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VULNERABILITIES IN THE CARE FROM THE PERSPECTIVE OF MOTHERS OF INFANTS WITH MICROCEPHALY

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ABSTRACT. The general objective of this study was to understand elements of vulnerabilities involved in the care of children with microcephaly, from the perspective of the mothers. It was an exploratory study with a qualitative approach. To collect the data, a sociodemographic questionnaire and interview based on the Method of Scenes were used. The analysis of the interviews was performed using the thematic categorical analysis technique. Thirteen mothers with a mean age of 25 years, ranging from 16 to 37 years old, participated. It was observed, in the statements of the participants, elements of vulnerabilities, related to the doubts and tensions about the discovery of the congenital malformation in the child, above all, considering the unpreparedness of the health team at the time of diagnosis; as well as the lack of confirmation about the causes of microcephaly. In addition, deficiencies related to social support were observed as a family and/or companion, demanding from these women an exclusive dedication to the care of their children, mainly in the face of a daily routine of care. It concludes by pointing to the relevance of this study, since when referring to a recent epidemic, such data can assist the practice of health professionals, in addition to being able to contribute to the construction, updating and implementation of targeted public policies for children with microcephaly and, consequently, their families.

Keywords: Microcephaly; vulnerabilities; mothers.

VULNERABILIDADES ACERCA DO CUIDADO NA PERSPECTIVA DE MÃES DE BEBÊS COM MICROCEFALIA

RESUMO. O objetivo geral deste estudo foi compreender elementos de vulnerabilidades envolvidas no cuidado de crianças com microcefalia, a partir da perspectiva das mães. Tratou-se de um estudo exploratório, com abordagem qualitativa. Para a coleta dos dados fez-se uso de questionário sociodemográfico e entrevista baseada no Método de Cenas. A análise das entrevistas foi realizada por meio da técnica de análise categorial temática. Participaram 13 mães com média de idade de 25 anos, variando entre 16 e 37 anos. Observou-se, nas falas das participantes, elementos de vulnerabilidades, relacionadas às dúvidas e tensões acerca do descobrimento da malformação congênita no filho, sobretudo, diante do despreparo da equipe de saúde no momento do diagnóstico; bem como em relação à falta de confirmação acerca das causas da microcefalia. Além disso, foram observadas deficiências relacionadas ao apoio social como família e/ou companheiro, exigindo destas mulheres uma dedicação exclusiva no cuidado dos filhos, principalmente diante de uma rotina diária de cuidados. Conclui-se apontando para a relevância deste estudo, uma vez que ao se referir a uma epidemia recente, tais dados podem servir de auxílio para a prática de profissionais de saúde, além de poder contribuir para a construção, atualização e efetivação

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de políticas públicas direcionadas para as crianças com microcefalia e, consequentemente, suas famílias.

Palavras-chave: Microcefalia; vulnerabilidades; mães.

VULNERABILIDADES ACERCA DEL CUIDADO EN LA PERSPECTIVA DE MADRES DE BEBÉS CON MICROCEFALIA

RESUMEN. El objetivo general de este estudio fue comprender elementos de vulnerabilidades involucradas en el cuidado de niños con microcefalia, desde la perspectiva de las madres. Se trata de un estudio exploratorio, con abordaje cualitativo. Para la recolección de los datos se hizo uso de cuestionario sociodemográfico y entrevista basada en el Método de Escenas. El análisis de las entrevistas fue realizado a través de la técnica de análisis categorial temática. Participaron trece madres con promedio de edad de 25 años, variando entre 16 y 37 años. Se observó, en las declaraciones de las participantes, elementos de vulnerabilidades, relacionadas a las dudas y tensiones acerca del descubrimiento de la malformación congénita en el hijo, sobre todo, ante la falta de preparación del equipo de salud en el momento del diagnóstico; así como en relación a la falta de confirmación acerca de las causas de la microcefalia. Además, se observaron deficiencias relacionadas con el apoyo social como familia y / o compañero, exigiendo de estas mujeres una dedicación exclusiva en el cuidado de los hijos principalmente ante una rutina diaria de cuidados. Se concluye apuntando a la relevancia de este estudio, una vez que al referirse a una epidemia reciente, tales datos pueden servir de ayuda para la práctica de profesionales de salud, además de poder contribuir a la construcción, actualización y efectividad de políticas públicas dirigidas para los niños con microcefalia y, consecuentemente, sus familias.

Palabras-clave: Microcefalia; vulnerabilidades; madres.

Introduction

The Zika virus was first detected in 1947 in the African continent (OMS, 2016); however, the first outbreak of the disease was only recorded in the mid-2000s, occurring in 2007 in several islands in the State of Yap (archipelago of the Federated States of Micronesia). In recent years, occurrences of the disease have also been recorded in French Polynesia (2013/2014) and, more recently, in Brazil (2015/2016), the last occurrence being a public health concern worldwide (Kindhauser, Allen, Frank, Santhana, & Dye, 2016; Petersen, Jamieson, Powers, & Honein, 2016).

The emergence of cases related to the Zika virus in Brazil occurred concurrently with a 20-fold increase in the incidence of microcephaly in infants, especially in the Northeastern Brazilian region (where the virus epidemic was more frequent), attracting the attention of health professionals (OMS, 2015). After a series of investigations carried out by several researchers from Brazil and the world, only in 2016 the association between the Zika virus and the observed cases of microcephaly was confirmed (Mlakar et al., 2016). The fact, as Diniz (2016) stated, is that “there would not be an epidemic like the one that observed in Brazil if the territory were not inviting to rapid spread: mosquitoes, precarious sanitation and a fragile health policy to deal with the new disease” (p. 38). Thus, the Zika epidemic reinforced the public health crisis in the country, especially because *Aedes aegypti*, the main vector responsible for virus transmission, had been known to the Brazilian population for more than four decades and was responsible for epidemics of dengue every summer. In addition, it is known that mosquito proliferation usually occurs in more vulnerable areas, in households with poor conditions, inadequate sanitation and poor collection of garbage (Henriques, Duarte, & Garcia, 2016). Given this situation, the disease spread throughout the country, reaching the entire population, but with greater aggravations and concerns related to the female population, due to its relationship with the birth of babies with microcephaly.

Regarding the profile of women infected with the Zika virus, data presented by the last epidemiological bulletin published by the OMS (2016) show that it is mostly women of childbearing age (20 to 49 years old), low schooling and self-described browns, revealing a profile associated with the portion of the population that is in a state of social vulnerability.

In the same period, there was also an increase of 1,923% of notifications related to the birth of microcephalic children in Brazil. In the first half of 2016, there was an increase of 157% of cases (Diniz, 2016). In line with the Epidemiological Bulletin #6, published by the Ministry of Health (2017), in the period from 2015 to 2016, 10,232 suspected cases of newborns and children with microcephaly were reported. Of these, 21.5% were confirmed, with 0.4% being classified as having probable association with the Zika virus through vertical transmission. Most of the notifications were concentrated in the Northeast of Brazil (65.7%), followed by the Southeast (20.6%) and the Central-West (6.5%). The five states with the highest prevalence of reported cases were: Pernambuco (21.3%), Bahia (14.3%), Paraíba (9.0%), São Paulo (8.1%) and Rio de Janeiro (7.8%).

Beginning in 2016, while the first generation of children with microcephaly was developing, television and electronic newspapers began to report the difficulties that mothers faced in seeking treatment for their children. Such difficulties tend to involve territorial, structural and organizational aspects of the health care network, since many reside far from medical centers and need to move several kilometers to reach treatment sites. Moreover, the experience of these mothers involves a routine of care, examinations, consultations, stimuli, where most of them have been dedicated exclusively to this praxis. Other reports show the challenge of taking care of this generation of microcephaly, in addition to reporting, even in a complaint, the abandonment of the partners after the knowledge of the diagnosis of their children, many of whom depended or continue to depend financially on their husbands. Thus, it is questioned: what elements of vulnerability are present in the care of mothers with children with microcephaly?

In the field of health, the concept of vulnerability emerges as a strategy to address the various dimensions that involve the health-disease phenomenon. For authors such as Ayres, Paiva and França Jr. (2012), while keeping several aspects of the concept of Health Promotion, the perspective of vulnerability projects a new look at the health-disease process, also including, in this binomial, the ‘care’, seeking not only to understand the mutual relations between agent, host and environment, but understanding its entire course, taking into account even the various knowledge and resources (or lack thereof) in this process, as well as the sociopolitical, cultural, intersubjective context of the subject, bringing to light an important element in the process of illness, the social and intersubjective part. Still in agreement with the authors mentioned above, the concept of vulnerability is built from a political perspective, focused on human rights, by understanding that “people and groups that do not have their rights respected and guaranteed have worse profiles of health, suffering, illness and death" (p. 82). That is, they are in situations of potential vulnerability. It is understood, therefore, that the idea of vulnerability accompanies the phenomenon of illness, being considered the chance of people getting sick due to personal and collective interrelated aspects, whose three-dimensionality (individual, social and programmatic) acts inseparably (Ayres, França Jr, Calazans, & Saletti Filho, 2003).

In the context of microcephaly, for example, such dimensions could explain whether health beliefs or the level of knowledge of mothers who had babies with microcephaly due to the Zika virus influence the pathological process; how family, friendships, affective-sexual and professional-users relations can interfere with the process of caring for their children; and to understand which political and economic aspects interfere with the implementation of specific and multisectoral policies on microcephaly and Zika virus.

Therefore, it is observed that the course of illness is not static, encompassing determinant factors ranging from a micro- to a macro perspective, involving biological, behavioral, psychological, social and governmental aspects that exert influence in all sections of the pathological process, from the elements that can promote its emergence, through the development and final part of the process, as well as the possibilities of a rejoinder to the determinants of the problem (Ayres et al., 2003).

With regard to the Zika epidemic, imprecision of the data and lack of knowledge about the virus and its consequences can directly influence the vulnerability of mothers of infants with microcephaly, even affecting their prevention and care. In this sense, the general objective of this study was to understand elements of vulnerabilities in the health of mothers in the care of children with microcephaly.

Method

This was an exploratory study with a qualitative approach with participation of 13 mothers of microcephalic infants, living in three states of Northeast Brazil (Alagoas, Paraíba and Pernambuco). In Paraíba, the meeting place between the researcher and the participants took place in the Foundation for Support to the Disabled (FUNAD); in Alagoas, the meeting place was the Association of Physically Disabled of Alagoas. Participants who had difficulties to go to the meeting places as well as the respondent from the State of Pernambuco were part of the survey through an instant messaging application. The mean age of participants was 25 years, ranging from 16 to 37 years. Most were married or lived in a stable relationship, had a family income of up to 02 minimum wages and had only one child, the average age of children who had microcephaly 1 year and 1 month, 7 of them being female. The table below presents this data in more detail.

Participation took place in a non-probabilistic and for convenience, having as selection criteria the Snowball technique, starting from three participant matrices (one in the State of Paraíba, one in the State of Pernambuco and the other in the State of Alagoas). Regarding the ethical aspects, the participation of the interviewed women was conditioned to a Free and Informed Consent Term, thus ensuring the privacy of the subjects, secrecy and confidentiality of the data in accordance with Resolution of the National Health Council (CNS) 510/2016.

For data collection, a sociodemographic questionnaire was initially applied to characterize the participants. Then, a semi-structured interview was applied, based on the Method

Table 1. Characterization data of participants

Sociodemographic Variables		n
State	Alagoas	7
	Paraíba	5
	Pernambuco	1
Marital status	Married / Stable Relationship	10
	Single	3
Education	Incomplete Elementary School	1
	Complete Elementary School	3
	Incomplete High School	2
	Complete High School	4
	Incomplete Higher Education	2
	Incomplete Graduation	1
Income	1 minimum wage	1
	2 minimum wages	9
	3 or more minimum wages	3
Number of children	1 child	7
	2 children	3
	3 children	3
Currently working	Yes	2
	No	11

of Scenes, proposed by Paiva (2012). This method considers that from the description of a given scene, it is possible to bring to the surface elements, contexts, actors and senses that are involved and can be significant for the condition of vulnerability to the sickness of people. According to the author, when working through daily scenes, it is possible to understand the subjectivity of people and their socio-cultural context, which can contribute to the verification, for example, of violation and/or neglect of rights, contributing to certain populations being in greater vulnerability than others. For this study, the moment of discovery of pregnancy was used as an evocative scene. Data from the interviews were analyzed using the thematic analysis technique proposed by Figueiredo (1993).

Results and discussion

From the interview data emerged three thematic classes, which had their respective categories and subcategories, as can be seen in the table below:

Table 2. Thematic categorization of interviews

THEMATIC CLASSES	CATEGORIES	SUBCATEGORIES
From Pregnancy to Childbirth	1. Pregnancy	a) Unplanned b) Unknown pregnancy
	2. Zika virus and the Microcephaly outbreak	a) Doubts and tensions about the disease b) Preventive Aspects c) Pre-natal and suspicion of the disease
	3. Microcephaly diagnosis	a) Discovery of Microcephaly after childbirth b) Unpreparedness of the health professionals/team to reveal the diagnosis c) Confirmation by Examinations
	4. Reaction and Family support	a) Family b) Companion/husband
Social assistance care	1. The Zika virus as the cause of Microcephaly	a) Lack of confirmation
	2. Congenital syndrome of the Zika virus	a) Symptomatology b) Care Routine and Appointments and Examinations c) Information about the disease
	3. Access to health services	a) Public vs. private care b) Intra- and inter-regional differences
	4. Social support	
Mothers’ experiences of care	1. Daily difficulties	a) Care routine b) Exclusive dedication
	2. Prejudice	
	3. Guarantee of social rights	

In the first thematic class, the category Pregnancy emerged, in which it was observed that the majority of the participants reported that they had not planned the pregnancy or that they discovered it at an advanced stage. Many participants said they did not know they were pregnant when they had symptoms of the Zika virus. What is worth mentioning is the lack of family planning, in contrast to Law 9263/1996, which provides for it in the health services of the Unified Health System (SUS), demonstrating a certain difficulty in the implementation of this policy, corroborating with research which indicate that 55.4% of pregnancies in Brazil are not planned (http://brasil.estadao.com.br/noticias/geral,55-das-maes-nao-queriam-ter-filhos-aponta-pesquisa,10000092047). Although it was not questioned whether these women had access to information and contraceptive methods, it is assumed that the majority of participants in this study should be aware of human reproduction, since seven of the interviewees had at least incomplete high school.

In the second category, *Zika virus and the Microcephaly outbreak*, the interviewees reported that when they discovered that their children had microcephaly, many doubts arose about the disease, starting from the origin to the possible consequences caused in the baby, as well as questions about the treatments and sequelae. Despite being an old pathology, it was with the advent of the Zika virus epidemic that microcephaly reverberated throughout the world, gaining media space. According to the participants, many were the information, coming to generate suffering in them, as reported below:

> *When my son completed a month of life, started the reports on TV and on the internet. I got to the point of not watching and not accessing the internet! I had a little depression, but not because of my son, but because of what was said on TV ... On TV I only said that babies would not develop, they even said they could not resist! And they talked about it all the time. Then I started to cry a lot, to feel very scared. The issue they said they could have seizures tormented me! As I said, I disconnected from social networks.* (Mother 7, 18 years)

Within this same category also emerged the *Preventive Aspects* about Zika virus infection, in which the mothers verbalized that even developing habits that tried to prevent mosquito bites and a possible infection, as recommended by the Ministry of Health and widely publicized by the media, it was still not enough. Therefore, it is important to note that vulnerability in the context of microcephaly goes beyond the frontier of individuality, although this woman is commonly blamed for the prevention, who is charged to make use of repellents, long-sleeved clothing and pants, which can generate guilt when the infection occurs. With regard to the subcategory *Prenatal and suspicion of the disease*, it was possible to understand that despite technological resources, there was often no detection of congenital malformation during pregnancy, which points to the need for better preparation and qualification of equipment and professionals especially in the face of an epidemic. It is worth remembering that, despite the outbreak experienced by the Brazilian population, microcephaly is not a new disease, as previously mentioned.

In the absence of a diagnosis during prenatal care, the third category, *Diagnosis of Microcephaly*, presented in its first subcategory, known as *Discovery of Microcephaly after childbirth*, reports of mothers about their experience of knowing their children, the first contact, the first glance, encountering the joy of birth and the surprise at realizing that the cephalic perimeter of his baby was smaller than normal:

> *... as soon as she was born I noticed in the delivery room ... When she was born I noticed that she was a bit disproportionate, there I was told that her cephalic perimeter was around 31.5, but that she was all proportional, it was the same thing I was told when I was pregnant... I saw her in profile, and then the moment I saw her was a shock, because I had seen a lot of baby with microcephaly, not personally, I saw*

> *it because there was a lot ... anyway ... the television network covered the case a lot and then I saw a lot. And then when I saw her in profile I figured something was not right, even because I had zika in the second month of pregnancy.* (Mother 2, 26 years)

In this sense, the interviewees also voiced questions that involved the *Unpreparedness of the health professionals/team to reveal the diagnosis*, as the second subcategory was called. To characterize it, follow the reports below:

> *The doctor already knew and did not tell me, you know, she did not want to tell me, I do not know why. She said she was not prepared to say ... she hid it from me ... but there it was a medical error, it was for her to have told me, to prepare me for the news, since 6 months, I should be prepared for such news ... I did not go to the doctor anymore because I did not trust her anymore.* (Mother 3, 23 years old)
>
> *I went into the delivery room by myself, I saw her soon and they commented in front of me that she had microcephaly. Without even making examinations they still commented, and it hurt a lot.* (Mother 8, 19 years old)

The discourses of both mothers reveal that professionals are not always ready for the moment of revealing the diagnosis of malformation, indicative of programmatic vulnerability. This is an important scene, since it can motivate family members to seek appropriate treatment according to the level of disability of their children, as it can be a traumatizing moment and may negatively influence the child's rehabilitation process (Barbosa, Chaud, & Gomes, 2008) and even generate a rejection, as well as other psychological repercussions for the mother and the mother-baby relationship.

In the third subcategory *Confirmation by Examinations*, the participants explained the necessity of performing imaging tests to confirm the diagnosis of microcephaly, which is a necessary conduct of the professionals and a necessity of the mothers themselves, in order to avoid doubts.

The last category of this first thematic class dealt with the *Reaction and family support*, in which two subcategories *Family and Companion/husband* emerged. In the first one, it was observed that the feelings experienced by the mothers are also extended to the family, which shares the same emotions regarding the idealized baby versus the real baby, and there is even resistance in accepting the diagnosis. Regarding the reaction of the father, for example, it was found that those who assumed paternity also had feelings of incredulity about the diagnosis of their child. However, it was also possible to verify that some parents did not continue with their partners after the diagnosis, nor are they present in the care of their children, leaving these mothers in a situation of greater fragility. This is because, according to the mothers, they become the main responsible in the routine of childcare, which alone is tiring, especially in a situation of disability, which requires treatments, stimuli, appointments with several professionals weekly, in addition to those that already have other children to care for, indicating that *"... the father and the mother is me, for everything, for everything, in the difficult hours, in the hours of joy, it is just me" (Mother 13, 34 years old).*

The second thematic class, classified as *The Social Assistance Care*, presented in its first category *The Zika virus as the cause of Microcephaly*. It was verified that of the thirteen mothers interviewed, eleven reported that they had not yet received confirmation that the microcephaly diagnosis of their children was due to the congenital infection by the Zika virus. Thus, there is a gap in the confirmation of the cause of this diagnosis. It is not known if the results are reaching professionals and services and are not being passed on to the main interested or if these results are not even coming. Because it is a new correlation between cause (Zika virus) and effect (microcephaly), there may be a delay in confirming these results. However, this situation can cause even more distress to mothers, since even the cause of this anomaly is not known to them.

In addition, because of the large number of cases of microcephaly, the population and the health authorities of the country were caught by surprise, and many doubts arose about the disease that perpetrated the socially shared knowledge. As the cause of this increase was not known, several rumors appeared that tried to explain the outbreak, ranging from a vaccine applied in the pregnant women to its transmission by the dengue mosquito (popular name of *Aedes aegypti*), besides the possibility to have caused by larvicides that were added to the water supply system (Diniz, 2016). Such doubts continue to permeate the imagery of the mothers who participated in this study, which are reinforced by the absence of an examination that proves such correlation:

> *So far, I have not received any exam. Geneticists from São Paulo came here to FUNAD, they collected the blood to tests, to see what it really was, but so far ... Some say yes, that was zika, others say no, much is suspected of vaccine expired, there nobody knows ... because these tests were not proven, in national network no examination was proven that really was zika. Where the X of the question is, because we do not know it, stand not knowing.* (Mother 4, 29 years old)

On this correlation, it is important to emphasize that research has shown that the consequences of congenital infection by the Zika virus go far beyond microcephaly, and it is still rash to say the size of the involvement of this flavivirus in the development of children. Clinical, laboratory data, imaging examinations, and psychomotor development of congenitally infected children suggest a spectrum comprising Zika Congenital Syndrome characterized by signs such as: epilepsy, visual and hearing impairments, delays in psychomotor development, excessive and redundant scalp skin, ventriculomegaly, dysphagia, irritability, arthrogryposis, among others (OMS, 2016; Rasmussen, Jamieson, Honein, & Petersen, 2016; França et al., 2016; Van der Linden et al., 2016; Diniz, 2016).

In this sense, the second category that addresses aspects related to the *Congenital syndrome of the Zika virus*. Being under investigation, there is still some difficulty in characterizing this syndrome, both for researchers, health professionals and, above all, for mothers, who have to deal with the complexity of the symptoms that appear and the various diagnoses arising from the syndrome, as illustrated below:

> *It's ... anyway ... all that happened, and he had calcification in the brain, had ... I do not know how to explain, then, anyway ... he had the lesions. Then we went back to Maceió, so he started the follow-up with the neurologist, to do physiotherapy, tests, and then came the news that he had a visual loss, is ... he has a visual loss of the left eye, then he did a little ear exam, he has a left ear hearing loss as well. Yeah ... he started doing physiotherapy, and then he did another test, which is the electroencephalogram, and from there we discovered the seizures, which is very common, you know, in babies with microcephaly ... and that's it, so I think that is briefly that.* (Mother 1, 19 years old)

Thus, understanding the complexity of the syndrome and the various areas that may be affected, the second subcategory appears, which involves the *Care Routine and Appoint-*

ments and Examinations. By itself, a baby already demands a change in the daily life of the family, and this change is multiplied, above all, when the child needs redoubled care, multiprofessional care and various stimuli, a fact corroborated by the participants' speech. In spite of this, they also reported the ease they are having with marking appointments and examinations, since children affected by microcephaly have priority. However, the mothers complained about the delay in receiving the results of these tests, which is essential for monitoring development and could compromise the evolution of treatment.

Access to health services was also very much discussed in the speech of these women, with two subcategories emerging: *Public vs. private care* and *Intra- and inter-regional differences*. Regarding the first subcategory, the mothers emphasized some difficulties they are having, mainly about the time which they have to wait to get an appointment with a specialist, either by the SUS or by the health plan. According to them, the marking is fast, but the time between marking and the day of the appointment is very long. In addition, most of them reported making as much use of the private network as the public network, although in a complementary way, given the waiting time in this, especially in the case of these families whose routine is around the daily appointments of their children, in addition to the time they spend on domestic child care. Here, it is important to consider the peculiarity of these families around the routine of their children, since these difficulties must be treated as programmatic vulnerabilities, and it is therefore necessary to rethink the practice, structure and organization of public health services in a way to ensure that health care reaches this public in an equitable way.

There were also comments on *Intra- and inter-regional differences* in health services, access and quality of information, and treatments offered, pointing to some disparities in terms of progress in microcephaly care, and transportation that these mothers need to do systematically in order to have better quality health care, as this mother reports:

> *... because I always travel with him to Recife. ... I learn more things than here (Maceió), I think because the focus is there ... here there is no similar center, large, right, so we get more experience ...* (Mother 11, 19 years old)

The last category of this second thematic class refers to the *Social support* received by these women, especially among the mothers who had children with microcephaly, who reported that in these spaces is constructed a network of support, protection, exchange of knowledge and sharing of experiences, being of great importance. In addition, the support received by health departments and non-governmental organizations were also cited as important sources of support in the discovery of this new maternity, of this new way of dealing with a child with special needs, especially in relation to appointments and services required, as well as for the provision of information related to their rights, as can be seen in the following reports:

> *... But we are also accompanied by the Municipal Department of Maceió; there we have a group and everything and there is always a meeting for us to talk to the mothers. It's once a month. They accompany, provide assistance, get appointment, seek recourse, understood? Making a meeting with someone who helps us, some neurologist, someone from the INSS, someone of this type, did you get it? Then, we always take doubts away, these things .... We receive here, the mothers of Maceió, an aid of the Municipal Health Department, in relation to expediting appointments, marking, lecture, brings someone from the INSS, brings someone… some doctor*

> *... that kind of help, you know? Help to get treatment ... Also emotional assistance, these things ... We have a Whatsapp group with the secretariat staff, always looking for improvements, fraternization, anyway ...* (Mother 1, 19 years old)

> *The staff of the municipal department holds one meeting per month, with participation of mothers, grandparents, parents of children with microcephaly. We meet every month ... And some people came from Brasilia here at home to visit him. There came a staff ... from the department. They are from an NGO that is supporting families with children with micro.* (Mother 9, 37 years old)

Lastly, the third thematic class raised was named *Mothers' experiences of care* and its first category concerns the daily difficulties experienced by the mothers. In it, they were able to report the complexity of the *Care routine* that ultimately requires these women, most of the time, an *Exclusive dedication* to their child with microcephaly. The participants spoke about the difficulties of reconciling their study/work routines together with the routine of care of the child, since it has a weekly schedule surrounded by multiprofessional appointments and consultations, demanding that this woman give up some personal goals in favor of this routine of care, as this mother reports:

> *…and so, it is not easy to deal with college having a normal child, who stays with anyone, who has none ... let's say 'issue' of staying with someone, no extra care … And it's all different with him, right? He abuses a lot, he cries a lot, he only stays with me, I have to be careful, he has to have physical therapy, I have to know how to reconcile with a doctor, with routine, anyway ... I've thought about giving up so many times, you know? Every beginning of semester I think: My goodness, it will start all over again.* (Mother 1, 19 years old)

It is in this sense, often do not have someone or somewhere to leave their child, precisely because they demand more attention and care, that this mother's exclusiveness is required for the care of this child, leading her even to give up activities *"I want to work, but I can't, because I can't leave her anywhere, I can't leave her with anyone, because not everyone has the patience that I have" (Mother 3, 23 years old).*

It was not enough that these mothers struggle from pregnancy to the demanding routine of caring for their children, they also reported that they still have to deal with the daily struggle of society *Prejudice* against their child with microcephaly, as presented in this second category, exemplified in the following reports:

> *... The prejudices that I have already suffered in relation to my son were in the Instagram, that there are people who have no idea of things and sometimes comments with a fake profile or even with the normal profile, it has no face, it thinks it has the right to do these things, already happened about five times. And personally, there are many comments mainly from elderly people, people like that, who is unaware, and they ask: - 'and he is sick? Hey, it's the zika boy, hey, it's the mosquito boy, he has been bitten by the mosquito' - those inconvenient comments, you know? That usually always appears, but there you have to know how to deal.* (Mother 1, 19 years old)

> *... I did not care for anything that nobody spoke, although everyone who came spoke of her little head. What hurt me was when I was in the room and a woman came with her daughter and said, "look, she is different from us, this girl. Look at my how beautiful daughter is.* (Mother 8, 19 years old)

The society as a whole still has great difficulty in dealing with the different, reason that causes feeling of strangeness, incapacity and frustration. Although the way of understanding the deficiencies has evolved enough, it is noticed that to reach the level of naturalness, there is still much to be done (Roecker, Mai, Baggio, Mazzola, & Marcon, 2012).

Lastly, aspects related to the *Guarantee of Rights* were raised, in which participants stated that the main or only assistance they are receiving is the Continuous Benefit. According to a survey carried out by the Department of Social Development, Children and Youth of the State of Pernambuco, the preliminary data made it possible to check that 57.3% of the mothers of babies notified with microcephaly and/or congenital zika virus syndrome are included in care programs of the Federal Government, 69% are in extreme poverty, with a per capita income of R$ 77 per person (http://agenciabrasil.ebc.com.br/especial/2016-11/um-ano-de-zika-mulheres-no-centro-da-epidemia accessed April 20th, 2017). In addition, according to the same source, 70% of the mothers of these children are young, aged between 14 and 29 years, 77% are black and 89% would be eligible to receive Continuous Benefit. Such data may show a possible relationship between social vulnerability and the Zika virus epidemic and, consequently, microcephaly.

Final considerations

In view of the above, it is verified that the three-dimensionality of the Vulnerability Model is permeating the context of the mothers of infants with microcephaly who participated in this study. With regard to the individual dimension, the unplanned pregnancy of many of them and the lack of information about the Zika/microcephaly epidemic may have contributed to the illness process. On the social dimension of vulnerability, the importance of the social support of other mothers of babies with microcephaly was verified. In addition, it was possible to perceive that the intense routine of care, examinations, doctors and stimulation, ends up requiring an exclusive dedication of these women. Finally, we also observed the presence of programmatic elements of vulnerability, both in relation to the lack of confirmation of the diagnosis of microcephaly of their children, and the time between the appointment and the care, which may interfere with the success of clinical follow-up and of the various specialties that a disabled child needs. This whole context of vulnerability generates other vulnerabilities that end up affecting the mental health and quality of life of these women and consequently of their families.

Our results indicate that the profile of the participants corroborates with that of the literature, pointing to the marginalization of these women, regarding the socioeconomic class, although some of them have an average level of schooling or even graduation level, still present a disadvantaged economic level, as they have been presented in the epidemiological bulletins published by the Ministry of Health. This has led us to reflect on the reasons why the Zika virus and microcephaly epidemic have affected predominantly the most vulnerable population, unlike the dengue virus, for example, which affects indiscriminately, although they have the same transmission vector.

Regarding the exercise of care, it was verified that the mother ends up being the sole or primary caregiver of this child, who itself requires some attention, even more when daily treatments and consultations are required, requiring the exclusive dedication of this woman.

This study confirms what was found by Guerra et al. (2015), who verified that the mother ends up being the owner of the integral care of the children. It should be emphasized that the role of the primary caregiver of the child was based on mothers' perceptions and discourses, however, other studies that involve other family members can confirm whether or not the responsibility for care involves only the mothers or extends for other members who make up the family dynamics.

Because it is a recent epidemic, it is considered the relevance of studies in order to assist in health practices and in the qualification of these professionals, in addition to being able to contribute to the construction, updating and implementation of public policies aimed at children with microcephaly and, consequently, their families.

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