Fellings and perceptions mothers before the microcephaly diagnosis

Sentimentos e percepções maternas diante do diagnóstico de microcefalia

Sentimientos y percepciones maternas antes del diagnóstico de microcefalia

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RESUMO

Objetivo: Apreender sobre os sentimentos e percepções maternas, dado o diagnóstico de microcefalia. **Método:** Qualitativo e descritivo, realizado com três mulheres do interior da Bahia. Os dados foram coletados a partir de entrevista semiestruturada e analisados mediante análise de conteúdo. A pesquisa obedeceu aos princípios éticos, sendo aprovada por um Comitê de ética em Pesquisa. **Resultados:** Três categorias emergiram a partir da análise dos dados: Idealizações da maternidade: Construção X Desconstrução da maternidade idealizada; O sentir diante do desconhecido e suas descobertas; Sentimento materno frente à patologia e a busca pela aceitação social diante do medo da culpabilização. **Considerações finais**: O impacto pela descoberta da doença transpassa por vários sentimentos majoritariamente negativos, que são intensificados quando há falta de informação e apoio profissional e estão interligados com o modo como essas mães vivenciam a condição de vida dos seus filhos.

Descritores: Microcefalia; Anomalias Congênitas; Aceitação Social.

ABSTRACT

Objective: To learn about maternal feelings and perceptions, given the diagnosis of microcephaly. **Method:** A qualitative and descriptive, carried out with three women from the interior of Bahia. **Results:** From the content analysis, three categories emerged: Idealizations of motherhood: Construction X deconstruction of idealized motherhood; The feeling when faced with the unknown and its discoveries; Maternal feeling about pathology and the search for social acceptance in the face of fear of blame. **Final Considerations**: It has been well-known that the impact of the discovery of the disease is influenced by a number of mostly negative feelings, which are intensified when there is a lack of information and professional support and are also intertwined with how these mothers experience the condition of their children's lives.

Descriptors: Microcephaly; Congenital Abnormalities; Social Desirability

RESUMEN

Objetivo: Aprender sobre los sentimientos y percepciones maternas, dado el diagnóstico de microcefalia. **Metodo:** Uma metodologia cualitatica y descriptiva realizado con tres mujeres del interior de Bahía. Los datos se obtuvieron de una entrevista semiestructurada y se analizaron mediante el análisis del contenido de Bardin. La investigación obedeció a los principios éticos, después de haber sido aprobada por un Comité de Ética en Investigación y todos los participantes firmaron el Término del Consentimiento Libre e Informado. **Resultados:** Del análisis de datos surgieron tres categorías: Idealizaciones de materialización: Construcción X Deconstrucción de la maternidad idealizada; El sentimiento ante lo desconocido y sus descubrimientos; Sentimiento maternal sobre la patología y la búsqueda de aceptación social frente al miedo a la culpa. **Consideraciones finales**: El impacto del descubrimiento de la enfermedad está influenciado por una serie de sentimientos, en su mayoría negativos, que se intensifican cuando falta información y apoyo profesional, y se entrelazan con la forma en que estas madres experimentan las condiciones de vida de sus hijos.

Descriptores: Microcefalia; Anomalías Congénitas; Deseabilidad Social.

Introduction

Microcephaly is an anomaly in which the Head Perimeter (CP) is less than two or more standard deviations (SD) from the reference for sex, age or gestation time. It can be associated with several factors, depending on its etiology ranging from structural malformations of the brain to diverse secondary causes.[1]

As of 2015, cases of microcephaly became more visible due to the installed epidemic of the Zyka virus, in which the direct relationship between the two epidemiological outbreaks was identified, which made the eyes of all institutional spheres turn to this problem, which soon came to be considered a public health problem.[2]

In the current context, all the impacts, questions and concerns that the pathology carries are correlated with the socially constructed stigma, in which the meanings given to the diagnosis can lead to the weakening of the mother and child binomial.[3] "Motherhood is built with socially imposed meanings. The ideals about the healthy baby, without any disabilities, become the life project of a vast majority of women".[4]

The perspectives of mothers change a lot when they receive the news of a child with disabilities, as there is a rupture in the existing idealization. Until the acceptance of this child is consolidated, the mother experiences several changes that may be related to emotional and social factors.[5] Based on this assumption, the question is: what are the perceptions and feelings of mothers regarding their children's microcephaly diagnosis?

It should be noted that there is a scarcity of studies on the theme, especially those involving maternal subjectivities, feelings and desires related to the diagnosis. Most studies are based on lines aimed at hegemonic medicine, addressing causes, signs and symptoms, where affected children are seen numerically from the number of notifications. In this sense, there is a silence regarding the mother and the whole context that she fits into. Thus, this study aims to: Learn about maternal feelings and perceptions given to the diagnosis of microcephaly.

Method

This is a qualitative and descriptive study, whose participants were mothers, who have children with microcephaly, living in a municipality in the interior of Bahia. Mothers who were under 18 were excluded from the study.

The collection took place at the participants' homes, in the period of December 2017, with previously scheduled times and days according to their availability. The collection started after approval by the Ethics and Research Committee CEP of the University of the State of Bahia[6] on February 20, 2017, under the protocol number: 1,933,064.

The information was collected through semi-structured interviews. In order to maintain the anonymity of the participants, they were identified with names related to the phases of the moon, namely: New Moon, Waning Moon and Full Moon. The organization of the data followed the content analysis method proposed by Bardin, composed of three phases: pre-analysis; material exploration and treatment of results, inference and interpretation.

Results e Discussion

The presentation of the results obtained begins with a description of the participants using codenames, followed by the sociodemographic characteristics and the categories that emerged with the data analysis.

FULL MOON: 21 years old, married, incomplete high school, mixed race, from home, 2 pregnancies and 1 child. She was doing prenatal care at a private clinic and soon after the diagnosis, she started doing it at the reference FHS in the neighborhood where she lives. He got the diagnosis that his baby had microcephaly at 24 weeks, through ultrasound. Reports having had Zyka virus infection when she was 14 weeks pregnant.

NEW MOON: 26 years old, married, incomplete primary school, black, from home, 3 pregnancies and 3 children. She did prenatal care at the reference FHS in the neighborhood where she lives. She obtained the diagnosis at 37 weeks of gestation, through ultrasound, and one day after the discovery of the diagnosis, she went into premature labor. Reports having had Zyka virus infection when she was 23 weeks pregnant.

WANING MOON: 23 years old, single, incomplete elementary school, mixed race, from home, 1 pregnancy and 1 daughter. She was doing prenatal care at the reference FHS in the neighborhood where she lives, but she started prenatal care late, as she was in the second trimester of pregnancy, when she started. He only obtained the diagnosis at the time of the child's birth. She reports having had Zyka virus infection, but she cannot say whether she was already pregnant or not.

The categories that emerged with the data analysis are presented below:

Idealized motherhood: construction x deconstruction

During pregnancy, mothers begin to make plans and imagine what the child will be like. Thus, the child's life project starts long before birth. Usually, these plans are formulated and thought about considering a child who has psychic and physical abilities considered to be “normal” and, therefore, create their expectations based on the idealization of the perfect child.[7]

When asked what feelings emerged when the pregnancy was discovered, two of the interviewees showed feelings of idealization, anxiety, emphasizing that they have since imagined what their respective children would be like, which is possible to ascertain in the statements described:

> *I already started to imagine how he would be born, if he was going to be a boy or a girl, if he was going to look like me or his father, you keep thinking all the time how it is, how it will be, if he will grow up, run, play [...] But deep down I just wanted him to be born alive and healthy* (FULL MOON).

> *It was a moment of great happiness, discovering that you have a life to take care of, emotion defines it, I wanted to choose a name, said he would look like me, I imagined playing with him in the park, running and jumping* (FULL MOON).

As you say, the idealization of the perfect child is expressed, to exalt a child who is obliged to be considered healthy, will have growth and development according to what is expected by society and follows the beauty standards stipulated by the community in which the parents are inserted. None of the interviewees reported that they were thinking about the possibility of the child presenting any pathology that would condition them to a standard of life different from the one they idealized, based on the socio-cultural construction to which they are subjected.

“From a very early age, women tend to idealize and exercise motherhood, whether in games during childhood, in people's speeches and demands when they reach adulthood and even from their own families”.[8] This can be confirmed by the speech of the women participating in this study.

However, disagreeing with the other interviewees when asked about the predominant feeling, the interviewee Waning Moon demonstrated the non-desire to be a mother when discovering pregnancy. Contrary to the generalization put forward by some authors, regarding the positive feelings related to pregnancy, we emphasize that people have very own feelings, and women in this context have different feelings, in which not everyone wants motherhood, with no idealization of children when they discover pregnancy, especially when pregnancy is not desired, as it is possible to identify in the highlighted speech:

> *I didn't want to get pregnant. So I didn't feel anything, only that my world had collapsed, I just cried and didn't want to take it out. I didn't want to be a mother, I didn't imagine myself being a mother, I have no way of doing that. It is stressful, tiring, you have to think and do things for two. Before it was just me, now I am responsible for someone else* (WANING MOON).

“Motherhood is praised by most people, as if it were something inherent to women, and there is a deviation from this pattern by women, they are criticized”.[9] The speech presented demonstrates that despite emphasizing the non-desire to become pregnant and showing apathy with the pregnancy, she ends up giving in to socio-cultural appeals, deciding to keep the pregnancy unwanted. However, this woman goes through a process of feeling obliged to accept pregnancy and, consequently, motherhood, since its denial contradicts socially imposed norms and, in this case, there is no interest in bearing the burden of not follow the standards set by society.

Then the acceptance of motherhood begins, but without the perceptible idealizations in the other interviewees statements.

> *I just felt really down, it wasn't a pregnancy I had planned, it just happened and I wasn't going to take it off. I started getting used to it, liking my daughter, wanting to protect from everything and everyone, but I didn't like being pregnant* (WANING MOON).

There is an approximation of feelings among the study participants when it is discovered that the baby they expect will not be the one with socially accepted characteristics, since there is, from the diagnosis of microcephaly, the certainty of the physical and developmental differences that escape from the expected standard for a baby said to be normal.

In this regard, when asked about the feelings after discovering the diagnosis of microcephaly, it is clear that they seek subterfuge in religion and in the hope of a diagnostic error. However, the idealization of child's coming is replaced by insecurity correlated with the child's future, especially the fear of losing the child early, as a consequence of the pathology, which until then is little known and thus deconstructing the psychology of 'idealized motherhood'.

These aspects can be observed in the excerpt highlighted in the speech of the interviewee codenamed Full Moon:

> *When you discover that you are pregnant you start imagining your child, thinking about everything, from small to large, following life. When you discover a disease like this you don't imagine anything else, you just want it to be born alive. My feeling for him didn't change, but thinking about the future made it difficult, in fact, I just wanted my son, regardless of how it was, he was my son.*

There is a maternal emotional instability, provided by the uncertainty of the child's future. Such a situation generates fear, anxiety and worry. "Initially they experience mourning, not the child who can survive, but the imagined child, who 'died', even before being born. Then the diagnosis is accepted, but fear becomes the death of the living child ".[10] With the interviewee codenamed New Moon, it is clear that this deconstruction process is happening gradually, after the baby's birth, from living with it, with the perception of the child's limitations. In the moments that preceded the delivery, including the diagnosis and later the delivery, the interviewee made it understand that she remained incredulous regarding the limitations that were to come, which only became more evident with the passage of time. She was unaware of the compromises that the pathology would bring to her son:

> *It took me a while to understand what microcephaly was. Even when he was born, I still thought that he would do everything, I didn't know that he would be disabled due to microcephaly, now that I'm getting real.* (NEW MOON).

The mother always expects the perfect child. Upon receiving news of a diagnosis of congenital malformation, this idealization is deconstructed and, therefore, begins to redefine that dream, passing the perfect son to the real son.[5]

After diagnosis, overcoming the fear of early death, and experiencing daily what it is like to be a mother of a child diagnosed with microcephaly. The interviewees were able to express all the feelings involved in this process, as it is possible to identify in the highlighted statements, about what motherhood in these conditions means, for them.

> *It is to be a more special mother. It is knowing how to live in a world of things that we have no answers to* (NEW MOON).

> *It is to be a mother 24 hours a day, because it is the biggest rush, you have to take it in physiotherapy, pediatrician, neurologist, nurse ... You have to take a five-minute bath, not eat, not sleep ... this is all part of being mother*

> *of a child with microcephaly* (FULL MOON).
>
> *It is a difficult mission, almost impossible, not everyone could take it. It is a tired person all the time, for life for them, we stop living and pass to the mother* (WANING MOON).

With the reconstruction of the royal son, with all the imperfections, the feelings that were before fear and anguish are now overcome. It is through love, maternal care and the various forms of coping that they are able to feel special mothers, those who have a mission and need to take care of their children.[11-12]

We evidenced from the reports that there is a similar discourse regarding activities related to the care of children in a special situation. All of them emphasize the excess of consultations necessary for the follow-up of children diagnosed with microcephaly, which consequently leads them to a tiring routine, in addition to the need to abdicate social life, and sometimes self-care.

To justify the selflessness they impose on their own lives, some of the interviewees point out that altruism makes them 'special mothers'. This is the case of Full Moon and New Moon, which refer to how special they are for taking care of children whose dependence on the mother figure is integral. In addition, there is an exacerbation of feelings, which is noticeable in the speech referring to the happiness related to new discoveries and achievements regarding the growth and development of their children.

The interviewee Waning Moon brings a counterpoint when compared to the other interviewees, as her speech is always based on negativism, emphasizing tiredness and a sense of continuous loss of professional, personal and study opportunities. She highlights the necessary abdication, however reluctantly, of her social life, in favor of motherhood.

Feeling before the unknown

With the increase in cases of microcephaly, mainly associated with the Zyka virus, many mothers are apprehensive when they receive confirmation that their children have microcephaly and demonstrate uncertainties regarding the care to be taken, regarding the pathology and the future of their children.[13]

The speeches, in sequence, show this statement:

> *I didn't even know what this disease was, I didn't know anything, nor that it existed, I never heard of it. H How would I accept without even knowing it? Then I found out by researching on the internet and saw that my son was going to have a smaller brain and was going to be special* (FULL MOON).
>
> *I thought it was a very serious case, but now I see that it is not, that many people think like that because they do not know what it is, because they do not ask* (NEW MOON).

The participant Full Moon brings in her speech the difficulty of accepting a pathology that until then was completely unknown to her. She also reports that the acceptance of her son's diagnosis started concomitantly with the moment when she started researching the pathology, thus knowing its etiology and forms of treatment. In addition, it sought reports from other mothers about the maternal meanings in the face of adversities and possibilities for the development of children with different disabilities.

This study corroborates what is reported by Coll C, Marchesi A, Palacios J14, 'who sees as positive the continuous search for knowledge in the face of the unknown which, in so doing, generates uncertainty'. However, it is emphasized that in view of the permanent observation of motherhood and the discovery of new knowledge about the pathology, there is a resignification of the singularities presented by special children.

The participant New Moon in her speech evidences that what scared her was the fear of the unknown, the doubt about a son who would have needs that would go beyond what, until then, she saw as natural. However, as you become familiar with the pathology, your maternal experience takes on new meanings.

The lack of knowledge about the disease generates prejudice both on the part of mothers and on the part of society and this makes the acceptance process painful, after all, mothers will discover the singularities when they give life to their children.[5] In fact, it is possible to notice this difficulty in the speech of Waning Moon:

> *I was desperate because I didn't know anything, I started thinking ugly things. Questioning God if it was punishment because he didn't want to have a child and then he sent him in trouble. I wanted to die at that moment.*

In view of what was exposed by the participant, it is understood that the moment when he receives the news that the child has a disability can directly influence the acceptance of the diagnosis, since all mothers experience fear of the unknown, causing suffering, guilt and conflicts.[12]

However, when parents are already informed during the gestation period of the probability of an anomaly, this impact or shock may be milder or not happen at the time of birth.[15]

The research participants experienced the diagnosis of their respective children in different ways, not least because they were given at different stages of pregnancy/birth. It is noteworthy in the speech of Full Moon that upon receiving the diagnosis, there was denial and difficulty understanding what was happening. However, soon after searching for information about the pathology, he began to accept and prepare for the birth of his son. It can be seen in the highlighted speech:

> *I received the diagnosis at 5 months of pregnancy and it was horrible, I despaired and said that my son was not a person, he was not human, I left there desperate, anguished, sad* [...] *Shortly after I got home, I took a breath and started looking on the internet to find out what it was, I started to understand, prepare to receive my son, I saw that everything would be different and it just crossed my mind that I wanted to win it all* (FULL MOON).

Receiving the news before birth is a positive factor, as the process of acceptance of the child begins, which allows a better adaptation of parents and family, seeking support networks earlier and clarifying all doubts before having contact with the child.[16]

For the New Moon, who also received the diagnosis during pregnancy, in the 3rd trimester, acceptance of the diagnosis happened gradually, passing through the stages of denial and despair, but there was no time to seek information, as there was a physiological anticipation of delivery, right after the news that the son would have microcephaly.

The lack of knowledge related to the pathology intensified the denial phase of this woman after delivery, in front of the newborn, supported the belief that it would not be microcephalic, despite the physical evidence. This acceptance is happening gradually, after the baby's birth, through the experiences and obstacles that the pathology causes, in the changes of life every day.

> *I was diagnosed when I was 8 months pregnant, it was the worst feeling of my life, I was so nervous that the other day he was born. Then it was even more scary, but when I saw my son I thought he was normal, I thought the doctor was going crazy, the 'record' is falling now* (NEW MOON).

The anxiety present during the pregnancy period may intensify after the diagnosis, generating consequences and prolonging the denial phase, in which mothers ignore their child's problem as if it were not true. They question the diagnosis reliability or the professionals competence, believing that there was an error.[17]

Unlike other mothers, Waning Moon received the diagnosis at the time of child-birth and for this reason there was no prior psychological preparation, which negatively potentiated the feeling in relation to the time of diagnosis. Acceptance is still in progress.

> *I only found out when she was born and saw that she had a strange face, I started to cry saying that my daughter was sick and that she was going to die, in my head there was already death, even today I feel anguished about it* (WANING MOON).

In the birth of a child with a disability, there is an intense shock in the mothers, which is often not mitigated so quickly, perpetuating for some time the acceptance and the feeling of sadness regarding the pathology and living conditions.[19] Another factor that influences feelings towards the pathology, as well as the acceptance of it, is the way the diagnosis is made by the health professional.

When a health professional suspects or proves the existence of a baby's disability, it is natural to have difficulty communicating with the family, but this can be mitigated when the professional has knowledge about the syndromes. The reactions of fathers and mothers at the time of diagnosis can be very confusing, full of doubts and uncertainties about their future and that of their child, such a circumstance can be aggravated depending on how this news is given.[9] It was possible to identify in the speech of Full Moon*:*

> *I received it by the doctor, instead of calming me down and explaining it to me, he freaked out and freaked me out, he said: I've never seen such a thing here in the city, I've never seen such a thing in my life, this is not a human being. Then I despaired. The other doctor was more understanding,*

> *then he explained to me that it was normal, that there were already other cases and that now he came back because of Zyka, then he calmed me down and I became more calm.*

The way the diagnosis was given to the aforementioned participant was a factor that negatively influenced the maternal feelings.

When looking for another health professional, this participant reports having reduced her anxiety a little, as she was able to have a better understanding of the diagnosis.

New Moon had a different experience:

> *The doctor came and asked me if I knew about microcephaly, I said no, then he said my baby had... Then I got crazy and he went to explain me, but he only talked about the size of his head, he didn't say how he was going to look, but he calmed me down* (NEW MOON).

What is said by the health professional at the time of diagnosis ends up affecting the mothers' guidance and acceptance. The less the professionals responsible for the diagnosis focus on the child's difficulties and the more their potential, the better the way these parents will perceive and accept the new child.[18-21] For Waning Moon the moment he received the diagnosis brought a lot of discomfort:

> *The doctor said that she was strange, had a smaller head, then the nurse asked if I already knew she had microcephaly and had not told them [...]. They were already making a surprise and I was scared without knowing what it was about* (WANING MOON).

The birth of a child with a disability is not accompanied by feelings of happiness, on the contrary, it is followed by feelings of discomfort on the part of society.[19]

Maternal feeling towards pathology and the search for social acceptance in the face of fear of blame

It is socially imposed that the mother exclusively bears the obligation to take care of the baby, as well as making a commitment to participate directly in the child's development.[20] Thus, mothers experience adversity, facing them without support, including from fathers, and when trying to provide the best conditions for their children, they end up abdicating their personal desires. It can be identified in the following statement by the research participant*:*

> *I can only do the possible and the impossible to take care of him. Protecting from everything and everyone* (WANING MOON).

The reports on the experiences with the children condition are based on notions of "sacrifice", "struggle", "strength", "blessing" as opposed to an idea of mourning, sadness or dejection (21). And in fact, this is what we identified in the excerpts of:

> *It's crying in every smile, achievement, victory* (FULL MOON).
>
> *One day I pray before sleeping, the next I sleep praying and the next I sleep crying* (NEW MOON).
>
> *I love my daughter, but I feel tired for so much. I wish I hadn't* (WANING MOON).

In view of the differences found in the statements of the participants above, it can be inferred that each of these women meant the pathology of their children in a different way. The feelings of sadness and anguish are often present and the mothers do not expose them, imagining that the exposure of the non-acceptance of the fact can be understood with the attitudes of a 'bad mother'.[21]

The social and cultural representations existing in our society is a limiting factor for the acceptance of a diagnosis of the special child, because for many the disability has a stigmatizing meaning, in which the appearance of normality or the invisibility of deviation from the norm are the main elements for social inclusion or exclusion, which leads to the blaming of mothers of children with disabilities.[15] The speech in sequence highlights these existing influences:

> *Only the other people that I said my son was going to have microcephaly in, who looked surprised, said that I was supposed to take it out, that it was ugly, that I was young and then I was going to have a normal child, that was not to accept a sick child, they kept asking what I had done to be like this* (FULL MOON).

Therefore, mothers develop protective measures to protect their children, even if these measures impose a restriction on social life and the isolation of babies, so that they are not seen and arbitrated by others.

> *The fact that he was different and everyone wanted to see it bothered me. I was afraid to leave the house and someone would laugh at him* (NEW MOON).
>
> *I didn't tell anyone. I thought the people were going to accuse me, blame me, say I wasn't careful. I hid it, 'I took the case'. I don't think I ever went out with her other than as a doctor, it's not easy for a mother to notice someone laughing at her daughter* (WANING MOON).

At birth, babies are faced with a world full of conceptions and if they have a disability, together with their mothers, they can face prejudices and difficult situations in their relationships. Thus, mothers and family members as a whole develop a concern that affects them intensely after birth.[9]

Another aspect, perceptible in the study, is the need that mothers have to reaffirm to society that despite the condition imposed by the pathology, their children will have ample conditions for development, although they intimately demonstrate uncertainties related to the 'normality' of social life of your children.

> *Today I already make a point of talking to people about it (NEW MOON)".*
>
> *"It's having to talk to people all the time that, despite the difficulties, limitations and head size, my son is a human being and can be happy* (FULL MOON).

The ability of mothers to overcome a difficult experience is a process that involves personal, relational and social aspects and that in the creation of new personal and collective resources can arise from suffering, as it is the mother who fights against social indifference, a battle whose target is your child's well-being and acceptance with society.[23]

It is also reported the resignations related to the social roles of mothers: wife, woman, professional, student, mother of other children. They start to dedicate themselves exclusively to the care of children with microcephaly. As evidenced in the statements:

> *Everything has changed, today there is him, now everything is for him, I forgot myself* (FULL MOON).
>
> *I studied and stopped, I don't work, I don't have friends, I don't have family, always just me and her* (WANING MOON).

The cultural environment and society, due to sociological constructions, will demand from these mothers behaviors that they deem appropriate in the face of motherhood, often demanding that they abdicate everything to take care of their children, otherwise they will not be considered and neither feel good mothers.[20]

Final Considerations

The way mothers of microcephaly's children managed to signify their feelings from the diagnosis to the present moment was shaped according to their experiences, adding to the time of adaptation to the diagnosis and, above all, from the knowledge they acquired about the disease. pathology, whether acquired through research and / or contact with health professionals.

We evidenced that these mothers feel the need to renounce important aspects of their social, professional and personal lives, starting to dedicate themselves only to caring for their child with microcephaly. However, this abdication does not occur without trauma and / or suffering and, in some situations, was motivated by the existing social and cultural demands.

It was notorious that the impact of disease discovery leads to several mostly negative feelings, which are intensified when there is a lack of information and professional support, and which are interconnected with the way these mothers experience their children's life conditions at the present time.

Regarding the health professionals mentioned by the participants during the interview, given what was posted, it was realized that they need to get closer to maternal perceptions regarding the pathology in question, since this approach allows the development of the feeling of empathy, without being dissociated from technical knowledge and ability to solve problems.

As limitations of the research, it is possible to point out the scarcity of studies focused on the theme. And the existing ones pointed out more aspects related to pathology or the increasing numbers of cases of microcephaly in the context of the zyka virus. In addition, the reduced number of participants may have limited the expression of other meanings and perceptions, however, as it is a less common condition, even in the face of the outbreak, the sample proved to be satisfactory.

We believe that there is room for further research on microcephaly, especially in terms of meanings, whether maternal or family, as it is known that holistic and humanistic approaches are capable of promoting wide-ranging transformations in people's lives whose experience is associated with chronic pathologies.

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