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Itinerary of children with microcephaly in the health care network[a]

Itinerário da criança com microcefalia na rede de atenção à saúde

Itinerario de los ninõs con microcefalia en la red de atencion de salud

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ABSTRACT

Objectives: To investigate the therapeutic itinerary of children with Zika-associated microcephaly in the health care network; and describe the experience of mothers concerning the itinerary taken to treat their children. **Method:** This study was guided by Thematic Oral History, conducted in a philanthropic public institution in João Pessoa, PB, Brazil. Ten mothers of children with microcephaly were interviewed from April to August 2017. The empirical material was subjected to thematic content analysis. **Results:** Health professionals have difficulty diagnosing children with microcephaly, and they are not prepared to inform parents, compromising the therapeutic itinerary of these children. The experiences of mothers seeking treatment for their children are marked by stress, fear, disappointment caused by fragile family support network. This results in maternal overload. **Conclusion and implications for the practice:** The restructuring of the flows and counterflows of the Health Care Network for children with microcephaly and their families becomes essential, as well as the strengthening of the support network for mothers.

Keywords: Microcephaly; Zika Virus Infection; Maternal Exposure; Infant.

RESUMO

Objetivos: investigar o itinerário terapêutico de crianças com microcefalia associada ao Zika na rede de atenção à saúde; e descrever a vivência das mães em relação ao itinerário percorrido para o tratamento de seus filhos. **Método:** Estudo norteado pela História Oral Temática, realizado em instituição pública filantrópica do município de João Pessoa-Paraíba. Foram entrevistadas dez mães de crianças com microcefalia entre abril e agosto de 2017. O material empírico foi submetido à análise de conteúdo temática. **Resultados:** Os profissionais de saúde têm dificuldade para definir o diagnóstico de crianças com microcefalia, e se encontram despreparados para informá-lo aos pais, comprometendo o itinerário terapêutico dessas crianças. As experiências das mães em busca de tratamento para seus filhos são marcadas por estresse, medo, decepção e pela frágil rede de apoio familiar, resultando em sobrecarga materna. **Conclusão e implicações para a prática:** A reestruturação dos fluxos e contrafluxos da Rede de Atenção à Saúde às crianças com microcefalia e seus familiares torna-se imprescindível, assim como, o fortalecimento da rede de apoio às mães.

Palavras-chave: Microcefalia; Infecção por Zika virus; Exposição Materna; Lactente.

RESUMEN

Objetivos: Investigar el itinerario terapéutico de los niños con microcefalia asociada al Zika en la red de atención de salud; y describir la experiencia de las madres en relación con el itinerario tomado para tratar a sus hijos. **Método:** Estudio guiado por la Historia Oral Temática, realizado en una institución pública filantrópica en la ciudad de João Pessoa-Paraíba. Se entrevistó a diez madres de niños con microcefalia entre abril y agosto de 2017. El material empírico se sometió a análisis de contenido temático. **Resultados:** Los profesionales de la salud tienen dificultades para definir el diagnóstico de niños con microcefalia y no están preparados para informar a los padres, lo que compromete el itinerario terapéutico de estos niños. Las experiencias de las madres que buscan tratamiento para sus hijos están marcadas por el estrés, el miedo, la decepción y la fragilidad de la red de apoyo familiar, lo que resulta en una sobrecarga materna. **Conclusión e implicaciones para la práctica:** La reestructuración de los flujos y contraflujos de la Red de Atención de Salud para niños con microcefalia y sus familias se vuelve indispensable, así como el fortalecimiento de la red de apoyo para las madres.

Palabras clave: Microcefalia; Infección por el Virus Zika; Exposición Materna; Lactante.

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INTRODUCTION

In Brazil, in 2015, there was a substantial increase in cases of microcephaly in newborns associated with Zika Virus. According to the epidemiological bulletin of the Ministry of Health (MoH), 3,071 cases of microcephaly and/or alterations of the Central Nervous System were confirmed, possibly related to Zika virus infection, being 1,804 cases in the Northeast. Among the northeastern states with the highest incidence, Paraíba stands out, with 198 cases.[1]

Microcephaly is a malformation in which the cephalic perimeter is smaller than expected for age and the gender of the child, so measuring head size is an important action to monitor the child's brain growth. The World Health Organization (WHO) defines microcephaly as a cephalic perimeter of equal or less of 31.9 cm (1.53 in) for boys and 31.5 cm (1.22 in) or less for full-term girls (37 to 42 weeks gestation),[2] which may range from mild to severe.[3]

A study conducted in the state of Paraíba with 19 children with microcephaly, aged 19 to 24 months, found that most of the study sample had severe motor impairment, seizure disorders, hearing and visual abnormalities, and difficulty sleeping.[4]

Given this reality, it is essential to have early stimulation and longitudinal follow-up of these children by rehabilitation professionals who make up the services of the Health Care Network (Rede de Atenção à Saúde, RAS).[5] This network has as its communication center the Primary Health Care (PHC), responsible for coordinating care and ordering the flow of care for the resolution of complex health conditions of this population,[6] in line with monitoring by the early stimulation program.[7]

Thus, both services and health professionals need to support families in coping with microcephaly associated with Zika virus, so that the child's therapeutic itinerary (TI) segment is directed to the specialized services correctly, through effective referrals. The therapeutic itinerary refers to the search for health care and seeks to describe the paths that are taken by individuals in an attempt to solve their health problems.[8] It is important to emphasize that the itinerary is not only limited to the identification and availability of the health services offered, but is also related to the different individual searches and personal characteristics.[9]

People are driven by their health needs and, for the sake of autonomy and well-being, the user sets his own path of regulation within the health system, aiming for a stable care map with which he has security and confidence to address his different needs. However, the care map is neither recognized nor valued.[10] A study that investigated the path taken by mothers seeking care for the health of their children with disabilities, shows comings and goings to various health institutions, often without the resolution of the problem, leaving the itinerary long and distressing.[11]

In light of the above, it is essential to rethink public health programs on monitoring children with Zika-related microcephaly, the social and emotional impact, and the financial burden on families involved with this problem so that they can effectively target RAS.[12] Considering that children with microcephaly need continuous and resolute multidisciplinary care, the question is: How has the therapeutic itinerary of children with Zika-associated microcephaly been traced in the health care network? How are mothers experiencing this therapeutic course? Thus, the study aims to investigate the therapeutic itinerary of children with microcephaly in the health care network; and describe the experience of mothers in relation to the itinerary taken to treat their children.

METHOD

Qualitative research[13] that sought to understand the therapeutic path of children with microcephaly in the health care network and the experience of mothers facing the challenges of this treatment.

This approach was chosen because it made it possible to know the object of study intimately, bringing depth to the universe of meanings, motives, aspirations, values and attitudes, which represents a deeper space that cannot be quantified.[13]

Due to the relevance and complexity of the research object, for the understanding of the senses, this methodological course was guided by the Oral History (OH) method, more precisely, Thematic Oral History.[14] OH is a resource used for the preparation of records, documents, archiving and studies regarding the social experience of people and groups. It is always a present-day story, also known as a living story.[14]

The Thematic Oral History has a social, dialogical character and is committed to establishing the narrator's opinion about a defined event, promoting enlightenment and overcoming the doubts that justify the project.[14]

This study was conducted in a reference philanthropic institution for the treatment of children with microcephaly located in the city of João Pessoa-Paraíba. The collaborators were ten mothers of children with microcephaly associated with Zika Virus.

The invitation to participate in the interviews took place through telephone contact and had as inclusion criteria: the child being diagnosed with microcephaly associated with Zika virus, be the mother and main caregiver of the child with microcephaly, living in the city of João Pessoa-PB. During data collection, two mothers were invited but refused to participate in the interview.

Data collection took place between April and August 2017. During this period, 36 children with microcephaly associated with Zika virus were being accompanied by the multiprofessional team (speech therapists, physiotherapists, music therapists, visual stimulation professional, etc.) at the reference institution.

To substantiate this research, it was necessary to define the concepts target community, colony, and network.[14] Community of destination is understood as people affected by subjective dramas that have marked identity elements of a community, through memory and lived dramas that impose radical changes in group life. Cologne is defined by the general standards of the share of people in the same destination community. The network is a colony subdivision, being the smallest part of the destination community. The network exists to identify even narrower segments that have unique features.[14]

The network was drawn by the mothers of children with microcephaly associated with Zika Virus who agreed to participate in the study. After the end of each interview, a mother indicated which next collaborator to interview.

After recording, each collaborator's oral report, the *corpus documental,* went through the transcription, textualization and transcreation phase.[14] The transcript corresponds to the process of moving from the oral recording stage to the written code. At textualization any questions that, merged in the answers, outweigh their importance is suppressed and it is at this stage that the vital tone of the interview is identified. The transcreation corresponds to the recreation of the text in its entirety, which will be redone several times by removing or adding words and phrases.[14]

Then, the empirical material obtained went through exhaustive reading to apprehend the lived, the subjectivity of the memory, the language and the senses said and expressed with the identification of the vital tones. To assist in the analysis phase, the empirical material was understood through the technique of thematic content analysis, which consists of discovering the nuclei of meaning that make up a communication, whose presence or frequency have meaning for the analytical object targeted.[13]

The thematic analysis is divided into the following steps: pre-analysis, which corresponds to the first contact with the field material, using the floating reading and determining the record units; the exploration of the material that will reduce the text through a thorough reading of the material in order to classify and aggregate the data for categorization into themes; and finally; treatment of the obtained results and interpretation[13] in order to answer the proposed objectives and it was configured in the identification of the thematic categories.

Regarding the institutions mentioned in the empirical material, the following nomenclatures were used: state institution, philanthropic institution, private institution, federal institution, municipal reference institution and municipal maternity.

This study complied with CNS Resolution No. 466/12 of the Ministry of Health and was approved in 2017 by the Ethics Committee under Opinion No. 2,118,590 and CAAE No. 61498116.0.0000.5183. The research collaborators signed in two copies the informed consent form and the letter of assignment of rights on oral testimony. To preserve the anonymity of the collaborators, the term Mother was used, followed by Arabic numeral in the order of the interviews (Mother 1, Mother 2), and so on.

RESULTS

Of the ten collaborating mothers in the study, seven were between 20 and 28 years old and three between 35 and 40 years old. One mother had to leave her job after childbirth to dedicate herself to the exclusive care of her child, and the other had no employment relationship. In addition, four of them reported help/participation of the father in caring for the child with microcephaly, five reported that their father abandoned or did not help in care, and one reported being a widow. All mothers lived in the study municipality before the microcephaly diagnosis of their child. All children with microcephaly whose mothers collaborated with the research were infants.

The following thematic categories were identified: From diagnosis to early stimulation: pathway of the child with microcephaly associated with Zika virus in the Health Care Network; Maternal experiences in the therapeutic itinerary of children with microcephaly associated with Zika virus.

From diagnosis to early stimulation: path of children with microcephaly associated with Zika virus in the Health Care Network

According to reports of some study participants, even their children being accompanied by professionals, both Primary Care and specialists, it was difficult to identify microcephaly, leading to delayed diagnosis and onset of TI and possible interference in the progress of neuropsychomotor skills of the child.

> *I went through speech therapist, physiotherapist, nurse, pediatrician and each one who gave the report. My doubt has increased, because how does one say he has microcephaly and another team says he doesn't? (...). She was followed and even so, it took five months to find out* (Mother 2).
>
> *I started doing his normal childcare on the health center and as time went on, he didn't get hard. When he was 4 months old, a doctor came to the PSF and realized that I was insisting with her, she was kind of rude with me, because she asked me what he had, and I had nothing to say. For me either I was crazy, or I was seeing too much* (Mother 7).

Receiving a diagnosis of microcephaly in a child can generate several reactions in the family, especially because it is a disease with a difficult prognosis. The mothers expect from the professional a humanized attitude, but they report that the way the diagnosis is transmitted can be disastrous.

> *He* [doctor] *examined her, was super cold and said 'mother, your daughter has microcephaly. I don't know if she will walk, if she will speak, no one can predict anything'. I felt like the floor was falling out from under me, because I was not prepared for it* (Mother 2).

In addition to the delayed diagnosis, some demands from children have not been promptly welcomed by the institutions due to the overload of services.

> *I went straight to* [name of state institution] *because it's a reference and everyone goes, but there was a waiting line (...). The institution was not prepared* (Mother 3).

Thus, some mothers report that the search for institutions occurs without professional guidance, but through their solitary efforts to ensure assistance to their children.

> *The day after the diagnosis, I already started researching where to find attendances. I called to* [name of state institution] *which is a reference for me, I searched on my own. I search myself for stimulation services, it was more on my own* (Mother 2).
>
> *His treatment would be stopped if I had not gone after it, because they will do it (...) I went on my own on the services. No professional indicated, we searched after* (Mother 3).

This reality, coupled with the lack of communication between services, makes mothers look for different reference places for the treatment of children with microcephaly. Reports show that several institutions are used at the same time.

> *For treatment I go to* [name of state institution], to *the* [name of philanthropic institution] *(...). At* [name of private institution] *once a week (...) and I go to* [name of municipality reference institution] *which is consultation with neuro* (Mother 2).
>
> *I go to* [name of municipality reference institution] *twice a week. He now also goes at* [name of private institution], *twice a week. At* [name of the philanthropic institution] *I went by referral of the other mothers, to hear so much of the people speaking there at* [municipal reference institution] *and I asked them to refer to the* [name of the philanthropic institution]. *But at* [name of private institution] *was by the WhatsApp group* (Mother 3).

The fragmentation of specialized therapies in various services increases the commitments on the schedule of children and their mothers, causing greater physical, mental, financial wear and time wasting.

> *I organize my schedule and her schedule to take to the therapies she does every day from Monday to Friday* (Mother 2).
>
> *I'm going to* [name of state institution], *to* [name of philanthropic institution]*to* [name of municipality reference institution] *and* [name of municipality maternity hospital] (Mother6).

Another difficulty evidenced in the reports of mothers refers to the fragility in the coordination of care by the Family Health Strategy (Estratégia Saúde da Família, ESF), causing delay in care and access to early stimulation.

> *It's a bureaucracy, difficult even to get the service, because it has to go through many professionals and the child is wasting time to be stimulated (...) a month, a day makes a difference* (Mother 2).

The absence of defined flows for the microcephaly child is also reflected in the access to specific exams that are important for the treatment and segment of the therapeutic itinerary.

> *The electroencephalogram exam I'm waiting to do until today, by six months. I count six months, but I think it's longer* (Mother6).
>
> *It lacked professional because there are few people (...), assistance from the public falls short. They do not have this time; it was to have priority in the care of these children. There is child who has not made a MRI until today, because the mother has no financial conditions and the government did not do it and does not have a MRI for the neurologist to be able to diagnose correctly* (Mother 8).

The difficulties faced by the collaborators, such as the fragmentation of therapies in various institutions, lack of defined care flows, lack of professional guidance, can have significant impacts regarding adherence and resolution of the treatment of children with microcephaly, leaving their TI full of obstacles.

Maternal experiences in the Therapeutic Itinerary of children with microcephaly associated with Zika virus

The experience of treating a child with microcephaly leads to accumulation of demands, requiring redefinition of the roles of people who will be involved in the practice of care. The experience lived by mothers seeking treatments for their children generates stress, fear and disappointment.

> *The fight is big. There are times when desperation comes, because most children are very attached to their mothers and you can't do anything else* (Mother 2).
>
> *It's complicated to be a mother of a child with microcephaly. I didn't expect him to be so dependent on me. It's stressful, it's tiring. There are days when we are sad, because we do not see evolution, sometimes he is so sad, it hurts us who are mothers* (Mother 4).

Many difficulties are faced by the mother-child binomial in search of the itinerary for treatment and specialized therapies. The family is the main social support institution and plays a crucial role in strengthening the subjects involved in care.

> *My family was very important, I received from them total support; from everyone* (Mother2).
>
> *I am supported by my family; they participate in care* (Mother 3).

Family support makes caring for the child less arduous, not only in routine activities, but also in the pilgrimage in search of the child's treatment. However, not all mothers have a consolidated family support network.

> *I am alone for everything. Everyone sees that I need it, I have no help from anyone. I'm very distressed, family that lives close and never comes to me to say, 'are you needing something? ´, no one comes! But to point out, to speak, to say 'oh, this is an ordeal she's going through, just let it go'* (Mother 6).

Another important factor reported is the absence of the father figure in the life and treatment of some children with microcephaly, which makes the experience of the therapeutic itinerary even more difficult for some mothers.

> *The father you count on him for nothing, he helps nothing. I wish he was more present because it makes a difference in the child's development* (Mother 2).
>
> *The father doesn't care, he left* (Mother 4).
>
> *I have no one to help me with her. Her father is in Sao Paulo, andhe saw her a few times, didn't see her even ten times* (Mother9).

With the absence of the fathers, it is only for mothers to take care of their children who require a lot of attention, constant visits to therapies and consultations with pediatricians and other specialists. However, despite the anguish experienced, these mothers show strength and perseverance to continue their journey in search of care, always aiming at a higher quality of life for their children.

> *I said, I'll stay with her until the end, taking care of her (...) so she can get better* (Mother 5).
>
> *My life now is taking care of her, I don't live for myself anymore, I only live for her. It's just going to doctor now* (Mother 6).
>
> *I often say it's a fight with love and it's an unconditional love. Because I don't know how I never got into depression, because I didn't expect to receive my son like that. I am here with him, fighting, fighting, fighting and there will always be struggles, but love will always prevail* (Mother 4).

The experience of the path taken in search of treatment for the child with microcephaly is complex. Some mothers, in addition to facing the lack of family support, such as paternal absence, still suffer from the prejudice of society regarding their children's disability.

> *I suffer from the prejudice of people on the streets, they keep looking a little strange, they talk (...) because his head is small. All this one gets sad. There was a time I went to the market with him and a lady looked at my face and said 'if I had such a child, either I killed, or I abandoned'* (Mother 10).

Another important gap in the support network is governmental disengagement, which does not promote effective care and support for children with microcephaly, leaving them at the mercy of donations from individuals and private companies.

> *If they wait for the government, they die, and they don't look at these children (...) On the part of the government, I think there should be more humanity in relation to us and these children because it is not easy* (Mother 4).
>
> *In the services I go to, I feel supported by the professionals, but not by the government, not by the state, not by the government* (Mother 8).

DISCUSSION

The outbreak of the microcephaly associated with Zika Virus epidemic still generates many uncertainties for the healthcare team.

Early identification of the diagnosis of microcephaly favors the intervention and care plan of the child with the greatest opportunity to initiate early stimulation, which will favor the development of their potential.[15] It is noteworthy that the diagnosis of microcephaly brings with it several aspects that may restrict the therapeutic itinerary, such as the existence of qualified professionals to recognize the signs of the disease and to communicate the diagnosis.[16]

In this sense, it is emphasized the need for professional training not only to identify the signs of microcephaly, but also for a careful and qualified listening to mothers, as they are the ones who take care of their children daily and, often, are the first ones to recognize signs of developmental delay. Corroborating these findings, a study shows inadequate communication between professionals and family, omission of information and lack of emotional support and clarification about the disease and treatment, revealing the lack of preparation of the health team to communicate humanly the child's diagnosis to their family members.[17]

The search for mothers by reference institutions for the treatment of children with microcephaly is part of their therapeutic itinerary in the RAS. According to the protocol of health care and response to the occurrence of microcephaly associated with Zika virus, the child must be cared by a multidisciplinary team so that its potentialities are worked and developed.[7] Acknowledging the warning signs is the first step to early diagnosis and correct referral to RAS. The well-trained professional, who knows the health system flows and places of reference, can assist and assertively guide the family of the child with microcephaly, and facilitate their therapeutic itinerary.

Therefore, the lack of guidance causes these mothers to be lost in the network, without knowledge about the peculiarities of microcephaly, as well as with difficult access to specialized services and therapies recommended by the early stimulation program. Such difficulties may impact the therapeutic itinerary of the child with microcephaly and his family, which should be guided by health professionals and made available by the services, to facilitate the beginning of neuropsychomotor stimulation. Conversely, adequate information could provide the family with greater security and understanding of their child's illness and allow objectivity in seeking care and skilled professionals, so that TI can be resolute.[11]

In addition, it is necessary for the health team to develop the singular therapeutic project (STP) for children with microcephaly, in order to direct the actions and treatment in a timely manner, as well as to uniquely and fully meet the needs of this population.

The STP is presented as a strategy proposed by the MoH to articulate strategies, knowledge and practices for the construction of integral, resolute and humanized care.[18] It should be done by the interdisciplinary team, rather than breaking the 'user into pieces'. The articulation in care enables a professional to know the other's action and add new knowledge to his practice.[19] The elaboration of the STP will correctly direct the child with microcephaly in the RAS, making appropriate referrals, coherent orientations, which will facilitate the search for referral services and their therapeutic itinerary.

Given this context, it is observed fragility in the care of these children due to the absence of STP and failure to coordinate and order the RAS, whose health services are not articulated and do not share the pertinent information for the care of children with microcephaly. Studies show that the disarticulation of the network and the lack of communication of health professionals and services appear as limitations for the continuity and qualification of care.[20-22]

The findings also evidenced simultaneous use of therapeutic centers by mothers, which can cause disorders such as time overload for mothers and burden health services, as it may cause restriction to those children with other health problems, but who also need special care, and they are not monitored due to vacancy, time and professional unavailability.

Given this, there is a need for the RAS managers of the municipality under study to organize referral services so that they can offer the largest number of specialties and therapeutic modalities in the same institution, for the effective treatment of children with microcephaly associated with Zika virus, as recommended by the early stimulation program, with availability of places and easy access. Once that is done, it would be up to the mother to choose the service that best met her child's treatment needs, as well as the one in which she felt welcomed and safe.

Facing this reality, it is necessary to reflect on the time that is spent for the mother's displacement between the institutions, since this time could be used to perform other activities such as stimulation of the child at home, self-care of women, family life, leisure, etc.

Considering that the child with microcephaly should have its stimulation started as soon as it is diagnosed, in order to better reach its development potential,[5] it is essential that the care flows are well defined and planned to ensure integral, resolute and timely care.[21] Research conducted with mothers of children with microcephaly shows difficulties related to health services, such as lack of reception and access to specialties, being also mentioning the reduced number of neurologists to meet the demand of these children,[23] reinforcing the reports presented in this study.

It is pertinent to emphasize that the microcephaly treatment is long and exhaustive, with continuous follow-up that requires from the caregiver a reorganization of their daily living,[24] since it is dedicated almost exclusively to the care of the child. Thus, the social support network needs to be articulated, and the family institution is fundamental for overcoming adversity and autonomy to provide care and help in the TI of children.[25]

Emotional support for mothers is even more important in coping with the TI of children with microcephaly, due to stressful changes due to chronicity and lack of knowledge imposed by the association with Zika virus. Given this, the feeling of insecurity of mothers is strongly evidenced and emerges the need for family and social protection,[16] on the part of the services/health professionals.

Although extremely important, family members do not always provide the necessary support to children with microcephaly and their mothers. Research highlights that the father's involvement in caring for the child with chronic disease is little reported,[16] as well as cases of non-recognition of paternity and distancing from the child.[23] In the present study, the paternal abandonment of the conviviality and treatment of children was also reported. Therefore, the father absence, in addition to blaming only the mother for care, also negatively influences child development.[23]

It should be noted that the social support network is directly associated with the success of care for children with complex and continuous treatment, being the lack of family and society support the main gap for home care failure.[25,26]

While society is able to support the family, it can also cause suffering to it, given the prejudice related to the child with microcephaly. Fear of non-acceptance of family and prejudice suffered creates insecurity for mothers, as they fear that their children will suffer from discrimination or any form of violence,[27] making them even more vulnerable as their condition a priori makes them fragile.[23]

Such a reality justifies the indignation of some mothers, who feel helpless and discredited in the government.[23] Until managers recognize the importance of planning public policies and programmatic actions with the ability to communicate with the network, the children with chronic illness will remain invisible to the health system, without direction to the line of care and lacking assistance.[20] Therefore, government instances that have the power to guarantee the social right of children with microcephaly should develop specific health actions to meet the needs of this population and invest in resources that universalize the coverage of services, focusing on the completeness of care.[15]

Faced with numerous weaknesses in the support network, the solidarity developed between mothers of children with chronic diseases who share the same fears, difficulties and anxieties is characterized as a fundamental device for emotional support. The sharing of experiences enables the interaction of experiences, the reception of pains, the encouragement to overcome the adversities of daily care and the construction of other visions about reality, thus weaving a support network of their own.[23]

The experience of caring for children with chronic conditions is intrinsically impacting on the lives of women and all the people involved. The mothers, even immersed in pain, show learning lessons after childbirth, transforming their view of caring for a baby with special needs. Such teaching implied the appreciation of the little things in life, the discreet achievements achieved,[23] making them more confident about the child's treatment and helping in the process of acceptance and assimilation of the diagnosis, improving their path in the therapeutic itinerary.

In addition, health professionals need to become an active component of the support network and sensitize their practice, realizing the uniqueness of children and planning effective strategies capable of providing qualified care[16] to mothers and in the child's TI. The governors need to look at the children with microcephaly and expand their care plans and projects to address the different demands, through decisive and resolute actions.

The society also needs to ally with these mothers' militancy and join forces so that the rights of the children are not forgotten. And above all, to empathize with the struggle that these mothers were braving every day in search of a dignified and quality life for their children.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The child with microcephaly associated with Zika virus encounters numerous problems along the therapeutic itinerary, among them, the simultaneous use of services, lack of specialists, structural problems at RAS, gaps in care and governmental disinterest. The lack of definition of the therapeutic itinerary triggers overload in the network, which is not prepared to meet the special health demands of these children, and points to the need to restructure it to make it efficient and able to optimize access to different services and specialized therapies.

The therapeutic itinerary of the child with microcephaly in the health care network of the municipality studied is happening, mostly, without professional guidance, occurring on the initiative of mothers, who seek for themselves the institutions that they think they would provide the support their children need as they were not referred by any service and/or health professional.

Concerning the experience of care, it was noticed that the position of women as the responsible for raising and assisting the child with microcephaly is still predominant, causing maternal overload. Paternal absence weakens the support network, whose consequences have implications for the quality of life of children with microcephaly and show the need for this network to be solidified.

Given this context, the support network for children with microcephaly must be well established to support caregivers who need help and guidance. Thus, the various care actors should appropriate their role for effective monitoring of children with microcephaly at the RAS.

During data collection, two mothers were indicated and invited to participate in the interviews, but they refused by complaining about the researchers' great search for studies realization, but they are not sought after the end of the research to know the result of their participation. It was also considered as limitation the non-listening of the managers of the services of the RAS, in order to better understand the therapeutic itinerary of children with microcephaly associated with Zika virus.

Thus, it is recommended that further research be conducted considering the point of view of health managers who formulate and/or implement public policies aimed at the care of children with microcephaly associated with Zika virus.

AUTHOR'S CONTRIBUTIONS

Study conception and design. Data collection, analysis and interpretation. Results discussion. Content writing and/or critical review: Article final version approval. Responsibility for all aspects of the content and integrity of the published article: Rafaella Karolina Bezerra Pedrosa. Altamira Pereira da Silva Reichert. Study conception and design. Data analysis and interpretation. Results discussion. Content writing and/or critical review: Article final version approval. Responsibility for all aspects of the content and integrity of the published article: Elenice Maria Ceccheti Vaz. Data analysis and interpretation. Results discussion. Content writing and/or critical review: Article final version approval. Responsibility for all aspects of the content and integrity of the published article: Anna Tereza Alves Guedes· Anniely Rodrigues Soares· Neusa Collet.

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