-up clinic by means of public transportation. This indicates the need for distance not to be taken in isolation for the displacement discussion of these women and their children. A study on accessibility and space mobility carried out in the metropolitan area of Belo Horizonte indicates that people spend an average of 1,12 hour to reach their destinations[21], which corroborates with the inference.

It was identified in participants' speeches that limited financial resources may be difficult to attend the specialized clinic[22]. It should be emphasized that this factor combined with a poor public transport system and long distances from the follow-up service may constitute additional barriers to non-follow-up. Findings from national and international studies have indicated that families with lower purchasing power tend to discontinue follow-up of their children[6,18,23-24].

Fragility in the social support was observed in the speech of M16, where it was possible to identify its difficulty to attend consultations due to lack of companion. In this study, 5 of the participants had no partner. This is relevant information due to the possibility of greater difficulty in raising children in situations where there is paternal absence[25], and there may be greater overload due to the demand for differentiated care in situations in which children are at risk[24]. These findings indicate the importance of planning the consultations so that they are performed considering the mothers' other daily activities and the possibilities of support they have to ensure children follow-up[26].

In addition to the fragility in social support, the maternal health condition emerges as a di-fictive factor for the outpatient follow-up, as it is possible to observe in the speech of M04. Going against this finding, a survey conducted in Iran showed that 42% of mothers of newborns from the NICU reported, to some degree, postpartum depressive symptoms. Maternal depression was associated with low adhesion to follow-up programs when compared to mothers who did not report depressive symptomatology[22].

Regarding child hospitalization, there is a lack of communication between the health services in the speech of M09, when reporting that the child's rehospitalization was not informed about the continuity of outpatient follow-up. According to the Ministry of Health, hospital rehospitalizations are situations in which returns must be rescheduled. It is essential to closely monitor the patient who uses health services more frequently, with emphasis on emergency and emergency services[27].

Aspects related to the disarticulation of service networks, lack of orientation of professionals at the moment of hospital discharge[18,28], socioeconomic conditions and fragility in the support network for child care[24] have been evidenced as factors predisposing to the discontinuation of follow-up of the child who is not enrolled at NICU.

Referral and counter-referral represent a form of health services organization that allows follow-up of users by professionals and favors their access to all existing levels of care. It is important that Primary and Secondary Care integrate and operate in an articulated way, in an organizational design that contributes to the production of comprehensive care and in keeping with the dynamics of situations experienced by children[29].

As for the follow-up service aspects that interfere with its continuity in a specialized outpatient clinic, the lack of time and the difficulty to schedule were noted, the service is performed on a first-come, first-served basis, and dissatisfaction with the attendance per student, which fragments and delays.

Schedules restriction for appointments booking, according to the mothers, makes it difficult to act and predisposes to discontinuity. In another study carried out in Belo Horizonte,

consultations appointment proved to be a determining factor for access or not to the service. This difficulty is related to the lack of specialists and the lack of knowledge of a regulation of interval between appointment booking[18].

It was also mentioned as a difficult aspect of the arrival and entry organization in the follow-up service of Hospital B for care, exemplified in the speech from M07 and M08, as a moment of concern due to the children's exposure to time and the prolonged wait. Authors reinforce that the way services are organized may offer barriers to comprehensive care[18,30].

Attention should be paid to the uniqueness of families that are served, in order to rethink practices that, in fact, promote comprehensiveness and continuity of care, in order to define periodicity and priorities in care. For this, teamwork is essential, with well-defined and established roles of each member for the outpatient follow-up organization and embracement of users in services. A study with Primary Care professionals in the city of Belo Horizonte indicated that based on the established bond between professionals and the family, it was possible to understand the needs of the child, set priorities for scheduling, and schedule subsequent outpatient appointments[31].

Another aspect reported relates to the fact that the children are cared for by students who, according to the mothers, besides spending more time, at each visit it is necessary to repeat the same information. It is part of the process of teaching students to experience health services through services provided to users but it is important that it be developed in a way that does not compromise the care to be performed[26].

Findings show the complexity of investigating the various aspects that predispose to discontinuity. Although the study in question has a potential contribution to the understanding of outpatient follow-up discontinuation of at-risk children, the results discussed here have emerged from the unique experience of mothers of children who are not enrolled in a NICU in a local context. It is suggested the development of researches with other methodological designs that allow greater knowledge about the discontinuity of outpatient follow-up, as the longitudinal ones.

One of the strengths of this study is the use of the qualitative approach, including participants served at two different follow--up places. Another aspect was the possibility of research with mothers who were absent from outpatient follow-up, which was methodologically challenging. A limitation refers to the fact that it was performed with women residing in a single municipality, presenting limits for the transferability of the findings, although they may be used in populations with similar characteristics and contexts.

FINAL CONSIDERATIONS

Aspects related to mothers' perception of the need for outpatient follow-up, service organization, socioeconomic status of the family and social support perceived by mothers were related to the lack of adhesion of families of newborns at risk to outpatient follow-up.

It is recognized that the change in the reality of outpatient follow-up discontinuation demands intersectoral strategies in the medium and long term, involving both health services that make up the care network and other sectors such as social care and transportation. Results indicate the need for professional training so that they can provide clear information to caregivers about the children's health needs so that they understand the benefits of follow-up and the risks of discontinuity. In addition, it is necessary to build professional-family bond in order to consider the individuality of each family and to meet their health needs.

Interventions are proposed, especially those related to the service organization, such as flow reorganization for care and surveillance regarding risk factors for non-follow-up. Families should be addressed early and information shared, offering new perspectives that guide their decisions regarding outpatient follow-up.

FINIANCIAL SUPPORT

This study was financed by the National Council for Scientific and Technological Development (CNPq - *Conselho Nacional de Desenvolvimento Científico e Tecnológico*), Process 480206/2013-9 and the Research Support Foundation of Minas Gerais (FAPEMIG - *Fundação de Amparo à Pesquisa de Minas Gerais*) Process: APQ-01889-13.

REFERENCES

1. Synnes AR, Lefebvre F, Cake HA. Current status of neonatal follow-up in Canada. Paediatric Child Health [Internet]. 2006 May;11(5):271-4. Available from: https://www.ncbi.nlm.nih.gov/pubmed/19030287
2. Fuller MG. Factors associated with high risk infant follow-up attendance [thesis]. San Diego: University of San Diego; 2015. Available from: https://digital.sandiego.edu/cgi/viewcontent.cgi?article=1022&context=dissertations
3. Rover MMS, Viera CS, Silveira RC, Guimarães ATB, Grassiolli S. Fatores de risco associados à falha de crescimento no seguimento de recém-nascidos de muito baixo peso. J Pediatr (Rio J.) [Internet]. 2016 May/Jun;92(3):307-13. Available from: http://www.scielo.br/scielo.php?pid=S0021-75572016000300307&script=sci_arttext&tlng=pt
4. Pereira LB, Abrão ACFV, Ohara CVS, Ribeiro CA. Vivencias materna frente às peculiaridades da prematuridade que dificultam a amamentação. Texto Contexto Enferm [Internet]. 2015 Jan/Mar;24(1):55-63. Available from: http://www.scielo.br/pdf/tce/v24n1/pt_0104-0707-tce-24-01-00055.pdf
5. Feliz MC, Medeiros ARP, Rossoni AM, Tahnus T, Pereira AMV, Rodrigues C. Aderência ao seguimento no cuidado ao recém-nascido exposto à sífilis e características associadas à interrupção do acompanhamento. Rev Bras Epidemiol [Internet]. 2015 Oct/Dec;19(4):727-39. Available from: http://www.scielo.br/pdf/rbepid/v19n4/1980-5497--rbepid-19-04-00727.pdf
6. Ballantyne M, Stevens B, Guttmann A, Willan AR, Rosenbaum P. Maternal and infant predictors of attendance at Neonatal Follow-Up programmes. Child Care Health Dev [Internet]. 2014 Mar;40(2):250-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/23294101
7. Martins CBG, Pedro RP, Lima FCA, Gaíva MAM. Neonatos de risco: avaliação das famílias sobre os atendimentos em situações cotidianas e de alteração na saúde. Ciênc Cuid Saúde [Internet]. 2015 Jan/Mar;14(1):805-13. Available from: http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/21680

8. Reis ZSN, Aguiar RALP, Ferreira AAT, Viegas AC, Anchieta LM. Analysis of the summary content in obstetric discharge reports in a reference maternity hospital. An opportunity to rethink the strategy of continuity in maternal and neonatal care. Rev Méd Minas Gerais [Internet]. 2015;25(4):476-83. Available from: http://www.rmmg.org/artigo/detalhes/1860
9. Petrokas RC. A experiência materna no cotidiano de cuidados dos bebês de risco [dissertação]. São Paulo: Universidade de São Paulo; 2017. Available from: http://www.teses.usp.br/teses/disponiveis/5/5170/tde-23042018-114527/publico/RejaneCristinaPetrokas.pdf
10. Carvalho VD, Borges LO, Rego DP. Interacionismo Simbólico: Origens, Pressupostos e Contribuições aos Estudos em Psicologia Social. Psic Cienc Profs [Internet]. 2010;30(1):146-61. Available from: http://www.scielo.br/scielo.php?pid=S1414-98932010000100011&script=sci_abstract&tlng=pt
11. Hsieh H, Shannon S. Three approaches to qualitative content analysis. Qual Health Res [Internet]. 2005 Nov;15(9):1277-88. Available from: https://www.ncbi.nlm.nih.gov/pubmed/16204405
12. Instituto Brasileiro de Geografia e Estatística - IBGE (BR). Estudos e Pesquisas Informação Demográfica e Socioeconômica: Síntese de Indicadores Sociais Uma análise das Condições de Vida da População Brasileira 2014. Rio de Janeiro: IBGE; 2014.
13. Fundação João Pinheiro (MG). Boletim PAD-MG Belo Horizonte: Indicadores Básicos Documentos Metodológicos. 2013. Belo Horizonte: Boletim PAD-MG; 2014. [cited 2016 Jan 6]. Available from: http://www.fjp.mg.gov.br/index.php/docman/cei/pad/502-boletim-pad-7-dezembro-19-11-2014-site-2/file
14. Seixas LEVC, Siqueira FPC, Mazzeto FMC. Consulta de enfermagem em ambulatório de seguimento para recém-nascido prematuro: ferramenta para o empoderamento materno. Rev Eletr Acer Saúde [Internet]. 2017;(Sup.9):S665-74. Available from: https://www.acervosaude.com.br/doc/REAS41.pdf
15. Lemos RA, Veríssimo MLOR. Development of premature children: caregivers' understanding according to the Bioecological Theory. Rev Esc Enferm USP [Internet]. 2015; [cited 2018 Apr 5]; 49(6):898-906. Available from: http://www.scielo.br/pdf/reeusp/v49n6/0080-6234-reeusp-49-06-0899.pdf
16. Dornellas LF, Duarte NMC, Magalhães LC. Atraso do desenvolvimento neuropsicomotor: mapa conceitual, definições, usos e limitações do termo. Rev Paul Pediatr [Internet]. 2015; [cited 2018 Apr 20]; 33(1):88-103. Available from: http://www.scielo.br/pdf/rpp/v33n1/pt_0103-0582-rpp-33-01-00088.pdf
17. Leite RAF, Brito ES, Silva LMC, Palha PF, Ventura CAA. Acesso à informação em saúde e cuidado integral: percepção de usuários de um serviço público. Interface (Botucatu) [Internet]. 2014;18(51):661-71. Available from: http://www.scielo.br/pdf/icse/v18n51/1807-5762-icse-1807-576220140653.pdf
18. Aires LCP, Santos EKA, Costa R, Borck M, Custódio ZAO. Seguimento do bebê na atenção básica: interface com a terceira etapa do método canguru. Rev Gaúcha Enferm [Internet]. 2015; [cited 2018 Feb 26]; 36(no. spe):224-32. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472015000500224&lng=en. DOI: http://dx.doi.org/10.1590/1983-1447.2015.esp.56805
19. Costa JP, Jorge MSB, Vasconcelos MGF, Paula ML, Bezerra IC. Resolubilividade do cuidado na atenção primária: articulação multiprofissional e rede de serviços. Saúde Debate [Internet]. 2014 Oct/Dec;38(103):733-43. Available from: http://www.scielo.br/pdf/sdeb/v38n103/0103-1104-sdeb-38-103-0733.pdf
20. Ballantyne M, Stevens B, Guttmann A, Willan A, Rosenbaum P. Transition to Neonatal Follow-up Programs. J Perinat Neonatal Nurs [Internet]. 2012 Jan/Mar;26(1):90-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/22293647
21. Lobo C, Cardoso L, Magalhães DJAV. Acessibilidade e mobilidade espaciais da população na Região Metropolitana de Belo Horizonte: análise com base no censo demográfico de 2010. Cad Metrópole (São Paulo) [Internet]. 2013 Dec;15(30):513-33. Available from: http://www.scielo.br/pdf/cm/v15n30/2236-9996-cm-15-30-0513.pdf
22. Ravarian A, Vameghi R, Heidarzadeh M, Nariman S, Sagheb S, Nori F, et al. Factors Influencing the Attendance of Preterm Infants to Neonatal Follow up And Early Intervention Services Following Discharge from Neonatal Intensive Care Unit during First Year of Life in Iran. Iran J Child Neurol [Internet]. 2018;12(1):67-76. Available from: https://www.ncbi.nlm.nih.gov/pubmed/29379564
23. Morais AC, Quirino MD, Camargo CL. Social support in caring for premature infants after hospital discharge. Rev Eletr Enferm [Internet]. 2012 Ju/Sep;14(3):654-62. Available from: https://www.fen.ufg.br/revista/v14/n3/pdf/v14n3a23.pdf
24. Lakshmanan A, Agni M, Lieu T, Fleegler E, Kipke M, Friedlich PS, et al. The impact of preterm birth <37 weeks on parents and families: a cross-sectional study in the 2 years after discharge from the neonatal intensive care unit. Health Qual Life Outcomes [Internet]. 2017 Feb;15(1):38. Available from: https://www.ncbi.nlm.nih.gov/pubmed/28209168
25. Macana EC, Comim F. O papel das práticas e estilos parenterais no desenvolvimento da primeira infância. In: Pluciennik GA, Lazzari MC, Chicaro MF, orgs. Fundamentos da Família Como Promotora do Desenvolvimento Infantil: Parentalidade em Foco. 1ª. ed. São Paulo: Fundação Maria Cecília Souto Vidigal - FMCSV; 2015.
26. Gontijo ML, Cardoso AA, Dittz ES, Magalhães LC. Evasão em ambulatorio de seguimento do desenvolvimento de pré-termos: taxas e causas. Cad Bras Ter Ocup (São Carlos) [Internet]. 2018;26(1):73-83. Available from: http://www.cadernosdeterapiaocupacional.ufscar.br/index.php/cadernos/article/view/1784/945
27. Ministério da Saúde (BR). Manual do Método Canguru: Seguimento Compartilhado entre a Atenção Hospitalar e a Atenção Básica. Brasília (DF): Ministério da Saúde; 2015.
28. Zanello E, Calugi S, Rucci P, Pieri G, Vandini S, Faldella G, et al. Continuity of care in children with special healthcare needs: a qualitative study of family's perspectives. Ital J Pediatr [Internet]. 2015 Feb;41:7. Available from: https://www.ncbi.nlm.nih.gov/pubmed/25882884
29. Franco CM, Franco TB. Linhas do cuidado integral: uma proposta de organização da rede de saúde. [Internet]. [cited 2014 Jul 20]. Available from: http://www.saude.sp.gov.br/resources/humanizacao/homepage/acesso-rapido/formacao-tecnica-em-acolhimento-na-atencao-basica/passo_a_passo_linha_de_cuidado.pdf
30. Viegas APB, Carmo RS, Luz ZMP. Fatores que influenciam o acesso aos serviços de saúde na visão de profissionais e usuários de uma unidade básica de referência. Saúde Soc [Internet]. 2015;24(1):100-12. Available from: http://www.scielo.br/scielo.php?pid=S0104-12902015000100100&script=sci_abstract&tlng=pt
31. Duarte ED, Silva KL, Tavares TS, Nishimot CLJ, Walty CMRF, Sena RR. Desafios do trabalho da enfermagem no cuidado às crianças com condições crônicas na atenção primária. Esc Anna Nery [Internet]. 2015;19(4):648-55. Available from: http://www.scielo.br/pdf/ean/v19n4/1414-8145-ean-19-04-0648.pdf