

# EXPERIENCES OF MOTHERS WHO HAD CHILDREN WITH MICROCEPHALY

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## VIVÊNCIAS DE MÃES QUE TIVERAM FILHOS COM MICROCEFALIA

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## EXPERIENCIAS DE MADRES QUE TUVIERON HIJOS CON MICROCEFALIA

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**Objective:** understand the experiences of mothers who had children with microcephaly. **Method:** this is a qualitative study carried out with eight women aged 18 years and older. The semi-structured interview technique was applied in April 2017. For the analysis of the data, the technique of content analysis was used. **Results:** three analytical categories emerged: the experience of the diagnosis of microcephaly; mothers' optics; encounters and disagreements of the parents and the family in the care of the child with microcephaly; learning with the challenges of microcephaly. The speeches revealed the willpower and determination of the mothers in facing the difficulties, despite the experience marked by expressions of suffering and pain. **Conclusion:** the situation experienced by mothers who had children with microcephaly generates uncertainties regarding the future of the child, changes the family dynamics, the relationship of the couple, and the income, and defines the option to abandon the professional work to take care of the child.

**Descriptors:** Mothers. Microcephaly. Child Care. Zika Virus.

*Objetivo: compreender as vivências de mães que tiveram filhos com microcefalia. Método: estudo qualitativo realizado com oito mulheres, maiores de 18 anos. Foi aplicada a técnica da entrevista semiestruturada em abril de 2017. Para a análise dos dados, utilizou-se a técnica de análise de conteúdo. Resultados: emergiram três categorias analíticas: a vivência do diagnóstico da microcefalia; ótica de mães; encontros e (des)encontros dos pais e da família no cuidado à criança com microcefalia; aprendizado com os desafios da microcefalia. As falas revelaram a força de vontade e a determinação das mães no enfrentamento das dificuldades, apesar da vivência marcada por expressões de sofrimento e dor. Conclusão: a situação vivenciada por mães que tiveram filhos com microcefalia gera incertezas em relação ao futuro do filho, altera a dinâmica familiar, a relação do casal, o rendimento financeiro e determina a opção de abandonar o trabalho profissional para cuidar do filho.*

*Descritores: Mães. Microcefalia. Cuidado da Criança. Zika Vírus.*

*Objetivo: comprender las experiencias de las madres que tuvieron hijos con microcefalia. Método: estudio cualitativo realizado con ocho mujeres, mayores de 18 años. Se aplicó la técnica de entrevista semiestructurada en abril de*

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2017. Para analizar los datos, se utilizó la técnica de análisis de contenido. Resultados: emergieron tres categorías analíticas: la experiencia del diagnóstico de microcefalia: punto de vista de las madres; encuentros y (des)encuentros de los padres y de la familia en el cuidado del niño con microcefalia; aprendizaje con los desafíos de la microcefalia. Los relatos revelaron la fuerza de voluntad y la determinación de las madres al enfrentar las dificultades, a pesar de la experiencia marcada por expresiones de sufrimiento y dolor. Conclusión: La situación vivida por las madres que tuvieron hijos con microcefalia genera incertidumbres relacionadas al futuro del hijo, altera la dinámica familiar, la relación de la pareja, el rendimiento financiero y determina la opción de abandonar el trabajo profesional para cuidar al hijo.

Descriptores: Madres. Microcefalia. Cuidado del niño. Zika Virus.

## Introduction

Pregnancy represents an existential moment of joy within the family. When news of the possibility of a new member arrives, there are many expectations about this new being. However, this family joy can give rise to feelings such as fear and insecurity, in the face of the diagnosis of malformation and consequent deficiency of the baby<sup>(1)</sup>.

Law no. 13,146, of July 6, 2015, known as the Disabled Persons Statute, defines the term person with disability as “[...] one who has a long-term physical, mental, intellectual or sensorial disability, who, in interaction with one or more barriers, may obstruct their full and effective participation in society on an equal basis with other persons”<sup>(2)</sup>. Thus, the discussion on microcephaly is part of that context.

Zika virus infection in the gestational period brought visibility to cases of microcephaly. Although the virus was already known and studied scientifically, with reports in several countries, little was known about its possible teratogenicity. The relationship with microcephaly was only studied and investigated in Brazil after the finding of viral genetic material concentration in the nervous tissue of stillborn infants affected by microcephaly in the affected regions<sup>(3)</sup>.

The first confirmed cases of Zika virus infection in Brazil occurred in March 2015, in Natal, capital of Rio Grande do Norte<sup>(4)</sup>, and in Camaçari, Bahia state<sup>(5)</sup>. In the year 2015, Bahia totaled 64,478 notifications of suspected Zika cases in 296 (70.98%) municipalities in the state. At the time, the data showed a scenario

of epidemic of the disease, since the total of registries throughout the state represented more than 90% of the cases of Zika notified in Brazil<sup>(4-5)</sup>.

The Zika virus is a flavivirus of the same dengue family. It is transmitted by the *Aedes aegypti* mosquito to humans, mainly through the bite of the infected mosquito. It was first isolated in Africa in a Rhesus monkey female in the Zika forest in the year 1947. Later it spread to Asia, Oceania and the Americas, and today it is responsible for an emergent arbovirolosis in the world<sup>(6)</sup>.

Although the main route of transmission of the virus occurs by vectors, there is evidence in the scientific literature that transmission can also occur through sexual, perinatal, and transfusion way<sup>(7)</sup>. Although the disease is apparently benign, currently more severe conditions with compromised nervous system in fetuses of affected mothers have been confirmed and registered, especially in Brazil. This shows that there is still little knowledge about this occurrence and the vulnerability of this pathology<sup>(6)</sup>.

The relationship between the Zika virus and microcephaly was first confirmed at the end of the year 2015 by the Ministry of Health (MS, acronym in Portuguese), due to the finding of the high number of microcephaly in regions that presented a large notification of Zika cases<sup>(4)</sup>. The term microcephaly means incomplete development of the skull; it is a congenital malformation, in which the brain does not develop completely, making the head small compared to the length of the body. It is

characterized by a cephalic diameter with two or more below average standard deviations (SD), and a reduced production of neurons during the embryonic phase, which may or may not be associated with structural changes. Currently, the values defined for the diagnosis of microcephaly after cephalic perimeter measurement are 31.9 centimeters for boys and 31.5 centimeters for girls<sup>(3)</sup>.

The causes of microcephaly may be associated with several factors, such as malnutrition, toxicity, drug use and infections during pregnancy. Several metabolic and genetic syndromes as well as environmental aggressions can affect brain development, causing mental disorders. However, due to the large number of neonates identified with microcephaly in regions with numerous Zika virus outbreak rates, and also due to the fact that this virus can overcome the placental barrier and infect the fetus in the uterus, especially in the first trimester, studies have been increasingly performed in order to better understand how this transmission occurs, in which gestational phase the woman is more vulnerable to transmitting the virus to the fetus, and what other malformations, in addition to microcephaly, this virus can cause the newborn<sup>(7)</sup>.

In Feira de Santana, Bahia, the first suspected cases of Zika virus infection were reported as of March 2015, when the disease was mistakenly diagnosed as dengue or Chikungunya, due to the clinical similarity between these diseases, as well as transmission of these arboviruses in the municipality. Municipal Epidemiological Surveillance (VE, acronym in Portuguese) data show a total of 1,497 suspected Zika cases in 2015, 325 cases in 2016 and 204 cases in 2017, with a predominance of 20 to 49 year olds in the period. With regard to cases of microcephaly in newborns, possibly associated with congenital Zika virus infection, 58 suspected cases were reported up to December 2017, of which 23 were confirmed, 27 were discarded, three were under investigation and five were cases of death<sup>(8)</sup>.

Therefore, given the complexity of the problem and the experience of living a severe and still unknown situation among health

professionals and mothers of babies with microcephaly, the present study has raised the need to answer the following question: What has been the experience of mothers who had children with microcephaly in the municipality of Feira de Santana, Bahia? It was defined as an objective to understand the experiences of mothers who had children with microcephaly.

## Method

This is an exploratory study, using a qualitative and descriptive approach, developed in the Municipal Health Department (*Secretaria Municipal de Saúde – SMS*), specifically in the Epidemiological Surveillance (*Vigilância Epidemiológica – VE*), in the municipality of Feira de Santana, Bahia, where childcare was started and where the follow-up to mothers who had the diagnosis of children with microcephaly is held today.

Eight women, older than 18 years, who had a clinical epidemiological diagnosis of Zika virus infection during pregnancy, and were followed up by the VE of the city of Feira de Santana (BA), with the consequent birth of children with microcephaly.

Because it is a qualitative study, the number of participants did not need to be defined a priori, but rather the meanings attributed to their speeches<sup>(9)</sup>. In this study, ten women were initially selected due to issues related to the National Registry System – Plataforma Brasil. However, during the collection and analysis of the data, with some limitations, it was observed that the objective of the research was reached with the testimony of eight women by the criterion of data saturation.

In order to avoid subjectivation of analysis, eight steps were taken to process the theoretical saturation: make the raw data records available; immerse in each record; compile the individual analyzes; gather the themes or types of statements for each pre-category or new category; nominate the data; allocate themes and types of statements; check the theoretical saturation for

each pre-category or new category; and display the saturation<sup>(10)</sup>.

The first step recommends that, in addition to the full transcripts of recorded dialogues, digital files with audio recordings are made available for the process of interpretation. In the next step, each of them is apprehended. The third, guides the compilation of statements captured in the lines. As a fourth step, for each category, the statements identified with the respective excerpts from the interviews that describe them are grouped together. The fifth is the naming of the data that represent the set of ideas, expressions and feelings that encompass the manifestations of the participants, so as to lead the understanding of the object studied by the researcher. The sixth step is the allocation of data to allow the visualization of the analytical elements. The seventh seeks to verify the theoretical saturation, through a treatment dynamics and data analysis, characterizing the interruption of new participants, noting the theoretical robustness intended, based on the available empirical data and the analytical and interpretative expertise of the researcher. Finally, the eighth and final step enables the categories that have emerged to be visualized by means of representation elements, such as theoretically well-constructed analytical frames, confirming the theoretical saturation<sup>(10)</sup>. Thus, after applying the saturation criteria adopted, the data collection was closed without impacting the construction of the study and the analysis.

The semi-structured interview was used as data collection technique. The interviews were held in April 2017, recorded with the permission of the participants, regarding privacy and maintenance of anonymity. The names of the deponents were replaced by flower names to guarantee absolute secrecy, in compliance with the ethical principles of Resolution no. 466/2012, of the National Health Council (*Conselho Nacional de Saúde* – CNS). The instrument for data collection consisted of a script that had the following guiding question: How has your experience as a child's mother with microcephaly been?

The analysis of the data was systematized through the technique of content analysis<sup>(9)</sup>, structured in three phases. The first was the organization of the data, with the transcription of the recorded interviews and the reading of the collected empirical material, which allowed the construction of the recording units. In the second phase of data classification, a thorough and repeated reading of the interviews was carried out in order to understand the sense and meanings of the latent contents, not only of the manifest contents, at which point the analytical categories emerged. In the third phase, which refers to the final analysis, the results were articulated with the theoretical basis, paying attention to the research question and the purpose of the study.

The research was only initiated after the acceptance of the institution and approval by the Research Ethics Committee (*Comitê de Ética em Pesquisa* – CEP), on January 3, 2017, of the State University of Feira de Santana (UEFS), Favorable Opinion number 1,884,681.

## Results and discussion

Study participants were between 23 and 35 years old. Although they were of productive age, most of them gave up work to take care of their children. Only two were employed, one worked as an autonomous professional and the other as a farmer. Regarding skin color, three reported being black, two white, and three were brown. In terms of schooling, six women declared to have a complete secondary school; one, the incomplete 2<sup>nd</sup> grade and one, the incomplete 1<sup>st</sup> grade.

Five were married. At the time of the study, three of the husbands were employed, only one unemployed and the other living underemployed. Two women were not married and one had a stable marriage.

As far as religiosity was concerned, five were Catholic and three were evangelical. Spirituality was observed as a source of support for these women to deal with the child's pathology and the new existential conditions.

*Experience of microcephaly diagnosis:  
mothers' optics*

The arrival of a new being represents a moment of great joy and expectation in the family nucleus. When the news is received, there are many expectations about the child. However, this joy may give rise to feelings of insecurity and uncertainty, given the diagnosis of the birth of a child with some type of pathology<sup>(1)</sup>.

In this sense, when faced with the reality of the birth of a child with a disability, mothers experience, at first, the loss of the idealized child and experience "mourning". Nevertheless, a specialized professional accompaniment favors a behavior of overcoming, leaving the mourning to the fight<sup>(11)</sup>. Thus, the way the professional makes the communication should be well planned. Frequently, the news may not be adequately conveyed, which increases family distress and, consequently, increases the difficulty in accepting the child. Sometimes the distant and impersonal posture of health professionals can cause despair and fear in parents, as the following statement relates:

*[...] and the way they gave me the news. The pediatrician, in the case, did not call a psychologist; he didn't even wait for the effect of the anesthesia to pass. He broke into the infirmary, asked me who I was [...] and said, "Look, your son has microcephaly!" [...] When I received the diagnosis, I thought: My life is over! Now my life will be for him alone. (Lily).*

The timing of the diagnosis of any disease involves innumerable situations, difficulties, feelings, and emotions that may worsen, depending on how professionals host the family and communicate information about the child. The arrival of a child with pathology in the family nucleus can generate complex situations due to lack of preparation and adequate information to deal with the feelings that will arise at that moment<sup>(1)</sup>. It was possible to observe in this study that the news of the diagnosis was not adequately communicated, which increased the suffering of mothers and their relatives, making the acceptance of the child difficult.

Feelings and reactions of shock, sadness, mourning, fear, and denial are frequent at this

time. In addition, when the family receives the news of the disease, it goes through a phase of despair and transition through the mourning of the desired and idealized child. However, the moment parents begin to accept their children, they begin to love them and include them in the family and in society. This acceptance leads them to overcome prejudice and acquire more power to face the situation<sup>(12)</sup>.

*At the moment, I was desperate because in pregnancy I didn't expect, and when he was born I got the news [...] I didn't want to accept it. I wondered why this happened to me. (Rose).*

*Then the husband who was in the room suddenly burst out. I got desperate; I asked a million questions. Then I came home, my mother asked what had happened. Then I freaked out and started to cry. (Gardenia).*

Knowledge of the child's disability and the losses resulting from the diagnosis can trigger a state of maternal depression that may lead the mother to the removal of her child<sup>(13)</sup>.

*Then when we found out, he got really struck, the father got really scared! [...] Then I went into a deep depression. I was not in the mood for anything, to take care of my son; I wouldn't leave home. (Iris).*

The way a clinical situation is reported can change mother's reactions, which may affect the family's attachment to the child and generate expectations that will influence the acceptance of the disability. In addition, there are cases in which unprepared professionals end up giving misleading and insecure information to mothers, which leads them to despair more and more at diagnosis<sup>(1)</sup>.

*I stopped buying the layette because the day I left Dr. [...] he gave me no hope and the doctor who accompanied me used these words: "Dear, we know he will last". (Gardenia).*

On the other hand, in this study, it was possible to find humanized professionals, who, even when faced with doubts, tried to give hope and comfort to these mothers. This conduct represents a call for attention to the effectiveness of the public policy of humanization of health care, in order to defend the integrality and resolubility of the demands of those who seek care in the public sector.

*It was easier, because I found the support of the secretariat of the health post and of the doctor who assisted me.*

*Because I went into the room upset by the news, but he comforted me so much that I left there feeling like my daughter had nothing[...] and I felt very reassured because the doctor told me so many good things. (Sunflower).*

When analyzing the report of Sunflower, it can be inferred that the humanizing characteristic is a strategy to develop the entire process of the professional relationship between patient and health. Health professionals should be able to report the diagnosis of disability to mothers and fathers, since there is no control of the feelings that can emerge in the face of a complex phenomenon such as disability<sup>(13)</sup>.

Therefore, the way in which the diagnosis will be provided should be planned, with the purpose of providing support and clarifying the doubts of the families, so that they may have an understanding of the disease. The sensitivity of the health professional who communicates the diagnosis of the disability to the parents can be a determining factor for the acceptance and adaptation of the family to the new reality, before a disabled child.

In this way, with the child's re-signification, the parents can find out that their child has abilities and they (the parents) can help him. With this, they even find satisfaction, pleasure and pride in this child<sup>(13)</sup>. Therefore, the approach to parents at the time of diagnosis, as well as multiprofessional support in the following stages of the follow-up of these families becomes essential for family empowerment and balance.

Thus, the ideal would be for the family to be supported by a multiprofessional team, prepared to provide the necessary support and information, taking into account that parents are fragile and confused with the diagnosis, which means reestablishing a new family structure.

#### *Meetings and disagreements of mothers and family in the care of the child with microcephaly*

Although the deficiency of a family member generates changes throughout the family structure, the importance of restructuring lies in the fact that the child will initially learn to live

and discover life and the world through intra-family relationships. Initial crisis reactions in the family may, over time, generate possibilities for adjustments in family relationships in a healthy way, with an understanding of the differences, potentialities, and limits imposed by the disability<sup>(13)</sup>. Therefore, the deficiency of a child can bring with it the possibility of mutual help among family members. This support is described in the speeches, which reflect the importance of the role of the father and the family nucleus in this process.

*I called my husband and told him about microcephaly. He told me: "Look, in any way he is, whatever it is, we're going to love him anyway." He calmed me in every possible way, and I felt reassured. (Amaryllis).*

Authors consider that "[...] for mothers, the participation and involvement of the father in the care of the child is fundamental for the child's emotional balance"<sup>(14:50)</sup>. The complicity of husbands provides security, leading mothers to feel protected and understood. They live the sharing of experiences and decide, together, the issues related to the child<sup>(14)</sup>. However, the father and the family do not always accept and support the child with a disability. The discovery and experience of having a child who has a congenital disease may have reflexes in the life of the couple. "The challenges imposed both emotionally and in daily life can lead to dissatisfaction, divergences of opinion and, consequently, friction between the couple"<sup>(15:16)</sup>. The following is illustrative:

*When we got home, his father didn't want to hear from him. He packed his things, left and we got divorced [...] I had no support from anyone. I had no support from him or from my family. (Iris).*

In these cases, when mothers do not receive the support of their husbands and family as they had hoped for, they seek other support references in order to feel backed up and welcomed. The impact of a disabled child on the marital relationship has been reported in other studies. What is generally observed is that the mothers are the ones who are most involved in the process of rehabilitation of their children<sup>(13)</sup>. Many mothers in this study found this support

by searching for EV in SMS, where professionals and industry employees embraced their stories, supporting and guiding them as best as possible in the treatment of their child, and providing the necessary support so they seek the strength to live this new phase of life, as the following statement elucidates:

*That's when I started to look for the Health Department. Who gave me support was [...] they were the two people who welcomed me when I got here. They are two mothers to me. They embraced my cause with me and that's when I had the strength to take care of myself and my son. And so, I overcame it. (Iris).*

After the diagnosis of the disability, mothers modify their family routine, as well as personal and professional life habits to attend to and prioritize the child's needs<sup>(14)</sup>.

According to the reports, some mothers were faced with the need to leave the professional work to take care of the children. They feel lack of ability to lead a life as before the arrival of the disabled child. Therefore, they begin to impose demands on child care.

*I will not tell you that it was easy because, after it was confirmed and I left the hospital, the struggle began. Several examinations and several medical appointments were made [...] I left the job just because of it. I stayed home for 6 months; I went on vacation; then I talked to my bosses at work and they understood it; so I left my job with all my rights [...] I really enjoyed my job, very much, but I had to give it up and today I can't anymore, it's very difficult. (Amaryllis).*

The difficulties faced by mothers of disabled children, such as overload, abdication, abandonment, and exhaustion, cause suffering in the face of the situation experienced. In addition, there are family pressures with which they have to deal; they also have to face the pressures exerted by the social forces, since the society has difficulties of coexisting with differences<sup>(12)</sup>.

When receiving the news, many mothers worry about the reaction of the people to the child with a disability<sup>(16)</sup>. The following report is enlightening:

*On receiving the news, what worried me was the reaction of the people. I was afraid of people's reactions because, like it or not, we have and suffer from prejudice. He will suffer from now on; when he starts to study, people will have prejudice. [...] We think it's not going to happen, you know? But, there is always one or another that will have a prejudice. I'm afraid of that. (Rose).*

Society is still rooted in prejudices, valuing only healthy individuals who can produce. If the individual does not fit this pattern, it is excluded and segregated. How the disabled child will be accepted in the family and in society will largely depend on the attitude of acceptance of the mother<sup>(12)</sup>. The testimony of one of the mothers expresses this prejudice:

*So, I overcame my prejudice, but at the beginning I didn't accept it either; It was when society accepted me and when the Secretariat accepted me [...] So I had to fight my prejudice, so that the people out there would fight it too. (Iris).*

In this study, it was learned that, even with all the difficulties found, these mothers were psychologically strengthened, experiencing moments of pain and difficulties experienced by the child with microcephaly, overcoming barriers and including them in society. When the child with deficiency is no longer understood by its deficit and becomes perceived as an integral person by the parents, attitudes and postures that will enable their development come from this new look<sup>(14)</sup>.

The impact of the diagnosis, the need to adapt to the new situation and also the social stigma can lead to overload, conflicts and fear, which may compromise the ability to care for the disabled child. Despite some advances in society regarding how to react to people with malformation, there are still taboos. There must be studies and discussions that can help, mainly, the families to understand and live with the malformations and deficiencies that produce limitations in the affected people.

### *Learning with the challenges of microcephaly*

The presence of a disabled child in the life of the mother and the family can change routines and styles, as it is a new development. It can also be perceived as a new, traumatic, difficult, and suffering situation that provokes internal conflicts and develops feelings similar to those experienced in a process of mourning. In this sense, overcoming the news about the child's

disability is one of the first challenges to be faced by the parents of a child with a disability<sup>(17)</sup>. In the following report, the reaction of a mother to the lack of support is illustrative:

*Then, when we found out, we suffered a thump [...] but I had to get up, because I had no support from anyone; I didn't have the support of him [husband]; I didn't have the support of my family. I had to take care of things by myself. (Iris).*

When the birth implies the arrival of a disabled child, the couple is faced with a stress factor. Situations before the new are strengthened, making the parents, especially the mother, more vulnerable, as they will have to adjust and adapt to the new and unknown situation<sup>(13)</sup>. Thus, the strategies that mothers use to deal with difficult situations will be responsible for the transformations of adaptation to the new situation, as exemplified in the following report.

*The stress is even stronger because of the rush of my life, of always running after a doctor. In the beginning, adapting was very complicated, because I had never heard about any case. So everything was new for me [...] I get really exhausted and discouraged, but then we ask God for strength and start it all over again [...] And with a hint here and there, we're always trying to get things right. (Sunflower).*

Mothers try to find ways to live with what is not considered normal by society. They try to overcome suffering and pain<sup>(12)</sup>. In this study, mothers' maturing in the face of their child's illness means they found ways of overcoming previously unimaginable limits, as one contributor stated.

*Much has changed in my life; I have changed a lot as a mother; my way of thinking and of treating my other children has changed a lot [...] it was a child that made me see life in a different way. Today I can have more tenderness, more love, more affection for my children, which I didn't have before. (Daisy).*

They outlined paths that could be tackled to meet and adapt to the new situation. In this sense, being the mother of a disabled child can be an enriching and personal transformation experience<sup>(13)</sup>.

*Today, everything I went through made me more mature! Most of the time, God gives us a child like this, so that we can learn to take better care of ourselves and the family. And from everything I went through, if there was prejudice and abandonment, I still thank you anyway, because with that, I became stronger, I learned to value my son,*

*I learned that life is not what we think, I learned from [...] that we have to love everyone, not to be prejudiced to anyone [...] I learned all this. (Iris).*

The psychological strengthening of these mothers translates into the capacity to overcome the obstacles of life<sup>(12)</sup>. In addition to these efforts, faith and hope are also used as coping strategies to face adversity.

*There are days that I get exhausted, but there is a day that I grow, because I have to fight now to be better in the future [...] No one is happy today. We have moments of happiness. So we live in search of these moments, not in search of absorbing everything. What I can't do, I put in God's hands. (Lily).*

After experiencing and overcoming the news of the child's disability, the mothers reported changes in their lives, valuing some factors and building new feelings. They now seek to live, enjoy the pleasant moments, value and support their child in living with disability<sup>(12)</sup>.

*I would tell other mothers never to give up. Always love them, because love causes people to react and change what they find impossible. Always love in every way, no matter what difficulties your child has. You have to love him anyway, because it will make him grow strong and will make us change, even if we find it impossible. (Amaryllis).*

*I would tell other mothers not to be afraid, not to be ashamed and to always love, above all else! Because being ashamed of the very son you have begotten... you have to see that he is like any other child. It is an unconditional love. It is a boundless love. I am not ashamed to show my daughter; those who don't want to see don't look, but she is there to rub in the face of anyone, to show that she is superior to anyone. (Sunflower).*

Accepting the disabled child makes it possible to build the bond between mother and child. The child then becomes included in family and social life, overcoming prejudices<sup>(17)</sup>.

In this way, mothers who were able to overcome negative feelings re-signified their lives, helping their children in physical, psychic, social and educational development, including them in society, with the possibility of fighting for conditions to exercise their citizenship.

Some limitations were experienced in carrying out the research. Among them there is the availability of time for mothers to participate in the interview due to the overload of activities. Although the interviews were carried out at the place of care, the demands for child care



before or after the consultation sometimes made it difficult to conduct interviews and the frequency of successive hospitalizations of these children also contributed to reduce the number of mothers participating in the study. It is noteworthy that, due to the difficulty of access to the etiological diagnosis, it was not possible to be sure that cases of microcephaly occurred because of infection caused by the Zika virus or by other etiological agents.

## Conclusion

The study sought to understand the experiences of mothers with children with microcephaly, in order to reveal the complexity of experiencing this existential situation. When the unexpected occurs during gestation, such as the arrival of a disabled child, the information generates psychological imbalance in this woman and in the family, forcing them to reorganize themselves in order to live through this complex moment.

The birth of a child with microcephaly alters family dynamics, lifestyle, couple relationship, and financial income, and affects work, as some mothers have to give up work outside the home to provide full care to the child. In addition, faced with the existential situation, there are innumerable uncertainties regarding the future of these children.

However, one can perceive the willpower and determination of these mothers in facing the difficulties, despite the experience marked by expressions of suffering and pain. In mothers' speeches the ability of these women to adapt to the situation emerges and they find a new way of understanding life and experiencing motherhood. Often, as a way of overcoming, they seek support in religiosity, as a comfort for the difficult moments.

The study pointed out that the presence of a health professional at the time of diagnosis and prognosis helps parents in terms of the behaviors to be adopted, in order to enable the reduction of fear after the discovery of the deficiency and the uncertain future.

## Collaborations:

1. conception, design, analysis and interpretation of data: Mayra Cordeiro Oliveira, Rita de Cássia Rocha Moreira, Maricélia Maia Lima and Rosana Oliveira Melo;

2. writing of the article and relevant critical review of intellectual content: Mayra Cordeiro Oliveira, Rita de Cássia Rocha Moreira and Maricélia Maia Lima;

3. final approval of the version to be published: Mayra Cordeiro Oliveira, Rita de Cássia Rocha Moreira and Maricélia Maia Lima.

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