



## Mothers' experiences of children with microcephaly

### Vivências de mães de filhos com microcefalia

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**Objective:** to comprehend the mothers' experiences that had children diagnosed with microcephaly. **Methods:** qualitative study carried out in an assistance Reference Center for microcephaly. It was included 18 mothers of children with microcephaly. Data collect was performed through semi structured interview whose data were submitted to Content Analysis. **Results:** the way the diagnostic of microcephaly was informed and the partner abandonment constituted negatives experiences. The mothers needed dispense integral care that brought intense changes with social repercussions. The participants showed worry with development of children, fear of falling ill/die, and be unable to care for the child. **Conclusion:** it was unveiled feelings of shock, sadness, revolt, blame and impotence after diagnostic, devaluation and rejection by partners and concern regarding growth, development and future of children.

**Descriptors:** Microcephaly; Mother-Child Relations; Family; Caregivers; Biography.

**Objetivos:** compreender as vivências de mães que tiveram filhos diagnosticados com microcefalia. **Métodos:** estudo qualitativo, realizado em Centro de Referência no atendimento de microcefalia. Foram incluídas 18 mães de filhos com microcefalia. Coleta de dados realizada por meio de entrevista semiestruturada, cujos dados foram submetidos à análise de conteúdo. **Resultados:** a forma como o diagnóstico de microcefalia foi informado e o abandono do parceiro constituíram vivências negativas. As mães necessitavam dispensar cuidado integral que acarretou mudanças intensas com repercussões sociais. As participantes demonstraram preocupação com o desenvolvimento dos filhos e receio em adoecer/morrer e não poder prestar cuidados à criança. **Conclusão:** desvelaram-se sentimentos de choque, tristeza, revolta, culpa e impotência após o diagnóstico, desvalia e rejeição por parte dos parceiros e preocupação em relação ao crescimento, desenvolvimento e futuro dos filhos. **Descritores:** Microcefalia; Relações Mãe-Filho; Família; Cuidadores; Biografia.

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## Introduction

The term experience refers to a life experience that generates good and bad marks in a person in a lasting way. Since the beginning of pregnancy, women experience intense emotions about herself and the baby, thus the gestation represents a complex period, in which physical, social and psychic factors interact. Expectations related to the child also build up, then it initiates the dialectic between the internal baby as external subject, that is, between the child with the characteristics that the mother expects and the child as it is<sup>(1-2)</sup>.

It is highlighted the increase of cases of congenital infection by microcephaly in Brazil between 2015 and 2017, in which 13.835 suspected cases of alterations in the growth and development were notified. Among the confirmed cases: 1.433 were receiving childcare; 1.100, early stimulation; and 1.524, were on specialized care service. New cases have been notified, however in smaller numbers than in the 2015 epidemic. The Brazilian Ministry of Health informed that on May 11th 2017 the end of national emergency in public health for Zika and microcephaly<sup>(3)</sup>.

The discovery of the child's limitation, still during gestation, can provide, in some cases, concerns for the mother, social embarrassment and isolation, and the mother may become more exposed and vulnerable because she is the main caregiver. Thus, raise a child with a malformation can be a difficult coping experience, whilst others adapt with success to the situation and even so, experience positive results<sup>(4)</sup>.

In this sense, mothers of children with microcephaly can experience emotions that vary from sadness, disappointment, fault, suffering and shame, by the fact the child is "imperfect". These feelings can arise from the necessity to try to find a cause for the child's malformation, which makes her search for genetic antecedents and even remember how she behaved during the pregnancy<sup>(5-6)</sup>.

In Brazil, the number of suspect cases of microcephaly in 2015 was 1.756. Pernambuco was the state with higher frequency, registering 804 cases related to infection by the Zika virus and other infectious etiologies. This occurrence had international repercussion<sup>(7)</sup>. In this period, many pregnant women or that planned to get pregnant went through fear and worry against the possibility of a microcephaly diagnosis on their child<sup>(2-3)</sup>.

A child with microcephaly may need lifelong care, but that is normally confirmed after the first year of life, in accordance with the level of impairment of the brain. Among the most common alterations associated with microcephaly, it can be pointed: intellectual deficit, epilepsy, cerebral palsy, language and/or motor development delay, strabismus, ophthalmologic, cardiac, renal and urinary tract disorders, among others<sup>(8)</sup>.

It is emphasized that nursing is a profession that has the care as its work object, with important performance on assisting families in adaptation to new demands. In the face of microcephaly situations, both mother and child need care, and the professional needs scientific knowledge to attend the necessities that may occur in the course of the disease<sup>(9)</sup>.

Thereby, it is believed that this research can increase the visibility of the problematic of microcephaly and arouse interest for quality assistance in similar populations. The health professional, especially the nurse, must be able to appoint the chances of development of the child with microcephaly, besides giving the needed attention to the parents, in order to consider the feelings that come from the situation, in order to promote self-confidence to care the child and overcome the difficulties.

In this context, it was questioned: what is the experience of mothers, related to life experiences, with children diagnosed with microcephaly? The study aimed to comprehend the experiences of mothers who had children diagnosed with microcephaly.

## Methods

Qualitative study, based on the narrative approach and biographic. The biographic interview is always a social interaction, in which the situation of interview, by itself, determines, in great part, the speech collected, being that the forms and content of the narrative vary according to the type of dialogue between subject and interlocutor. This type of interview should be extended to allow constant interaction between the researcher and informant, and also for "the interlocutor be taken by the desire to report and that he himself leads the conversation"<sup>(10:24)</sup>.

The scenario of this study was a Reference Center of microcephaly care, located in a maternity hospital in Teresina PI, Brazil. The participants were women who had children diagnosed with microcephaly, the child's main caregiver and was followed-up at the center in which they were chosen from the inclusion criteria: be 18 years or older and self-declare main caregiver by child care. It were excluded those who were not attending the service at the moment of data collect.

The interviews were concluded after data saturation and the reaching of objectives proposed which culminated with the interruption of capture of new components and, thus, determination of the sample. Therefore, 18 mothers participated in the research. Data collect occurred from June to September 2017, through semi structured interviews, in which lasted on an average of 40 minutes and were conducted in a private environment, as from the following guiding question: "talk about your life from the moment of microcephaly diagnostic of your child" It was used a script to avoid dispersion of theme and to facilitate the interview's conduction, with the means to thematize the experiences. In addition to talk about the statement, the participants also filled a sociodemographic form for group characterization and signed the free and informed consent form.

The 18 transcribed interviews and field notes for each participant were analyzed thematically and

the following phases were followed: pre-analysis, analytical description and referential interpretation. The speeches were organized and categorized in the analytical description phase. Then, the documents were coded and categorized on the analytical description phase. At last, the findings were interpreted in light of the available literature on the subject<sup>(11)</sup>.

The name of the participants were coded according to the names of precious stones. Therefore, three thematic axes were determined: Experiencing gestation and the discovery of the diagnostic of microcephaly in the child; Changes in life facing the new reality; and Plans for the future.

The study complied with the formal requirements contained in the national and international regulatory standards for research involving human beings and was approved by the Research Ethics Committee, according to report n<sup>o</sup> 1,982,658.

## Results

The participants' ages varied from 18 to 34 years old, predominated by the divorced or abandoned by partners right after the child's diagnostic of microcephaly, had completed high school and family monthly income between one and two minimum wage. The age of children with microcephaly varied between three months to two years old. Most of participants discovered the diagnostic only after the child's birth.

In the results, the thematization was elaborated according to the qualification of elements present in the speeches of the interviews, as evidenced in the categories: Experiencing gestation and the discovery of the diagnostic of microcephaly in the child; Changes in life facing the new reality; and Plans for the future.

### Experiencing gestation and the discovery of the diagnostic of microcephaly in the child

This category discourses about how was the pregnancy, if it was planned or not, if it was well accepted or not, the expectations against the child, the

way they received the microcephaly diagnostic and the feelings experienced on the information.

When talking about the pregnancy, six participants reported it was planned, twelve said that although it was not planned it was well accepted and none of the women described not accepted pregnancy, all affirmed to have done more than six pre-natal consultations: *I planned my pregnancy, even if he didn't come perfect, I always wanted a child* (Ruby). *My husband and I went to all the consultations, even after we discovered microcephaly in our baby* (Diamond). *My pregnancy, despite having being troubled, I imagined since always how my child would be, loved even in the belly, I know he suffered with me, but today we live for each other* (Sapphire).

In relation to the moment of the child's diagnostic and about the way how they received the news, many reported that the diagnostic was informed in a dehumanized way, without worrying about choosing appropriate words, to explain what was happening, as well as what in fact was microcephaly, the limitations and future potentialities the children could have: *On the ultrasound, the doctor only said that the baby was going to be born with microcephaly, but didn't explain it right, only said for me to look for a specialist. The doctors said as our children were wretched* (Topaz). *He measured her head and said she had microcephaly and that is it* (Crystal). *In a cold way, he said my daughter had microcephaly and that could not live for many years and asked me to leave and to call the next patient* (Ruby).

The mothers' speeches showed that the professionals' attitude, the absence of involvement and the necessary support for adaptation of them to these situations, besides the lack of information for making decisions regarding childcare, were experienced in many moments. For the mother, it is troublesome to find unconformity among the emotional turmoil itself and the professionals' insensitivity.

Moreover, in a lot of reports, the mothers mentioned partner abandonment still being pregnant after the diagnostic, for not being able to accept having to live together with a child with microcephaly: *I loved him more than anything, but at the time we got to the hospital, he just looked at me and said he would not bear to have a child like that* (Emerald). *Most of men can't handle the work, my husband at the*

*time he knew about the diagnostic, kicked me out of home, and said he would not raise an animal* (Topaz). *That coward when he saw that our baby was going to need more care than the others, cheated me with a 16 year old girl and left me* (Diamond).

On the other hand, six participants, indicated greater involvement of the partners after the diagnostic of microcephaly, characterized by the knowledge and the implementation of directions received still in the clinic: *When we heard the news, he said that we would face the whole fight together* (Agate). *He wanted a child, regardless of how it came, if it was with a big or tiny head, he has been a great dad* (Amethyst).

Next, it was requested they reported their feelings experienced by them facing the news of the diagnostic. The mothers, initially, manifest feelings of shock, sadness, pain, rage, anguish, fear, doubt, disappointment, fault and impotency. They found it difficult to find an explanation for the diagnosis and relied on common sense, hope for a cure or spirituality. After, they adapted, however many of these feelings remained for all their lives and search to develop their children in every way to include them in society: *When I got out of the clinic, my husband was waiting for me, but I was in shock without knowing what to say, nothing came out of my mouth* (Ruby). *I was in shock, had a crying crisis, got desperate, questioned God why this happened to me and spent days locked in the bedroom until I accepted that it was true* (Jade). *I cried. I wanted a healthy child of course, but my husband and I, despite the scare of the news, I started loving him more, only the care would be more intense* (Crystal). *At first, I entered in despair and shock, because I didn't know how I was going to raise a child like this, I cried a lot and I just thought about her future* (Onyx).

### **Changes in life facing the new reality**

This category deals with the changes of the mothers' lifestyle on the child's care, how their daily lives became, how the childcare was fulfilled, and if she received family or social support.

The reports have shown changes in the lifestyle in order to attend the child's necessities. Needs perceived by mothers as greater than those given to

healthy children: *Every child needs special care, mine has microcephaly and only needs redoubled care (Onyx). I couldn't have a normal life as I did before, so I worked two shifts and I quit working (Pearl). I went to college and I had to abandon to give all my attention to my kids (Crystal). Before I loved to go to parties, now I can't even sleep well because my kid wakes up each hour crying a lot (Opal).*

Regarding the facilitator points and challenges for child care with microcephaly, most of the mothers reported family support as primordial in this care process, in which the mother feels incapable of having a life like it was before the child's arrival and, thus, launches the demands imposed by the situation on the family. The mother feels the necessity of family support and of the listening attitude as an emotional and practical support for socializing and caring for the disabled child: *There are a lot of care, my child doesn't understand good things, needs help with everything, so the family has to help too, because if not I can't handle it alone (Turquoise). I can't do anything, even to bath is a fight itself, I need help with taking him to consult, financial help, it's a lot (Pearl). If it wasn't for dad helping me, I would literally be dead from so much work (Agate).*

It was also reported the exchanges of experience in the Reference Center as a factor for support aid for their child. Some mothers reported that it was very motivating to see other mothers experiencing the same situation and the same conflicts, because this left them more secure and supported: *When I saw many mothers with the same objective, I realized I was not alone (Ame-thyst). I tell my experiences and other moms also tell me, and we go helping each other (Ruby).*

### Plans for the future

Regarding the feelings and the expectations for the future, the interviewees "saw" the future with uncertainty, leading not to think of plans for their own life and their children: *I had so many dreams. I wanted her to play sports, play, be healthy and strong, I don't know how her future will be (Emerald). Yes, I think about his future, I want him to be a child as healthy as possible, independent that it dreams and does everything it wants (Granite).*

For love and the wish to give the child the op-

portunity to develop it's possibilities, mothers go out looking for treatments, rehabilitation, education and return from religion or beliefs, among other resources, on the certainty of doing what it has to be done, even if it brings her physical and emotional wear. Also, regarding future expectations of her own life, they focus on concerns in not being there for the child: *My life is so sad and rushed with this kid that I don't have time to think about our future, if I die I can't even imagine who's going to take care of her (Topaz). I am worried if I were not here tomorrow who will take care of this child (Ruby).*

### Discussion

Although relevant, the study presents limitations regarding the results generalization, because the data was collected in a single scenario. However, the divulgation of these findings becomes necessary in the current scenario of Brazilian health services, in order to sensitize professionals that receive mothers who have had children diagnosed with microcephaly to provide humanized care, in reception, diagnostic and in the transmission of information about limitations of the health condition studied.

In this study, it was evident the lack of information about the consequences of microcephaly diagnostic and the lack of knowledge about the subject was of great impact in the monitoring and coping of the situation by mothers and fathers, repercuting on family crisis. A study performed, with eleven Brazilian fathers, showed similar results, in which these, on the moment they discovered about the diagnostic and limitations of the child would have among its life, experienced family conflicts<sup>(12)</sup>.

Among this context, it is needed that a multi-professional team, in particular the professional that will inform the diagnostic, know how to recognize the prejudices experienced both by the disabled people lived with it their whole lives, and the parents that are directly associated with that child<sup>(13)</sup>. One must always promote self-confidence and adequate psychological support for better day-to-day family performance. Pa-



rents' empowerment can also be enhanced by promoting well-being, healthy coping with living conditions, improved access to and support for needed services and the facility for better services to families.

Just like the mothers, fathers also experience many feelings regarding the child's condition with microcephaly<sup>(14)</sup>. In this context, the father can express the feeling of rage, while mothers, contrary to that, feel saddened when discovered that the child has microcephaly and that, consequently, will develop limitations through life. A study performed by psychology professionals involving mothers that had children diagnosed with some type of malformation, concluded that women directed all the attention and care only for the child, and ended up forgetting not only themselves, but also their partners. In these situations, it is common that the father feels excluded and experiences the child as a rival that may take him away from the partner<sup>(15)</sup>.

A study showed the fact that happiness is the most common feeling among women when they discover they are pregnant, which was not observed in this study; in fact, the discovery of pregnancy caused "shock" and surprise in some women, for being an unexpected event. These findings are explicable, once there could be stressful events and negative factors which lead to difficulties in accepting the pregnancy of a child with microcephaly, like abandonment or the father's absence, financial problems, unfamiliarity with microcephaly, etc<sup>(16)</sup>. It is of extreme importance the father's active participation, because it is on this father figure that most mothers gain strength to deal with the daily challenges with the children, who take most of the time being the caregivers of these children<sup>(17)</sup>.

Still in pregnancy, both father and mother idealize this human being generated in the womb. They imagine a child with all the perfection a child can have. When this child isn't born in the idealization pattern, it is expected for the parents to be unfamiliar with being different from what it was imagined. In addition, they only start to have new dreams and idealizations

when they accept the reality of the child's limitations, reaching new daydreams that provide other possibilities for bonding<sup>(18)</sup>.

A study carried out with mothers who are direct caregivers of children with microcephaly, showed similar results to this study in which many changes were identified on the life of woman who had a child with microcephaly, among these, stands out the impossibility to do extra domiciliary activities and interrupt or postpone studies and leisure activities<sup>(17)</sup>. This happens by the fact these mothers meet the demands of childcare and also because of the initial difficulty in dealing with the feelings and conflicts experienced. It should also be noted that society perceives that mother as the only caregiver and as determinant agent in this situation<sup>(19)</sup>.

The fatigue and difficulty of mothers in administer simultaneously chores; take care of the child, husband and other children; deal with society's comments and, yet, with exaggerated exposure on social media, are some of the diverse situations that these women can confront every day<sup>(17)</sup>.

It was identified, also, that for the mother, participation and involvement with family contribute on childcare and constitute a fundamental factor on emotional equilibrium. These findings are corroborated by literature, in which the attitude of complicity by the husband provides her with security and tranquility, leading her to feel supported and understood. This behavior is shown how complicity and acquittal of a probable feeling of guilt, making it possible to share the experiences and decide together the issues concerning the child<sup>(13)</sup>.

It is pointed out that the exchanged experiences by other mothers that went through similar situations can be positive and facilitating points to the life of these caregivers. When considering that other mother's experience similar situations, or maybe worse, and when compared to them, the mother feels supported to deal better with the situation, supporting with resignation the situations experienced<sup>(16)</sup>.

Another cause of preoccupation is regarding

the future of this child, in which there is concern about the functional independence, education and the coexistence of this child in society<sup>(19)</sup>. The mothers can worry about their own future, imagining possible illness, aging and also death, reporting the fear of not being present on the life of this child and fearing the attention and maintenance of the children with so many special necessities and with the overload of responsibilities that will be attributed to the child without a disability or to another person, if they are prevented from caring for them or come to die<sup>(17)</sup>.

The kid, when growing up, can meet conditions to enter the job market and acquire autonomy and independence. Logically, in such case, mothers and father will be at ease. The real concern of mothers is those children in which deficiency limits the autonomy, which prevents basic self-care necessary for survival<sup>(16)</sup>.

To understand yourself as responsible for a child with development disorders is a complex situation, of intense changes, discoveries and learnings. To approach the life story of families in this condition, this is, feelings, fears, anxieties and desires in this circumstance is certainly great opportunities for institutions and health professionals to invest in education actions, self-management and health care, with interventions centered on parental needs. The lack of specific measures that identify properly the parents' necessities of children in this condition is notorious<sup>(18-19)</sup>.

The health team can develop strategies that facilitate the family's learning, enabling them for the specific care. Thus, it is believed that it will be possible for the mothers and the children an assistance that approaches the integrality and humanization proposed by the Unified Health System<sup>(20)</sup>.

## Conclusion

To comprehend the aspects of the mothers' experiences who had children diagnosed with microcephaly made possible to reveal feelings of shock, sadness, rage, fault and impotence after the diagnostic, devaluation and rejection by the partners

and concern about the growth, development and future of the children.

## Collaborations

Costa ES contributed to conception, data analysis and interpretation, writing of the article and relevant critical analysis of the intellectual content. Magalhães RLD and Viana LMM collaborated with analysis and interpretation of the data, article writing and relevant critical analysis of the intellectual content. Bonfim EG contributed to the conception and project, analysis and interpretation of the data and approval of the final version to be published.

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