ORIGINAL ARTICLE

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FATHERS' EXPERIENCE AFTER THE ZIKA VIRUS-RELATED MICROCEPHALY DIAGNOSIS

A EXPERIÊNCIA PARENTAL APÓS O DIAGNÓSTICO DA MICROCEFALIA POR ZIKA VÍRUS

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ABSTRACT

Objective: the objective of the present study was to identify the experiences and perceptions of fathers and male caregivers of children with sequelae of Congenital Zika Syndrome. **Methodology:** qualitative study, carried out in the municipality of Montes Claros with fathers who have children with some sequela from the Zika virus. Data collection was carried out in the first half of 2020, in the periods between the months of February and March and the interviews followed the script of guiding questions and were recorded by an electronic recorder. **Results:** at first, upon receiving the news of the diagnosis, fathers experience feelings of sadness and anguish; however they seek to understand better the child's condition and seek to prioritize his/her quality of life. **Conclusion:** despite all the difficulties found in the routine of families with members with microcephaly, fathers always look for therapies that help improve their children to provide the best care for them.

Keywords: Congenital Abnormalities; Microcephaly; Zika Virus; Fathers.

RESUMO

Objetivo: o objetivo do presente estudo foi identificar as experiências e percepções dos pais e cuidadores do sexo masculino de crianças com sequelas da Síndrome Congênita do Zika. **Metodologia:** estudo qualitativo, realizado no município de Montes Claros com pais do sexo masculino, que tem filhos com alguma sequela do zika vírus. A coleta de dados foi realizada no primeiro semestre de 2020, nos períodos entre os meses de fevereiro e março e as entrevistas seguiram o roteiro de questões norteadoras e foram gravadas por um gravador eletrônico. **Resultados:** no primeiro momento, ao receber a noticia do diagnóstico, os pais passam por sentimentos de tristeza e angústia, entretanto buscam entender melhor a condição do filho e buscam priorizar a qualidade de vida deles. **Conclusão:** portanto, mesmo com todas as dificuldades encontradas na rotina de famílias com membros com microcefalia, os pais sempre procuram terapêuticas que auxiliem na melhora dos filhos para proporcionar o melhor cuidado para os mesmos.

Palavras-chave: Anormalidades Congênitas**;** Microcefalia; Vírus Zika; Pai.

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INTRODUCTION

Congenital Microcephaly, also known as primary microcephaly due to its presence in the uterus or at birth, is a descriptive term for a structural defect in which the head (skull) circumference of a fetus or child is smaller than expected when compared to other fetuses or babies of the same gestational age, sex, and ethnic origin. Congenital microcephaly can be diagnosed in the postnatal or prenatal period and is usually defined by the measurement of the occipital-frontal circumference (head circumference) above 2 standard deviations (SDs) below the mean for age and sex or below the 3rd percentile for age and sex. Thus, severe microcephaly is defined as head circumference over 3 SDs below average for age and sex. (1)

The prevalence of microcephaly in the 15 states of Brazil, with transmission confirmed in laboratory by the Zika virus, was 2.8 cases per 10,000 live births, significantly higher than in the four Brazilian states without Zika virus transmission (prevalence of 0.6 cases per 10,000 live births). Another review from northeastern Brazil, using three different criteria, showed markedly variable rates. (2)

The causes of congenital microcephaly are extensive, highly variable and heterogeneous, and include known and undetermined etiologies. Any condition that affects the brain growth process can result in microcephaly. Several factors corroborate genetic disorders, including metabolic disorders, perinatal brain injury due to maternal diseases or teratogen exposure, including exposure to drugs in the uterus or toxins and infectious agents such as toxoplasmosis, rubella, cytomegalovirus, Herpes simplex, syphilis, parvovirus B19 and chickenpox (TORCH infections - Toxoplasmosis, Rubella, Cytomegalovirus, and Herpes simplex virus) during pregnancy. These exposures in the uterus, along with postnatal brain injury due to infections, infarction or trauma, represent the most common known causes of microcephaly. (3)

Families who have a child with CZS face an immediate set of demands for specialized care and a lifelong responsibility. The cumulative burden of other factors, such as economic impact, stigmatism, marital tension, spouse, and limited family support, uncertain future outcomes for children, and lack of access to appropriate information or health care will add more tension to parents or other caregivers trying to deal with a child with a significant disability. The long-term needs of families and the final social burden are not yet known, but the human impact is great and will last for a generation or more. Identifying and addressing the risk and protective factors associated with child development and family well-being are critical to understanding and maximizing family adaptation. (4)

Four CZS resources will certainly have special implications: medical complexity and severity of impact on children with obvious abnormalities at birth, along with anticipation of a lifelong care and economic burdens; uncertainty about the consequences of CZS for obviously affected children, as well as for children without symptoms at birth; limited professional knowledge about the course of the disease and treatment options; and social distancing. Finally, the impacts of these and other factors may include high stress, anxiety and depression, with potential for adverse effects on well-being and quality of life, factors that should be considered in providing comprehensive services for children and families. (5)

The aim of this study was to identify the experiences and perceptions of fathers and male caregivers of children with sequelae of Congenital Zika Syndrome. Thus, the following guiding question arises: how are the situations experienced by those responsible for children with sequelae of the Zika virus?

METHOD

The present study is qualitative with hermeneutic approach, was carried out in the municipality of Montes Claros, northern Minas Gerais. According to the 2010 census, this municipality has a population of 361,915 inhabitants, with an estimated population for 2017 of 402,027 people. The study population was composed of fathers and male caregivers of children who were diagnosed with some sequela related to the presence of Zika Virus. According to data from the Municipal Health Department, in the city of Montes Claros, in November 2018, there were approximately 14 children in this situation.

Data were collected in the first half of 2020, between February and March. The initial contact was made by telephone, following the nominal list made available by the Municipal Health Department (MHD), to present the research proposal and schedule the interviews. The interviews followed the script of guiding questions and, due to the occurrence of the COVID-19 pandemic, they could not be performed in person, being performed by WhatsApp and audio.

The interviews were conducted until reaching theoretical saturation. Soon after data collection and transcription, analysis and interpretation were performed using the content analysis technique, categorizing the information using themes from the relevant answers. The characterization data of the individuals were presented as text in the first category of results. There was a subsequent discussion, establishing comparisons between the data obtained and the literature researched, thus serving as a support for the formulation of conclusions about the research.

The research followed the ethical principles that govern the research involving human beings, and was approved with REC opinion n. 3.165.436. All research participants had access to the informed consent form, and their statements were only recorded after their permission and signature.

RESULTS AND DISCUSSION

Six fathers were interviewed. The data obtained show that the interviewees are between 23 and 42 years old, and most have high school education as their level of education. In three cases, children with functional limitations were only children and in the other three cases, the children had siblings. In relation to the interviewed fathers, none of them had another child with a disability and did not have follow-up with a psychologist (Table 1).

Of the interviewees, in one case, the father is not the biological father of the child with microcephaly (F1), but married to the child’s mother and has helped with care from the first months of the child’s life. In one case, the father is unemployed, has no fixed monthly family income and 80% of the interviewees have a fixed family income below 2,000 BRL.

Table 1 – Sociodemographic data of the interviewees collected in the city of Montes Claros-MG, Brazil, in 2020.

Interviewees	Age	N. of children	Schooling	Occupation
Father 1 (F1)	30	01	Post-graduation	Monitor
Father 2 (F2)	42	04	High School	Assistant Mason
Father 3 (F3)	29	02	High School	Own-Account Worker
Father 4 (F4)	24	01	High School	Assistant Producer
Father 5 (F5)	35	02	Higher Education	Supermarket Manager
Father 6 (F6)	23	01	High School	Driver

Source: The authors.

Feelings regarding the microcephaly diagnosis

In the course of the interviews, through the father’s perception, the family context of the child with microcephaly is completely revealed. At first, in most of the reported cases, when the fathers received the news of the diagnosis, they were shocked and worried, but sought to know more about the impacts that the virus could cause and look for ways to adapt to the situation.

> *"At first, I was shocked, because I was not expecting my children to be special. I felt insecure to deal with the situation, where to start, what professionals and treatments they would need. It was also a shock to friends and family, but thank God they gave me strength and positive words" (F3).*

Most people do not expect receiving information that the child has microcephaly, since many do not yet have knowledge about this pathology. Others had heard about the disease on television or on the Internet and already lived with the fear of the disease. It is noteworthy that fathers follow a hard path, from the period of suspicion to the diagnosis, surrounded by omissions, incomplete or late news. (6)

When the baby with microcephaly is born, the entire dynamics of the home is affected, since he/she brings feeling of anguish, frustration and anxiety. The child with congenital malformation leads fathers to instill the plans outlined and dreams planned. (7)

It is worth mentioning that the mother is the family member who is often responsible for the care of children with disabilities, so she has a heavy routine of activities performed together with the child. Thus, this situation can influence the way women see being a mother and interfere with their quality of life.

It can be seen that fathers have a sense of denial at first derived from the process of disbelief, when they do not allow themselves to accept their children's real condition, since the "different" causes strangeness. However, after that, the fathers tried to adapt to the situation experienced, accepting their children's condition.

> *"At first, I was desperate, I did not know what to do and did not know the disease that much, but as the days went by, we got to know and accept more." (F4).*
>
> *"There is no denying it was an impact. We were all surprised, astonished, but I confess that it was a very big surprise, but expectations and hopes increased a lot, because the mere fact of having her with us was our goal. So, regardless of what was to come, the expectation was too high for us to have her in our arms" (F5).*

Thus, remembering the exact moment of diagnosis of a pathology such as microcephaly and its limitations gives rise to the thought that it is a period of great anguish for the family and is always followed by feelings such as fear, anguish, crying, amazement and, often, denial. (8)

At first, the shock phase occurs, when the feeling of fear occurs. Then comes the denial phase, when fathers flee from the real situation, thus moving to a state of sadness. When this phase is overcome, the reaction phase begins, where the situation is understood and they seek to adapt to raising a disabled child. All fathers analyzed in the interviews are already in the reaction phase, seeking the best for their children. (7)

Professional life dynamics while coping with microcephaly

In most cases, parents noticed some change in their professional life with the birth of their child with Zika virus-related microcephaly, some routines changed for the better and others, became fuller and busier.

> *"It changed for the better my routine, because she was my first daughter. Her happiness when she sees me coming from the service makes up for the changes" (F2).*

Fathers living with children with congenital malformation need to take different care with the child, requiring a lot of available time and that they learn concepts to adapt better to the situation. It is noteworthy that the family usual routine changes and, as a result, professional life also changes, modifying the sources of income. (9)

> *"I received support and help to fund his treatments where I used to work, but unfortunately it was short-term because the company fired me" (F3).*
> *"There was a change, but as I work the night shift, it was easier. The change was that during the day I used to sleep and rest. After Pedro, I have less time to rest, because I have to take him to therapies, doctors, etc. "(F4).*

The mother and child bond can be one of the impediments to the mother's social participation, since the mother gives up her personal activities, such as dropping out of college, work and relating to friends and family. (10)

As a child with congenital malformation requires more care, for some fathers, it became difficult to reconcile the care of the child with professional life, since many jobs do not provide flexibility of schedules. Thus, fathers choose to take greater care of their child, which requires more time, leaving the professional life a little aside.

Contributing to the statements of the cases reported, a study points out that most fathers who have a disabled child have to abandon studies and work and start living exclusively according to the child, providing greater care for him/her. (11)

Nevertheless, even in the midst of the adversities faced by fathers in the professional environment, they do not hesitate to leave the professional life a little aside to seek the best for their children, always providing a good quality of life for children.

> *"In my professional life, I started to dedicate more to her, which was a bit affected, I believe so, because I dedicate myself more to her, and the professional life comes as a pillar, a foundation, so that I can offer my best to my daughter" (F5).*

A study shows that there is a break in the expected and an obligation to reorganize life in order to adapt to the new tasks brought by a child's birth, because the disabled child requires greater care. Parents of children with microcephaly need to deal with specific care due to their health condition. Thus, there should be a redoubled care with the child, and the use of specific medications and specific care with feeding should be performed. (12)

Family and marital life while coping with microcephaly

Some interviewed fathers noticed a difference in social life, since the child's arrival required a longer time for the childcare, limiting social interactions; however, they reported the family support to deal with the situation. According to a study (13) (p. 1) "the experience lived by fathers of children with microcephaly by Zika Virus has caused changes in family structure."

> *"As I have two children, I have been a little deprived, I do not go out as much as before, but I manage to reunite with family and friends once in a while" (F3).*
> *"We have a very well-connected life with many supporting our daughter's every development, many acquaintances who seek instructions, at first we even heard a lot of information about updates about microcephaly and a lot of information came to us through friends and family" (F5).*

Therefore, the impact caused on the family structure after receiving the diagnosis of the baby with microcephaly becomes evident, and families have to organize themselves to take care of the new child in the best possible way. Despite fathers' support and interest in helping, the mother is often the one who assumes the integral care of the child (14) As can be seen in the following statements:

> *"Yes, many friends disappear in fact. But my social life is sort of cool; my son is more with his mother and they stay more at home" (F4).*
> *"His mother and I are separated, but I always try to be there. My family treats his disability normally, of course I heard many comments at first, but everyone treats him normally" (F6).*

The interviewees' statements corroborate another study, which points out that the impact occurs for the family, causing unexpected disorders and judgements in the family environment. New routines are used, new priorities arise and there is a need to develop strategies to help cope with the situation. (15)

Many fathers also reported a change in marital life, since it becomes a complex routine, because the child requires greater care, but they manage to deal with the situation and rely on family support.

It is noteworthy that having a child with microcephaly is not determinant for the emergence of marital crises; however, it intensifies some individual characteristics of the couple, being perceived in speeches as a conflicting factor. In the study, one can understand the existence of two situations:

marital distancing or the couple's greater rapprochement. (16)

> *"Marital life has changed a little because the routine is very exhaustive" (F3).*
> *"Our marital life certainly has changed a little, because sometimes, due to such dedication to her, my wife is on her own… this causes a physical wear and, unfortunately, compromises our marital life a little, but we try to reconcile the two situations" (F5).*

Usually, the most affected member of the family is the mother, because she takes responsibility for the care of children with congenital malformation, in a solitary way, which ends up affecting all segments of her life, personal, emotional, social and professional.

Thus, the help from a support network is essential to allow these families to have the emotional support they need, obtain varied information and moments to share the experiences lived about the care they have with the disabled child. (15)

Feelings while seeking a treatment

The arrival of a child with microcephaly brings with it the need for adequate care, leading fathers to a new life: accepting that the child has health problems that can mean life risks. With this arises the need to meet with specialists from various areas in the search for good therapeutic services, thus increasing monthly expenses. (7)

Fathers also reported the difficulties and suffering in the exhaustive search for their children's treatment. They also mentioned the constant search for the best professionals and treatments to ensure the best therapy for their children.

> *"At first as I was unaware of it, it was very difficult to find a neurologist. We started therapies through the UHS, twice a week. The delay was awful and I had to put up with people's mocking comments. Then my wife traveled to Paraíba seeking a more evolved treatment, stayed there for three months. There she learned more about the disease and the best treatment. Now we do everything in the private network" (F4).*

A study corroborates the answers obtained and states that children with congenital malformation experience several difficulties in performing the treatment, such as simultaneous use of services, lack of specific professionals and lack of interest of the government in assisting in the child's therapy, thus requiring restructuring the system, making it efficient and providing for the optimization of access to services and therapies that they need to live. (17)

> *"Our government has not made it much easier for us, they try to beat us by tiredness, responses to documents that take months and years, nights in lines, documents, stacks of documents and*

> *sometimes we face a negative situation. Only God can give strength and insistence" (F2).*

From the suspicion of the disease and even after the prescription of treatment, the day-to-day of the family member changes and becomes full of comings and goings to health services regularly; however, an appointment with specialist physicians or high technological density tests arise concerns regarding the time spent and the price of consultations. (18)

To streamline the therapeutic itinerary, many family members seek the support of friends to assist and mediate the scheduling of consultations in order to reduce the long wait for treatment. If the treatment requires a high amount of money, fathers campaign among friends and family in order to be able to raise the money needed to carry out the treatments.

> *"We had long moments waiting for care and they had no physiotherapy for months many times" (F6).*

A study shows that most fathers of children with microcephaly report the various difficulties they suffer in seeking professional care that children need. They also express problems with the transportation offered and the lack of medical specialists in their regions. (19) Thus, they need to resort to treatment in other locations, as can be seen in the following statements:

> *"I confess that I am capable of anything for my daughter, proved by a trip to Belo Horizonte to do a specific exam, a trip from here to São Paulo for a consultation, to reach our strengths and a little beyond I am able to do for my daughter ... We have already changed several physical therapists, we have been to many specialists... wherever something can be done I will be there searching for it" (F5).*

Thus, fathers need to be helped, with the support of health professionals, especially primary care professionals, since they are inserted in the communities and have greater access and reliability, making it possible to follow and guide these families according to their home experience, intervening when necessary and providing support and care to them. (20)

The number of parents interviewed can be cited as limitation of this study, and the results are partially restricted to a local reality.

FINAL THOUGHTS

The results obtained in the present study reveal that the experiences and perceptions of fathers and male caregivers of children with sequelae of Congenital Zika Syndrome are initially marked by feelings of anguish, frustration and anxiety. As the days go by, fathers accept the situation and seek to understand a little more about the child's conditions, so that they can cope and adapt in the best possible way.

Thus, with the emergence of a new family routine, some areas of the members' personal lives are affected, such as professional life. As fathers have to dedicate more to their children, which requires more time, they end up leaving the professional life a little aside. Another area that is affected is the family and marital area, since the child's arrival requires reserving a longer time for his/her care, which limits the social interactions. However, they do everything for the love of their children.

The research allowed concluding that there are difficulties and much suffering related to the exhaustive search for the children's treatment. Nevertheless, all parents are constantly searching for the best professionals and best treatments to ensure the best treatment for their children.

Studies and research projects related to the theme addressed are extremely important for the family, the child with microcephaly and to provide instruments for health professionals, so that they will intervene in the situation more positively, reducing the impacts caused in the first moment. It is worth mentioning the importance of primary health professionals support, because they are in society and are reliable, providing adequate guidance for the child and his/her family, making possible support and the necessary assistance.

Thus, according to the results of the study conducted, it was possible to observe that parents report having difficulties in accessing health care, again evidencing the need for health professionals to know better their patients' needs, accompany them from childhood with home visits and offer the population greater accessibility to the necessary therapies for the childcare.

Due to the small number of studies found on the theme and this study being limited to the feelings experienced by fathers, further investigations should be carried out.

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