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THERAPEUTIC ITINERARY OF FAMILIES OF CHILDREN WITH MICROCEPHALY

ITINERÁRIO TERAPÊUTICO DAS FAMÍLIAS DE CRIANÇAS COM MICROCEFALIA

ITINERARIO TERAPÉUTICO DE FAMILIAS DE NIÑOS CON MICROCEFALIA

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Objective: analyzing the therapeutic itinerary of families of children with microcephaly in the countryside of the state of Bahia. Method: qualitative and descriptive-exploratory study, carried out in the Center for the Support of the Parents of Children affected by the Congenital Syndrome associated to the Zika Virus in the countryside of Bahia. Nine relatives of children registered in the service participated. Data were collected from July to November 2017, through semistructured interviews, and analyzed through Bardin's Content Analysis. Results: three categories emerged: The Itinerary towards a Diagnostic, The Therapeutic Itinerary for the follow-up of the Child with Microcephaly, and the Social Support for the care of the child with microcephaly. Conclusion: the therapeutic itinerary of children with microcephaly in the countryside of Bahia highlighted the professional system, including the difficulties in finding a diagnostic, in addition to the social network and spirituality, which were shown to be important support tools for these relatives to provide daily care, and for the valuing of beliefs and of the daily care of families, which allowed for a greater link with the health team.

Descriptors: Social Support. Family. Family Caregivers. Child Care. Microcephaly.

Objetivo: analisar o itinerário terapêutico de famílias de crianças com microcefalia no interior da Bahia. Método: estudo qualitativo, descritivo-exploratório, realizado no Centro de Apoio aos Pais de Crianças acometidas pela Síndrome Congênita associada ao Zika Vírus no interior da Bahia. Participaram nove familiares de crianças cadastradas nesse serviço. Os dados foram coletados de julho a novembro de 2017, por meio de entrevista semiestruturada, e analisados por meio da Análise de Conteúdo de Bardin. Resultados: emergiram três categorias: Itinerário para o Diagnóstico, Itinerário Terapêutico para acompanhamento da criança com Microcefalia e Suporte Social para o cuidado da criança com microcefalia. Conclusão: o itinerário terapêutico de famílias de crianças com microcefalia no interior da Bahia destacou o sistema profissional e incluiu a dificuldade para o diagnóstico, a rede social e a espiritualidade, que apareceram como importantes suportes a esses familiares para o cuidado cotidiano, e valorização das crenças e cuidado cotidiano das famílias, que permitiram maior vínculo com a equipe de saúde.

Descritores: Apoio Social. Família. Cuidadores Familiares. Cuidado da Criança. Microcefalia.

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Objetivo: analizar el itinerario terapéutico de familias de niños con microcefalia en una ciudad de la región campesina del estado de Bahia. Método: estudio cualitativo y descriptivo-exploratorio, hecho en el Centro para el Apoyo a los Padres de Niños con la Síndrome Congénita asociada al Virus Zika en una ciudad en la región campesina de Bahia. Se colectó a los datos desde julio hacia noviembre 2017, con entrevistas semiestructuradas analizadas por medio del Análisis de Contenido de Bardin. Resultados: tres categorías emergieron: El Itinerario hacia un Diagnóstico, El Itinerario Terapéutico en el Seguimiento del tratamiento al niño con Microcefalia, y el Apoyo Social para el cuidado con el niño con microcefalia. Conclusión: el itinerario terapéutico de niños con microcefalia en una ciudad de la región campesina de Bahia destacó el sistema profesional, incluyendo las dificultades en encontrar un diagnóstico. La red social y la espiritualidad también se mostraron herramientas de apoyo importantes para que esos familiares pudieran ofrecer cuidado diario, y para valorizar sus creencias y cuidar diariamente de sus familias, permitiendo que tengan una conexión mayor con el equipo de salud.

Descriptores: Apoyo Social. Familia. Cuidadores Familiares. Cuidado del Niño. Microcefalia.

Introduction

Microcephaly is a condition in which the capacity of brain development is not as it should. It can be associated to structural malformations of the brain or be a secondary effect of several other causes(1). With the increase in the cases of microcephaly associated to congenital infections by the Zika virus (ZIKV), the Brazilian Ministry of Health (MS), in 2015, aiming to increase the sensitivity of its information system, adopted a 33 cm cephalic perimeter (CP) for both sexes as the cutoff point of the guidelines to notify suspected cases of the disease. However, as new scientific evidences emerged, new parameters were established. From August 30, 2016, following recommendations of the World Health Organization (WHO), the country started adopting, as a reference for the first 24-48 hours of life, the parameters of the Intergrowth table. According to this table, microcephaly is characterized when the CP is lower than two standard deviations (SD) below the mean of children in the same age and sex. Therefore, for a child who was born after 37 weeks gestation, the reference measurement expected will be 30.24 cm for girls and 30.54 cm for boys(1-2).

After birth, follow-up is necessary to observe the evolution of this perimeter and the later diagnostic confirmation, since malpractice may take place during the execution of the measurement technique, and there are even borderline cases which require other diagnostic findings to confirm whether the child has this condition(3).

In 2015, there was a change in the number of episodes, with an increase in the total number of cases registered with regards to previous years. This called national and international attention and was associated to the Zika, Dengue, and/or Chikungunya viruses, meaning that mothers who had some type of contact with these viruses during gestation could give birth to microcephalic babies as a result(1-2).

In Brazil, until July 2016, according to the Ministry of Health, 1,709 confirmed cases of microcephaly suggested the possibility of congenital infection. In the Northeast region, in the same period, 1,466 microcephaly cases were notified. This data is very significant, since it indicates that 85.7% of cases were in a single region of the country, where the incidence rates for these specific viruses is high. Additionally, it should be highlighted that undernotification may have also taken place, due to the difficulty of reaching the diagnostic (during gestation or after birth), which is in turn linked to the lack of information, the quality of the prenatal, and diagnostic and/or complementary exams, among other factors(3).

When confronted with a malformation diagnostic, in addition to emotional alterations, this condition may lead to sudden changes in the daily life of a family, whose members will need to adapt their roles, take on new responsibilities, and seek social and health services. These challenges have a financial impact and require time and dedication. However, they can bring on their wake a continuous learning experience for the family, for society, and for the professionals who, in some way, will be in touch with these people(4-5).

In all societies, the activities of health care and attention must be studied in a systematic way, as socially organized answers to the disease, constituting health systems constructed based on a cultural perspective according to which the disease is seen as a subjective process, an individual experience, and a social construction. From this point of view, the cultural outlook each family has directly interferes in the therapeutic itinerary (TI) they have to go through to care for the health of the family members(6).

The TI – defined by both conventional medicine (self-medication and faith-healers) and modern medicine (advanced care organizations) as the succession of steps that go from the beginning of the disease on, representing the pathway the family went through to deal with health issues, including personal and sociocultural family habits – is essential for all analyses to be carried out based on the personal experiences and conceptions developed from perspectives that originate within the particularities of each family(5).

Therefore, TIs can be seen as relevant methods for the creation of therapeutic projects destined to the families of children with microcephaly, since they seek to value the experiences and uniqueness of each individual, being based on their current state(7).

Considering these premises, the following question arises: How does the therapeutic itinerary of families of children with microcephaly take place in a city in the countryside of Bahia?

This study aimed at analyzing the therapeutic itinerary of families of children with microcephaly in the countryside of the state of Bahia.

Method

This study is qualitative, descriptive and exploratory. It was carried out in the city of Feira de Santana, in the countryside of Bahia, in the *agreste* region, in a zone that involves part of the *sertão* and of the *zona da mata* regions of Bahia. The field of data collection was the Support Center for Parents of Children affected by the Congenital Syndrome, a reference service of the Municipal Health Secretariat.

The participants were nine relatives of children with microcephaly. The following inclusion criteria were adopted: participants must have a child older than 3 months (minimum time for the confirmation of the diagnostic, since the microcephaly found by CP at birth needs such a follow-up to ratify the results) and younger than 24 months old (considering that this length of time is enough for the family to establish the diagnostic); identify themselves as the relative who is responsible for the child; accept voluntary participation in the research; and agreeing with the Free and Informed Consent Form. Exclusion criteria included: participants who were deaf, mute and/or presented psychiatric conditions, due to the technical limitations the researcher had to perform data collection; and those who were minors, since this would mean that other settings and social networks would be the ones to characterize the setting of the care of the child.

Insertion in the field of the research took place through previous contact with the service coordination, in which the waiting room was prioritized for pediatric attention in Tuesday and Friday mornings. Before the interviews, the researcher introduced herself to the health teams to explain about the research and describe its inclusion and/or exclusion criteria with regards to family members, so that the team could help in the selection of participants. Eligible relatives were contacted in the waiting room. From the 11 guests, 2 rejected the invitation. One of them denied that the diagnostic was correct, and another believed they would not be able to answer the questions, even after clarifications.

The semistructured interviews lasted for a mean of 20 minutes and were conducted in the health service itself, in a private room (to guarantee the privacy of the participants). Before the interview, sociodemographic data was collected, and was essential to understand the family context and the itinerary each family went through, separately.

To guarantee the respect to the participants and the reliability of the answers, all interviews were recorded and later transcribed. For data collection, the following guiding questions were established: Tell me, how is it for you and your family to care for a child with microcephaly. What was the path to arrive at the diagnostic of microcephaly? After the child was born, tell me what services you took your child?

The Content Analysis is carried out through the application of several techniques which allow for a description of the content of the interview, using the spoken or written statements of the participants. Therefore, the technique is characterized by a systematic procedure, which enables the emergence of evidences and the inference of data(8-9).

As a result, three categories emerged: The Itinerary towards a Diagnostic, The Therapeutic Itinerary for the follow-up of the Child with Microcephaly, and the Social Support for the care of the child with microcephaly.

This study was approved by the Research Ethics Committee (CEP) of the Universidade Estadual de Feira de Santana (UEFS), under C.A.A.E. 68402417.80000.0053. The identity and confidentiality of participants were preserved through the adoption of names of flowers, chosen by the relatives themselves and used as codes to identify them. To guarantee the privacy of the children, their names were replaced by the letters from A to L. In addition, the names of the health services mentioned were replaced by the letter X.

Results

Analyzing each relative's sociodemographic data enables understanding aspects directly related to the Itinerary, since it is elaborated according to the family, social, and cultural resources of each family in the process of care/caring(10).

Most participants identified themselves as mothers or fathers of the children. With regards to religious beliefs, most were catholic, while two were protestants and two did not belong to any religion.

With regards to their educational level, only one participant had complete higher education; five had complete high school; one had complete elementary school; and two had incomplete elementary school. Regarding their marital status, four were single, four were married, and one was in a stable union.

Four participants declared to be black, while five declared to be *pardos* (light-brown skin). Regarding family income, most live with only one minimum wage. With regards to current work, five family members felt the need to abandon their jobs due to the needs of their children. Three participants had other children, in addition to the child with microcephaly.

The itinerary towards a diagnostic

A microcephaly diagnostic can be found through ultrasonography carried out during gestation and confirmed at the birth of the child by measuring the cephalic perimeter. Other exams, such as computed tomography or brain MRIs, also help in the diagnostic. However, relatives revealed that, despite prenatal routine exams, such as obstetric ultrasonography (USG), abnormalities were only found late(11).

> *We found it in the last ultrasound we made* [...] *we went to the hospital* [...] *and then they found there was chance of micro* [...] *so far we didn't know. And then it was only confirmed at birth.* (Tulip).

> *At first, I didn't know he had micro, because in the ultrasounds everything was normal* [...] *in the last ultrasound I did, the physician didn't understand why the baby was so small.* (Rose).

These fragments show the difficulties in finding an early diagnostic, indicating that it was delayed until the moment of birth or even after it. Other participants also pointed out that even when the exams showed alterations, professionals often could not interpret them correctly:

> *Everything was normal. I went to all prenatal consultations, got 5 ultrasounds, and only one showed an abnormality in the size of the head, the fourth one* [...] *On the fifth one* [ultrasound] *the doctor didn't say anything. She said that,*

> *she thought that the problem was that it was very well fit and that is why there were alterations in the size of the head.* (Sunflower).

The Ministry of Health prescribes that at least four obstetric ultrasonography sessions must be carried out per women. However, for them to be effective, the professionals must be aware of the indications of the exam and trained to correctly interpret the results. Factors such as the quality of the equipment and the ability of the health professional who is performing the exam can interfere in the results(12).

The difficulties in establishing an early diagnostic, and the lack of clarification for relatives in microcephaly cases negatively interfere in the establishment of the path these families must take, since early identification can help in the preparation for the arrival of the baby, in addition to helping the process of acceptance of this condition(11-12), as indicated in the statement of Cactus Flower:

> *There he didn't have microcephaly, because the ultrasound shows this* [...] *No, there isn't that. And the difference, when he was born, the difference in the cephalic perimeter is* [...] *very large.*

This extract shows the indignation of the mother with regards to the quality of the exam. She vehemently questions the incompatibility of the condition in which the child was born and the one found in the last exam. Therefore, the importance of an adequately trained professional stands out, one with technological resources that make it possible to carry out quality prenatal and childcare, and to diagnose perinatal and neonatal situations as early as possible.

The lines of Daisy 2 reveal the inexperience of the professionals with regards to addressing microcephaly, leading to a peregrination through many health services until she found a professional that seemed more secure and reliable with regards to the technique to lead the situation:

> *I know that the first doctor we went to was* [...] *the orthopedist? Yeah, I think that's it* [...] *yes. And then he started showing the problem and we went. Everywhere we went, we were referred to another doctor, then another, another doctor, and there we went* [...]

The microcephaly diagnostic is difficult for the families who receive it, which is coupled to the delays and difficulties in confirming it, which by themselves can lead the family of these children to be prejudiced by the constant comings and goings in the search for an answer – not to mention the children themselves, since the delay in a diagnostic in turn delays the beginning of early stimulation.

The Therapeutic Itinerary for the follow-up of the Child with Microcephaly

When a person is affected by a disease, it is common to try and find a way to solve the issue, that is, to find a treatment and a cure. Therefore, the individual outlines pathways and alternatives, drafting a TI. This search is focused in a System of Care made up of three spheres of knowledge: popular knowledge ("non-professional specialists" of healing, who use, as a tool for the cure, secular and religious practices), family knowledge (which originates from the individuals and the members of their social network) and professional knowledge (mostly formed by the biomedical power)(6).

In the case of the families of children with microcephaly, the knowledge about a TI has special features, since it is a chronic condition, meaning it can involve many different spheres and mobilize care throughout a longer period of time, recruiting many systems to improve the quality of life of the individual(13).

Another specificity of microcephaly is that it can be related to other symptoms, such as: convulsions, blindness, deafness, muteness, cardiovascular and respiratory disorders, muscular disorders, and motor defects that lead to difficulties in eating and movement disorders. These symptoms can be associated to one another and lead to systematic complications, meaning these patients are difficult to manage therapeutically(2), which makes the TI of these families even more unique, since the condition requires early stimulation and multiprofessional interventions.

Maybe this explains why many participants mentioned the "referral" of these children to different professional health services. Also, regarding the referrals, it can be noted that, for the relatives, this is a positive feature of the services:

> *They* [...] *are very good services, you know? We get out of there with a bunch of documents and they refer you right there, right? We don't get confused, lost. Everything is referred, everything is OK, easy to schedule. The attention is great. So they are, like, great services.* (Rose).

Therefore, the ease to access health services and the availability of information from the professionals positively contribute to confront the difficulties experienced by the families of children with microcephaly. The use of many different health services was pointed out by almost all the families, who used at least three professional health services to stimulate these children.

> *Look, on Mondays she goes to the speech therapist in the morning and to the physical therapist in the afternoon; on Tuesdays she goes to the physical therapist in the morning; on Wednesday she does nature therapy; on Thursday she goes to the occupational therapist in Salvador* [...]; *and on Friday, she goes to the occupational therapist here in Feira; and on Saturday she goes to swimming classes. So, there is every day of the week...* (Orchid).

> *She has been following up with a nutritionist, a pediatrician, a geneticist, a gastroenterologist, a neurologist, a physical therapist, an occupational therapist and a speech therapist.* (Sunflower).

The number of follow-up appointments can lead to moments of exhaustion (both for the relative and for the children submitted to so many activities), in addition to financial and time expenditures. Participants recognized this exhaustion, but evaluated it as positive, due to the development of the babies.

> *It's hard, some days the body asks you not to go, but you have to go, you have to get up. There are days like this. But thank God, I feel happy to see he's developing.* (Jasmin).

Another aspect that interferes in the TI is the financial situation of the families, since some specialized services are uncommon in the public health network and are expensive in the private services, as mentioned by Lotus Flower.

> *I was going to enroll him into hydrotherapy, in the water, right? But I couldn't find it through SUS* [the Unified Health System] *and the sessions are too expensive.*

The TI of each family has many pathways, not only those institutionalized by the SUS, since, in order to deal with the health needs, healthcare is formed, sought, and managed, according to the experience the family is having with the disease. The invisibility of informal care stands out, both during the search for a diagnostic and the follow-up of these children(9).

> *We only followed medical referrals, really* [...] *we didn't take the baby anywhere by ourselves* [...] *we only followed the orders here.* (Daisy 2).

The case of children with microcephaly has similarities to premature children cases, in which informal and popular sectors are underestimated when compared to the formal sector. That is associated to the fact that, oftentimes, informal sectors do not have acceptance. The prevalent perspective is one according to which hospitals and their professionals have the scientific knowledge that, for the families, can solve their needs, and that cultural aspects regarding health would be less important or noneffective since they "do not have" scientific bases.

Considering this reality, it can be noted that popular and informal care sectors are absent from the statements of the relatives. These sectors would be related to non-professional cure specialists, such as those connected to religious and secular groups (healers, faith healers, preachers, mediumistics, or care developed in the sacred places of the Candomblé religion), all of which could be included in the establishment of a TI for the families. Although the professional sector presents difficulties to treat microcephaly, popular or non-conventional medical actions are treated with a certain level of fear or distance.

Social Support for the care of the child with microcephaly

Interpersonal relations are meaningful for human beings. They allow different people to influence the attitudes and behaviors of one another, creating bonds that certainly contribute for the life of each individual, including in areas of physical and/or mental health(14).

Although the terms support network and social network have similar characteristics, it is important to say that they have important conceptual differences. The social support network is made up of people who have some type of social bond, including the family, the neighborhood, work colleagues and friends. The nature of this support is informational and it can help generating resources, including exchanges. It provides accessibility, reliability, and emotional resources, as well as inclusion, material, and cognitive resources. It has a positive effect on the individual and makes it so they distance themselves a little from their problems. It can be exemplified by religious groups or unions(15). There is no consensus about the meaning of the concept of social support. The different researchers of the theme debate different principles regarding interpersonal relations, which shows its complexity(16).

However, despite its complexity and difficult conceptualization, this study adopted the concept of social support, which has this common feature to its description: a personal dimension, in which members of the social network can generate resources for their families, directly bringing physical, emotional and behavioral benefits(14). A social support that can be counted on in the care to the child must be taken into account with regards to the family. The family can receive, for instance, emotional support, something essential to keep the motivation to care for the child. This support must be constant, and adapt to each situation experienced, since, in each stage of the disease, the family will have specific needs. Therefore, the support must be individualized and unique, since each individual has certain characteristics and ways to cope(15).

The easy access to social and psychological support aids in the care, and guarantees more well-being to these families, since it can help relatives guide their emotions and choose their actions.

> *Well, to these activities in the morning, it's me, I take her. But I receive help from my mother, my father, my sister, from her father, you know? From my brother-in-law* [...] *it all helps. Apart from God that's what gives me strength. Having my family, you know?* (Orchid).

Among the three sources of support – emotional, instrumental and informational – the first one, emotional support, refers to individuals who perceive to be loved by others, who are able to care for them and for their lives(16).

> *We have emotional support. The type of support I get, from my family, is only that one.* (Cactus Flower).

People also seek emotional support in religious institutions. Faith and spirituality contribute to minimize the suffering and pain experienced by families who are facing certain situations and helps them feel safer. Spiritual support is an important emotional support for the family with regards to chronic diseases in children, and the needs of the different beliefs of each family need to be explored(14).

Spirituality and religion are important support tools for the families. Especially during diagnostic, they are sources of strength for families to steady their footing and start seeking a better quality of life for their children.

> *God has been giving me the strength to fight for his health.* (Jasmin).

> *My spiritual brothers helped me... what I learn in the Bible also helps... The faith I have in God helped me and still helps me.* (Cactus Flower).

The instrumental support is connected to the practical help offered to the family, such as financial resources (money lent or bills paid) or through actions (such as accompanying the individual to health services, consultations, etc.);

> *Everyone helps. A. will need two orthoses, in hand and foot. It's a bit expensive right?* [...] *so I made a raffle and people in our society are helping, they are buying it.* (Lotus Flower).

> *Today most of the help I get is from the man who lives with me, and his mother, who is my mother-in-law. Whenever I leave, she goes with me. Whenever I go to the doctor, she stimulates B., plays with B.* (Jasmim).

The statements of Cactus Flower and Rose also made it clear that the family is strongly tied to this type of support. However, the direct care to the children is still intrinsic to the parents. Cactus Flower justifies this, saying that, considering the chronic condition of A., the family is afraid to call to themselves the responsibility of offering this type of care.

> *If we need someone to take care of him* [...] *there's my mother or my sister, but you know, if the need is extreme and for little time. But, you know, I understand* [...] *they are afraid. So, it's just me and him* [the husband]. (Cactus Flower).
>
> *The family always supports, they really accompany, but to offer care... they are just companions.* (Rose).

This can be related to the fact that, oftentimes, the life conditions of these children require types of care that are directly related to the risk of death. Therefore, relatives do not feel able to take on such a responsibility. The statement of Tulipa, on the other hand, shows the absence of this type of support:

> *Help, no. In my house, it's me, my wife and my son. It's just us for everything. My family comes from Salvador and hers... when it's time to work, everyone disappears. For better and for worse, it's me and her for everything.* (Tulipa).

The third source of support, named informational, is related to acquiring, from other individuals, instructions, counsel or recommendations that are appropriate to certain situations regarding common moments in life that demand the resolution of some problem. Health services and the Epidemiological Surveillance sector (VIEP) of the city Feira de Santana, in which this research was carried out, can be mentioned as part of this source of support. Despite not being a common demand in the sector, the need for these parents to receive some support was supplied by this instance, while the service network is still articulating and adapting to attend these children and, consequently, these families. In addition to the services offered by the VIEP, the statements of the participants mentioned health and social services professionals, in addition to reference institutions whose names are not going to be mentioned due to ethical concerns.

Therefore, a bond was created between the VIEP and these family members, thanks to the attention offered by the health professionals. This relation is extremely important to build the TI of these families and to offer quality management of these children, providing guidance to these families, and making their access to available services easier(17).

The importance and the recognition of the professionals from the health services and referral institutions, such as social support, are evidenced in the following statements:

> *To the team, I have nothing to say but thanks* [...] *it's a very good team. The team, they visit us right? I think that's a lot.* (Orchid).
>
> *When this microcephaly epidemic started, they offered such a great support. We managed to schedule a lot of things here. We called, talked to X, she scheduled it immediately, prepared everything; she let everything ready and we just had to go.* (Tulip).

It can be noted that, as the professionals establish bonds with the families, they become important links in the chain of daily care for these children, offering them information, helping them in developing strategies of care, and making themselves available to help with complications.

The lack of social support can bring emotional and physical overload to the family of a child with microcephaly. Despite the fact that the support is not connected to direct care offered to these children, as the statements above indicated, the support, be it emotional, instrumental, informational or all of the above, helps the family to react better to the situation of the child, since they feel in certain points supported, and even safe, even in the process of outlining a TI.

Discussion

Most participants were mothers – there were only three fathers –, corroborating the findings in literature. The relationship of women and care is a cultural and historic process. Offering care still stands out among the many roles women exercise, especially when related to children with special needs. Women are seen as the main caregivers of the family and feel pleasure in exercising this role. Despite the help of other relatives, these only participate in indirect care, offering support(18-19). It stands out that men appear in this study as aids to indirect care.

A study carried out with cancer patients points out that religiosity/spirituality are seen as sources of strength and confidence in the confronting of the disease. Therefore, this aspect can help, even as a form of social support the family has to continuously care for the child with chronic diseases or who needs specialized care(20). When evaluating parents of children with disabilities(21), it was found that those who were actively religious showed resilient attitudes and behaviors and were more likely to report positive experiences.

A recent study(22) found that a lower educational level from mothers is one of the factors related to this health problem. In this case, the educational level stands out as a risk factor for the health problem, but it was mainly a condition associated to the establishment of different types of care. This study highlighted the fact that the only mother with complete higher education had access to a private health insurance, as well as to different private sector services to help the development of the child, who underwent several activities, daily. On the other hand, the other participants only had access to the public health services.

When considering the condition of black persons under the ethnic-racial perspective in Brazil, racism is found to be a social determinant that can directly intervene in the health-disease process of these individuals. This data is relevant, since, in the current Brazilian setting, the present situation of racial issues makes it more difficult for black persons to access health services, implying in a more difficult or lower quality prenatal follow-up(9,22).

Low family income suggests that people from popular classes are more vulnerable to factors that increase the risks (close contact with other humans, insects, and animals that are disease vectors, unordered population growth, lack of basic sanitation, among others) of exposure to infectious diseases and the adequate access to prevention and care, as well as to a quality prenatal service(23-24). In addition, family income is associated to the network of care established, since some early stimulation services that are essential for the development of these children are scarce in the public health network, and interfere in the TI of these families.

Abandoning work to care for the child is a common behavior of families in which chronic children diseases are installed, and one of the members of the family (usually the woman) is expected to abandon work to take on caring for the child, the house, and other children. Others, usually men, maintain financial support(25).

Having other children is a condition that may interfere in the creation of a TI, since, when the child has siblings, the family also has to worry about them, since, despite being children, they suffer as witnesses of the condition of their sibling, and due to the lack of attention received from their parents(25).

Conclusion

This study reached its goal of analyzing the TI outlined by the relatives of children with microcephaly. The analysis based on the experiences of each relative during the complex path of an Itinerary also led to the emergence of new data, which complemented the analysis and showed the impact of the diagnostic of a congenital condition.

Family, as the first unit of childcare, is responsible for the care, especially the mothers. They are the ones who, considering sociocultural history, take on this role. That means the need of the children are prioritized, leading mothers to accumulate multiple roles and enter in a state of physical and emotional overload.

Considering the diagnostic itself, many feelings are provoked by this unexpected and/or unplanned for reality. Among them, one finds denial, depression, acceptance, and readaptation. In the case of families with microcephaly associated to the Zika virus, the difficulty to establish a diagnostic, coupled with the insufficient number of explanations as to the cause of the problem, may delay the acceptance, prolong the suffering of relatives, and induce them to seek their own responses and explanations, in addition to potentially delaying the search for the essential care required by the children, such as early stimulation.

Although TI is defined as the search for the solution of a health problem based on the social and cultural experiences of each individual, families in the study did not mention resorting to any type of care other than the professional one, despite the existence of family and popular care.

This weariness that leads families to restrict themselves to the professional systems is justified by the fear they have to seek other types of care than the formal ones, when it comes to caring for the child with Zika virus associated microcephaly. The disease is understood to be a rare condition and is oftentimes associated to malformation, bringing forth the fear of exposing the health of the children.

As a result, this study can promote a broadening of the understanding about the Itineraries of these families, with regards to microcephaly. Additionally, it can bring about important findings that can help professionals reflect on the importance of valuing the individual who has personal (social and cultural) experiences, while also valuing the role of the individuals in their own health. Finally, the study can lead to changes in the practice of care, thus improving the quality and responsibility of services made available to the children with microcephaly and their relatives.

Collaborations:

1 – conception, design, analysis and interpretation of data: Manuela de Jesus Souza, Aisiane Cedraz Morais and Maricélia de Maia Lima;

2 – writing of the article and relevant critical review of the intellectual content: Manuela de Jesus Souza, Aisiane Cedraz Morais, Isamara de Souza Lima, Jéssica Souto Mascarenhas, Maricélia de Maia Lima and Rita da Cruz Amorim;

3 – final approval of the version to be published: Manuela de Jesus Souza, Aisiane Cedraz Morais, Isamara de Souza Lima, Jéssica Souto Mascarenhas, Maricélia de Maia Lima and Rita da Cruz Amorim.

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