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## EVALUATION OF PUBLIC POLICY FACING CHILDREN WITH MICROCEPHALY IN THE CARIRI REGION ACCORDING TO GUARDIAN'S VIEW

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### ABSTRACT

In 2015 Brazil experienced an outbreak of Zika virus infection, which resulted in the birth of newborns with microcephaly. As a result, the Ministry of Health launched public policy protocols for microcephaly and Zika Virus. Based on that, the objective of this study was to evaluate both the quality of assistance provided and the effectiveness of public policies aimed at children with microcephaly, in the Cariri region, Northeast, Brazil, according to their parents / guardians perspective. This is a qualitative exploratory descriptive research. The study was carried out with the parents / guardians of children with microcephaly, who are monitored by the specialized attention of a Polyclinic in the Cariri region. Data collection instrument was formulated based on three modules from public policy protocols for microcephaly by the Ministry of Health, and it took place through a semi-structured interview. Firstly, sociodemographic data was sought. Secondly, an instrument based on the Theory of Uncertainty in Illness was applied and the answers were recorded and analyzed according to Minayo's content analysis and then classified following three steps. Finally, the research was appreciated and approved by the Ethical Principles for Research with human subjects. In short, data analysis showed parents / guardians satisfaction of public policies. Nonetheless, the feeling of incapacity they feel due to the desire of finding a cure for their children is remarkable, which requires a psychic approach directed at these parents / guardians.

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## INTRODUÇÃO

In 2015, Brazil presented a high number of cases of microcephaly. After analyzing the facts, scientists associated ZIKV to a flavivirus (flaviviridae family), transmitted through the mosquito *Aedes Aegypti*, which was isolated from a female febrile Rhesus monkey in

the Zika forest, in Uganda, on April 20th, 1947<sup>1</sup>. It is a congenital malformation characterized by a head circumference of less than 33 centimeters that can be associated with several other facts such as structural malformations of the brain, environmental and genetic exposures, use of drugs during pregnancy, and also with some infections<sup>2</sup>. According to the latest survey by the World Health

Organization (WHO), more than 7,000 suspected cases have been investigated. As a result, a National Plan to combat microcephaly was created, as a mobilization to prevent the advance of cases. In addition, the National Policy for Integral Attention to Children's Health (PNAISC) was created in 2015, which incorporates the Program of Integral Attention to the Health of the Child (PAISC) with a view to the intervention of different areas of child healthcare, that can be targets of public health<sup>3,4</sup>. Social and emotional impacts, in addition to families financial burden, as well as the lack of appropriate preparation of health teams, especially of physiotherapists, represent challenges to both assessment and appliance of methods of early mobilization to promote changes in public policies over time.

All things considered, the question is: What is the perception of parents / guardians about public policies regarding their quality and resolution; and how do they perceive the difficulties faced?

Therefore, the objective of the study was to assess the quality of care provided and the effectiveness of public policies aimed at children with microcephaly in the Cariri region, Northeast, Brazil, according to their parents / guardians perspectives.

## METHOD

It is characterized as a descriptive exploratory research with a qualitative approach<sup>5</sup>. This approach can be understood as a totalization process that never reaches a definitive stage. In the specific case of service evaluation, the way of perceiving all aspects that make up the quality evaluation is part of a whole, which implies concepts that are produced historically and socially<sup>6</sup>. The aim of the study is to explore the set of opinions and social representations on the topic intended to investigate<sup>7</sup>. The study collaborators were parents / guardians of children who have delayed language, cognition and motor development as a result of microcephaly, due to Zika virus infection, who attended and were assisted by the Center for early stimulation of a Polyclinic in the Cariri region. Regarding the inclusion criteria, it was: parents / guardians of children with microcephaly monitored by the polyclinic, registered in the Early Stimulation Program, who have accepted to participate in the research and have signed the Free and Informed Consent Form - TCLE, in addition to being present on the day of collection. Regarding the exclusion criteria, it was: parents / guardians of children who were born with a gestational age greater than or equal to 37 weeks; birth weight greater than 2,500g, with no complications during pregnancy or childbirth, and without cardiorespiratory changes; with absence of signs of neurological impairment, congenital malformations, syndrome or sensory changes, such as visual and hearing impairment. The collection instrument was formulated in the light of the three modules from public policy protocols for microcephaly by the Ministry of Health: Module I - Observation at the Specialized Service Unit; Module II - Interview with the professional team in order to check documents at the Unit; Module III - Interview with the user, which aims to verify the satisfaction and perception of users regarding health services, with regard to their access and use, as well as their anxieties regarding the pathology of their children. Therefore, data collection started with a first contact with the parents /guardians, by health professionals, explaining the research in order to have better acceptance, in which they signed the TCLE, followed by a semi-structured interview which was recorded with the authorization of the collaborators. The interview was held in a private room in the polyclinic to ensure anonymity and reduce the risk of embarrassment. Data collection was carried out during the sessions in which the research facilitator observed module I, module II and module III. The closure of data collection was done by the criterion of saturation or redundancy. It was realized that the topics were already depleted, as the responses were repeated. After collecting the data, it was analyzed based on Minayo's content analysis and then classified following three steps: 1- the participants' speeches were fully transcribed and organized to be analyzed; 2 - the material was explored, identifying the nuclei of understanding of the text and classifying it, based on grouping ideas; 3 - the most relevant themes were categorized,

analyzed, interpreted, discussed<sup>7</sup>. As for the ethical and legal aspects of the research, the rules of Resolution No. 510/16, of the National Commission for Ethics in Research with Human Subjects, were respected and followed. The project was sent to the Human Research Ethics Committee of Juazeiro do Norte College No. 2,297,683.

## RESULTS AND DISCUSSION

Even though the inclusion criteria takes into account parents and / or guardians who are users of the healthcare provided by the polyclinic, it is noticeable the dominance of 100% of mothers as directly responsible for these children. In the reflections of the interview, anonymity was chosen. Each participant was numbered in order to facilitate access: (Mother1) refers to the responses of interviewee 1, (Mother2) to interviewee 2, and so on. In (Table 1), mothers were classified into categories referring to their socio-demographic profile, and subsequently it was analysed the mothers' perception of microcephaly and the effectiveness of public policies, in addition to assessing the effectiveness of the service offered and the difficulties encountered.

Table 1. Mothers socio-demographic profile

VARIABLES	N0	%
<i>AGE (years old)</i>	-	-
20-23	3	21
24-28	10	65
29-33	2	14
<i>MARITAL STATUS</i>	-	-
Married	5	33
Divorced	2	13
Stable Union	2	13
Single	6	40
Widowed	0	-
<i>Origin</i>	-	-
Inner city	15	100
<i>EDUCATION</i>	-	-
Illiterate	1	7
Incomplete Fundamental education	0	0
Complete Fundamental Education	2	13
Incomplete Medium education	4	7
Complete Medium education	7	47
Incomplete Higher Education	1	7
Complete Higher Education	0	0
-	-	-
<i>OCCUPATION</i>	-	-
Housewife	4	27
Hawker	4	27
Janitor	3	20
Hairdresser	1	7
Administrative Agent	1	7
Student	1	13

Source: Developed by Authors, 2017

In order to explain the understanding of parents and children's experiences, the data was presented in categories, as follows : Does the mother have knowledge? or Doesn't she? 2) The idealized child and the real child 3) Challenges and difficulties of treatment 4) Services and support networks.

### Category 01: Does the mother have knowledge? or Doesn't she?

The awareness of having a child diagnosed with fetal malformation due to microcephaly is unveiled by their mother based on the child's diagnosis, in which they become aware of this pathology and its consequences. As a result, they all become proactive in improving their children's quality of life.

According to mother's reports:

*"I do. knowing about this diagnosis was very difficult. It is microcephaly and it lasts forever. It was sad, it was terrifying, I was broken heart"* (Mother 4)

*"Yes. During prenatal I already knew that he was going to have microcephaly. It was horrible and very distressing for everyone, it is a situation I don't like to remember" (Mother 3).*

*"Yes, I have brief knowledge about it, the minimum to take care of him. It was sad, I do not wish this for anyone, I was feeling very bad" (Mother 2).*

*"I do. I know that my son will always be like this and that he might always be like this. It was sad, very difficult" (Mother 12).*

*"It is very serious, a huge disability, they cannot even walk. It was on a Wednesday when he was born, that the doctor told me at the hospital. I cried a lot, but my son was there and alive" (Mother 6).*

*"It is a disease in which the child is not normal and it is dangerous. Yes, my baby won't be normal, but I love it so much. I suffer from it because I won't see my baby grow and run. It was terrible, I cried a lot, I was in a panic and my husband couldn't stand it, so he left the house" (Mother 9).*

In view of the diagnosis of microcephaly, the family, especially the parents and the microcephalic child, need psychological support, according to <sup>8</sup>. Sá & Rabinovich<sup>9</sup>, explain that when the child is born with a disability, it will be difficult to meet the expectations of the parents, and rejection may occur, not always with the child, but with the destruction of the idealization of a perfect child. It is necessary to "register" this child, and the parents must learn to balance the child's demands with their own needs, managing conflicts and dilemmas in caring for them. This moment is traumatic and can cause a strong disruption in family stability. Gomes & Piccinini<sup>10</sup>, point out that the news of the diagnosis inflicts a narcissistic wound on the parents, since their fantasies related to the expected child are not achieved. In addition, the time it takes for this wound to heal can extend for years, equivalent to the time it takes for the psyche to rebuild, which can influence the paternal function. In another study they report that, in general, parents go through phases of overcoming. Initially there is the shock phase, in which there are feelings of fear, threat and guilt; subsequently, the phase of denial is experienced, in which parents avoid reports of their child's disability; from that moment on, the parents go through an immense sadness, with feelings of anxiety and anger. After this period is over, there is a reaction phase, in which one seeks to understand the situation and adapt to it and; finally, there is the reality phase, in which they face the raising of a disabled child<sup>11</sup>.

## Category 02: The idealized child and the real child

It can be noticed in the mother's discourse the idealized and the real child. The pain they feel, the anguish of not being able to do anything for their children, the image of a perfect child and the faith that they will improve are very present in their daily lives.

According to mother's reports:

*"It will be difficult to know that my daughter will suffer, as she will always need me, but when I compare her with other children, my baby is fine, she is healthy in her own way" (Mother 13).*

*"Yes, this first phase is being very difficult for accommodation. I had to reorganize my life to suit the needs that my son needs. I only foresee improvements" (Mother 3).*

*"Yes, she will depend on me, but she will be a healthy girl, it is difficult to understand that she will always be like this, but my faith is greater than it" (Mother 10).*

*"I know, I also know the limitations that he will have. I have faith that he will be always stable and that he will walk, at least" (Mother 11).*

*"One thing is certain, no one expects to have a disabled child at home. Nobody has that perspective. You imagine a child who will walk, talk, play, run, do what a normal child does, you know" (Mother 1).*

Parents hope to deliver a healthy baby who will grow up like any other child, since it represents the couple's self-image and it is then, their mirror. The problem is when these same parents, full of expectations, goals and idealizations, have to face the reality of delivering a child diagnosed with a disability, such as microcephaly. According to Coll, Marschesi and Palacios<sup>12</sup>, there is a long way to go, having several phases, starting from the verification of the disability until its acceptance. The shock phase occurs at the moment when the diagnosis of the deficiency is communicated, causing, in most cases, a general stunning, which can hinder or even prevent the encoding of the information, messages and orientations received. It has a traumatic character, however when the parents are informed beforehand, during the gestation period, about the probability of an anomaly, this impact or shock may be milder or not happen at all, at the time of birth. In a similar study by Dantas Filho<sup>13</sup>, a father who had agreed to participate in the research, at the time of the interview, escaped. A distancing relationship between him and his baby was noticed, repeating the pattern of relationship he previously had with his own parents, in his family of origin. When listening to his wife, she drew a traditional father profile about her husband, showing no emotional involvement with the baby. When it comes to "being a man", this particular father fits the Northeastern stereotype of being a strong male, in which courage, braveness and fearlessness, are the main attributes required. Moreover, the role of a father is marked by authority, excluding the emotional field, in order not to be considered feminine. It was observed that all care actions for this baby are thus centered on the figure of the mother, resulting in an overloading to her. Given the diagnosis of microcephaly, it is possible that the mother together with the family faces difficulties in the arrival of this new child, difficulties that are related to acceptance, prejudice, and feeling of insecurity due to the countless unpredictable occasions that will have to be faced after birth. For this reason, it is extremely important that society and the scientific community are attentive to this parent-child interaction and how it contributes to the child development. It is worth mentioning, how relevant is the support of a professional team composed of doctors, psychologists, occupational therapists, among others, who can help not only the father, but the family in general, for this new life adaptation<sup>14</sup>. According to Barbosa, Chaud and Gomes<sup>15</sup>, the emotional impact generated by the confirmation of the disability, through the diagnosis, triggers in the great majority of times, the emergence of feelings of irritation, guilt, sadness, disappointment and hopelessness, given the possibility of not obtaining or achieving the fulfillment of future expectations that is attributed through the birth of an idealized child and that now, presents itself differently from what was expected. This causes a period of great suffering and concern, as a result of many doubts they have. Regarding the interviewed mothers, it was observed that they achieve a certain emotional calm, being, at the beginning, enough to demonstrate a more realistic look, which helps in the development and elaboration of objectives and means of how to help the child, leading them to the adaptation phase (acceptance). It is worth mentioning that each subject will experience this moment subjectively with more or less intensity.<sup>12</sup>

## Category 03: Challenges and difficulties of treatment

Lima<sup>16</sup>, evaluated the maternal involvement in the physiotherapeutic treatment of children with disabilities and concluded that the professionals who assist the child play a fundamental role in transforming the view of the parents in relation to the child. He considers that this view, socially shaped by misinformation, in addition to prejudice and negative historical load, can be transformed with offered knowledge and support. This study corroborates with the researcher that 100% of the interviewees are satisfied with the services and support network.

According to mother's reports:

*"Here, it is new, well organized, clean and has everything my son needs, doctors are all good" (Mother 4);*

*"I love to bring my son here because it is in our region and the best was done. Everything here is good, each professional does everything for your baby and monitors you" (Mother 9);*

*"Here, it is easy to access, when the government built it, it was thinking about improvements. Everyone who works here supports the whole family. I thank God every day" (Mother 15).*

#### Category 04: Services and support networks

The research showed the importance of the role of professionals in the face of telling the news of the diagnosis, from the clarification of the pathology, to the way it is transmitted, offering adequate support to the family. The impact of the news of a disabled child mobilizes emotional and sentimental reactions until they can readjust themselves and get psychologically prepared to take care of this disabled child. In other studies, based on the data available in the interview, the importance of psychological monitoring was found to establish the bonds between parents and their children. Given the diagnosis of microcephaly, it becomes difficult for the father to face the difficulties experienced by his child, thus hindering the interaction between them. Several institutions are concerned with the well-being of mothers of children with microcephaly, leaving aside the importance of the father in the child's development<sup>17</sup>. For Umphred, therapeutic and family psychological support is a fluent process, as all individuals are in a process of change. Moreover, everyone needs to be involved to enable the child to have a better quality of life, which supposedly promotes growth in all areas. It is worth highlighting the relevance of the involvement of the multiprofessional team together with psychologists, who can help not only the father, but the whole family for this new life adaptation<sup>14</sup>. In a large population study carried out in Canada and in another with a similar methodological design developed in Australia, it was found that patients and family members showed dissatisfaction with the information received from the health team (doctor, physiotherapist, speech therapist, occupational therapist). Items classified as unsatisfactory include: I wish to be informed about treatment options, to have information about the child's progress, to obtain information about the child's disability condition (causes, evolution, predictions)<sup>18</sup>.

Paradoxically, the results showed that the provision of little information did not influence satisfaction with the service received. This clearly demonstrates that families have not yet realized the importance of being better informed<sup>19</sup>. In recent years, much has been done to restructure the training and performance of health professionals. The New Curricular Guidelines for Health Courses, approved on September 12th, 2001, which establish the profile, competences and skills of these professionals, recommend generalist, humanistic, critical and reflective training for performance at all levels of health care, as well as the mastery of essential epidemiological contents. Nonetheless, this cannot be restricted to the individual, and must include the family and social realities<sup>20</sup>. Although the guidelines propose curricular reformulations, there are gaps in professional training and practice. The physiotherapist, for example, has their history linked to rehabilitation actions and a professional identity linked essentially to curative actions. This image may be modified by expanding the professional's actions<sup>21</sup>. On one hand, it can be noticed mothers' satisfaction with the service offered. On the other hand it is necessary to better prepare professionals and structure health services with strategies that contribute to better family-therapist-patient interactions, thus decreasing the family's resistance to the therapeutic proposals aimed at the child, as well as the professionals' resistance to families participation, since due to the limitation and the need for special care, it can generate unfriendly behaviors by parents towards those professionals.

#### Final Considerations

The literature highlights that the impact of the diagnosis, the need to adapt to the new situation and other facts lead to specific needs not only for the child, but also for their family members. All of these axes must be considered for determining strategies to be drawn. In short, we were able to get answers from mothers satisfied with the service. Nonetheless, the birth of a child with a disability fragments the feeling of capacity and reliability, causing a slow and deep

narcissistic wound that is difficult to recover. The difficulty with the news reveals marks on the couple, because they feel guilty for the loss of an idealized and planned child, surfacing ambiguous feelings, facing this new being. Therefore, it was possible to observe how professionals are involved in politics and with users, since they are committed to incorporating health care, demanding to understand that the behaviors initiated at this age are crucial for the rest of their lives, because they affect the person's integral development.

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