

Microcephaly and family dynamics: fathers' perceptions of their children's disability

Microcefalia e dinâmica familiar: a percepção do pai frente à deficiência do filho

Microcefalia y dinámica familiar: la percepción del padre frente a la discapacidad del hijo

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doi: 10.1590/0102-311X00220316

Abstract

The family is a key pillar in an individual's psychological life, influencing behavior patterns, feelings of social belonging, and emotional health. The family structure can be shaken by the arrival of an infant with microcephaly associated with the Zika virus, defined in newborn boys as head circumference less than or equal to 31.9cm and in newborn girls as less than or equal to 31.5cm. The study analyzes the impact of an infant's diagnosis of microcephaly on the paternal function. Interviews were held with five fathers of children with microcephaly from three communities in rural Paraíba State, Brazil. The instruments were a questionnaire and semi-structured interview that was taped and submitted to thematic and categorial analysis. All five fathers were participating in the routine care of their children, with this involvement "conditioned" by their work as well as by the disability's severity. Some aspects were common to all five fathers, such as their reaction to the diagnosis and their concerns.

Family Relations; Fathers; Zika Virus; Microcephaly

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Introduction

The family is considered a social structure capable of influencing individuals in their relationships, serving as a key pillar in their psychological life, besides influencing behavior patterns, feelings of social belonging, and emotional health ¹.

This study addresses the theme of the family at the time of birth of a son or daughter with disability, when the couple has to adapt and establish new roles and relations. Most couples dream of having a perfect child, which becomes a socially expected event. The birth of a child with a disability thus involves the “destruction” of a grand family dream ².

The birth of a child with a congenital malformation affects the family dynamics, triggering feelings of anguish, anxiety, and frustration. Microcephaly in the infant leads the family to question their life plans, dreams, and wishes.

Despite the importance of the pregnancy and the baby’s arrival in the family, this stage has still received relatively little attention from the father’s perspective. This gap led to the interest in studying the father in the family context *vis-à-vis* the diagnosis of a congenital malformation in the infant, aimed at understanding the father-child relationship in this context. The notion that the father’s only role is that of family breadwinner has been replaced by the perception that assigns possibilities to this family member in playing numerous other significant roles, including companion, protector, caregiver, and counselor ³.

However, male and female roles in Brazilian culture favor the persistence of stereotypes, where the man traditionally plays the role of breadwinner to the detriment of affective functions and care (some recent changes notwithstanding).

Confirming this perspective, the approach taken by Brazilian research on the microcephaly epidemic in Brazil since late 2015 has failed to properly address the father’s role, and the interventions in families of children with this condition focus only on the mother. The research has failed to give a voice to the fathers to learn about their views and how they deal with the child’s disability.

Given the above, this study aimed to investigate the impact of the birth of infants with microcephaly on the family dynamics, based on the father’s perceptions, in the context of Northeast Brazil, where most of the cases occurred in the epidemic of the congenital Zika syndrome.

Disability in the family

Expecting a baby is a time that usually represents social achievement, a symbol of the father’s masculinity and the mother’s emotional fulfillment. Despite some fear and anxiety, the expecting couple fantasizes, makes plans, and imagines how the child will be. The child’s life project thus begins with the parents long before the actual birth. Such plans are customarily imagined and conceived as a child that possesses what are considered “normal” psychological and physical skills. The more the real child differs from the parents’ dream, the more difficult their adaptation when the child is born ².

A condition that differs from this standard normality involves disabilities caused by congenital malformations, leading parents to grieve for their imaginary infant ⁴. Congenital malformation is defined as any functional or structural anomaly of fetal development, resulting from a factor originating before birth, whether genetic, environmental, or unknown ⁵.

The birth of a child with a malformation requires specific care and requires that the parents face a “new reality”: to admit that their child has a series of health problems that can even pose a risk to life, raising the need for numerous trips to specialists, like pediatricians, physical therapists, and psychologists, among others, and visits to hospital services, which greatly increase the family’s costs and sacrifices.

This impact from the news provokes doubts in parents as to their own capacity for action, hindering their acceptance, the formation of a bond with the infant, destabilizing the family’s routine, and forcing changes in roles and life projects ⁶.

From this perspective, the man’s presence and participation have changed in the prenatal phase and especially during childbirth. The beliefs and expectations concerning the paternal role in raising children have undergone transformations. The “new father” entails a concept beyond the role

of breadwinner, related to love and care for the child. In the case of a child with a congenital malformation, the family expects support from the father. Often the father either fails to see his own needs acknowledged, or feels that he has been assigned secondary “priority” compared to the mother and child ⁷.

Microcephaly

Microcephaly can result from congenital anomalies or originate after birth. According to the World Health Organization (WHO), microcephaly is defined as head circumference less than or equal to 31.9cm in newborn boys and less than or equal to 31.5cm in newborn girls. The causes of microcephaly can involve genetic and environmental factors ⁸. Infants with microcephaly can present developmental delay and intellectual deficits, seizures, physical limitations, and hearing and visual impairments. However, some of these children will have normal neurological development.

Microcephaly is just one of the signs of Zika virus infection in pregnancy, and the expression “congenital Zika syndrome” is used to designate the series of effects produced by the Zika virus in the infant’s body. In addition to microcephaly, such effects can include ocular and auditory problems, microcalcifications in the central nervous system and other organs, and bone and muscle malformations ⁹. In addition to what has already been discovered, “specialists fear that some infants, apparently healthy in childhood, may present schizophrenia or bipolar disorder in adulthood” ¹⁰ (p. 189).

The microcephaly epidemic first emerged in October 2015, months after Zika virus transmission in Brazil, beginning with an unexpected increase in the birth of children with microcephaly, initially in the State of Pernambuco and currently throughout the country. From the beginning of the epidemic until 2016, the Northeast was the region with the most confirmed cases of Zika-related microcephaly. In 2017, the Central and North showed the highest incidence rates: 38.2 cases/100,000 inhabitants and 12.2 cases/100,000 inhabitants, respectively ¹¹.

The *Aedes aegypti* mosquito is the vector for the Zika virus, besides the viruses for dengue, chikungunya, and formerly urban yellow fever. Elimination of the mosquito’s breeding sites is a complex task in Brazilian cities, especially where there are precarious conditions in and around housing, inadequate sewage disposal and water supply, and irregular garbage collection ¹². The proliferation of diseases caused by *A. aegypti* and the consequences have emphasized the need for investments to improve the living conditions in more vulnerable communities.

Macro determinants of microcephaly and psychosocial consequences for the family

Considering precarious health conditions and social determinants such as poverty, plus the vector’s massive presence, Brazil has been susceptible to the consolidation of the Zika epidemic as a serious public health problem. The impact of the Zika virus varies considerably according to social class, group, and gender ¹³.

A technical and biomedical discourse has prevailed during the Zika epidemic, prioritizing mosquito control and limiting control of the disease to “*Aedes* policies”. The neglected issues have included the father’s role and support in care for the child, the social determinants of the disease, and problems with health systems infrastructure ¹⁴.

Zika mainly affects people that lack adequate housing and sanitation, sanitation infrastructure, and information on disease prevention ¹⁵. In relation to microcephaly, action is still limited to the mother and child. The father is invisible in the process of care, raising a number of questions related to the challenges of patriarchal society ¹⁵.

In short, Zika and its association with microcephaly is much more than a “mosquito problem” with technological or pharmacological solutions. It also includes complex social, cultural, and political problems.

In this context, the fathers experience emotional instability due to the uncertainty of their newborn infant’s future. All the family members experience new roles ¹⁶, changes in their way of dealing

with others, changes in their way of life, home routine, and medical and hospital routines, and even value changes.

The family has to deal not only with acceptance of difference by others, but also with issues that circumscribe the family in these conditions, generally in a context of greater social and economic vulnerability, making the family virtually invisible, unacknowledged as a social group¹⁷.

Method

A descriptive qualitative study was conducted with a survey of cases of microcephaly in follow-up by the Municipal Health Departments of three towns in rural Paraíba State, Northeast Brazil, an average of 34.6km from Campina Grande, where there is a referral service receiving children with microcephaly from the three towns. The three municipalities were chosen because there were cases of congenital Zika syndrome and due to receptiveness to the study and the proximity to the referral service. After this survey there was a field study of multiple cases¹⁸, with participation by five fathers of children with microcephaly. The contacts were communicated to the study team by the respective Municipal Health Departments, and the interviews were scheduled in advance and lasted an average of 30 minutes. The participants were named P1, P2, P3, P4, and P5 in order to protect their identity. Interviews were held in the participants' homes at times scheduled by them, in late 2016. During the interview, at the participant's request, only the father and the interviewer (a graduate researcher in psychology) were present. The researchers are health professionals, but there was no prior contact with the above-mentioned health services other than the fathers' contact information.

Data collection began following approval of the study by the Ethics Research Council of the State University of Paraíba, under case review CAAE: 60691116.9.0000.5187, in compliance with *Resolution n. 466/2012*, dealing with research in human subjects.

Inclusion criteria were: agreement to participate in the study, being the father of a child with microcephaly, caused by congenital Zika syndrome, and residing in one of the three municipalities. Data collection used a taped semi-structured individual interview. The interview script consisted of five open-ended questions on the father's knowledge of microcephaly, the impact of the diagnosis and the arrival of the child with disability on the family dynamics, and the father's difficulties and expectations concerning the child's condition. Additional questions were formulated based on the content emerging from the interviewee. Transcription of the interviews was followed by thematic-categorical content analysis.

The categories emerging from the fathers' discourse featured reactions to the diagnosis of microcephaly, denial and coping strategies, lack of information, family dynamics in the wake of microcephaly, prejudice, inclusion, the child's functional limitations, family burden with the disability, and difficulty reconciling work activities with the paternal role.

Results

Interviewees ranged from 20 to 35 years of age, with limited schooling. In four cases, the children with functional limitations were only children. None of the five fathers had another child with disability, and none had psychological follow-up for themselves. Four of the five wives were in follow-up with a psychologist (Table 1).

Family income was one minimum wage or less (about USD 250,00/month at current values). Four of the five participants lived in the countryside, corroborating data from other studies¹⁹ (p. 135): *"the epidemic in rural communities and among poor people does not display the same reality of women in the country's urban elites"*.

During the interviews, the family context of the child with microcephaly was gradually unveiled from the father's perspective. As reported by the fathers, news of the diagnosis of microcephaly came as a surprise to the family.

"It came as a shock [sic], and we were afraid. I felt a little sad, because we wanted him to be normal and he has this problem. But he's still my son, right?" (P5).

Table 1

Sociodemographic data for five fathers of infants with microcephaly.

Interviewee	Age (years)	Number of children	Schooling	Occupation
Father n. 1 (P1)	29	2	Complete Secondary	Self-employed
Father n. 2 (P2)	34	1	Complete Secondary	Self-employed
Father n. 3 (P3)	35	1	Incomplete Primary	Farmer
Father n. 4 (P4)	20	1	Incomplete Primary	Self-employed
Father n. 5 (P5)	20	1	Incomplete Primary	Unemployed

"In the beginning it was hard. We were scared" (P1).

"A person doesn't react very well, it's a surprise. To learn this kind of thing is discouraging for any father, but what can you do? There's not much you can do" (P3).

"Before he was born I was really afraid, because I didn't know exactly what it was, what he was going to have. No psychologist or anybody had talked to me" (P2).

The fathers' remarks corroborate studies pointing to paternal difficulty in verbalizing and working through the arrival of a child with a disability and the invisibility of paternal depression in this context²⁰. Public policies and health professionals have failed to include the father in the psychosocial follow-up of families of children with microcephaly, as if the father does not exist.

A child born with a disability rarely meets the father's expectations, and rejection may occur, not always of the child, but of the destruction of the ideal image of a perfect child⁶. News of the diagnosis inflicts a narcissistic wound on fathers, since their fantasies about the child are not realized²¹. The intensity and extent of the difficulties increase the risk that the narcissistic wound in the father *vis-à-vis* the infant's malformation will fail to "heal". Hence the importance of psychological follow-up, rarely offered to the father.

Fathers often go through phases of overcoming²². First comes the shock, with feelings of fear, threat, and guilt. Then comes denial, when fathers avoid reports of the child's disability. From this point on, fathers enter a phase of immense sadness, with feelings of anxiety and rage. Having gotten beyond this period, a reaction phase begins, when they comprehend the situation and adapt to it. Finally comes the reality phase, when the fathers face raising a child with disability. The study revealed the predominance of the denial phase in the participating fathers, who displayed difficulty in verbalizing the child's disability.

"So, a baby was born like that. But he didn't come with such a big deformity as in a lot of those babies" (P1).

"He going to get through all this and is going to become a normal child" (P2).

"I only found out after she was born. I realized it was a thing she could overcome in life" (P4).

The difficulty is so great that a sixth father had agreed to participate in the study but declined when it came time for the interview. We observed a distancing in this father's relationship to his infant, repeating the pattern in his relationship to his own parents. When the wife was interviewed, she described her husband as the stern, traditional father, with no emotional involvement with the baby, limiting himself to the breadwinner's role. As for "being a man", this particular father fits the figure of the traditional Northeast Brazilian male, in whom courage, bravado, fearlessness, and machismo are the main attributes²³. The father's role is marked by authority. All the infant's care is performed by the mother, overloading her. The father avoids even talking about the subject.

Denial of the disability results from a process of daze, numbness, and disbelief, in which the fathers do not allow themselves to admit the reality, since what is "different" appears strange and uncanny, contradicting the normal standard imposed by society. After the initial denial, the family undergoes a process of adaptation, transforming relations among its members, deconstructing the father's traditional provider role, as voiced by the fathers themselves.

"He really is ours, and we're going to have to care for him" (P5).

"I change her diapers when I'm home, I do physical therapy with her at home, I'm always accompanying her. When she has appointments or tests, I go" (P4).

As for difficulties experienced by the fathers, lack of knowledge about the malformation before and/or after the child's birth led to the search for information and orientation on how to proceed, how to care for and guarantee the child's life after its birth. The fathers expressed dissatisfaction with the information provided by health professionals.

"No psychologist or anybody had talked to me, so my head was all full of things" (P2).

"I got nervous and didn't know what it was, so I tried to find out for myself" (P4).

"I didn't believe it when I saw on television that a mosquito could really do all that" (P5).

The less the health professionals in charge of the diagnosis focus on the child's difficulties and the more on the child's potentialities and qualities, the better these fathers will perceive and accept this new child ²⁴.

Other aspects in the infant's life that caused stress and shook the family structure were the functional limitations and the child's care.

"He's going to be a child who's completely dependent on us" (P5).

"They cry a lot" (P4).

"If you don't know how to feed her, she chokes, she can suffocate" (P1).

"Everything in her is slow, everything she learns, everything is going to be slow. That's how it all is, slow" (P3).

"My wife won't be able to work any longer" (P1).

Various factors can overburden the parents: the time spent caring for and raising the child, reducing their social and cultural contacts; social limitations marked by societal prejudice; and increased expenditures, since the parents cover part of the treatment costs ⁶. The fathers mentioned the financial issue in their experience. Even with follow-up by the Brazilian Unified National Health System (SUS), the arrival of a child with microcephaly requires care that leads to increasing expenses for the family.

"The only assistance we receive is the city government's car to take him to physical therapy. The rest is up to us" (P2).

"The biggest difficulty is her medicine, which is expensive. And there's the difficulty with transportation, which sometime doesn't come on schedule. She misses a lot of appointments. By the time we get there, her appointment has passed, since the treatment is all scheduled at exact times" (P3).

Most of the towns with cases of congenital Zika syndrome lack specialized care and have cooperative agreements with other municipalities, but sometimes there is difficulty even in guaranteeing regular transportation for the children's treatment, as reported by the fathers. Socioeconomic status can determine greater or lesser access to treatment, making the children's functional limitations more severe and compromising their independence, autonomy, integration, and socialization ⁶.

The fathers reported the family's suffering from prejudice.

"Even today, a lot of people don't understand, because they're full of prejudice. For example, she has a dress that you realize she's grown out of. If you want to pass it on to another child, the other family doesn't want it because they're afraid the disease is catching. You can't even talk to a lot of people because of the prejudice" (P3).

"There were people that said she was going to be born with a toad's face. Right here on this street, somebody was saying that, and thought we didn't know about it. To this day my wife can't look that person in the face. So, I'm afraid, because our daughter wasn't even born yet, and somebody was already prejudiced, so just imagine when she's older. But God is going to open these people's minds and do away with all that. I hope the schools will be supportive in the future" (P1).

Such prejudice should not be interpreted only according to individuals' psychological perceptions, but also according to culture and society. The reactions involved not only parents and siblings, but also relatives, friends, and neighbors ¹⁵. And the reactions varied considerably, ranging from openness to the family, to distancing due to shame, prejudice, or fear of the unknown. The "odd" or "funny looks" towards the infant bother many fathers and lead them to avoid their children having contact with others, possibly even compromising their treatment adherence. The child's disability is viewed as if it were partially that of the father, causing anxiety and distress ²⁵.

In Brazilian culture, the word for disabled (*deficiente*) has a stigmatizing connotation, in which the appearance of normality and the invisibility of the deviation from the norm are the principal elements that can determine social inclusion or exclusion ²⁶. The issue of disability should be faced from the biopsychosocial point of view, contemplating the individual as a whole.

And conceiving this totality, one cannot exclude the father. In the interviews, the father figure appears predominantly as provider, responsible for supporting the household, while the mother is in charge of the child's treatment.

"My wife is the one that mainly goes to the appointments, because I have to work. I go when I can. Some days my wife hardly gets any housework done" (P1).

"Since I work in a market, I don't have much time" (P2).

"It's always the mother that goes, because I don't have time, I'm working, because if I go she'll be short [of money]. You have to work to get by, right?" (P3).

The father's role in society has been changing, especially in the context described here. The fathers' care, affection, and concern for their children appeared in the interviews. They support their wives and give the family emotional support²⁷, beyond their traditional breadwinner role. But none of them has received psychological follow-up to cope with all these demands.

The fathers wage a struggle trying to reconcile family life with work, often sacrificing their paternal role. Depending on the context's demands, they tend to alternate the roles of father and worker. The multiple disabilities in congenital Zika syndrome place other demands on the father.

"As a father, I feel the same as with any other child, but with even more care, more love, more affection" (P4).

"For me, he's normal: I hold him, we talk, I change him..." (P5).

Parenthood is more than the parents' influence on their children. It involves the psychological processes and subjective changes produced in parents based on the desire to have a child²⁸. Each family member understands and lends meaning to the family relations according to their own life history and personal resources²⁹. Fathering involves the father's affective bond as a participant in all aspects of the infant's care³⁰. He is expected to be more involved in raising and educating the children at all ages, and not only providing the family's economic support. This means that the father allows himself to participate in the child's life.

In the father-child relationship, the father reproduces his values and expectations while raising the child, considering formal schooling essential for the child's personal development and upbringing: *"This child is only going to become someone because of school"* (P1).

Another significant aspect relates to the suffering experienced by siblings of the child with microcephaly, since the care and attention are disputed daily: *"My other son says, 'My dad only does this or that, only plays with Jasmine [fictitious name used to protect the infant girl's identity]'"* (P1).

Given the need to adapt to the child with disability and provide the care he or she requires, the parents change their relationship to the other children, who may feel that they are blamed for their sibling's disability, jealous, or at a disadvantage, believing that the sibling with disability enjoys privileges and too much attention from the parents³¹. Care for the child with disability often means less attention for the other children, potentially triggering jealousy, animosity, and more conflicts in the family context¹⁵.

It is not easy for parents to manage this situation. While they need to deal with the loss of the imagined child and help the infant that requires more care, they have to reconcile their tasks with the other children, having to support them in their needs with all the loving care they can muster.

The fathers described the child's disability as something different, outside the standard of normality acknowledged by society.

"We thought he was different, because we already had a child who was born healthy, with no abnormality whatsoever" (P1).

"He's not a normal child" (P2).

"We'll see if the little creature walks, if she's going to be a normal child" (P3).

"She's not a normal child, not at all" (P4).

"We wanted him to be normal" (P5).

The interviews revealed the fathers' tendency to pathologize the disability, focusing on a standard of normality and making comparisons with able-bodied children. This normal-versus-pathological standard for disability results from an internalized discursive positivity, disseminated by the medical model, viewing the disability as the consequence of a bodily lesion and the disabled person as the object of biomedical care, aimed at approximating the person to an ideal of normality³². This view differs from the prevailing social model that sees disability as a functional diversity in which society

needs to adjust to the specificities of each person with disability, considering their individual and collective actions, codes, attitudes, beliefs, and behaviors concerning the disability³³.

Finally, spirituality was mentioned by the fathers as a way of coping with the difficulties associated with the disability.

"With God's help, she can thrive" (P4).

"His future is in God's hands. I have faith in God that he'll have a promising future, with the love and affection we have for him. Anyway, we're going to love and care for him" (P2).

This corroborates another study³⁴ in which coping can focus on the problem, on the emotion, or on both, and can include different kinds of strategies, like religion, for example. Spirituality can thus be an important source of refuge and support for many people, as reported by P4: *"I realize that it's a very serious disability, but with God's help she can thrive"*.

One way of coping with illness and death is directly linked to the strength of one's faith and religious beliefs³⁴, that is, ways of expressing spirituality. Nowadays, to contemplate an individual from a biopsychosocial perspective, spirituality is a widely used form of coping, and it is important to consider when dealing with health services users.

Psychology plays an essential role in the lives of these individuals, since it helps them redefine the trauma and allows them to be happy based on other possibilities, even though they are contrary to what is proposed as the model for society to follow. It is thus indispensable for both the parents and the infants diagnosed with the congenital Zika syndrome to be accompanied early in the child's life by an interdisciplinary health team, including a psychologist.

Discussion

The news of a newborn child with a fetal malformation destabilized the family dynamics, requiring a process of working through the mourning for the ideal infant, a series of uncertainties concerning the child's functional limitations, and each family member's role in caring for the child, demanding adaptation by everyone. In the cases analyzed here, all the family members were affected directly or indirectly. The interviews allowed learning about the fathers' experience in realizing that the dreamed-of child had not arrived, in addition to the suffering from sacrifices, uncertainties, financial difficulties, and social prejudice.

The fathers had received no explanation as to their infants' clinical condition. Their lack of knowledge on the children's condition had further aggravated their distress. They were forced to live with the anguish of not knowing how things would unfold from then on. This was apparent not only from their words, but also from the fact that they all got choked up as they reported their experience. With affection and a firm voice, they communicated their responsibility towards the child, the wife, and the family, that they would persevere together in the search for guidance in order to provide the best care for their children. Given all of the above, they sought strength in spirituality to believe that the treatment by the multidisciplinary team would produce positive results. In these fathers, after the initial impact, the arrival of the child with microcephaly further strengthened the family's emotional ties.

However, the focus of care for these families had been on the mother and the infant, while the father had been overlooked by public policies and health professionals. The father is part of the family, and all the family's implications affect him greatly. A child born with a disability needs the father's participation in order to develop, and the father suffers just as much as the mother from the loss of the idealized child²⁴.

An important aspect to minimize social prejudice and the fathers' distress is education, as voiced by some of them. Education can give greater social visibility to the parents and children, where society "takes stock" of their existence, thus fostering greater social equanimity¹⁵. Inclusion of children with microcephaly in the school system is already happening in municipal daycare centers in Campina Grande, the municipality serving as the reference for treatment of the children whose fathers participated in the study.

Final remarks

With all the transformations in society related to the father figure, the traditional authority role has now been enriched with that of provider of affection and attention, acting in the children's education and upbringing, as evidenced in the data collected here. However, in the wake of the microcephaly epidemic in Brazil, which was later found to be one of the deficiency pictures from the Zika virus congenital syndrome, fathers have still been largely overlooked by public concerns and policies. The society that pressures men to be loving, caring, and attentive towards their children is the same society that discriminates against and segregates them.

The study showed, in the fathers' own words, the effects of microcephaly on the family, revealing how fathers experience the news of their children's disability, how they engage in care and family support, potentially allowing health professionals to adopt strategies of solidarity and care without focusing exclusively on the mothers. These men need help and support, involving quality of life for themselves and their families, since in family relations, one family member influences the others.

The results presented here are a snapshot of the reality and give food for thought on the progress needed in psychological and social aspects in studies on microcephaly and congenital Zika syndrome. This context opens possibilities for further studies on the theme of family and microcephaly, in order to elucidate family relations from different perspectives and thus collaborate with science and support public policies and health professionals, in order for them to know how to proceed to help these families, giving them the opportunity to voice their concerns, anxieties, and wishes.

Contributors

V. P. S. R. Félix and A. M. Farias equally participated in the preparation of the article.

Acknowledgments

The authors wish to thank the fathers for agreeing to participate in the study.

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Resumo

A família é um dos pilares da vida psicológica dos indivíduos, influenciando os padrões de comportamento, o sentimento de pertencimento social e a saúde psíquica. Tal estrutura pode ser abalada quando há um membro com microcefalia associada ao Zika vírus, que ocorre quando o menino apresenta perímetro cefálico igual ou inferior a 31,9cm, e a menina, igual ou inferior a 31,5cm. Esta pesquisa visa analisar o impacto do diagnóstico de microcefalia do bebê na função paterna. Para tanto, foram realizadas entrevistas com cinco pais de crianças com microcefalia em três municípios do interior da Paraíba, Brasil. Os instrumentos foram questionário e entrevista semiestruturada gravada, submetida à análise temático-categorial. Todos os pais entrevistados participam da rotina dos filhos, sendo esse envolvimento “condicionado” pelo trabalho, bem como pela severidade da deficiência. Alguns aspectos são comuns, como reação ao diagnóstico e preocupações.

Relações Familiares; Pai; Zika Vírus; Microcefalia

Resumen

La familia es uno de los pilares de la vida psicológica de los individuos, influenciando patrones de comportamiento, sentimiento de pertenencia social y salud psíquica. Esta estructura puede desmoronarse cuando existe un miembro con microcefalia, asociada al virus Zika, que se produce cuando el niño presenta un perímetro cefálico igual o inferior a 31,9cm, y la niña, igual o inferior a 31,5cm. El objetivo de esta investigación es analizar el impacto del diagnóstico de microcefalia del bebé en el desempeño paterno. Para tal fin, se realizaron entrevistas a cinco padres de niños con microcefalia en tres municipios del interior de Paraíba, Brasil. Los instrumentos fueron: cuestionario y entrevista semiestructurada grabada, sometida a un análisis categorial temático. Todos los padres entrevistados participaron en la rutina de los hijos, encontrándose su implicación “condicionada” por el trabajo, así como por el grado de severidad de la discapacidad. Algunos aspectos son comunes como la reacción al diagnóstico y las preocupaciones.

Relaciones Familiares; Padre; Virus Zika; Microcefalia

Submitted on 30/Dec/2016

Final version resubmitted on 19/Jan/2018

Approved on 26/Jan/2018