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RESEARCH

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FOLLOW-UP OF CHILDREN WITH ZIKA-ASSOCIATED MICROCEPHALY IN PRIMARY HEALTH CARE: THE MATERNAL LOOK

Seguimento de crianças com microcefalia associada ao zika na atenção primária à saúde: o olhar materno

Seguimiento de niños con microcefalia asociada al zika en atención primaria de salud: mirada materna

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ABSTRACT

Objective: To analyse the follow-up of children with microcephaly in Primary Health Care, according to mothers report. **Method:** Qualitative research, conducted with nine mothers of children with microcephaly from a large city of Paraíba, through semi-structured interview. Data interpretation followed the principles of thematic analysis. **Results:** Mothers reported receiving poor care because of the lack of an articulated health care network; do not value the monitoring of Primary Health Care for children with microcephaly, choosing to consult their children with specialists, compromising the provision of continuous and comprehensive care for the promotion of child health. **Conclusion:** It is essential to strengthen the Health Care Network, with the construction of a bond, having Primary Health Care as coordinator and orderer of care for children with microcephaly.

DESCRIPTORS: Microcephaly; Child; Mothers; Primary health care.

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RESUMO

Objetivo: Analisar o seguimento de crianças com microcefalia na Atenção Primária à Saúde, segundo relato de mães. **Método:** Pesquisa qualitativa, realizada com nove mães de crianças com microcefalia de um município de grande porte da Paraíba, por meio de entrevista semiestruturada. A interpretação dos dados seguiu os princípios da análise temática. **Resultados:** As mães relataram receber assistência pouco resolutiva devido à inexistência de uma rede articulada de cuidado em saúde; não valorizam o acompanhamento da Atenção Primária à Saúde para as crianças com microcefalia, preferindo consultar seus filhos com especialistas, comprometendo a oferta da atenção contínua e integral para a promoção da saúde infantil. **Conclusão:** É indispensável o fortalecimento da Rede de Atenção à Saúde, com construção de vínculo, tendo a Atenção Primária à Saúde como coordenadora e ordenadora do cuidado à criança com microcefalia.

DESCRITORES: Microcefalia; Criança; Mães; Atenção primária à saúde.

RESUMEN

Objetivo: Comprender el seguimiento de los niños con microcefalia en atención primaria de salud, según el informe de las madres. **Método:** Investigación cualitativa, realizada con nueve madres de niños con microcefalia de una gran ciudad de Paraíba, por medio de una entrevista semiestructurada. La interpretación de los datos siguió los principios del análisis temático. **Resultados:** Las madres informaron que recibieron poca atención debido a la falta de una red articulada de atención médica; No valoramos el monitoreo de la Atención Primaria de Salud para niños con microcefalia, prefiriendo consultar a sus hijos con especialistas, comprometiendo la provisión de atención continua e integral para la promoción de la salud infantil. **Conclusión:** Es esencial fortalecer la Red de Atención Médica, con la construcción de un vínculo, teniendo la Atención Primaria de Salud como coordinador y encargado de la atención de niños con microcefalia.

DESCRIPTORES: Microcefalia; Niño; Madres; Atención primaria de salud.

INTRODUCTION

Child Health has progressed in recent decades, however, this progress has not been enough to guarantee Brazilian children full access to health.[1] Seeking to ensure the reception, access and resoluteness of health actions, in 2011, the Federal Government established the Stork Network, which, among its objectives, addresses the organization of the Network of Maternal and Child Health Care.[2]

Health Care Networks (HCN) are organizational arrangements for integrated health actions and services through technical, logistical and management support systems that seek to ensure the integrality of care.[3] The HCN are able to intervene effectively in the fragmentation of health care systems, seeking to restore the health situation with predominance of chronic conditions.[4]

It is noted that according to the Brazilian Institute of Geography and Statistics (IBGE), chronic non-communicable conditions constitute a relevant health problem and account for more than 70% of the causes of deaths in Brazil.[5]

In 2015, microcephaly, a chronic health condition, suddenly affected a significant number of newborns in Brazil. Faced with this fact, in order to investigate the causes of the outbreak, researchers reached a scientific consensus that indicated a causal relationship between ZIKV infection in the gestational period and microcephaly.[6]

Microcephaly is a clinical sign in which the child has a substantially smaller head measurement compared to other children of the same sex and age.[7] It is usually associated with alterations such as intellectual deficit, epilepsy, cerebral palsy, delay in language development and/or motor, strabismus, ophthalmological disorders, cardiac, renal, urinary tract disorders, among others.[8]

Until the year 2018, 3,332 cases of newborns with microcephaly and/or changes in the central nervous system related to Zika virus[9] infection were registered, most of them being in the Northeast region, mainly in the states of Pernambuco, Bahia and Paraíba, totaling 89.8% of the cases.[10]

In this perspective, the arrival of a newborn baby at home with microcephaly impacts the family, triggering feelings of distress, fear and unpreparedness in the care of this baby.[10] Due to the complexity of the follow-up of these children, it is essential to support a multi-professional team at all levels of attention.[6] However, in order to ensure the continuity of care, Primary Health Care (PHC) should be the coordinator, ordinator and articulator of health care services.[11]

Therefore, it is necessary to extend the understanding of the strategies and technologies used in the PHC to provide assistance to this population. Thus, this research was based on the following guiding question: How is the follow-up of children with microcephaly in PHC based on the maternal gaze? In view of the above, the present study aimed to analyse the follow-up of children with microcephaly in PHC, according to mothers' reports.

METHOD

Qualitative, exploratory-descriptive study with theoretical support in the concepts of Primary Health Care. Carried out in a reference institution for the care of children with microcephaly located in a municipality of Paraíba. This institution provides multidisciplinary care to approximately 44 children with microcephaly.

The participants were nine mothers of children with microcephaly, who met the following inclusion criteria: being a mother of a child with microcephaly due to the Zika virus, living in the city under study, and being registered at the family health unit assigned to the residence.

The data collection took place from April to June 2017, from a semi-structured roadmap interview containing the question: "Since you received the diagnosis of microcephaly from your child, how is assistance in the Family Health Unit?" The interviews were conducted in a reserved room of the aforementioned institution with privacy, silence and free from outside interference.

The choice of participants was made for convenience while waiting for consultations in the reference institution. The interviews were recorded in digital media with the consent of the participants through the signature of the Free and Informed Consent Term (TCLE), with an average duration of 20 minutes and were transcribed in full to carry out the analysis.

The empirical data were analyzed by means of the thematic analysis technique, which consists of discovering the meaning cores that make up a communication, whose presence has meaning for the targeted analytical object. In this way, three steps were followed: pre-analysis; exploitation of the material; and processing, inference and interpretation of the data. The first stage was the organization of the ideas themselves, in a systematic way, by floating and vertical reading of the empirical material.[12] In the second stage, the empirical material was explored in order to identify the registration units and the theme in relief, with a view to the recurrence of the data from the mothers' report as a whole, in a classification movement.

In the starting of the seizure, and the compilation of the information obtained in the third step, it was possible to build in two categories: "Follow-up of the child with microcephaly: from pre-birth to first week of life," and "(Dis)continuity in the care of the child with microcephaly in Primary Health care".

The lines of the participants in the study were identified by the letter "M", referring to mother, followed by the ordinal numeral of the sequence of the interviews. The criteria for closing the data collection was saturation, that is, when the content seized by the empirical material was sufficient to meet the proposed objective.[12]

It should be noted that the development of the research has met the ethical recommendations set out in Resolution No. 466/2012 of the National Health Council, effective in Brazil, mainly with regard to the guarantee of its anonymity and secrecy. This study is linked to the project entitled "Monitoring the development of children with microcephaly in Primary Health Care", approved by the Ethics Committee in Research (CEP) in June 2017, under Protocol No. 2.118.590.

RESULTS AND DISCUSSION

Table 1 shows the characterization of the nine participants in the study, followed by the presentation of the thematic categories constructed.

Table 1 - Characterization of mothers with regard to the age, conjugality, schooling, occupation and age of the child - João Pessoa, PB, Brazil, 2017

Participant	Age	Conjugality	Schooling	Occupation	Age of the child
M1	27 years old	Single	Incomplete High School	Home maker	1 year and 2 months
M2	20 years old	Single	Incomplete High School	Home maker	1 year and 5 months
M3	28 years old	Single	Complete High School	Home maker	1 year and 3 months
M4	31 years old	Married	Incomplete Higher Education	Home maker	1 year and 6 months
M5	19 years old	Married	Complete High School	Home maker	1 year and 7 months
M6	26 years old	Married	Incomplete Primary Education	Home maker	1 year and 9 months
M7	40 years old	Widow	Complete Higher Education	Home maker	1 year and 8 months
M8	27 years old	Single	Incomplete Primary Education	Home maker	1 year and 7 months
M9	37 years old	Single	Incomplete Primary Education	Home maker	1 year and 9 months

Follow-up of the child with microcephaly: from prenatal to first week of life

Changes resulting from infection with the Zika virus during pregnancy are seen as a biological risk to the child's health. Therefore, it is indispensable that the intervention of the Family Health Strategy (FHS) be effective, providing means for a quiet and safe pregnancy for the mother-son binomial, bearing in mind that PHC is the preferred gateway and the communication center of the HCN.[13]

In this perspective, the Ministry of Health (MS) recommends that pregnant women infected by the Zika virus and children with microcephaly be accompanied at the FHS, and may request the support of the multidisciplinary team of the Family Health Support Nucleus (FHSN) to implement health actions during prenatal care, home visits and childcare.[10]

Despite MS guidelines for prenatal treatment to be carried out preferably in PHC, in order to promote the healthy development of gestation, leading to a birth without complications and without impact on maternal and child health,[14] most mothers reported prenatal treatment in reference hospitals, after the finding of microcephaly in the fetus.

> *[...] I took the result to the doctor and she referred me to the maternity ward. I finished the rest of my prenatal at the maternity ward with the doctor there. I went to follow up there because it was a risky pregnancy.* (M3)

> *[...] I looked for an obstetrician from the University Hospital and finished my prenatal there. I didn't continue my prenatal*

on the basic health unit, I stayed at the University Hospital because the people at the BHU thought it was better. (M5)

From the diagnosis of microcephaly, the FHS team sent the pregnant woman to do prenatal work on HCN reference services. However, according to the *Protocol for health care and response to the occurrence of microcephaly related to Zika virus infection*,[10] if there is isolated microcephaly diagnosis, gestation is not considered to be of high risk, therefore the prenatal monitoring routine performed in FHS should not be altered.

On the other hand, MS itself suggests in *Basic Attention Notebook No. 32: Attention to the Low-Risk Prenatal*, that pregnancy with fetal malformation be characterized as risky. This dubious information of MS can lead health professionals to have different behaviors,[14] there is the need to establish a protocol in the specific cases of microcephaly by Zika virus, due to its endemicity in Brazil.

Still with regard to the behaviors of the professionals in the basic attention, it is essential the creation of bond, reliability and professional support, mainly in the face of the diagnosis of microcephaly, which makes the Family Health Unit a privileged scenario due to the relationships that are established in this model of health care.

[...] I did all the prenatal at the FHU, so much so that when my son was born even the nurse cried along with me. (M2)

In this direction, a study developed with 323 family health teams from Rio de Janeiro and 1,313 users pointed to the gradual consolidation of PHC as the preferred gateway for HCN, in that users identified resoluteness for their health problems and found units equipped with basic inputs for the procedures.[15]

The availability of professionals to listen and establish an efficient communication with the woman and/or family and foster the relationship of trust are essential factors for the consolidation of the PHC.[16] In this sense, a mother reported that she preferred to do prenatal work in the private service because of the existing link with the health care professional.

*[...] A nurse's prenatal is much better done than a doctor's, but I wasn't going [*to FHS] *because it was easier for me to go to my doctor, because I already had follow-up.* (M4)

It is emphasized the importance of the link between users and health professionals and the need for FHS professionals to adopt the qualified listening and help the mother in whatever she needs. From the strengthening of the bond, the mothers will feel welcomed in this service and will have confidence in the health professional.

The link between the pregnant woman and the FHS team favors the promotion of health and follow-up throughout pregnancy until the birth of the baby, with continuity of this in the home visit after the child's birth.[17]

This time of home visit should take place, according to the Ministry of Health, until the fifth day of life of the newborn, called "The Fifth Day of Integral Health", in which the essential health actions for the baby and its mother should be carried out in the first contact after the discharge of maternity.[18]

Considering the vulnerability of the child in the first five days of life, a prominent tool in the FHS is the lasting link between users and health professionals,[19] that is, the longitudinal nature of care. In the maternal reports we observe the recognition of this link:

[...] As soon as I arrived from maternity, the nurse and the doctor came. They took a picture of his exams, wrote down everything in the chart, asked if I needed anything, if I was feeling well, how we were doing. (M1)

[...] I received a visit, they went there to make data, took a picture of her. And I always get a visit from the health worker, she always comes to my house. She asks for things, medicine, if everything's all right. (M4)

With regard to longitudinal studies, one mother mentioned the following interventions:

[...] The nurse examined me, listened to my belly, measured my PC, weighed, listened to my heart, measured size, everything, examined him. She asked if I was already referred to the Specialized Reference Center, what procedures they had done with me. (M2)

The referral of the child with microcephaly to the early stimulation program should happen as soon as this condition is diagnosed, because the time when the treatment starts interferes with the evolution of the development of the same. Thus, it is essential that FHS coordinate and operationalize the different health services run by the mother-child binomial[19] since prenatal.

(Des)continued care of children with microcephaly in Primary Health Care

It is recommended that, in the neonatal period from the first consultation to child care, which is based on the monitoring of the child's growth and development, and the promotion of breastfeeding and healthy eating, immunization, and guidance on the prevention of accidents and care for prevalent diseases in childhood.[20] Therefore, the childcare of babies with microcephaly must take place according to the guidance of *Basic Attention Booklet No. 33: Child Health – Growth and Development* and not only by the specialized service.[10]

Despite this guideline, the results of this study demonstrate weaknesses in the follow-up of children with microcephaly in the PHC regarding the realization of childcare.

[...] I started to do childcare, but then I didn't go anymore, because every two months I go to the neurologist and she already weighs and measures, it's already "a lot". (M1)

The mother's lines contradict the MS, when they explain the absence of follow-up of their children at the FHS, suggesting

not to value the childcare carried out at this level of health care and often only seek this service for the application of vaccines in the child. In addition, they point as an obstacle the fact of having to take the child to various places of care for the effectivation of early stimulation, attributing to this the abandonment of the child childcare consultation in the PHC.

In addition, FHS professionals have not incorporated new technological arrangements in their work processes to meet this demand. Thus, the family has only sought the FHS services for referrals to specialists and renewal of prescriptions for controlled medicines.

> *[...] I only go to the unit sometimes when I'm going to get a prescription for a medicine and that's it, but I'm not at the clinic every month. Because the care there is not suitable for her, there she has no pediatrician, she has no neurologist, she has nothing. When she gets sick I take her to her pediatrician.* (M6)

> *[...] I only need the unit for the medical referrals, because if I don't have his stamp, no hospital will receive me. They* [FHS professionals] *don't have much to do for him there. The unit simply gave up my son, and at the same time that they* [FHS professionals] *gave up on him* [child]*, the University Hospital embraced him.* (M7)

The lack of welcoming and resoluteness of the PHC for the demands of children with microcephaly has weakened bonds and is even hindering the follow-up of these children in the FHS, triggering a process of devaluation of childcare, both by professionals and mothers.

This may be happening due to the health system in Brazil, not yet properly organized to bring answers to the health needs of the children's population in chronic condition, as well as for the fragility of the HCN. There is fragmentation of attention with punctual care, without communication between the services and professionals of PHC and of secondary attention. This organization is still focused on meeting the acute conditions, focusing on the disease. Thus, there is no room for the construction of a permanent partnership between family and health team, which is essential for Integral monitoring.[21]

This aspect is noted in data published in epidemiological bulletin No. 8/2019, which reveals that only 60.7% of children with microcephaly received childcare services in PHC and that the others were also not accompanied by specialized attention, since only 63.8% were routinely accompanied by experts.[9]

Therefore, the actions of care to these children should be shared in a process of co-responsibility among the different professionals and levels of attention, consequently, consultations with experts are relevant and should complement the actions of the PHC for the continuity of care, and not waiving their responsibilities. For the effective functioning of the HCN, it is crucial to establish partnerships, and the establishment of a network of care with information and referral, and counter-reference, since without the assistance shared between the FHS and the specialist, the longitudinality of care is weakened. [21]

In relation to the actions carried out in the consultation of childcare, the mothers explain dissatisfaction with the care of the nurse.

> *[...] The time went by and he didn't evolve, he kept standing, dying, I asked the nurse what was going on and she always told me that it was normal, that he was a lazy baby and in time he would get better and respond like a normal child, only that never happened. She weighed, measured his stature and tried to get his attention to see if he responded, saw his stimuli.* (M7)

This report highlights the professional's lack of preparation for identifying children with developmental problems, because, despite carrying out the childcare consultation, the nurse did not pay attention to possible changes in neuropsychomotor development and, therefore, to early behaviors. Therefore, it is essential to measure the PC of all children and perform the complete physical examination, the proper evaluation of development milestones for each age group, according to the foundations of child development surveillance.[10]

The surveillance of the child's development is an essential activity to be carried out by health professionals at all levels of attention, because it has the objective of detecting early alterations, with the possibility of stimulation of the child in timely manner to reverse possible permanent damage to its neuropsychomotor development. In order to do this, it is necessary that professionals have knowledge that equips them with qualified care. It is worth pointing out that for this evaluation, the opinion of the mothers/caregivers about their children should be valued, since they are the ones who live with the child and who know them the most. [22]

FINAL CONSIDERATIONS

The results show that mothers face many obstacles regarding the follow-up of children with microcephaly in PHC and receive little resolute assistance due to the lack of an articulated care network for that population. In describing their trajectories at FHS, some participants of the study explained that they are referred to the reference service in pregnancy, and it was possible to notice that there is dubious information from MS's manuals.

For this reason, it is suggested to update the *Primary Care Notebook nº32: Attention to Low Risk Prenatal Care* with the addition of the conducts to be performed in the face of the pregnancy of a child with microcephaly, given that some information contained in this document calls into question the conduct of professionals working in the FHS, as they are contradictory to the *Protocol of health care and response to the occurrence of microcephaly related to infection by the Zika virus.*

Moreover, because it portrays only a local reality, the study presents limitations, since the results cannot be generalized. Opposite to the perception of the loss of the mothers of children with microcephaly on the services of the PHC, there

is a need for studies that seek for the reasons why the health workers do not attend effectively to these children, given the relevance of this level of assistance for the integrality of child care.

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