



PARENTAL NEEDS IN THE CARE FOR CHILDREN WITH ZIKA VIRUS-INDUCED MICROCEPHALY

Produção de sentidos parentais no cuidado de crianças com microcefalia por vírus Zika

Producción de sentidos de los padres para el cuidado de niños con microcefalia por el virus Zika

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ABSTRACT

Objective: To identify parental needs with respect to the care for the development of infants and children with microcephaly caused by the Zika virus (ZIKV). **Methods:** Qualitative research conducted at a treatment and early stimulation center of the Federal University of Ceará, in Fortaleza, Brazil, in July 2016. A total of 23 guardians, either parents or relatives, of children diagnosed with Zika-induced microcephaly took part in the study, having their data collected by means of focus groups and analyzed through content analysis. **Results:** The participants reported the need for greater attention, understanding and psychosocial support from the institution and professionals involved; for more knowledge of the general context of the child's condition; and health education interventions with continuous follow-up focused on the real needs of the children and their families. **Conclusion:** The results evidenced the absence of and the urgent need for the development and implementation of health-related strategies and actions that favor the active and humanized listening of families, reduce the negative impact caused by the children's situation within the families and enable a greater and better development of infants and children with Zika virus-induced microcephaly.

Descriptors: Developmental Disabilities; Parents; Microcephaly; Zika Virus.

RESUMO

Objetivo: Identificar as necessidades parentais quanto ao cuidado para o desenvolvimento de lactentes e crianças com microcefalia causada pelo vírus da Zika (ZIKV). **Métodos:** Pesquisa qualitativa realizada em um centro de tratamento e estimulação precoce da Universidade Federal do Ceará, em Fortaleza, Brasil, no período de julho de 2016. Participaram do estudo 23 responsáveis, entre pais e familiares, de crianças com diagnóstico de microcefalia causada por Zika, cujos dados foram coletados por meio de grupos focais e analisados através da análise de conteúdo. **Resultados:** Os participantes relataram a necessidade de maior atenção, compreensão e apoio psicossocial por parte da instituição e dos profissionais envolvidos; mais conhecimento sobre o contexto geral da condição da criança; e intervenções educativas em saúde com acompanhamento continuado (follow-up) voltadas para as reais necessidades das crianças e suas famílias. **Conclusão:** Evidenciou-se nos resultados a ausência e urgência da necessidade do desenvolvimento e implementação de estratégias e ações em saúde que favoreçam a escuta ativa e humanizada das famílias, reduzam o impacto negativo causado pela condição das crianças nas famílias e viabilizem um maior e melhor desenvolvimento de lactentes e crianças com microcefalia causada pelo vírus da Zika.

Descritores: Deficiências do desenvolvimento; Pais; Microcefalia; Zika Virus.



RESUMEN

Objetivos: Identificar las necesidades de los padres sobre el cuidado con el desarrollo de lactantes y niños con microcefalia causada por el virus Zika (VZIK). **Métodos:** Investigación cualitativa realizada en un centro para tratamiento y estimulación temprana de la Universidad Federal de Ceará, Fortaleza, Brasil en el periodo de julio de 2016. Participaron del estudio 23 responsables entre ellos padres y familiares de niños con el diagnóstico de microcefalia causada por el virus Zika cuyos datos fueron recogidos a través de grupos focales y analizados por el análisis de contenido. **Resultados:** Los participantes relataron la necesidad de más atención, comprensión y apoyo psicosocial de parte de la institución y de los profesionales involucrados; más conocimiento sobre el contexto general de la condición del niño; e intervenciones educativas en salud con el seguimiento continuado (follow-up) dirigidos para las reales necesidades de los niños y sus familias. **Conclusión:** En los resultados se evidenció la ausencia y urgencia de la necesidad del desarrollo e implementación de estrategias y acciones de salud que favorezcan la escucha activa y humanizada de las familias, reduzcan el impacto negativo causado por la condición de los niños en las familias y que viabilicen un mejor y mayor desarrollo de los lactantes y niños con microcefalia causada por el virus Zika.

Descriptor: Discapacidades del Desarrollo; Padres; Microcefalia; Virus Zika.

INTRODUCTION

A large outbreak of Zika virus (ZIKV) infection has erupted in the Northeast region of Brazil in the last months of 2015⁽¹⁾. In November of that year, ZIKV infection was detected in the amniotic fluid of a Brazilian pregnant woman in the fifth month of pregnancy, whose fetus presented microcephaly^(2,3). In the same month, a Brazilian virologist detected the presence of this virus in blood and tissue exams of two stillborn infants with microcephaly, reinforcing and confirming a suspicion that it could be associated with congenital malformations⁽⁴⁾.

As recently as November 2015, the expression “syndrome associated with congenital infection by Zika” emerged, or simply “congenital Zika”⁽⁵⁾. Studies were published in the consecutive months, definitively confirming the association. Only in 2016, however, was this association recognized by the World Health Organization (WHO), making Brazil the pioneer country in correlating the viral infection to congenital defects and a variety of brain manifestations, including microcephaly in newborns⁽⁶⁻⁸⁾. Different publications have described the initial cases in Pernambuco, Brazil, with clinical and laboratory findings, and others are still under construction for a better understanding of the condition⁽⁹⁻¹¹⁾.

ZIKV is transmitted by mosquitoes of *Aedes* species, also related to yellow fever, dengue fever, West Nile virus and Japanese encephalitis. It was first identified in 1947 in the Zika Valley, in Uganda. The infection produces mild symptoms such as fever, rash and arthralgia, and has emerged from obscurity, drawing global attention for its association with the suspected “congenital Zika syndrome”⁽¹²⁻¹⁴⁾.

Microcephaly is the most commonly observed clinical feature in congenital Zika syndrome. It is characterized by the skull dimension or cephalic perimeter less than minus two (-2) standard deviations below the specific mean for sex and gestational age. The measurement of the head circumference is performed with a flexible, non-elastic measuring tape. The skull diameter is measured at its greatest circumference, with the band around the head, placed on the forehead, above the eyes, and the ears, by the most prominent part of the posterior side of the skull. In non-preterm infants, this perimeter should be greater than 32 cm (with little variation by gestational age and sex). The cephalic perimeter increases almost linearly up to 37-38 weeks of gestation⁽¹⁵⁾. Thus, training the personnel who perform the measurement is essential, and when this is found borderline or abnormal, it must be repeated.

The sudden expansion of the ZIKV epidemic may be one of the main causes of neuropsychomotor disorders and disabilities in a generation of newborns affected by microcephaly secondary to maternal infection with Zika virus, representing a great hindrance for the families involved and a high socioeconomic burden for the countries affected⁽¹³⁾.

A number of children and families throughout the Americas have had their quality of life negatively impacted by the ZIKV epidemic⁽⁴⁾. This number continues to grow, demonstrating that the repercussions on the long-term development of these children and the effect on their families are still largely unknown^(16,17).

The fetal and neonatal deaths, which occurred from 2015 to May 2017, totaling 366 suspected ZIKV deaths, were monitored, of which 270 (73.8%) were under investigation, 49 (13.4%) were disregarded, 30 (8.2%) were confirmed, and 7 (1.9%) were considered as probably related to congenital infection during pregnancy. Ten reported deaths (2.7% of the total) were excluded after a thorough investigation, because they did not fulfill the current case definitions. Most of the reported deaths are grouped in Brazil's Northeast region (54.9%), followed by the Southeast region (25.7%) and the Midwest region (10.1%). The five states with the highest number of cases reported and under monitoring are: Pernambuco (109), Rio de Janeiro (36), São Paulo (27), Ceará (25) and Minas Gerais (25)⁽¹⁸⁾.

Faced with this context, one ponders that the gestation itself is a period of relevant changes in the life of a woman and her family, with new roles for the father and the mother. In case this pregnant woman with suspected ZIKV infection, facing the possibility that her child may suffer developmental changes and/or have injuries such as those in the brain, does not have

the support and care provided by a partner or a close family member, or the health team does not address the disease, she may suffer a lot, being liable to become ill and develop physical, psychic and social changes at a time when she needs to take care of itself and the child(s)⁽¹⁹⁾.

Therefore, the research in question becomes fundamental to further the collective discussion about the role of parents and caregivers in the treatment of these children, helping in the understanding of the disease for a better understanding of the real needs of these families and their children. The results are expected to serve as a guide for the planning of policies and programs with strategies of guidance and approach to the health of families in that situation, ensuring an effective and efficient care plan for continuity of treatment and promotion of better outcomes in the physical and psychological health of parents and relatives of children with ZIKV-induced microcephaly.

Thus, given this context, this question arises: What are the parental needs with respect to the care for the development of infants and children with Zika virus-induced microcephaly? Thus, the study aims to identify the parental needs regarding care for the development of infants and children with microcephaly induced by the Zika virus (ZIKV).

METHODS

The research has a qualitative and descriptive approach⁽²⁰⁾ and considers the Standards for Reporting Qualitative Research (SRQR)⁽²¹⁾. It was developed in the Center for Treatment and Early Stimulation (*Núcleo de Tratamento e Estimulação Precoce - NUTEP*), a non-profit institution created in 1987, in the city of Fortaleza, Ceará, Brazil, which operates in the Hospital Complex of the Medical School of the Federal University of Ceará (UFC) with the mission of providing assistance to children aged 0-12 years who are at risk of/or bearing developmental disorders, as well as to their families, through a specialized, multidisciplinary and interdisciplinary health team, involving physicians, nurses, physiotherapists, speech therapists, occupational therapists, psychologists and social workers; with a focus on the socioeconomic and emotional reality of the clientele, intending to operate as a Referral Center for research and professional training⁽²²⁾.

The study was developed in the period of July 2016, after the analysis of 35 medical records of children being followed by NUTEP, which were assigned to this use by the institution. The researchers invited the parents to participate in the study at the institution, at the moment they were taking their children to the multidisciplinary care, being included as participants in the study the parents/family of nursing infants and children with clinical diagnosis of microcephaly associated with maternal infection by Zika virus, who had joined the NUTEP service less than six months prior to then, and who agreed to participate effectively in three group meetings, to be previously scheduled by NUTEP's research team. It should be noted that participants who did not attend at least two group meetings were excluded. Thus, the study had as sample 23 parents/relatives who met the inclusion criteria and accepted to participate in the research, by signing the Informed Consent Form (ICF) with authorization for recording and use of audio and image.

Focal groups were used as research and data collection method; involving the dialogue between the parents and relatives of the children and bringing to the group, in a participatory way, the speeches of the research participants^(23,24); generating and bringing to the wheel peculiar reports through which the individuals recognize themselves and are recognized^(25,26).

Three focus groups were conducted, held in an auditorium properly prepared and made available by the NUTEP institution. Each one lasted 30 minutes. All relevant discourse data were stored by means of audio and video recording features and in field journals for further analysis. Each focus group was chaired by three research moderators: (01) a physiotherapist, (01) a student of the Physiotherapy graduate program at UFC and (01) a psychologist. Participants were questioned by the three moderators about their life experiences and ideas regarding growth, development, microcephaly and therapeutic recommendations; but also about their greatest difficulties in providing care for the children.

Through the active and humanized listening of the parental speeches, the main objective of the focus groups was to explore the families intimately, the "never before said", which is "felt, but not expressed", "the denied"; seeking, within its specificity and complexity, the development of a more global, wide-ranging and attentive look on the parents and relatives of the children with ZIKV-induced microcephaly.

The material collected underwent a detailed content analysis, which was divided into stages of pre-analysis, exploration of the material, treatment of results and interpretation⁽²⁷⁾. First, the recorded speeches were heard and transcribed in full. They were then divided into categories for further significance and interpretation of the data. From then on, the critical points in the parental speeches and postures before the confrontation of the lived experience, the questions posed and the sharing of concepts and experiences exposed in the focus groups were determined from a biopsychosocial view of the individual, seeking to understand and to know more deeply what involves the parental environment and the care processes developed by the families in the development of the child with ZIKV-induced microcephaly.

Two categories were extracted: ZIKV-induced microcephaly and changes in the family context, and Stimulation service and the care for infants' growth and development.

The research followed the ethical determinations of Resolution no. 466/12 of the National Health Council on research involving human beings, being executed after approval by the Research Ethics Committee (COMEPE) of the Federal University

of Ceará (UFC), under Approval No. 1684521. All participants in the research had the right to secrecy and their identifications preserved. For this, the study adopted designations such as: Participant 01, Participant 02... Participant 23.

RESULTS AND DISCUSSION

Next, the thematic categories, with the participants' speeches, are presented.

Zika virus-induced microcephaly and changes in the family context

In this category, the participants expressed feelings of anguish, fear and frustration, both due to the loss of the expected child, understood as the ideal child by parents and relatives, and to the changes in the family context with the arrival of a disabled child, which demands higher economic expenditures and social changes for these families, usually including the need for one of the parents to stop working and/or studying. Family support is believed to be restricted, or even absent, and many families are considered one-parent families, that is, the mother is the only provider and the presence of a child with microcephaly transforms the whole family context.

(...) I had everything under control and my life was transformed (...) I've entered another world (...) (Participant 01).

(...) I am alone and no one helps me (...) I feel that I am changing and I do not want to (...) Everything in my home has changed (...) My other son has changed a lot too (...) I think he is in need of psychological help (...) I thought everything was under control, but it is not (...) (Participant 05).

Having a child with a neuropsychomotor developmental disability, a condition that can be perennial throughout life, with the prospect of an unwanted and unplanned future, becomes a powerful stressor for parents/relatives, as they are unable to relax, because of the daily obligations related to the children, and the time made available for medical treatments in hospital and at home, lacking time for personal interests and leisure activities. This can lead parents to loss of control, physical and/or emotional disability, chronic and repeated stress, anxiety and physical illness, including cardiovascular disease and immune deficiency⁽²⁸⁾.

The speeches indicate the indispensability of greater psychological and social support for these families, including home visits paid by the multidisciplinary team. Because this is a chronic condition, children need high levels of parental, social and educational support, emphasizing that they will indefinitely continue demanding high levels of basic personal care from their caregivers, in this case, the parents and family members involved; this may lead to impairments in parents' health and quality of life, including symptoms of depression, anxiety and muscular pain^(17, 29).

Insecurity was reported by the participants with regard to the health team's in-depth knowledge of the "new" microcephaly related to the mosquito, as stated by the relatives, because this is a disease of causes and consequences that differ from "other types of microcephaly":

(...) We, parents, grandparents and family, we do not know what the future of the child may be (...) not even you, health professionals, know of it yet, let along us (...) I know that this disease is completely new compared to other types of microcephaly (...) (Participant 04).

(...) I am learning to observe my son, one day at a time, what matters is today (...) If everything seems new to you, let along to us (...) (Participant 20).

It should not be forgotten that, since this is an emergency condition of these days, and relatively new, the information regarding ZIKV and its effects on pregnant women, fetuses, newborns, nursing infants and children, including other neurological complications and associated comorbidities, is gradually becoming known and made available to society, as research progresses, which causes considerable discomfort in society, especially in the health teams and families involved.

It is actually today that the congenital syndrome caused by ZIKV features a recognized pattern of congenital anomalies associated with the infection with this virus during maternal pregnancy, which includes microcephaly, intracranial calcifications, other cerebral abnormalities, ocular anomalies, and others⁽³⁰⁾. Keeping families and/or caregivers informed and up-to-date about a condition they are exposed to, its risk factors and consequences, is of utmost importance, not only for public health reasons, but also for enabling the generation of new knowledge and empowerment for these people in their communities⁽³¹⁾.

In this context, the capacity to cope with and prepare the health teams to deal with families in such a fragile mood still proves insufficient. It proves insufficient, above all, the capacity to face the challenge of implementing "active and humanized listening" in their clinical practices. And, added to that, continuous, effective and meaningful evaluations and intervention methods for the families.

Despite recognizing that the scientific evidence on the theme is still limited, it is essential that health care providers maintain horizontal and effective communication with the community about the risks related to the transmission of the Zika

virus and its consequences⁽³¹⁾, developing intersectorial actions of health education, capable of involving the community, changing perceptions and behaviors, promoting a favorable social transformation⁽³²⁾.

The tiredness and difficulty of mothers in simultaneously managing household chores; taking care of the child, the husband and other children; dealing with the society's comments and also with the exaggerated exposition of the theme in the media are evidenced in the speeches:

(...) I feel tired, actually exhausted (...) I'm not even reminded about myself... of who I am (...) (Participant 9).

(...) The media and society contribute a lot to the difficulty in coping with this disease, because such exposure of our children tears us apart (...) We feel invaded and frightened (...) (Participant 17).

Demanding caution, vigilance and a great deal of responsibility is necessary, especially on the part of the professionals in health services in relation to the exaggerated media exposure on the relatives of children with ZIKV-induced microcephaly by means of agencies and social media, as these can often provide inconsistent or contradictory information, with a great power to afflict and stigmatize these families. The news concerning this subject publicized in the media have widely reverberated in the Brazilian media, causing a devastating social and emotional impact on the affected families^(33,34).

Parents of children with disabilities and chronically ill are a vulnerable group with regard to health and quality of life. The high burden of care required from the parents and/or caregivers is associated with lower social participation, heavier financial burdens, and greater need for help within the household, which significantly contributes to increasing the risks to health⁽³⁵⁾.

In view of the various gaps still existing in the scientific knowledge about the ZIKV infection, it should be pointed out to the society that the information and recommendations disclosed are liable to review and changes with eventual incorporation of further knowledge and other evidence, as well as the need for adequacy of surveillance actions in future epidemiological scenarios and more in-depth studies^(36,37).

Stimulation service and the care for infants' growth and development

In this category, which addresses the early intervention service and its relationship with the growth and development of the infants, the parental discourses referenced reports of fear and insecurity in relation to the stimuli; questionings about materials and care that are favorable and/or feasible for the child in the household environment; and many doubts about the condition, prognosis, motor and intellectual evolution of the child with microcephaly:

(...) I wonder if I am doing it right... I saw on television that the more stimulation, the better (...) (Participant 08).

(...) I have many doubts (...) I wonder if the more we stimulate them, the better it is for them (...) This can also cause problems, because they cry so much, and I'm afraid something might happen there inside his head (...) (Participant 16).

(...) I wonder if they don't feel headache due to microcephaly? (...) (Participant 01).

Promoting self-confidence and providing adequate psychological support for a better day-to-day family performance can enhance the parental empowerment, favoring well-being, the healthy coping with the condition of life, better access to and support for the necessary services, and the facility to provide better services for families⁽³⁸⁾. In regard to family-centered approaches, parental empowerment is essential, especially by providing the necessary conditions for the parents to be able to evaluate themselves with regard to the management of their children, being directly related to internal resources and to the capacity to reach the appropriation of life⁽³⁹⁾.

In the present study, the need and the desire for a more attentive look on the part of the health team was clear, offering guidance and health education strategies that include parental training in the context of children with ZIKV-induced microcephaly:

(...) We need a workshop that helps us build supporting materials in the daily care for the baby ... This would be a way of guiding us on how to make toys and stimulate the child at home (...) This short time that we remain inside the rooms is not enough to learn everything (...) (Participant 03).

(...) I need to enter the care service, in order to see the stimulation and try to do it at home with him (...) (Participant 07).

(...) We need to know what to do at home to continue the treatment (...) because, sometimes, the child comes to the clinic, gets annoyed and tense while receiving care and doesn't take much advantage of it (...) I get worried (...) (Participant 09).

The changes most commonly associated with microcephaly are related to intellectual deficit and other conditions, which include: irritability; convulsions; epilepsy; cerebral palsy; language and/or motor developmental delay; ophthalmologic, cardiac, kidney and urinary tract disorders; among others⁽⁴⁰⁾. The involvement of parents and family members in the treatment and follow-up of the child in a disability condition is of utmost importance, since the family and social environment is the richest in stimuli for the child. The multiprofessional health team involved should inform the family about the aspects and the unfolding of the disease, orienting them about activities of daily living and how to use some moments, such as bathing, clothing, eating, self-care and, mainly, the recreational activities, in order to stimulate the neuropsychomotor development⁽³⁷⁾.

The families of the current research sketched out in their speech the difficulty in dealing with the crying, exacerbated irritation and stiffness of the child, mainly during the activities of practical and daily life (bath, hygienic cleaning, diaper change). According to the reports, the hypertonia is sharply increased when the infant is at a moment of irritation and crying.

(...) I have a lot of trouble when I bathe him, he gets all outstretched, I don't know what to do, nor how to hold him (...) (Participant 07).

(...) My God, what is that cry!?! (...) It's despairing, Doctor. (...) We don't know what it is! (...) Is it due to the microcephaly, the cry? (...) And when I despair, she gets even more annoyed. (...) (Participant 10).

Parents and/or caregivers play a cooperative role for the changes in the motor behavior in the development of children with motor disabilities. Therefore, providing continuous and appropriate guidance, in addition to the consistent monitoring of these families and/or caregivers, aiming for adherence and active participation in the treatment of these children, can lead to satisfactory results in the performance of their functional abilities⁽⁴¹⁾.

Caregivers take control of the maintenance of the child's care, but generally disregard the probable complications of the clinical condition. The great challenge issued to the team is still to continuously provide the necessary guidance for the management of the condition by the family. It is important that multiprofessional institutions and teams that assist the newborns, nursing infants and children with microcephaly insert in their care processes some aspects, such as: family involvement and teamwork with interdisciplinarity and therapeutic plan of early intervention, particularly in the very first childhood (0 to 3 years)⁽⁴²⁾.

The communication and support certify the development of relationships of trust between the families and the different agents involved, thus creating a space for reflection on early childhood intervention and effective intervention strategies in cases of established risk⁽⁴³⁾.

The speeches analyzed in the present study revealed the need for guidance on infant feeding, especially on the management of breastfeeding, weaning, types of foods, spacing of diets, introduction of supplements and use of adequate pacifiers when the baby is not exclusively breastfed. Moreover, the families' specific need to learn first-aid techniques emerged from the speeches, mainly in order to reverse gagging, caused by dysphagia, and airway cleansing and hygiene maneuvers in children, since infants have gastric reflux and difficulty accepting food (especially the milk), making it difficult to feed them properly. In the speeches one can apprehend a great deal of doubt, hesitation and extreme anxiety of the families in dealing with this reflux and the recommended diets:

(...) I'm very afraid of feeding my son. When it's time for him to eat, I step back (...) (Participant 04).

(...) He once choked and almost suffocated (...) I felt really bad, I wanted to disappear (...) I don't want to go through that anymore, no way (...) (Participant 11).

(...) I'm breastfeeding, but he cries a lot (...) I wonder if he feels pain (...) They say he does, because of the reflux (...) When will I be allowed to give him another food? (...) What do I do if he chokes? (...) (Participant 14).

An effective rehabilitation program for children with neuropsychomotor disorders needs to take into account the high levels of fatigue, depression, and anxiety in these children's mothers, who should primarily be provided with a close follow-up and be psychologically supported by the health teams⁽⁴⁴⁾.

Doubts, fears and wishes about vaccination and childcare were also expressed in the current research, and there were also reports about the hesitancy and even refusal from health professionals of the Primary Health Care Unit to vaccinate the children when they learn of their condition:

(...) I happened to take my daughter to the health unit and the nursing assistant told me that she could not manage to give her the vaccine, because she was special (...) (Participant 16).

(...) I know nothing about her vaccines (...) They can be given the vaccines normally like the other children, can't they? (...) She has no follow-up besides NUTEP's (...)

Understanding and sharing the difficulties experienced by caregivers of disabled persons can develop facilitative processes during the course of the disease experience, both for the caregiver and for the health team⁽⁴⁵⁾.

In the present study, it was perceived the urgency for an specific support related to attention to childcare, or parental counseling on the child's problems, together with psycho-emotional or general instrumental support and family support. In this way, it will be directly beneficial to the families and contribute significantly to the reduction of maternal and family stress levels. Research reports the urgent and unsatisfied need of parents and families of children with disabilities for a more comprehensive care that involves groups and networks of psychosocial and financial support, home care and the feasibility of home care for children for a better continuity of the treatment⁽⁴⁶⁾.

Through the reports it is noticeable that the families of the research in question undergo experiences of confrontations with the child's deficiency caused by microcephaly, as well as the acceptance of responsibility for the child care, even if there are feelings that go beyond these issues and afflict the families:

(...) When he was born, I didn't know it, but when I saw him, I said: My God, he's only a child, a baby (...) (Participant 05).

(...) I am a special mother, I was chosen to take care of her (...) and this wonderful team makes me continue (...) (Participant 08).

(...) He means everything to me (...) he's the joy of our home, of the family and brothers (...) Everyone takes care of him (...) and I will believe in his potentialities (...) One day at a time (...) (Participant 10).

Parents of children with disabilities become the spokespeople for their children. The children's incapacity and the complexity of the condition make the parents indispensable in understanding and conceiving the needs and desires of their children^(16,27,44).

The families, faced with their living conditions, re-evaluate their initial concepts regarding the disabilities, learn to cherish the child's potentialities, and demand a continuous reinforcement of their personal esteem in support of their learning process on how to deal with their limitations. Authors describe the experience of having a disabled child as a delicate moment for the families, in which parents usually seek strategies to better deal with the situation and, for this, professional support is of the utmost importance. Therefore, the health teams involved should be prepared to provide the necessary support^(40,47).

Understanding how to be responsible for a child with developmental disorders is a complex situation of intense changes, discoveries, and learning. Addressing the life history of families in this condition, that is, their feelings, fears, anxieties, and desires in such circumstance is certainly a great opportunity for institutions and health professionals to invest in education, self-management and health care actions, with interventions focused on parental needs. The scarcity of specific measures that adequately identify the needs of parents of children in this condition is notorious⁽⁴⁸⁾. Thus, health professionals providing care to families can and should strengthen the parental resources by supporting their involvement in decision-making regarding their child and family life, thus contributing significantly to the well-being of all concerned⁽³⁸⁾.

Based on the findings of the current study, it is corroborated that health professionals can and should subsidize parental training in a permanent and continuous way, reinforcing the empowerment of parents and family members of children with ZIKV-induced microcephaly with use of a continuous approach through home visits and involvement of the parents at each stage of childcare⁽⁴¹⁾.

With this aim, health professionals should seek to understand the specificity of the family context, especially in the home environment, and to construct a care in which the service responses are to the level of the parental needs and the capacity to fulfill them, so that these families can provide viable and appropriate continuity to health care and can exert a greater influence on the services provided to their children. As limitations of the present study, it can be mentioned that, in relation to the sample, there was a greater participation of mothers than of parents and other relatives.

CONCLUSION

Although the support of the institutions to the families facing the alterations in the development of infants with microcephaly and their possible comorbidities reveals itself as unconditional and seems comprehensive, the results of the present study has evidenced that it is not. There is an absence and urgent need in the development and implementation of research strategies and health actions by the institutions and professionals involved in this context. The strategies and actions should encourage the active and humanized listening of the families, so as to prioritize their actual needs for support to child care, especially through parental health education interventions and home visits on a permanent basis with guaranteed follow-up, with the primary purpose of improving care, reducing the negative impact on the families caused by the children's condition, and enabling a greater and better development of infants and children with Zika-induced microcephaly, focusing on the certainty that such condition is of high relevance to community health.

ACKNOWLEDGEMENTS

To the parents, family and health professionals, and to the Center for Treatment and Early Stimulation (NUTEP-CE).

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