Revista Brasileira em Promoção da Saúde
e-ISSN:1806-1230
Original Article
DOI: 10.5020/18061230.2021.11708

Search for health care: therapeutic itinerary of children discharged from the neonatal units

Busca por cuidados de saúde: itinerário terapêutico de crianças egressas de unidades neonatais

Búsqueda de cuidados de salud: itinerario terapéutico de niños de alta de unidades neonatales

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ABSTRACT

Objective: To understand the paths taken by mothers and caregivers while searching for care for children discharged from neonatal units. **Methods:** Qualitative and exploratory study, carried out between May and June 2018, with mothers and caregivers of children born between 2014 and 2015, discharged from two public neonatal units in a capital from a Northeastern Brazil state. Fourteen semi-structured interviews were conducted, and content analysis was used in the thematic modality. Three categories were found that show possible paths taken for the care, mostly passing through the three sectors: “the informal sector as a starting point for the care”, “the use of the popular sector as a healing practice”, and “the use of professional sector: an alternative for consultation”. **Results:** The informal sector was the most addressed sector by caregivers. In general, the first choice was for self-medication oriented transgenerationally by grandmothers. The use of the popular sector was influenced by the families’ prior knowledge and their perception of the health-disease process. Biomedical culture permeated the three sectors and influenced the construction of the therapeutic itinerary. In the professional sector, a fragile bond was identified, mainly in primary care. **Conclusion:** The paths taken by mothers and caregivers of newborns discharged from neonatal units pointed to an overlap of medicalization to detriment of popular culture. Hosting and managing families’ social and cultural repertoires contribute to strengthening therapeutic links with the professional sector. Primary Health Care needs to be strengthened to guarantee the qualification of care for children.

Descriptors: Health Care; Child Care; Traditional Medicine; Self-medication; Intensive Care Units, Neonatal.

Received on: *10/03/2020*
Accepted on: *01/14/2021*

RESUMO

Objetivo: *Compreender os caminhos percorridos por mães e cuidadoras na busca pelo cuidado de crianças egressas de unidades neonatais.* ***Métodos:*** *Estudo qualitativo e exploratório, realizado entre maio e junho de 2018, com mães e cuidadoras de crianças nascidas entre 2014 e 2015, egressas de duas unidades neonatais públicas de uma capital do Nordeste brasileiro. Realizaram-se 14 entrevistas semiestruturadas, e se utilizou análise de conteúdo na modalidade temática. Apreenderam-se três categorias que evidenciam possíveis caminhos percorridos para o cuidado, perpassando, em sua maioria, pelos três setores: "O setor informal como ponto de partida para o cuidado", "O uso do setor popular como prática de cura", "O uso do setor profissional: alternativa para consulta".* ***Resultados:*** *O setor informal foi o mais relatado pelas cuidadoras. Em geral, a primeira escolha era pela automedicação orientada de forma transgeracional, pelas avós. O uso do setor popular foi influenciado pelo conhecimento prévio das famílias e sua percepção do processo saúde-doença. A cultura biomédica perpassou os três setores e influenciou na construção do itinerário terapêutico. No setor profissional identificou-se vínculo frágil, principalmente na atenção primária.* ***Conclusão:*** *Os caminhos percorridos por mães e cuidadoras de egressos de unidades neonatais apontaram sobreposição da medicalização em detrimento dos saberes populares. Acolher e manejar os repertórios sociais e culturais das famílias pode contribuir para fortalecer vínculos terapêuticos com o setor profissional. A Atenção Primária à Saúde precisa ser fortalecida para garantir a qualificação do cuidado às crianças.*

Descritores: *Atenção à Saúde; Cuidado da Criança; Medicina Tradicional; Automedicação; Unidades de Terapia Intensiva Neonatal.*

RESUMEN

Objetivo: *Comprender los caminos recorridos por madres y cuidadoras para la búsqueda del cuidado de niños de alta de unidades neonatales.* ***Métodos:*** *Estudio cualitativo y exploratorio realizado entre mayo y junio de 2018 con madres y cuidadoras de niños nacidos entre 2014 y 2015 de alta de dos unidades neonatales públicas de una capital del Noreste brasileño. Se realizaron 14 entrevistas semiestructuradas y se ha utilizado el análisis de contenido en la modalidad temática. Se ha identificado tres categorías que evidencian los posibles caminos recogidos para el cuidado pasando en su mayoría por los tres sectores: "El sector informal para el punto de inicio del cuidado", "El uso del sector popular para la práctica de cura", "El uso del sector profesional: alternativa para la consulta".* ***Resultados:*** *El sector informal ha sido el más relatado por las cuidadoras. En general, la primera elección era el auto medicación orientada por las generaciones de abuelas. El uso del sector popular ha sido influenciado por el conocimiento previo de las familias y su percepción del proceso salud-enfermedad. La cultura biomédica ha pasado por los tres sectores y ha influenciado para la construcción del itinerario terapéutico. Se ha identificado un vínculo frágil en el sector profesional sobre todo en la atención primaria.* ***Conclusión:*** *Los caminos recogidos por madres y cuidadoras de niños de alta de unidades neonatales señalaron el solapamiento de la medicalización con pérdida de los saberes populares. Acoger y manejar los repertorios sociales y culturales de las familias puede contribuir para reforzar los vínculos terapéuticos con el sector profesional. Hace falta el fortalecimiento de la Atención Primaria de Salud para garantizar la cualificación del cuidado de los niños.*

Descriptores: *Atención a la Salud; Cuidado del Niño; Medicina Tradicional; Automedicación; Unidades de Cuidado Intensivo Neonatal.*

INTRODUCTION

Scientific advances in neonatology have enabled technological improvements that have been accompanied by changes in care for the newborn (NB)[1]. Neonatal hospitalization has contributed to increased survival, especially for those born preterm and/or of low weight, who are at higher risk of mortality, infection, nutritional problems, and developmental delays. These are complex problems that after hospital discharge need shared monitoring between Specialized Care and Primary Health Care (PHC). The discontinuation of this monitoring can lead to a higher risk of mortality and complications, including in the long term[2,3].

Therefore, when returning home, these children must be carefully monitored, as they may require interventions. Families are often faced with situations not only of fear and insecurity in the child care but also with socio-cultural issues focused on the symbolic dimension of their health understanding. Brazil's National Health Promotion Policy, recognizing the people and collectives subjectivity in the attention and care process, reinforces the expanded concept of health resulting from the life, organization, and production ways in a given historical, social, and cultural context, seeking to overcome the concept of health as the absence of disease, centered on biological aspects[4]. In this sphere, the transversality of health promotion is evident, which must occur in all scenarios of the health care network and society, employing different strategies of action[4].

When moving from the hospital care environment, users are inserted in a complex social, affective and symbolic network, in which unique routes and paths are defined for the continuity of care in the territory[5]. Some factors influence in this process: bonds established (or not) with professionals; family and community ties; previous knowledge,

perceptions, and experiences; cultural beliefs; the network of relations with the territory; access to health services; and social and subjective aspects that constitute the contemporaneity, such as digital culture and medicalization.

The path taken by users and their families in search of treatment and cure is called therapeutic itinerary (TI), which is comprised of three interrelated subsystems concerning health care: informal sector, a not systematized sector, which covers the care provided by the individual's family, community and social networks; popular sector, which includes healing specialists linked to religious or secular groups, such as faith healers, healers, "*pais de santo*" (saint fathers), midwives, among others; and professional sector, which consists of the formal health system and comprises the regulated professions[6].

In the search for acceptable care practices, mothers acquire experiences, and knowledge with the people close to them. Transgenerationality in the transmission of knowledge stands out, in which grandmothers play an important role[7].

We sought to carry out this study considering that the multiplicity of paths and choices of families directly influences the care of these children when they make their way in the search for attention to health and treatment. It is expected that this study will contribute to health promotion and to broadening the view of health professionals to therapeutic diversity.

Therefore, this study had the following guiding question: What are the paths taken by families after hospital discharge in the search for health care for children discharged from neonatal units?

This study aimed to understand the paths taken by mothers and caregivers in the search for care for children discharged from neonatal units.

METHODS

It is a qualitative, exploratory study[8], carried out from May to June 2018, with mothers and caregivers of children discharged from two public neonatal intensive care units (NICU) in the capital of a Northeastern Brazilian state.

165 children were identified from the analysis of medical records. Since this is a qualitative study, in which the choice of participants aimed to privilege the different attributes that are significant for the object of study[8], the inclusion criteria were: being a mother and/or caregiver of children born between 2014 and 2015, discharged from the NICU, and residing in the municipality where the research was carried out, the children's medical records were the starting point for their identification. The exclusion criteria were children born outside the period mentioned in the inclusion criteria. Thus, 34 children residing in the different health districts were previously selected, and interviews with the mothers took place until reaching the saturation criterion the moment of the fieldwork in which the data obtained is sufficient for the researcher to understand the internal logic of the group researched. So, the sample closure occurred with 14 interviews.

The first contact with mothers and caregivers occurred by telephone. On this occasion, the introduction of the researcher and presentation of the research objectives was carried out, and they were invitated to participate. There was no refusal among the contacted mothers. After acceptance, the interview was scheduled at a time and place convenient for the interviewees. The suitable place for conducting the interviews was the house. Only one opted for the clinic.

The techniques used for data collection were: structured questionnaire, filled with data extracted from the medical record to identify the birth data and clinical conditions of the children, and semi-structured interview conducted with mothers and caregivers. For the interviews, a script was elaborated containing closed questions about the sociodemographic data of the mothers and caregivers (age, education, marital status, income, number of children, and religion). Regarding the children, the following data were selected: age, sex, length of hospitalization and diagnosis, and the guiding question: What are the paths taken by families after discharge in the search for health care for children discharged from neonatal intensive care units?

The interviews were recorded and later transcribed. The interviewees showed availability and interest in talking about their practices, making evident the importance of being heard. The interviews took place in a private place, in a friendly atmosphere between the interviewer and the interviewee, and lasted approximately 30 minutes.

For data analysis and interpretation, content analysis was used in the thematic modality[9], which is understood as a set of communication analysis techniques aiming to obtain, through systematic and objective procedures for describing the content of messages, indicators (quantitative or not) that allow the inference of knowledge related to the conditions of production/ reception of these messages.

The first phase is characterized as pre-analysis when the floating and exhaustive reading of the statements occurs. The second phase is the material exploration, seeking, from the analytical categories, the thematic nuclei, which are significant expressions or words according to which the content of a speech was organized. In the final phase, inferences and interpretations were made, articulated with the theoretical framework designed initially and around new theoretical and interpretive dimensions[9], allowing the recognition of three thematic nuclei: "The informal sector as a starting point for care"; "The use of the popular sector as a healing practice"; "The use of the professional sector: an alternative for consultation".

This study is part of wider research entitled "Health care sectors used by children discharged from neonatal units", approved by the Research Ethics Committee of the University Hospital of the Federal University of Maranhão (HUUFMA), Opinion No. 2,626,632. The names of the participants were replaced by fictitious names, guaranteeing the anonymity and confidentiality of the information.

RESULTS AND DISCUSSION

Sociodemographic data of the interviewees and identification of children

Of the 14 interviews, 13 were conducted with the mothers and one with the maternal grandmother, the child's primary caregiver. Age ranged between 16 and 64 years, most of them were Catholic, with incomplete elementary school education. Six lived in a consensual union, five without partners, and the rest married, widowed, or divorced. The number of children varied, mainly between one and four. Family income ranged from less than one to four minimum wages. Eight said they received the family allowance benefit (*bolsa família*).

Regarding the children, at the time of the interview, they were between 34 and 47 months old, and eight were firstborn, most of them were male. The length of hospitalization in the NICU ranged from 2 to 110 days, the main diagnosis being prematurity. Other diagnoses were: meconium aspiration syndrome, respiratory distress, hemorrhagic disease, polycythemia, transient tachypnea of the newborn, anoxia, cleft palate, and cleft lipo. Two children were diagnosed with cerebral palsy, and another left the hospital with a tracheostomy.

Considering that the children were identified in the professional sector and who underwent neonatal hospitalization in highly complex services, it was expected that they would regularly use Specialized Care and PHC; however, only three children were being monitored in the specialized outpatient clinic, and two referred bond with PHC.

From the interviews, it was found that, at the time of discharge, after neonatal hospitalization, all were referred to their reference Primary Health Care Unit or followed up in a specialized outpatient clinic. From the TI constructed in the interviews, there was an overlap in the use of the health care sectors (professional, popular and informal), expressed in various ways and crossed by a cultural logic that highlighted the possible paths taken by mothers and caregivers for child care. The TI analysis did not follow fixed models and standards, which would leave aside the processes dynamics. Conceptions, choices, and coping strategies for illness situations are processes built by the subjects and their relational networks, ranging from family and friends to health services, in the culture in which they are inserted[10].

These paths will be presented below based on the thematic groups that emerged from the study: "The informal sector as a starting point for care;" "The use of the popular sector as a healing practice;" "The use of the professional sector: an alternative for consultation."

The informal sector as a starting point for care

This category shows that the first choices, at the initial moment of identification of the disease, were informal sector practices. Among these practices, the following were cited: self-medication, homemade remedies, and counseling with people with similar experience, with self-medication being the most frequent:

> *"But I always have it stored! My mom always tells me to have the medicine stored. My mom always asks me to keep it. In case he has a fever, so that I can give him medicine " (Lucas's mother)*
>
> *"Fever medicine... I give him cough medicine too. Usually, I give it on my own. Then, if I see that it didn't work, then I take him to the doctor" (Davi's mother)*

For some caregivers, self-medication was due to the guidance received by relatives, especially by grandmothers, who directly participated in the care, but the use of old prescriptions was also mentioned, as observed in the statements below:

> *"But if it is a problem I already know what it is, and if I take him to the hospital, it will be the same conduct, I will not. Because I already have all the prescriptions, I just go to the pharmacy" (Manoel's mother)*
>
> *"Because the doctor prescribed it, I went and bought two bottles, I keep one at home. When I see that he must have a sore throat, I go according to the medication. And paracetamol I always have at home... dipyrone, which I know he can take" (Paulo's mother)*

In this study, the informal sector was reported by mothers who had a greater connection with the professional sector. For them, the reappearance of signs and symptoms previously diagnosed and treated justified the use of old prescriptions. This practice, used by caregivers of children who receive more frequent medical follow-up, has been described in the literature, like a study that addressed the use of self-medication in children under 12 years of age, which showed greater use in the North and Northeast regions[11].

Another practice mentioned was the search for guidance in the purchase of medicines at the neighborhood pharmacy, as noted below:

> *"My mother-in-law tells me to buy medicine, I give it to her. She went to the pharmacy, then they prescribed it" (Ana's mother)*
>
> *"I go to the pharmacy, I explain... then the girl gives a medicine that is good for this... for diarrhea, right? Then I gave him and he got better... then I also gave coconut wate ... then he got better" (Pedro's mother)*

In Brazil, it is common the drugstore clerks to play the role of prescribers[12], and in the interviews it was not clear whether the guidance was given by a clerk or a pharmacist.

A study carried out in a pharmaceutic commercial establishment in the state of Ceará showed that drugstore clerks had a strong influence on self-medication and family and friends were the most influential in this practice. The practicality has been described as motivation, as it is easier to purchase the drug at the pharmacy than to schedule a medical appointment[12].

Families are very important in the care process, therefore, it is relevant to evaluate the context in which they are inserted, in order to verify the forms of treatment, and to promote their search for care[13].

In a study, it was found in the statements that the informal system is sought in the daily lives of these children's families, pointing out that culture impacts the resolution of the illness process, namely, how each family organizes its customs and promotes care to re-establish the disease health[13].

Thus, some practices were mentioned, such as teas and homemade remedies, especially influenced in a transgenerational way, by maternal grandmothers, who directly participated in the child care:

> *"It is because... my mother is from the countryside, so she always used... medicinal plants, natural remedies... to cure illnesses, diseases like... the flu. It is very common! They use a lot of "lambedor" (cough syrup)... and nowadays, I passed it on to my son, you know? And I see results, don't I?" (Yago's mother)*
>
> *"Because mom said that in the past there was no pharmacy, it was homemade remedies only, right? The elders gave it to us. So, she tells me to do it: 'look, daughter, do it like this'" (Saulo's mother)*

In the literature, the use of homemade measures by caregivers, especially the use of teas, is also commonly cited[14,15]. In some situations, when perceiving the disease, the use of teas, herbal baths, and syrups are considered the first choice[6] and are often administered concomitantly with other medications[16]. In general, this learning was acquired through observation and the exchange of information between family members, especially mothers and mothers-in-law[17], followed by grandparents and aunts, which corroborates the data found.

Practices related to religion, such as prayer and the use of anointed oil, also appear as resources used by caregivers to obtain healing in times of distress:

> *"I pray too much when they are sick. Sometimes, I do a prayer campaign when I see that they are so very sick. I go to the sisters and say: 'sisters, I want a prayer campaign, the boys are so sick'" (Saulo's mother)*
>
> *"One day he was like that, with a fever, he wasn't sleeping well... then I used the anointed oil on him. I felt some improvement, didn't I?! He improved, thank God! He slept well. So, it is in those times that I usually use faith in God, right?!" (Yago's mother)*

Religions modify how individuals position themselves against the disease and its treatment[18], assuming great relevance, especially for low-income populations[5].

Still related to the informal sector, two mothers reported sharing information and guidance with others who had similar experiences:

> *"The girl right here in the house in the front. She has a special baby too. He had used a probe for a long time, and she always tipped me like that... if there was something I didn't know, she'd tell me" (Elis's mother)*

It is clear that the way to face the disease and to minimize the impacts of unforeseen events on the health of individuals is also related to the individual capacity to make decisions, even with the influence of health, disease, and body conceptions, and also of the available health resources and the difficulty in accessing health services[10]. Besides, the possibility of failure to recognize the use of other sectors by health professionals may also influence the initial choice by the informal sector[14].

A study on TI of children under five, in response to health problems, found that 74.58% of the episodes referred to as diseases were initially treated at home[16]. Even when it comes to the child who was born premature, whose mothers seek assistance in several sectors, the informal sector is still usually the first one sought and, in general, directs the TI to be taken[13].

One of the consequences of biomedicine is medicamentalization (jargon created to refer to the medical control of the mind). The biomedical rationality linked to the competitive and high-performance logic created conditions for the culture of self-medication, which puts on the scene not only medical knowledge itself but the powerful pharmacological industry. The difficulty of access to health professionals and the disqualification of traditional knowledge create a kind of pressure on the informal sector, in which self-medication is the main daily resource[19].

The use of the popular sector as a healing practice

This category shows that, even in the case of children discharged from NICU, some with comorbidities, the practices of the popular sector are referred to in this study, although not predominant.

Mothers cited the use of popular practices for the treatment of problems associated with cultural issues, such as "evil eye", "hex" and "stomach problem":

> *"We were suspecting of an evil eye, right?! I took her there for a blessing... (Mel's mother)*
>
> *"She was two months old, I think, so we went out. Then, when we came back, she started to get sick... out of nowhere. She was vomiting, she was weak, she wasn't breastfeeding well... then we thought: 'they put on a hex' and it wasn't. It was an "vento virado" (stomach problem)" (Ana's mother)*

The blessing was and still is a widespread and socially recognized healing practice, especially for children care. It involves popular knowledge that is passed on from generation to generation[7,20]. However, popular medicine has been sought as an alternative or as a way to complement the treatment of traditional medicine, even by people with access to formal education and medical knowledge[20].

For one of the caregivers, the "hex" was placed by the neighbors and recognized by family members, who indicated the blessing as a treatment:

> *"She already got hex, things like that. Right when she arrived, she was really fat! Then the curious people on the street, everyone wanted to see what she looked like. Then they came here and hexed her" (Elis's mother)*

For some mothers, these diseases are not treated in the professional sector. These are diseases that the doctor does not know about and that health services do not have the competence to treat[16]. However, this was not a consensus. The use of the professional sector was mentioned in some situations when the practices of the popular sector did not produce the expected result:

> *"Then mom said: 'If she doesn't get better in a few hours, then you'll take her to the hospital" (Mel's mother)*

It is important to highlight the plurality of the use of sectors. Even faith healers, whose goal is to help everyone who seeks them, curing diseases of the body and soul, sometimes recommend seeking specialized medical treatment[20].

In addition to the sectors sought, perhaps the most important is to ask about what rationality or logic of life management such sectors are constituted of. The systems of meanings and senses of the disease end up being restricted to the medical intervention field, which phagocytes the other fields of meaning and senses. Scientific truth and the authority of medical knowledge are built, which negatively assesses any conception of the disease that is not under the evidence of contemporary biological sciences[10].

It is common for medical knowledge to have reservations about these practices, hindering an approximation between the knowledges[7,13,21]. Like any health-related practice, some may not be beneficial[15]. Thus, health professionals must approach this topic transparently and openly, recognizing that the dimensions of care go beyond scientific knowledge[13,15].

The perspective of health promotion would allow the insertion of popular practices and knowledge in the territories, which could be mediated by the professional sector through integrative and complementary practices (ICP), for example. In a study with children undergoing cancer treatment, the search for ICP was a therapeutic alternative motivated by the search for other forms of care, prevention, and better quality of life, with a complementary character to conventional treatment[21].

Giving visibility to other, non-hegemonic, care practices does not mean excluding the biomedical one; but going beyond this "culture of care" to open up to the "care in culture" respecting the diversity and therapeutic pluralism, valuing the totality of meanings, and opening up for the meeting, for the care of culture[10].

The use of the professional sector: alternative for consultation

This category shows the fragility of the bond between mothers and caregivers of children discharged from neonatal intensive care units with the professional sector, especially with the PHC.

The interviewees did not recognize the professional sector as the main place of health care for their children. Only one mother and one grandmother stated that they did not use homemade remedies or medicines without the doctor's knowledge due to the fear of child becoming ill or aggravating the clinical condition. Of those who claimed to use primary care services at some point, the most stated reasons were: consultations motivated by a specific problem and vaccination. The frequency of scheduling appointments did not meet the recommended regularity for each child. It was determined by the caregiver, according to their assessment of the need for care:

> *"Sometimes, I take him to the health center (Primary Health Care Unit) for a consult, but only sometimes. When the community health agent comes by, and makes an appointment, then I take him to it" (Lucas's mother)*
>
> *"It depends, if I think he has... a little bug... I take him to the health center (Primary Health Care Unit) to do an exam. But it usually can't be done there. I do it in the private sector and take it to the doctor at the health center (Primary Health Care Unit)" (David's mother)*
>
> *"When we make her an appointment, it is at the health center (Primary Health Care Unit). I take her like, every moth, every two months..." (Rebeca's grandmother)*

It is necessary to highlight that at the time of discharge, these children received guidance for attending regularly in the PHC for consultations, and also, for those who had indication, to follow up in a specialized outpatient clinic. Considering the importance of monitoring children in the first 1,000 days (period from conception to 2 years) for the promotion of their health and quality of life, regular non-attendance needs to be understood and may have, in its genesis, issues related to coverage of the Family Health Strategy (FHS), which, at the study site, is approximately 43%[22], as well as issues related to the work process and the one's perception of the FHS teams about their ability to act in the care of these children who were born at risk[3].

Of the children linked to the specialized follow-up clinic, none of the caregivers reported using the PHC services, and only two interviewees stated that they were visited by a community health agent. Studies carried out with PHC health professionals pointed out that, in the care of the child discharged from the neonatal unit, it is important to carry out articulated work in a network, advocating early communication between maternity and PHC[3,23].

The professional sector was used mainly in complications or urgency situations, associated with the severity assessment carried out by the caregivers themselves:

> *"When I see that it is a very serious case, like, a blow, an injury, or I see that he is very tired, then I take him to the hospital right away. Or when I see that the color of his pee is different, or he is in some pain, then I take him right to the doctor to find out what it is, if it is an infection. In this case, I look for professionals" (Yago's mother)*
>
> *"Oh! I know him! I only take him like... when he is really unwell, when he has a three-day fever, then I try to take him to the doctor right away" (Davi's mother)*
>
> *"When she is vomiting, when she has a fever... that's when I take her [to the hospital]" (Ana's mother)*

The understanding of gravity is subjective and its differentiation is based on the experience accumulated by the experience itself, by cultural habits, by the knowledge incorporated in contact with health professionals, by the coexistence and exchange of knowledge and experiences with acquaintances[16].

The most used gateway in the professional sector was the urgency and emergency services. The main motivation for this choice was the ease of access, resolution, and previous experiences, even though, many times, they could be resolved in the PHC:

> *"I really like to take him to the emergency unit, because I think the service there is better. [...] I take him only when he is sick, because when I go there, I ask the doctor to do lab exams to see how he is doing" (Tiago's mother)*
>
> *"Grandma prefers the doctor, she wants me to take him right away to the doctor. She goes: 'Ah, we're going to the emergency unit, take him to the emergency unit right away" (Pedro's mother)*

The singularized perception of the disease and the fear of getting worse allied to the certainty of resolutive care are decisive factors for the demand for urgent and emergency services[23]. The user seeks the service to solve needs that, at that moment, bring anguish and discomfort, even if they are not urgent, especially in the case of children under five years old[24].

The interpretation of what is relevant, what causes or prevents a problem, and the type of action required is, for health professionals, determined by biomedical knowledge. However, for individuals, it is determined by networks of symbols that articulate biomedical and cultural concepts, which determine characteristic ways of thinking and acting in the face of a specific health problem[6].

The decrease in autonomy and the self-care capacity is due to the medicalization of life as a process that produces, based on medical knowledge, an increase in individual and collective dependence related to the health-disease process[25].

It is essential to value family knowledge and their cultural context to ensure adequate guidance and monitoring[15,26]. The dialogue between the different health care sectors strengthens the bond between professionals and users and enables actions aimed at health promotion, which should create spaces for discussion and allow mothers and caregivers to talk about their knowledge and ways of caring. Adherence and motivation to change habits, behaviors, and cultural practices are not passively modeled. For this to happen, health promotion must be based on exchanges that integrate scientific knowledge with popular health knowledge[27].

Considering that one of the objectives of Brazil's National Health Promotion Policy is to value popular and traditional knowledge, it is hoped that the results of this research will enable the reflection of hospital care and PHC professionals, contributing to its strengthening and impacting on the quality of healthcare assistance[4].

This research had as a main limitation the choice, by interviewees, of the home as the place to carry out the interviews. The presence of other people, especially grandparents and aunts, may have influenced their responses. Another potential limitation, overcome by establishing a relationship of trust during the interviews, was the initial difficulty shown by the interviewees to talk about practices related to the informal and popular sectors for fear of judgment.

FINAL CONSIDERATIONS

Knowing the therapeutic itinerary of children discharged from the NICU allowed us to understand the paths taken by mothers and caregivers in the search for care. The interviewed families used all health care sectors, but the informal sector was the most used and, in general, led the TI, motivated by the families' prior knowledge and their perception of the health-disease process, which influenced their way of acting.

Weak bond with the professional sector were identified, mainly with PHC, showing organizational obstacles and difficulties in access, which influenced this process. The bond with the professionals who accompany children in hospital care seemed more established.

The interference of biomedical culture permeated the three sectors and also influenced TI. Welcoming and managing the social and cultural repertoires of families in singular therapeutic projects seems to be a fundamental clinical strategy so that the accumulations of the professional sector are well used and do not become a barrier to the autonomy of users.

CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

ACKNOWLEDGMENT

The authors would like to thank the Foundation for the Support of Research and Scientific and Technological Development of Maranhão (FAPEMA) for funding, the National Council for Scientific and Technological Development (CNPq) for scientific initiation grants and the Coordination for the Improvement of Higher Education Personnel (CAPES).

FUNDING

Foundation for the Support of Research and Scientific and Technological Development of Maranhão (FAPEMA); National Council for Scientific and Technological Development (CNPq); Coordination for the Improvement of Higher Education Personnel (CAPES) - Finance Code 001.

Article based on the master's dissertation entitled "Health care sectors: experiences of families discharged from the Neonatal Unit of the Federal University of Maranhão". 2019. 73 pages.

CONTRIBUTIONS

Hortênsia Coutinho da Rocha, **Zeni Carvalho Lamy**, **Lia Cardoso de Aguiar** and **Fernando Lamy-Filho** contributed to the preparation and design of the study; the acquisition, analysis and interpretation of data; and the writing and / or revision of the manuscript. J**oama Gusmão Pereira Moreira**, **Marina Uchoa Lopes Pereira**, **Yanca Lacerda Albuquerque** and **Tadeu de Paula Souza** contributed to the acquisition, analysis and interpretation of data; and the writing and / or revision of the manuscript.

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How to cite: Rocha HC, Lamy ZC, Aguiar LC, Moreira JGP, Pereira MUL, Albuquerque YL, et al. Search for health care: therapeutic itinerary of children discharged from the neonatal units. Rev Bras Promoç Saúde. 2021;34:11708.