



PATERNITY AND MICROCEPHALY BY ZIKA VIRUS: FEELINGS AND PERCEPTIONS

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PATERNIDAD Y MICROCEFALIA POR ZIKA VIRUS: SENTIMIENTOS Y PERCEPCIONES

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ABSTRACT

Objective: to describe the feelings and perceptions of parents of children with microcephaly by Zika virus.

Method: this is a qualitative, descriptive study performed with parents of microcephalic children. The data were obtained through a semi-structured interview, analyzing them through the technique of the Discourse of the Collective Subject. **Results:** four discourses of the collective subject emerged through the analysis of the data, namely: Feelings before the diagnosis of microcephaly; A coping strategy for congenital malformation of the child; Knowledge regarding the limitations of the child; Understanding about psychosocial monitoring.

Conclusion: it was concluded from the discourses that the feelings, given the diagnosis of a child's microcephaly, provoke an intense state of disorientation, fragility and concern regarding the overload of care that parents will have with their children. It was observed that religiosity was the main coping strategy adopted by the parents and, in relation to the knowledge about the limitations of the children, the discourse revealed that the parents had some information about the deficiency and limitations of microcephaly. The importance of emotional support was understood through the discourse about psychosocial accompaniment.

Descriptors: Paternity; Microcephaly; Zika Virus; Aedes Aegypti; Arbovirus Infections; Feelings.

RESUMO

Objetivo: descrever sentimentos e percepções de pais de crianças com microcefalia por Zika vírus. **Método:** trata-se de estudo qualitativo, descritivo realizado com pais de filhos microcefálicos. Obtiveram-se os dados por meio de entrevista semiestruturada, analisando-os por meio da técnica do Discurso do Sujeito Coletivo.

Resultados: emergiram-se, por meio da análise dos dados, quatro discursos do sujeito coletivo, a saber: Sentimentos frente ao diagnóstico de microcefalia; Estratégia de enfrentamento frente à malformação congênita do filho; Conhecimento frente às limitações do filho; Entendimento acerca do acompanhamento psicossocial. **Conclusão:** concluiu-se, com base nos discursos, que os sentimentos, frente ao diagnóstico de microcefalia de um filho, provocam um intenso estado de desorientação, fragilidade e preocupação referente à sobrecarga de cuidados que os pais terão com os filhos. Observou-se que a religiosidade era a principal estratégia de enfrentamento adotada pelos pais, e, com relação ao conhecimento frente às limitações dos filhos, o discurso revelou que os pais possuíam alguma informação sobre a deficiência e as limitações advindas da microcefalia. Percebeu-se, quanto ao entendimento acerca do acompanhamento psicossocial, por meio do discurso, a importância do suporte emocional. **Descritores:** Paternidade; Microcefalia; Zika Vírus; *Aedes Aegypti*; Infecções por Arbovírus; Sentimentos.

RESUMEN

Objetivo: describir sentimientos y percepciones de padres de niños con microcefalia por Zika virus. **Método:** se trata de un estudio cualitativo, descriptivo realizado con padres de hijos microcefálicos. Se obtuvieron los datos por medio de entrevista semiestructurada, analizándolos por medio de la técnica del Discurso del Sujeto Colectivo. **Resultados:** surgieron, por medio del análisis de los datos, cuatro discursos del sujeto colectivo, a saber: Sentimientos frente al diagnóstico de microcefalia; Estrategia de enfrentamiento frente a la malformación congénita del hijo; Conocimiento frente a las limitaciones del hijo; Entendimiento sobre el acompañamiento psicossocial. **Conclusión:** se concluyó, con base en los discursos, que los sentimientos, frente al diagnóstico de microcefalia de un hijo, provocan un intenso estado de desorientación, fragilidad y preocupación referente a la sobrecarga de cuidados que los padres tendrán con los hijos. Se observó que la religiosidad era la principal estrategia de enfrentamiento adoptada por los padres, y, con relación al conocimiento frente a las limitaciones de los hijos, el discurso reveló que los padres poseían alguna información sobre la deficiencia y las limitaciones provenientes de la microcefalia. Se percibió, en cuanto al entendimiento acerca del acompañamiento psicossocial, por medio del discurso, la importancia del soporte emocional. **Descritores:** Paternidad; Microcefalia; Virus Zika; Aedes, Infecciones por Arbovirus; Emociones.

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INTRODUCTION

Changes in the roles of mother and father are now being noticed, and the traditional family model has been replaced by new family arrangements. It is noticed that, in the contemporary society, one does not find a unique familiar standard in relation to the development of the education of the children.¹⁻²

With the significant changes taking place in society, the new father of the twenty-first century has a unique perception of his role, having a broader view of his responsibilities, allowing himself, for example, to lead a home, with regard to care and education of children and domestic chores.³

It is believed that, in this sense, it is not the pretension of the father of today to imitate old patterns, nor want to occupy the maternal place, but, yes, to be able to establish a greater affective involvement with his children, since society demands it.⁴

It is emphasized that the birth of a child is an odd moment, generates several expectations and idealizations and, in the case of a diagnosis of congenital malformation, among them, microcephaly, what was imagined and desired for the child becomes different of the real. It is known that the impact generated by the news, something that differs from the idealized one, produces in the parents doubts, fears and yearnings, causing preoccupations in thinking about what the future implications of this event will be and thus making it difficult to accept and train bond with the new baby.⁵

In 2015, Brazil had a high incidence of cases of children born with microcephaly, initially in the Northeastern States, a rapid spread of the virus to other regions of the country, followed by Brazil. significant increase in the notifications of newborns with microcephaly in the Vivo Birth Information System. The event was declared by the Ministry of Health, facing this new scenario, as an emergency in public health of national interest, revealing a recent and unexpected health demand.⁶⁻⁸

A period of intense research was initiated for a better understanding of the etiological factors of microcephaly and, thus, the relationship between maternal infection by the Zika virus in the gestational period and this malformation.⁶⁻⁸

Zika virus infection is transmitted by the same vector of the dengue virus, *Aedes aegypti*, and among the complications caused by Zika virus infection, microcephaly is a

condition in which a child has a head measurement compared to other children of the same sex and age. Microcephaly can only be one of the signs of the Zika virus in pregnancy, and other neurological complications exist that together constitute the Zika virus Congenital Syndrome (ZCS).⁹

It is added that, in this sense, with the diagnosis of microcephaly, the reality of the family is permeated by uncertain feelings, which will only be defined, more accurately, by facing each other in relation to the deficiencies that will be presented by the child. It is understood that these feelings experienced by the parents constitute a kind of conflict, as they were faced with an unexpected occurrence where they lost the idealization of the dreamed son.

The interest in this topic arose because it is a topic that has been under-explored, due to the increase in microcephalic cases and the impact they are currently causing, as well as a theme that needs to be better understood by health professionals, for the improving care for children and families.

Their realization is justified in view of the fact that, in principle, the parents present resistance and difficulties to accept such a diagnosis, leading parents to have conflicting thoughts and attitudes that do not correspond to the real situation, causing emotional disruption.

OBJECTIVE

- To describe the feelings and perceptions of parents of children with microcephaly by Zika virus.

METHOD

This is a qualitative, descriptive study carried out with parents of children with microcephaly by Zika virus, attended at a specialized support center, in a medium-sized city in the interior of Bahia. The study is part of a larger research project entitled: Social repercussions and strategies for coping with diseases related to the mosquito *Aedes aegypti*.

The following inclusion criteria were considered: parents with children with microcephaly associated with Zika virus infection, the children were registered in the specialized service and their parents accepted to participate in the research.

The collection was done through a semi-structured interview, using a script with sociodemographic and objective questions about the theme. The data were obtained between September and October 2017. Four

parents of the six children enrolled in the specialized care center were interviewed, two of whom refused to participate in the study. There was great difficulty in conducting the interviews according to the workday of the parents.

Data was analyzed through the use of the Collective Subject Discourse CSD technique, which is a method that allows expressing the thought of a collectivity, as if this collective was the emitter of a single speech, which represents the speech of the whole, which allows an analysis of the situation experienced by the interviewees, expressing a collective reality.¹⁰

The research was submitted to the Brazil Platform, with the number of CAAE: 67672217.0.0000.5032, approving it under the number of opinion of 2,082,039. It is reported that participation in the study was voluntary and effected by signing the FICT and, in addition, participants were informed about their rights, according to Resolution 466/2012 of the National Health Council.¹¹

RESULTS

The profile of the respondents who represented the survey sample is described as being between 35 and 47 years of age; with regard to schooling, they have between 8th grade and 2th grade; in the marital situation, everyone had a stable relationship; of these, two have another child besides the child with congenital malformation and two have only one child, all have their own residence and the monthly family income is one to three minimum wages.

Through the collected data, the construction of four collective discourses was allowed, namely: Feelings before the diagnosis of microcephaly; A coping strategy for congenital malformation of the child; Knowledge regarding the limitations of the child and Understanding about psychosocial accompaniment.

The following are the central ideas extracted from the participants' answers and the speeches that represent them.

Collective Subject Discourse 01 - Feelings before the diagnosis of microcephaly

It was a bit complicated, we feel very fragile, bewildered, you will not have a normal child, need a lot more care, no floor, the floor opened and wanted to fall inside. (Subject 01)

The father is seen, in this sense, in the face of the impact of the congenital malformation that can bring irreversible consequences to the babies, threatened by the uncertainty, attributing it to the new

condition in which his son finds himself, placing him in a situation of concern, insecurity , uncertainty and impotence, causing parents to postpone their plans and dreams, as they will have to take more time to meet the needs of their child.

Collective Subject Discourse 02 - Strategy of coping with the son's congenital malformation

We become very attached to God; for God, nothing is impossible, we believe in the God of the impossible, prayers, I cling to God asking for wisdom so that I can take care of it, ask God for strength. (Subject 02)

It was demonstrated in the collective discourse that religiosity was the main coping strategy adopted by the parents. The relevance of this dimension in the coping of crises and transitions of life is perceived, since it influences the way of thinking of the individual, this is reflected in the attitudes and the care.

Collective Subject Discourse 03 - Knowledge regarding the limitations of the child

We understand what can happen, but we also believe that he will walk, talk and that he will be a normal child, despite having the problem of microcephaly; I am learning to take care of her the way she is, she will improve more and more with faith in Jesus Christ, because God is a father. (Subject 03)

It is known that coping with a congenital malformation without possibility of cure has a great impact on the life of the patient and his / her family. It is noticed, through the collective discourse, that the parents understand the possible limitations due to microcephaly.

Collective Subject Discourse 04 - Understanding about psychosocial accompaniment

At first, we needed to, yes, because it was a very big thump, until we understood that it was complicated; I think it's very important, it's good because it helps even more, it's good to talk to someone, it opens up the mind. (Subject 04)

It was verified, from the collective discourse, the importance of the psychological support in the support to the parents in this new adaptation of the life.

DISCUSSION

It was evidenced that the feelings about the diagnosis of a child's microcephaly provoke an avalanche of reactions and feelings, among them: disorientation, fragility and concern regarding the overload of care

they will have with the children. Corroborating the findings of other surveys.¹²⁻³

It is pointed out that parents of microcephalic children, the moment they receive the diagnosis that the baby will be born with microcephaly to the family, go through moments of anguish and uncertainties. It is mentioned by one author that it is not possible to ignore the emotional impact that falls on the parents and the family with the discovery of the malformation of the expected child.¹⁴

It is evidenced that religiosity has acted as a coadjuvant in the process of coping with the consequent afflictions of the pathology, allowing emotional comfort to the individuals involved and providing more balance to deal with adverse situations, similar to the result of other studies.¹⁵⁻⁶

It is revealed that regardless of the religion that parents profess the faith in a supreme God makes them better able to deal with the adversities that the disease may cause. Through this faith in a superior being, they bring beneficial influences in the process of adaptation to the new situation lived.¹⁶⁻⁸ In this sense, the strategy of the religiosity adopted in the confrontation of a stressor condition, such as congenital malformation, for example, making them more hopeful in moments of distress.¹⁶

It is noticed that parents understand that their children may have limitations as a result of microcephaly, but, despite knowing the possible limitations, they still cultivate a faith that their children will be able to grow in normal patterns, and this result will to another study.¹³ In this perspective, each child develops different complications, including respiratory, neurological and motor, depending on the functions that are compromised, with varying severity of the cases and different symptomatology.²⁰

It is pointed out that the parents' understanding and acceptance of the new child will be more welcomed, the less the professionals responsible for transmitting the diagnosis will focus on the difficulties, but will stick to their potential.⁵ It is emphasized as necessary that the parents receive the diagnosis of a professional in a comprehensible way, with words of comfort, explanation in the simplest way, without using difficult terminologies, in a way that facilitates their understanding, that is, use appropriate tools to transmit, this diagnosis.

It was verified that the psychological assistance is of fundamental importance for the parents in this new phase of life, and a

study developed in the city of Rio de Janeiro corroborates the findings of this work.¹²

It complements that: "Psychology has the function of helping to redimension the trauma of the loss of the ideal child and to allow oneself to be happy from other possibilities, even if these are contrary to what is placed as a model to be followed by society"^{16:10}; thus, the support and posture of the psychologist before the family contributed to a more positive and realistic view of disability.²¹

It is mentioned that men are susceptible to suffering as much as women, in view of the diagnosis of congenital malformation of a child, therefore, the health team should also focus the attention and care to the father, giving him an integral attention, since, so the acceptance process will be better optimized.¹²

CONCLUSION

It is concluded that the feelings, in front of the diagnosis of microcephaly of a child, provoke an intense state of disorientation, fragility and concern regarding the overload of care that they will have with the children. It was observed that religiosity was the main coping strategy adopted by parents.

The discourse that the parents had some information about the deficiency and the limitations of microcephaly was revealed with regard to the knowledge regarding the limitations of the children, and it was noticed, with regard to the understanding about the psychosocial accompaniment, through discourse, the importance of emotional support.

The understanding of the feelings and the parents' perception of children diagnosed with microcephaly for the health team is of great importance, being necessary that it is prepared and able to attend them. It is believed that a structured support network and the multiprofessional team that help not only the father, but the family, in general, for this new adaptation of life are considered relevant, since, with the diagnosis of microcephaly, the family will face difficulties with the arrival of this new child. It is also important to note that the care provided by the health team to the parents, considering their needs and particularities, with the creation of more resilient and adaptive coping strategies in order to support their demands, especially the psychic.

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Submission: 2018/06/18

Accepted: 2019/02/14

Publishing: 2019/04/01

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