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RESEARCH

ARTICULATIONS OF MOTHERS FOR THE COMPREHENSIVE CARE OF CHILDREN WITH MICROCEPHALY ASSOCIATED WITH ZIKA VIRUS

ARTICULAÇÕES DE MÃES PARA O CUIDADO INTEGRAL À CRIANÇA COM MICROCEFALIA ASSOCIADA AO ZIKA VÍRUS

ARTICULACIONES DE MADRES PARA EL CUIDADO INTEGRAL DE NIÑOS CON MICROCEFALIA ASOCIADA AL VIRUS ZIKA

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ABSTRACT

Objective: to show the articulations performed by mothers in search of comprehensive care for children with microcephaly associated with the Zika virus. **Method:** qualitative research, carried out with 10 mothers of children with microcephaly associated with Zika virus followed up in two specialized reference services in the capital of Northeastern Brazil. The interviews took place from July to September 2018 and were interpreted by thematic analysis based on the concept of care management. **Results:** mothers take care of the child with microcephaly and build their support networks to readjust to the new routine. In the social network, they mobilize family members, the community, and a group of mothers to support them. The lack of resoluteness in the care of children with microcephaly associated with the Zika virus and their families makes the mothers carry out the necessary articulations in the community context and health care networks, seeking to provide the specifics of care for their child. In health services, they face difficulties in the operationalization of comprehensive care. **Final considerations:** the direct engagement of managers and health professionals is essential, pointing to actions that overcome the usual fragmentation of services and lead to the effectiveness of care management for a restructuring of the network to make it strong enough to supply the demands of this population.

Keywords: Microcephaly; Child Health, Mothers; Zika Virus Infection.

RESUMO

Objetivo: *evidenciar as articulações realizadas por mães em busca do cuidado integral à criança com microcefalia associada ao Zika vírus.* ***Método:*** *pesquisa qualitativa, realizada com 10 mães de crianças com microcefalia associada ao Zika vírus acompanhadas em dois serviços especializados de referência em uma capital do Nordeste brasileiro. As entrevistas ocorreram no período de julho a setembro de 2018 e foram interpretadas pela análise temática à luz do conceito de gestão do cuidado.* ***Resultados:*** *as mães assumem o cuidado ao filho com microcefalia e constroem suas redes de apoio para se readaptar à nova rotina. Na rede social, mobilizam familiares, comunidade e grupo de mães para apoiá-las. A falta de resolutividade do cuidado à criança com microcefalia associada ao Zika vírus e sua família faz com que as próprias mães realizem as articulações necessárias no contexto comunitário e nas redes de atenção à saúde, buscando prover as especificidades de cuidado de seu filho. Nos serviços de saúde, deparam-se com dificuldades na operacionalização da integralidade do cuidado.* ***Considerações finais:*** *torna-se imprescindível o engajamento direto de gestores e profissionais de saúde acenando para ações que superem a fragmentação habitual dos serviços e levem à efetivação da gestão do cuidado para uma reestruturação da rede a fim de torná-la forte o suficiente para suprir as demandas dessa população.*

Palavras-chave: *Microcefalia; Saúde da Criança; Mães; Infecção por Zika vírus.*

RESUMEN

Objetivo: *mostrar las articulaciones que realizan las madres en busca de una atención integral a los niños con microcefalia asociada al virus Zika.* ***Método:*** *investigación cualitativa, realizada con 10 madres de niños con microcefalia asociada al virus Zika seguidos en dos servicios de referencia especializados en una capital del nordeste de Brasil. Las entrevistas tuvieron lugar de julio a septiembre de 2018 y fueron interpretadas mediante análisis temático a la luz del concepto de gestión del cuidado.* ***Resultados:*** *las madres cuidan al niño con microcefalia y construyen sus redes de apoyo para readaptarse a la nueva rutina. En la red social, movilizan a familiares, comunidad y un grupo de madres para apoyarlos. La falta de determinación en el cuidado de los niños con microcefalia asociada al virus Zika y su familia hace que las propias madres realicen las articulaciones necesarias en el contexto comunitario y en las redes de atención de salud, buscando brindar la especificidad de la atención a su hijo. En los servicios de salud, enfrentan dificultades para operacionalizar la atención integral.* ***Consideraciones finales:*** *el involucramiento directo de los gerentes y profesionales de la salud es fundamental, apuntando a acciones que superen la habitual fragmentación de los servicios y conduzcan a la efectividad de la gestión asistencial para una reestructuración de la red con el fin de fortalecerla para atender las demandas de esta población.*

Palabras clave: *Microcefalia; Salud del Niño; Madres; Infección por el Virus Zika.*

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INTRODUCTION

Microcephaly was the first postnatal clinical finding to be reported at the beginning of the Zika virus epidemic in Brazil in 2015. Given the set of problems it causes, including more severe microcephaly, dysmorphisms with the marked occipital bone protuberance, closed fontanelles at birth, global hypertonia with hyperreflexia, irritability, swallowing disorder, auditory and visual impairment, and changes in imaging tests (diffuse punctate calcifications at the cortical-subcortical junction), it was designated as the congenital Zika virus syndrome (ZVS).[1] These children routinely need specialized care, with direct repercussions on the daily lives of their families.[2]

The routine and lives of mothers involved in child care change significantly with the birth of a child with microcephaly because they need substantial changes to include new assignments that meet the child's demands. This requires dedication, generates financial and emotional strain, culminating in changes in the family context.[3] Mothers of children with ZVS show a decrease in vital energy since they are in constant physical and psychological exhaustion, which can be a factor that promotes the emergence and/or worsening of mental disorders.[2]

This topic needs attention, considering that families experience realities marked by adversity and obstacles. They need the support of members of the social network and health professionals, who must welcome and support them to face the disease, minimizing suffering and burden.[4]

In the support search, mothers face difficulties in guaranteeing citizenship rights and suffer from precariousness not only related to access to services but also to materials that meet the urgent needs of the child. This context requires interactions and articulations beyond the family and professional environment, making a social and care network necessary to reduce the burden on the family and the suffering of children.[5]

The mothers have built this common support network to go through this painful period of illness for their children.[6] They instinctively relate to each other, create bonds of friendship and solidarity networks, supporting and sympathizing with each other with the suffering of others, as a way to seek mutual comfort.[7]

The Health Care Network (HCN) needs to use mechanisms to promote comprehensive care for children with microcephaly associated with the Zika virus and their families. Thus, it will be able to guarantee access to services, reception, and bonding between professionals, service and family and system leaders, for an organization of care production processes based on joint responsibility, in an articulated and shared way, to provide unique responses to the demands of this population.[8,9]

When investigating the experience of mothers in the therapeutic itinerary of children with microcephaly associated with Zika in the HCN, a study showed that the therapeutic itinerary is taking place, in most cases, without professional guidance. It emphasizes that mothers seek institutions that they believe are capable of providing better support for their children's needs, as they are not referenced by any service and/or health professional.[7]

The health teams must collaborate with the family to minimize the suffering at the birth of a child with the syndrome and provide opportunities to overcome adversity.[3]

Given the above, considering the need to articulate a humanization policy in defense of the lives of children with microcephaly associated with Zika virus that includes the production of comprehensive, longitudinal, and continuous care and to positively interfere in the existing practice in the health system,[8] this study aimed to highlight the articulations of mothers in search for comprehensive care for children with microcephaly associated with Zika virus.

METHOD

This is qualitative, exploratory-descriptive research, in which the Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to guide the structuring of the method.[10,11] We carried out the study in a state public service and is a philanthropic institution, both reference in rehabilitation care to children with disabilities, including, in addition to CZS, diseases such as Down syndrome, autism, cerebral palsy, visual and hearing impairments, among other chronic conditions.

This study is based on the concept of health care management defined *"as the provision or availability of health technologies, according to the unique needs of each person, at different times of their life, aiming for their well-being, security, and autonomy to continue with a productive and happy life"*.[6:589] From this perspective, the management of health care can be carried out in its multiple dimensions: individual, family, professional, organizational, systemic and societal.[6,9]

The individual dimension involves the individuals' ability to make choices for their life, producing new ways of living to cope with the disease; the family dimension encompasses family and friends as co-participants in care; the professional dimension is based on technical competence, ethical posture, and ability to form bonds; the organizational dimension involves the organization of the work process in the services; the systemic dimension aims to establish formal, regular and regulated connections between the network's services; and the societal dimension encompasses social policies and how the State and society play their role in these policies.[6]

The participants in this study met the following inclusion criteria: being a mother and main caregiver of the child with microcephaly associated with Zika virus and monitoring the child from the third appointment onwards in the institutions participating in the study. We believe that, from this experience, these mothers would have subsidies to report the articulations made in the search for comprehensive care for their children in different health services, highlighting the dimensions of care management. We adopted the following exclusion criteria: being a mother under 18 years old and/or having hearing or speech impairment, as it hinders the communication process. We selected these mothers randomly, while they awaited their children's appointments. We approached them at the reception of the study location and, if they accepted, we sent them to a reserved room for the interview. None of the mothers refused to participate and there were no dropouts.

The collection of empirical material took place between July and September 2018, through semi-structured interviews, after the consent of the participants. The interviews were conducted within the aforementioned institutions, with an average duration of 40 minutes, and the audios were recorded on digital media. We used a script containing three parts: mother's identification data, data regarding the child, and the following guiding questions: how have you sought care for your child in different health services? How do articulations in these services occur? Such questions allowed to encompass the management of health care, without the need to use this term, which could be incomprehensible to the study participants. The closure of the collection followed the sufficiency criterion when it was possible to draw a comprehensive picture of the object of study.[10]

We transcribed the reports in full and interpreted through thematic analysis,[10] following the following steps: organization of the interviews after exhaustive and repeated readings, starting the thematization of data based on the objective of this study; horizontal map for classification of reports, with a grouping of meaning cores; final analysis, with treatment and interpretation of results based on the concept of health care management and the pertinent literature.

The study met all ethical precepts of research involving human beings. The project received a favorable opinion from the Research Ethics Committee under protocols nº 2.676.464 and CAAE: 87018218.9.0000.5188. The participants received all the clarifications and, after acceptance, they signed the free and informed consent form in duplicate. To ensure their anonymity, they were identified by the letter M (Mother), followed by the sequence number of the interviews (M1, M2...M10).

RESULTS

Ten mothers aged between 19 and 40 years participated in this study. Four lived in the state capital and the rest in inland cities. Seven lived in a common-law marriage, two were single and one a widow. None of the participants had a paid job. The children's ages ranged between 24 and 33 months old, four males and six females. All children received the social benefit and used at least one continuous medication. Regarding the therapies for stimulation of the visual, auditory, motor, language, and cognitive, and social skills areas, six children received all these therapies and four received only three types.

In the analysis process, we constructed two thematic categories: articulations with the family and community and articulations with health services.

Articulations with the family and community

The mothers' first necessary articulation occurs internally, given the impact of the child's microcephaly diagnosis. Thus, the individual dimension of care management is evidenced when reporting the "shock" by the news, the difficulty in accepting the child with this health problem, and the concern with the possible prejudice he may be exposed to.

> *When she* [the doctor] *told me, I got a shock. It felt like they were giving me news of death. You expect everything in your life, except that you're going to have a boy with an illness. In our minds, it just happens that our children will suffer prejudice, they will stay on top of a bed* (M2).

> *In the beginning, it was difficult, because we don't expect a child with a disability. At first, it was a "shock", but then I got used to it* (M4).

> *I was in shock. I said I wouldn't accept it. What did I do to deserve a boy like that?* (M7).

Within the individual dimension, the mothers resorted to faith in God to face a new reality, because, even not practicing a religion, they believe that God contributes to facing the situation.

> *I cried a lot, but then I stayed with God and I had to overcome and wait for His goodwill, for His will to be done* (M6).

> *I don't attend any church. What helped me was my faith in God* (M8).

> *We believe in God, but we don't attend any church. What helped me the most, I think it was God's miracle* (M9).

The birth of a child with microcephaly triggers transformations and necessary rearrangements in family dynamics. This occurs mainly in the daily lives of mothers, as they assume responsibility for the care of the child, depriving them of leisure time and exercising work activities. Thus, they feel overwhelmed by the accumulation of therapeutic demands, housework, and care for other children.

> *I used to work as a cleaner, I had to leave. Who will take care of her?* (M5).

> *I feel so overwhelmed. I don't have time for myself, to get ready, or to go to the doctor. I go out early with him* [for stimulation] *and arrive at night. When I arrive, I have to give food, bath, clean the house, make lunch and go out again the next day.*

Thus, it is clear that mothers dedicate exclusively to caring for their child with microcephaly, leaving other aspects of their life in the background.

> [...] *my dedication is more for him than for things at home, when he sleeps, I go to make lunch, do some laundry, my focus is only on him* (M7).

Also, mothers transfer the care of healthy children to other family members to fulfill their responsibilities, when they have the support of the extended family. In this process, they are distanced from these children, as they are not always able to give them the necessary attention, as the child with microcephaly demands all of their attention.

> *She* [healthy daughter] *moved in with my mother after he was born. I couldn't pay attention to her. But I'll explain to her: your brother is different from you, he doesn't speak, doesn't sit, doesn't do anything, that's why you have to stay with your grandmother so I can take care of him* (M6).

> *I can't take care of both of them, so my sister took him [another child]. I only help her with money* (M1).

In the family organization, there is a redistribution of roles, and most of the fathers assume a secondary role in caring for the child with microcephaly. The father has a collaborative action, when he is not working, and not co-responsibility in the care process.

> *My husband, whenever he can, he helps* (M4).

> *When her father is home, he helps. He stays with her, cuddles her, sometimes puts her to sleep. The rest is me, bathing, changing diapers, putting on clothes. And I do the housework too. I carry everything on my back* (M8).

However, there are families in which the father does not participate in the care intended for the child, and the mother feels lonely in the daily care of the child.

> *His father didn't help me at all, it was all me. I was responsible and now it's still the same way, he [the father] doesn't help me at all, it's me, me, and me* (M3).

Despite feeling overwhelmed, in general, the mother does not entrust the care of her child with microcephaly to someone else.

> *I'm afraid that one day I'll get sick, and I think: "who will take care of her* [daughter]*?" I don't trust anyone to take care of her* (M10).

As the child with microcephaly demands full-time care, the family dimension is affected, with implications also for the marital relationship.

> *We are further apart* [couple]*, the attention is all for her* [daughter]. *The relationship was shaken, we don't talk as before, we don't go out alone anymore when we go out, it has to be the three of us, and we go out little* (M9).

> *The routine has changed a lot, I used to go out with my husband, now I left it aside, I now live for him* [son] [...] *the marriage started to wear out* (M3).

Living with other mothers whose children also have microcephaly provides an exchange of significant experiences and strengthens them to overcome the emotional impact of the diagnosis. It also contributes to better home care management.

> *It was difficult to accept right at the beginning. But, later, getting to know other mothers, talking to them, I accepted it* (M3).

> *After I started traveling, seeing other children with microcephaly, knowing how their development was going, how their mothers were taking care of them, I got over it* (M5).

Articulations with health services

The trajectory in the care network for children diagnosed with microcephaly associated with the Zika virus begins in maternity or primary care. Afterward, they are referred to a specialized service for early stimulation therapies, to enhance their neuropsychomotor development. Thus, mother and child begin the search for access to services that offer care that can contribute to a better quality of life for the child.

> *It was from the FHP* [Family Health Program, referring to the Family Health Unit]. *He sent a referral here* [institution B] (M1).

> *I came to institution A referred from the maternity hospital. After she was born, the doctor referred her.* [...] *we went through the screening, carried out an assessment, saw that there was a vacancy, and, on the same day, physical therapy began* (M9).

However, at times mothers face a lot of bureaucracy in the established flows or they build bridges between services to ensure that the child's demands are met.

> [...] *referral, no, I was recommended by the physiotherapist here* [institution A], [...] *and I got the appointment. I talked there* (M4).

> *When I need care from a neuro, a cardiologist, it's more complicated, because I have to go to the FHP, take a referral to the Department (of the city's Health) and there is still waiting to schedule the exam* [...] *she needs (M6).*

We observed that children receive care once or twice a week and not all receive the necessary therapies in a single service. Mothers express dissatisfaction with the frequency of scheduling for motor stimulation, as they know that their children need constant and continuous stimuli. The lack of HCN articulation triggers a pilgrimage through the services, according to their perception. In general, they learn about services that treat children with microcephaly through conversations with other mothers who are in the same situation. Thus, they go looking for assistance in more than one institution, increasing their burden.

> *Before, I would only go to institution A where he was referred. There were only two days a week, but I wanted him to have more appointments, for me, two days was not enough. I got more appointments at another service, through the mother of another child with microcephaly who is seen at institution B. She asked me if I wanted an appointment with the visual stimulation professional, as I still didn't have a place at institution A. Then I got the other treatments as well* (M3).

Maternal dissatisfaction was also evidenced in the assistance provided to the child by the professional of the specialized service. When this happens, they look for the same type of service in another service and use the private network when they can pay it.

> *I asked to take him out of the speech therapist because he wasn't having a future. Now he is doing speech therapy at a private institution* (M6).

Over time, mothers realized that the links with services and professionals are being changed, as no efforts were evidenced by the HCN to support these families. The long wait for care, supplies, and equipment negatively affects the child's health, as stimulation care is discontinued.

> *Right at the beginning, it was good, then it changed, the professionals don't say they're going to be absent, they don't care. It's been four months since I've been there and they haven't even called me to find out why I'm not going* (M3).

> *I waited six months* [for an orthosis]*, then I gave up waiting and bought it, and I didn't buy the chair because I can't afford it* (M6).

In some situations, a process of disengagement formalized by primary care professionals is evident. These transfer the responsibility for monitoring the child with microcephaly to the specialized service.

> *Since the day he was diagnosed, the doctor there* [Family Health Team] *said that now he should be accompanied by a pediatrician specialized in his problem* (M2).

> *In the FHP, there is no pediatrician, there is only an adult doctor* [...] *when I took her there, he did not attend, he sent her to G [another municipality] because he said that there was no pediatrician there to give her medication,* [...] *because it is not his specialty* (M6).

On the other hand, we observed actions that show the care that approaches a certain integrality, with the establishment of a bond between the mother and the professional. This helps the mother to understand and participate in the therapies, as well as giving her confidence to continue the care at home.

> *I participate, they tell me what they are doing, they play with her* [daughter]*. They tell me to do at home what they do here, they teach me how to do it. The speech-language therapist teaches her how to eat, to teach her to chew, to brush her teeth because she locks her mouth a lot. They explain everything to me* (M5).

> *A consultation that I like is hydrotherapy* [...] *she* [therapist] *stays in the pool with him, and I go out and she says: "look, mother, this exercise is for this, this other one is for this thing". In physiotherapy, she also explains everything to me. If it's a stretch to help him sit up, she shows me and tells me to do it at home anyway. They are super cool, they work well* (M7).

DISCUSSION

The birth of a child with a disability is an event that parents never expected and has a significant emotional impact on everyone in the family. Thus, they show feelings such as fear and frustration regarding the child's diagnosis, added to the perception of loss of the desired baby and changes that will be triggered in the family scenario.[12]

To face this situation, mothers seek foundations in spirituality. Through faith, people who face difficult situations strive to overcome obstacles and maintain hope.[13] In this same perspective, the exchange of experiences with those who live in similar situations encourages mothers, who start to deal better with their situation.[3] Processes of this nature contribute for individuals to produce new ways of living, articulating the individual and family dimensions of health care management.[8]

For caregivers of children with chronic illnesses, childcare becomes a priority, making it difficult to experience other aspects of daily life.[1] The mother is the family member who dedicates more intensely to the care of children with chronic illnesses. Due to the exhaustive routine and difficulty in meeting the demands of the child, she is often forced to leave her job, interrupt or postpone studies and leisure activities.[14]

Thus, conflicting relationships and maternal burden interfere in the family dimension of care management.[8] However, when the mother feels supported and can share the tasks necessary to cope with the disease with other family members, these problems tend to be minimized.[15]

In patriarchal societies, the sexual division of tasks is still in force, with the financial provision responsibility of the man, while the woman is responsible for caring for the child and domestic activities.[16] In this perspective, the involvement of family members tends to be limited to emotional and financial support.[17] When addressing the impact of the birth of babies with microcephaly on family dynamics in the father's perception, a study highlighted that one of the family's adaptations is the transformation of the relationships between its members. Among these transformations, the traditional role of the father restricted as the provider is deconstructed after the initial phase of denial.[16]

The process of caring for a child with microcephaly is continuous and almost always irreversible. Although mothers feel overburdened, sacrificing their routine and often having an impact on physical, emotional, and social health, they have difficulties in entrusting the child's care to someone else. We observed similar results in a study whose mothers are in charge of care, believing that the father does not have the ability or obligation to perform certain tasks.

This attitude may assume that the mother does not need support, causing many parents to settle down, not routinely collaborating in care.[17]

On the other hand, a study revealed the willingness of fathers to participate in the care of children with ZVS and the need for more assistance from service providers to facilitate their role in supporting their partners.[1] This indicates that the care of children with associated microcephaly Zika virus begins with the articulation of the individual and family dimensions of care management, but it needs to be extended to the professional and organizational dimensions, given the importance of these other dimensions as care micro-spaces in the context of HCN. In this way, comprehensive care for this population that has special and unique health needs can be strengthened.

Specialized services offer this population physical therapy, speech-language therapy, occupational therapy, and visual stimulation. This is in line with the guidelines of the national plan for coping with microcephaly, whose focus is on early stimulation of the visual, auditory, motor, language, and cognitive and social skills.[18] However, not always the services work in an articulated manner to provide the necessary support to these children and their families.

Access to therapies is essential for the development of motor, cognitive and sensory skills, especially in the first years of life, a phase of greater neuronal plasticity. Thus, the services will be able to guarantee adequate stimuli to the child and expand skills in neuropsychomotor development.[18]

Due to gaps in the formal referral of the HCN services, mothers make their articulations so that their children have better chances of development. Because they believe in the need for continuous stimulation of their child, they are mobilized to guarantee four to five appointments a week, in different services, and with different professionals. In this way, they move and build their support network, exposing the fragility in the organizational and systemic dimensions of care management. These dimensions should provide a work process that constitutes formal, regular, and regulated connections between the network services to guarantee access and longitudinality of care.

Mothers build their paths through the network[7], facing and overcoming barriers, in an attempt to provide their children with what they consider best: guaranteed access to services for early and continuous stimulation. Therefore, they promote intentional displacements to the institute, producing new articulations in the care network to minimize fragmentation.

In this search to meet the health needs of children with microcephaly, mothers face difficulties in building the itinerary for specialized therapies, as they do not receive guidance and sometimes referrals from professionals. They seek institutions that can offer care and support to their children's demands,[7] articulate and use the tools available to ensure access to the different therapies needed.

In the real movement of patients in HCN, the way of constructing therapeutic itineraries escapes the rationality intended by the managers. The systemic dimension of health care management should be structured from the action of patients, workers, and managers, from the perspective of building comprehensive care.[8] However, for the therapeutic itinerary to resolve, the information needs to be adequate, in time and enable security and understanding of the family for better guidance for the care and specialized professionals.[19]

Therefore, the coordination of care and the ordering of flows and counterflows of patients must take place from the Primary Health Care (PHC) to the different points of care in the network, optimizing the access of children with associated microcephaly Zika virus to meet their demands. This connection is not limited to the health system, requiring links with other sectors for the effective development of these people. Education is one of these sectors as some children with microcephaly are reaching the school stage, and new challenges arise given the unpreparedness of the education system to receive them properly, given their singularities and vulnerabilities.[20]

This perspective implies necessary articulations with educational systems, support networks, community organizations, parents, and religious groups so that the child can develop in an inclusive society.[21] In this way, support can be offered to the family throughout the acquisition process of the child's biopsychosocial aspects.

The progressive involvement of the family with the child, through education, support, and the division and transfer of responsibilities, aims at the development of self-care, increasing the child's knowledge, valuing their experiences, and the support offered by the social network.[6]

Mothers recognize the benefits and advances in the child's development after starting early stimulation in specialized service and express the importance and desire to participate in this process, encouraging the child at home and providing care that can improve his development. This suggests that the health professional needs to be able to get involved in the care and point out the possibilities of development of the child with microcephaly associated with Zika virus, giving the necessary attention to parents, promoting self-confidence, and overcoming difficulties.[22]

However, there are weaknesses in the preparation of families to continue stimulating the development of children with ZVS at home, emphasizing the need for professionals to act from the perspective of "doing for them" and "doing with them" during the learning process of the family members. Demonstrating the activity to be done with the child and having them perform the actions makes understanding the "how-to" at home an easier and more accessible task, in addition to promoting closer relationships between professionals and families and concrete and comprehensive care with the child.[23]

Health education has been a powerful tool to strengthen the link between health services/professionals and families of children with microcephaly associated with the Zika virus. We highlight the importance of educational strategies with mothers in promoting the health of children with microcephaly, improving the quality of life of their children.[24]

Caring for the other requires solidarity and respect for differences, and it is necessary to go beyond qualified human resources and excellence in procedures.[25] When the main elements of the professional dimension of care management are contemplated such as building bonds, technical competence, and posture ethics, give the professional more ability to produce comprehensive care.[8]

However, in this study, the construction of a strengthened dynamic of a support network for mothers of children with ZVS was not evidenced. There are weaknesses in the relationships established with professionals and health services, and it is up to the mother to organize the necessary articulations to ensure that her child's demands are met.

We consider that this research adds content to the available knowledge, although it has possible limitations linked to the time of data collection since the interviews were carried out while the mothers awaited the consultations with their children, which may generate concerns about the time factor and, perhaps, diverting concentration from the focus of issues.

FINAL CONSIDERATIONS

The articulations performed by mothers in search of comprehensive care for children with microcephaly associated with the Zika virus involve the mobilization of a social network, made up of family members, community, and groups of mothers to support them in their daily lives, strengthening the individual and family of care management. With the frequent and continuous trips to different health services, the weaknesses in the organizational and systemic dimensions are evident, since the mothers carry out self-management of health care, making connections between the different points of the HCN.

This study highlights the need for actions that overcome the usual fragmentation of services and lead to effective care management, for a restructuring of the care network for children with microcephaly associated with Zika virus, making it strong and efficient in the supply of their demands. Furthermore, we suggest the awareness and accountability of managers and professionals involved in caring for these children to build strategies from the perspective of network care management.

REFERENCES

1. Human Rights Watch. Esquecidas e desprotegidas: o impacto do vírus Zika nas meninas e mulheres no nordeste do Brasil. Human Rights Watch. 2017[cited 2020 Mar 20]. Available from: https://www.hrw.org/pt/report/2017/07/13/306163
2. Bulhões CSG, Silva JB, Moraes MN, Reichert APS, Dias MD, Almeida AM. Repercussões psíquicas em mães de crianças com Síndrome Congênita do Zika Vírus. Escola Anna Nery Rev Enferm. 2020[cited 2020 Mar 21];24(2):e20190230. Available from: https://www.scielo.br/j/ean/a/Rg7jNFz39ncsf3CPbbWvGJt/?lang=pt
3. Gomes GC, Mota MS, Moreira MAJ, Jung BC, Xavier DM, Silva CD. (Des) preparation of family member for the care of children with chronic illness. Rev Enferm UFPI. 2017[cited 2020 May 16];6(1):47-53. Available from: https://revistas.ufpi.br/index.php/reufpi/article/view/5737/0
4. Silva MEA, Moura FM, Albuquerque TM, Reichert APS, Collet N. Rede e apoio social na doença crônica infantil: compreendendo a percepção da criança. Texto Contexto Enferm. 2017[cited 2020 June 20];26(1):1-10. Available from: https://www.scielo.br/scielo.php?pid=S010407072017000100317&script=sci_abstract&tlng=pt
5. Dias BC, Arruda GO, Marcon SS. Vulnerabilidade familiar de crianças com necessidades especiais de cuidados múltiplos, complexos e contínuos. REME - Rev Min Enferm. 2017[cited 2020 May 20];21:e-1027. Available from: http://www.reme.org.br/artigo/detalhes/1163
6. Cecílio LCO. Apontamentos teórico-conceituais sobre processos avaliativos considerando as múltiplas dimensões da gestão do cuidado em saúde. Interface (Botucatu). 2011[cited 2020 Mar 15];15(37):589-99. Available from: https://www.scielo.br/j/icse/a/sBcTQJFRbBYmMgwSpNRkSrt/abstract/?lang=pt&format=html

7. Pedrosa RKB, Guedes ATA, Soares AR, Vaz EMC, Collet N, Reichert APS. Itinerary of children with microcephaly in the health care network. Esc Anna Nery Rev Enferm. 2020[cited 2020 Aug 01];24(3):e20190263. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452020000300201&lng=pt

8. Mendes EV. A atenção primária e as redes de atenção à saúde. Brasília: OPAS; 2015[cited 19 May 2020]. Available from: https://bvsms.saude.gov.br/bvs/publicacoes/redes_de_atencao_saude.pdf

9. Santos AM, Giovanella L. Gestão do cuidado integral: estudo de caso em região de saúde da Bahia, Brasil. Cad Saúde Pública. 2016[cited 2020 Feb 20];32(3):1-15. Available from: https://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102311X2016000300708&lng=en&nrm=iso&tlng=pt

10. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 14ª ed. São Paulo (SP): Hucitec; 2014.

11. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Health Care Qual. 2007[cited 2020 Apr 20];19(6):349-57. Available from: https://academic. oup.com/intqhc/article/19/6/349/1791966

12. Campos MMMS, Sousa TC, Teixeira GP, Chaves KYS, Araújo MVUM, Sousa MR. Desafios e perspectivas de mães de crianças com microcefalia pelo vírus Zika. Rev Rene. 2018[cited 2020 Apr 10];19:e32839. Available from: http://periodicos.ufc.br/rene/article/view/32839/pdf_1

13. Pinheiro DAJP, Longhi MR. Maternidade como missão! A trajetória militante de uma mãe de bebê com microcefalia em PE. Cad Gen Div. 2017[cited 2020 Apr 09];3(2):113-32. Available from: https://portalseer.ufba.br/index.php/cadgendiv/article/view/22216/14755

14. Salvador MS, Gomes GC, Oliveira PK, Gomes VLO, Busanello J, Xavier DM. Estratégias de famílias no cuidado a crianças portadoras de doenças crônicas. Texto Contexto Enferm. 2015[cited 2020 Feb 11];24(3):662-9. Available from: https://www.scielo.br/pdf/tce/v24n3/pt_0104-0707-tce-24-03-00662.pdf

15. Okido ACC, Zago MMF, Lima RAG. O cuidado do filho dependente de tecnologia e suas relações com os sistemas de cuidados em saúde. Rev Latino-Am Enferm. 2015[cited 2020 May 22];23(2):291-8. Available from: https://www.scielo.br/scielo.php?pid=S010411692015000200015&script=sci_arttext&tlng=pt

16. Félix VPSR, Farias AM. Microcephaly and family dynamics: fathers' perceptions of their children's disability. Cad Saúde Pública. 2018[cited 2020 Apr 20];34(12):e00220316. Available from: https://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102311X2018001205012&lng=en&nrm=iso&tlng=en

17. Ramos RM, Nóbrega VM, Fernandes LTB, Machado NA, Collet N. Cuidado paterno à criança e ao adolescente com doença crônica: percepção materna. Rev Gaúcha Enferm. 2017[cited 2020 Apr 20];38(3):1-8. Available from: https://www.scielo.br/scielo.php?script=sci_arttext&pid=S198314472017000300400&lng=en&nrm=iso&tlng=pt&ORIGINALLANG=pt

18. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Diretrizes de estimulação precoce: crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor decorrente de microcefalia. Brasília: MS; 2016[cited 18 Mar 2020]. Available from: http://portalarquivos2.saude.gov.br/images/pdf/2016/janeiro/13/Diretrizes-de-Estimulacao-Precoce.pdf

19. Cerqueira MMF, Alves RO, Aguiar MGG. Experiences in the therapeutic itineraries of mothers of children with intellectual disabilities. Ciênc Saúde Colet. 2016[cited 2020 July 20];21(10):3223-32. Available from: https://www.scielo.br/scielo.php?pid=S141381232016001003223&script=sci_arttext&tlng=en

20. Peiter P, Pereira R, França I. Dimensional analysis of access to health of children with Congenital Zika Syndrome (CZS) in the Metropolitan Region of Rio de Janeiro. Saúde Soc. 2020[cited 01 Aug 2020];29(2):e200064. Available from: https://www.scielo.br/scielo.php?script=sci_arttext&pid=S010412902020000200202&tlng=pt

21. Cano JCF, Calvo ML, Zamora NR, Anguita MEA, La Paz MG, Yañez SB, et al. Modelo de atención y clasificación de ninos y adolescentes con necesidades especiales de atención en salud-NANEAS: recomendaciones del Comité NANEAS de la Sociedad Chilena de Pediatría. Rev Chil Pediatr. 2016[cited 2020 Apr 20];87(3):224-32. Available from: https://scielo.conicyt.cl/scielo.php?script=sci_arttext&pid=S0370-41062016000300014

22. Sá FE, Andrade MMG, Nogueira EMC, Lopes JSM, Silva APEP, Assis AMV. Produção de sentidos parentais no cuidado de crianças com microcefalia por vírus zika. Rev Bras Promoç Saúde. 2017[cited 2020 Mar 12];30(4):1-10. Available from: https://periodicos.unifor.br/RBPS/article/view/6629/pdf

23. Junqueira CCS, Leôncio ABA, Vaz EMC, Santos NCCB, Collet N, Reichert APS. Estimulação de crianças com síndrome congênita pelo Zika vírus no domicílio: desafios do cuidador. Rev Gaúcha Enferm. 2020[cited 2021 Mar 03];41:e20190247. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S198314472020000100416&lng=en

24. Santos DBC, Prado LOM, Silva RS, Silva EF, Cardoso LCC, Oliveira CCC. Sensitizing mothers of children with microcephaly in promoting the health of their children. Rev Esc Enferm USP. 2019[cited 2020 May 2020];53:e03491. Available from: https://www.scielo.br/scielo.php?pid=S008062342019000100701&script=sci_arttext&tlng=en

25. Andrade SR, Schoeller SD, Oliveira MCS, Pozza CML, Erdmman AL. La contribución del registro multidisciplinario en la gestión del cuidado de una persona con lesión medular. Index Enferm. 2017[cited 2020 June 20];26(1-2):10-4. Available from: http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1132-12962017000100003