The difficulties faced by mothers in caring for children with microcephaly

As dificuldades enfrentadas pelas mães no cuidado à criança com microcefalia

Las dificultades que enfrentan las madres para cuidar a los niños con microcefalia

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RESUMO

Objetivo: Conhecer as dificuldades que mães cuidadoras de crianças com microcefalia vivenciaram desde a descoberta até experimentarem as práticas de cuidado. **Método:** Estudo qualitativo, descritivo e exploratório, realizado com mães de crianças com microcefalia nas cidades de Campo Formoso e Senhor do Bonfim-Ba, cujas análises se deram por método de análise de conteúdo. **Resultados:** O conteúdo analisado foi agrupado nas seguintes categorias: Vivenciando o medo; Assumindo responsabilidades: é hora de cuidar; As especificidades do cuidado; O desafio do acesso ao serviço de saúde e Deslocamento: problema que gera problema**. Considerações Finais**: O estudo permitiu perceber que os familiares enfrentam diversos tipos de dificuldades, estas surgem no momento da revelação da microcefalia e se estendem no cotidiano familiar, entretanto, mesmo diante das adversidades existentes, as mães cuidadoras se empenham para ofertar o melhor cuidado possível à sua criança.

Descritores: Microcefalia; Criança; Cuidado Materno.

ABSTRACT

Objective: To know the difficulties that mothers who care for children with microcephaly experienced since the discovery until they tried the care practices. **Method:** Qualitative, descriptive and exploratory study, conducted with mothers of children with microcephaly in the cities of Campo Formoso and Senhor do Bonfim-Ba, whose analyzes were carried out by content analysis method. **Results**: The analyzed content was grouped into the following categories: Experiencing fear; Taking responsibility: it's time to take care; The specifics of care; The challenge of access to health services and displacement: a problem that creates a problem. **Final Considerations:** The study made it possible to perceive that the family members face several types of difficulties, these arise at the moment of the disclosure of microcephaly and extend into the family routine, however, even in the face of existing adversities, the caregiving mothers strive to offer the best possible care to your child.

Descriptors: Microcephaly; Child; Family.

RESUMEN

Objetivo: Conocer las dificultades que experimentaron las madres que cuidan a niños con microcefalia desde el descubrimiento hasta que probaron las prácticas de cuidado. Método: Estudio cualitativo, descriptivo y exploratorio, realizado con madres de niños con microcefalia en las ciudades de Campo Formoso y Senhor do Bonfim-Ba, cuyos análisis se realizaron mediante el método de análisis de contenido. Resultados y discusión: El contenido analizado se agrupó en las siguientes categorías: Experimentar miedo; Asumir la responsabilidad: es hora de cuidarnos; Los detalles de la atención; El desafío del acceso a los servicios de salud y el desplazamiento: un problema que genera un problema Consideraciones finales: el estudio nos permitió darnos cuenta de que los miembros de la familia enfrentan diferentes tipos de dificultades, que surgen en el momento de la divulgación de la microcefalia y se extienden a la rutina familiar, sin embargo, incluso Ante las adversidades existentes, las madres que se preocupan se esfuerzan por brindar la mejor atención posible a sus hijos.

Descriptores: Microcefalia; Niño; Cuidado Materno.

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ORIGINAL

Introduction

Microcephaly is a rare congenital malformation, defined by the head circumference (CP) below two standard deviations, in babies born at 37 weeks of gestation or more, with the measurement for boys equal to or less than 31.9 cm and for girls equal or less than 31.5 cm.[1]

Even though it was considered a rare event, in October 2015, the State Health Secretariat of Pernambuco, notified 26 new cases of the disease, and requested support to complement the investigations. Later, other states, mainly in the northeastern region, started to report new cases, it was an important event for public health.. [2]

Children with CP below the average can be cognitively normal, however, in most cases microcephaly is accompanied by motor, cognitive and sensory changes, which vary according to the degree of brain involvement. In general, cognitive impairment occurs in 90% of cases. [3]

Thus, these children need to be fully connected to health services for early stimulation sessions, monitoring growth and development, consultations with specialists, among others, making them dependent on these services and comprehensive care. [4]

The chronic condition in childhood also has implications in the family context, which can bring several difficulties in the routine experienced by the family. In these conditions, the family dynamics are modified, with new conditions imposed on the care of the child. Therefore, the mother generally takes responsibility for herself, as the only one capable of taking daily and direct care for these children and ends up modifying their habits by defending the idea that they are the only ones able to take care of their children.[5]

In this context, this study aimed to learn about the difficulties that mothers who care for children with microcephaly experience in their daily lives.

Method

This is a qualitative, descriptive and exploratory study, carried out in two cities in the interior of Bahia.

The research participants were located based on a previous screening of families in the Municipal Health Departments in which children with microcephaly are registered. Address and telephone number of those responsible were provided. Subsequently, there was an initial contact with the participant, and a visit was scheduled to carry out the research.

Participants in this study were mothers who actively act in the care of children with microcephaly. Parents who were over 18 years old, living in the same house as the child and an active component in care were included. Mothers with cognitive impairment were excluded.

Six children with microcephaly were identified, three in each city. Four mothers agreed to participate in the study. The participants are between 18 and 34 years old; three are married or living in a stable relationship, only one is single. As for education, two have completed high school, the other two have not yet completed.

Data collection took place through a semi-structured interview, recorded with an audio recorder and will be archived by the researcher for a period of five years.

The data were analyzed using the content analysis method proposed by Bardin. This method is seen as a set of techniques for analyzing communications that aim to obtain, through systematic and objective procedures for describing the content of messages, indicators (quantitative or not) that allow interfering with knowledge related to the production / reception conditions (inferred variables)) of these messages.[6]

This research was submitted and appreciated by both Municipal Health Departments and by the Ethics Committee of the University of the State of Bahia, approved on March 28, 2017, under CAAE n. 64627717.5.0000.0057 and Consubstantiated Opinion No. 2,244,143.

In compliance with Resolution 466/12 of the National Health Council (CNS)[7], the objectives of the study, its importance and other questions of the interviewees were clarified, the Informed Consent Form (ICF) provided by the researcher, was then read and signed individually, prior to the interview, guaranteeing the subject's anonymity and the use of data only for the purposes of developing the study.

Results and Discussion

After a careful analysis of the data, four categories emerged: “Experiencing fear”, “Assuming responsibilities: it's time to take care”, with the subcategory “The specifics of care”, “The challenge of accessing the health service”, followed by subcategory “Displacement: problem that generates problem”, which are presented below.

Experiencing fear

Most women, when they experience motherhood, create expectations about the child that is being formed, idealize it being healthy, without any defects, performing psychic and habitual activities to a normal child..[8]

When the diagnosis is given, the plans change and feelings of fear, anxiety and anguish begin to emerge, falling on the family and especially on the mother, who idealized her perfect child. From that moment on she starts to have a will to protection and a responsibility for the care of this child.[9]

> *So, at the moment I was shaken, because it is a new situation, a new case, you know, then I was so worried, how I was going to deal with the situation, but over time I got used to it. More love, affection and more responsibility came (E4).*

It is inevitable that mothers and family show concern when receiving the diagnosis, since this is a situation that was not in their plans, as well as the fear of the unknown, but soon, the feeling of love for their child starts to act, as shown the speech above and things start to organize in the mind, occurring to the deconstruction of idealized motherhood, for the real child.

Faced with this unpredictable situation, the family is faced with a new adversity, where instead of receiving an idealized child, they face the arrival of the child with unusual characteristics.[10]

The mother needs a more particular and professional approach at this time, since this is an embarrassing and difficult experience, it rigorously affects her personal maternity project. Being the health professional responsible for transmitting this news to the family, with great sensitivity, care and caution.[10]

> *It was a big scare when I did the first ultrasound, the doctor scared me and scared my family [...] he said that this was not a child, I didn't know what it was [...]. I said: My God, if my son is not a person, what will be? We stayed on the floor (E2).*

In view of the above report, it is clear that the family was shaken when receiving the diagnosis, it is natural that this happens, however, the way in which the health professional gave it could contribute to the increased fear. It is well known that some health professionals are not prepared to mediate such news, they transmit the diagnosis in an unkind manner, without thinking about how the family will behave in the face of the fact. In this context, the health professional must support the family, calming it down and unveiling ways for an effective coping with the disease.[11-12]

Society imposes care for children and the home environment for women and this impacts even more when the child presents some exclusive care, the diagnosis represents a new phase in the lives of these families, it is necessary to remodel the care functions for the new child, with that comes insecurity and the question of whether she will be able to assume this new responsibility[8,11], as shown in the statement below:

> *How will it be? [...] Will I be able to take care? Will I be able to do everything for him? Will I understand anything about him?(E2).*

It is common that during pregnancy the mother expresses doubts about how her child will be cared for, however when she finds out that her child will have limitations, these doubts increase even more, especially because they have never experienced a similar situation.[13]

Taking responsibility: it's time to take care

The arrival of a child in the family environment brings changes in every context, especially in the mothers' lives. This experience can become even more difficult, when the child has functional dependence, which will require comprehensive care. There are several difficulties experienced by these caregivers, who, after receiving the diagnosis of microcephaly, modify their habits, abandon their moments of leisure, work and mainly renounce their own self-care, to dedicate themselves to their child with microcephaly.[14]

In accordance with the statement of the authors above, one study participant reports that she has no help with regard to the care of the child, most activities are carried out with his presence, as there is no one to help her.

> *It's always me. If I go to the street, I have to take him, to go to the clinic it has to be me, there is no one to leave. It's me and him. Finding someone to look after him would be difficult. (E2).*

Sometimes mothers end up neutralizing themselves due to their child's life, giving up the role of being a woman and giving priority to motherhood. At the same time, they learn to deal with difficulties and find ways to face the situation in a milder way and provide the best possible care.[8]

> *You have to learn from it every day, because it is always a different day. Sometimes she's smarter, other times more calm, so she has to know how to interact, I can't demand too much from her (E3).*

Some mothers demonstrate that they have knowledge about the various limitations that the child has or will present throughout his life, as a result of microcephaly. They recognize the barriers that will be faced by them and their children. But even in the face of uncertainties about the future, most mothers believe in their recovery, even if it is a long and arduous process to go through.[12,15]

Children require a lot of care, and children with such a condition demand even more, due to the specifics of the living condition. Mothers fill their time by oscillating between giving attention to their children and carrying out domestic activities, in addition, there is a need to readjust the structure of the home.

> *I keep trying to play with him, calm down. I made him a car seat. I even made a protection on the door and on the window, I set up a little business so as not to enter the muriçocas. I leave it asleep and already take advantage and I will do something else(E2).*
>
> *She wants a lot of attention. If you're paying attention to her, she doesn't care about anything else (E3).*
>
> *You can't be alone for a moment, someone's always there (E4).*

In addition to the care given directly to children, mothers need to deploy to perform domestic activities and promote a safe environment for their children.

Specificities of care

Still surprised by the unexpected diagnosis, the family becomes aware of the difficulties that will arise in their new routine. The arrival of a child with microcephaly brings with it specificities that will be noticed on a daily basis. In this context, the family needs to find subsidies to face this situation.

> *I was going to have difficulty, I wasn't going to be a normal child to eat. Care at home was also going to be different. (E1).*
>
> *It wouldn't be the same care as a normal baby (E2).*
>
> *A special child is not like the care of a normal child. Everyone would have to turn around to take care of her [...] I would have more responsibility, more care (E4).*

Health professionals are essential, as they provide important information about how the child will be cared for, these clarifications serve in a certain way to prepare him for what lies ahead.

The performance of the multiprofessional team is essential in assisting mothers and their children with microcephaly, in the face of changes in the maternal environment and especially in view of the impact on the diagnosis. Mainly aimed at coping strategies, such as planning, strengthening support for families and welcoming these mothers.[15]

Parents with little or no guidance are unable to cope with this situation, so it is important that health professionals instruct them, as the family's expectation is to obtain positive feedback regarding the child's development, even if it takes time, but this response will ease your suffering and facilitate the acceptance process. [16]

Over time, when acquiring new information about the condition of your child, what was initially fear and doubt, can become an adaptation, permeated by intense learning. The adaptations that have taken place are necessary, since they outline a new way of caring for the child, adapting them to the chronic condition that the child presents.[17]

> *At bedtime, when eating, everything is difficult, because he doesn't eat well. [...] (he) chokes, understand? He cries a lot(E1).*
>
> *He chokes a lot [...] when he gets sick, he gets very agitated, he doesn't keep quiet, he just cries (E2).*
>
> *Only when she cries a lot, she gets very angry (E4).*

These mentioned situations happen routinely, and have a certain degree of complexity, since they are characteristics common to children with this life condition, such as the choking, reported by participants E1 and E2.

At this moment, mothers develop the awareness that their children will be different, the routine will not be anything they imagined for the idealized child, the daily life will be different and special. When they are experiencing the new care routine, the mothers have the possibility to perceive, on a daily basis, the characteristics and difficulties that their children have.

The challenge of access to health services

All forms of assistance to children with microcephaly are recommended by the Unified Health System (SUS). Health establishments must guarantee the complete evaluation of the child, following the development in Basic and Specialized Care, in the pediatric, neurological, ophthalmological and auditory scope, in addition to guiding families on the importance of early stimulation. Early stimulation brings many benefits to the child, since it minimizes their functional limitations and favors their neuropsychomotor development.[3,18]

Although SUS guarantees comprehensive assistance to children, families face some obstacles to obtaining it, especially with regard to highly complex services, as the municipalities where these families reside do not have them.

> *Here in the city we don't have the resources to deal with this. If I had treatment here in the city, it would be much better, it would be ideal (E4).*

The inexistence of an institution specialized in providing specific care is an obstacle in child care, which can directly affect its development, since more heterogeneous care is provided in these establishments.[19]

In addition to dealing with the lack of specialized services in their cities, family members also face setbacks in accessing primary health care, as they need to arrive earlier to get care, they suffer from a lack of vacancies and professionals, in addition to waiting time for Query.

> *Waiting for a date to be attended, when you go, takes a long time. The last time she was consulted at that post was a year ago. I couldn't get any more consultation (E3).*
>
> *Get up at dawn to get a card for her (E4).*

Primary health care is seen as a gateway for users to other services, where the patient must be welcomed and have good quality care, according to their individual and collective needs. However, in view of the statements, it is possible to notice that in some places it does not happen that way, making the assistance not effective.

Users of primary health care are dissatisfied with the organization and functioning of the service, requiring reorganization. Primary care must be effectively advantageous for children and their families, taking into account their health needs and reality. [20-21]

Thus, some families seek ways to complement the needs for assistance in health services and at home, through the search for guidance on how to proceed in certain situations, as well as through the use of private services.[21]

> *I try to know what's going on, what's going to happen. Doctor, if she has the flu, which medicine do I give? If she feels a stomachache? I order all the medicines right away (E2).*

> *There is no specialist doctor in this area here. I made a point of paying, but there is no review. Since you can't do anything, I'm going to take my leaps, regardless of anything (E3).*

Faced with the presented context, although the mother has presented feelings of denial when receiving the diagnosis, when adapting to the condition of her child, she starts looking for ways to offer better care to the child, consequently promoting improvements in her development.

Displacement: problem that generates problem

Although care for children with microcephaly is guaranteed by law, families face many barriers to achieving it, especially with regard to access to specialized services. Most of these are not offered in the cities where they live, causing them to move from one city to another, which may generate some obstacles.[16]

In this context, the study participants report that moving from one city to another is considered unpleasant, since they see their routine modified to meet their children's health needs, in addition to the obstacles faced during the itinerary.

> *The day that I find difficult is the day of traveling, having to leave here with him. (E1).*
>
> *He travels a lot, every 15 days I travel to Salvador. It's too horrible, you leave here at dawn. I leave on Tuesday morning, to be there on Wednesday (E2).*
>
> *Today I consult with her there in Salvador. There is no way to go by car. By bus it is very complicated for us to be driving there, especially with her. (E3).*
>
> *We have to move from our city to go somewhere else. If it were in the city, it would be much easier (E4).*

Moving from one city to another is one of the biggest problems, in addition to the tiredness and obstacles generated, the family has the consequence of the illness of their child.

> *Whenever we go, she gets sick. She never had a day for her to arrive and not get sick. He fell ill this week, got the flu (E3).*

In addition to dealing with the obstacles provided by the trip, in some cases families do not have support from public institutions to help them on this journey, as a result, the family stops taking the child to treatment because there are no conditions for it.

> *They don't want to release the car anymore. I am not able to go there because it is very complicated, especially in the rain, because I have to take a taxi, depending on the taxi again to go back, there is no car to take me there, there is not. You can't always go, because it's far, everything is far (E3).*

Families often do not have the financial means to meet the treatment conditions, thus, it is necessary the support provided by institutions, with regard to all the resources necessary for proper treatment.[21]

Final Considerations

This study made it possible to know some difficulties that mothers of children with microcephaly face on a daily basis. These difficulties go beyond the obstacles caused by the condition that children have, they are also related to the physical and emotional loads that the caregiver has.

The discovery of a pregnancy means something special for a family, which starts to idealize the baby that will arrive in the best possible way. However, the results showed that the discovery of a congenital malformation deconstructs all this imaginary and gives rise to fears, anxieties, doubts and concerns about the uncertain future that deals with new family adaptations.

The way in which the diagnosis is given contributes to the bad feelings to intensify. Thus, it is necessary that health professionals have more humanized attitudes when mediating such news, in addition to strengthening relationships with caregivers, through support, bonding and actions that promote improved care.

When conforming to the new condition, the family starts to adapt the routine according to the circumstances that the child presents, they perceive the limitations and difficulties, and organize the care process.

Care is organized according to the disposition of each member, however, the mother is seen as the main caregiver and occupies her time alternating between caring for the child and the chores of the home, causing her physical and emotional overload.

Mothers find it very difficult to seek child care, especially with regard to access to health services, due to the distance from the residence to specialized services of high complexity, forcing them to travel to the capital to achieve this type of care. of service.

Another obstacle refers to primary health care, which should offer shelter to these families, but it has met the demands in an unsatisfactory way, reflecting on the lack of assistance to the child and his family.

However, even if assisting a child with microcephaly is not easy, the family seeks ways to deal with the situation and provide excellent care to their child, seeing them well is their greatest satisfaction.

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