

## ITINERÁRIOS TERAPÊUTICOS DE MÃES DE CRIANÇAS COM MICROCEFALIA DECORRENTE DA SÍNDROME DO ZIKA VÍRUS

### *ITINERARIOS TERAPÉUTICOS DE MADRES DE NIÑOS CON MICROCEFALIA TRAS EL SÍNDROME DE ZIKA VIRUS*

### *THERAPEUTIC ITINERARIES OF MOTHERS OF CHILDREN WITH MICROCEPHALY DUE TO ZIKA VIRUS SYNDROME*

Andrea Perosa Saigh JURDI<sup>1</sup>  
Luísa CHIBANI MAUAD<sup>2</sup>  
Mariana FAGUNDES CINTI<sup>3</sup>

**RESUMO:** O objetivo do estudo foi conhecer o itinerário terapêutico de mães de crianças com microcefalia, decorrente da infecção pelo Zika Vírus, nascidas no período de outubro de 2015 a outubro de 2016, moradoras de um município da Região Metropolitana da Baixada Santista. Trata-se de um estudo retrospectivo de abordagem qualitativa que utilizou entrevistas com duas mães que tiveram Zika Vírus confirmado na gestação e cujos filhos nasceram com microcefalia no período da epidemia. Os resultados apontaram que as mães são as cuidadoras principais; as redes de apoio são construídas a partir da família próxima e outras mães de crianças com microcefalia; a religião é acessada quando o saber biomédico não apresenta respostas concretas.

**PALAVRAS-CHAVE:** Itinerário terapêutico. Microcefalia. Zika vírus.

**RESUMEN:** *El objetivo del estudio fue conocer el itinerario terapéutico de madres de niños con microcefalia provenientes de la infección por el Zika Virus nacidos en el período de octubre de 2015 a octubre de 2016, moradores de un municipio de la Región Metropolitana de la Baixada Santista. Se trata de un estudio retrospectivo de abordaje cualitativo que utilizó entrevistas con dos madres que tuvieron Zika Virus confirmadas en la gestación y cuyos hijos nacieron con microcefalia en el período de la epidemia. Los resultados apuntaron que las madres son las cuidadoras principales; las redes de apoyo se construyen a partir de la familia cercana y otras madres de niños con microcefalia; se accede a la religión cuando el saber biomédico no presenta respuestas concretas.*

**PALABRAS CLAVE:** *Itinerario terapéutico. Microcefalia. Zika virus*

<sup>1</sup> Federal University of São Paulo (UNIFESP), Baixada Santista, Santos – SP – Brazil. Professor of the Occupational Therapy. Department of Health, Education and Society. ORCID: <http://orcid.org/0000-0002-1111-5562>. E-mail: [andreajurdi@gmail.com](mailto:andreajurdi@gmail.com).

<sup>2</sup> Federal University São Paulo (UNIFESP), Baixada Santista, Santos – SP – Brazil. Undergraduate student of the Psychology course. ORCID: <http://orcid.org/0000-0003-1872-0594>. E-mail: [lulimauad@hotmail.com](mailto:lulimauad@hotmail.com).

<sup>3</sup> Federal University of São Paulo (UNIFESP), Baixada Santista, Santos – SP – Brazil. Undergraduate student of the Physiotherapy course. ORCID: <http://orcid.org/0000-0002-1111-5562>. E-mail: [marianafagundesc@hotmail.com](mailto:marianafagundesc@hotmail.com).

**ABSTRACT:** *The objective of the study was to know the therapeutic itinerary of mothers of children with microcephaly, resulting from the Zika virus infection, born from October 2015 to October 2016, living in a Metropolitan Region of Baixada Santista's municipality. This is a retrospective qualitative study that used interviews with two mothers who had Zika virus confirmed during pregnancy and whose children were born with microcephaly, during the epidemic period. The results showed that mothers are the main caregivers; support networks are built from the close family and other mothers of children with microcephaly; religion is accessed when biomedical knowledge does not present concrete answers.*

**KEY WORDS:** *Therapeutic itinerary. Microcephaly. Zika virus.*

## Introduction

The Zika virus is considered an arbovirus that was isolated for the first time in 1947, in Uganda, and was identified in Brazil in 2015. Since then, its circulation has been confirmed in 18 Brazilian states (VARGAS *et al.*, 2016; BRASIL, 2017; PETRÔNIO *et al.*, 2018; FRANÇA *et al.*, 2018).

In Brazil, data on live births are recorded from the Declaration of Live Births at the time of birth and recorded in the Ministry of Health Information System on Live Births (SINASC, Portuguese initials) (MARINHO *et al.*, 2016).

According to the authors, in Brazil, in the period 2000-2014, the number of live births with microcephaly showed stability. However, as of October 2015, there was an unexpected increase in cases, mainly in the northeast region of the country. In February 2016, the International Committee for the Regulation of Health Emergencies declared that the set of cases of microcephaly and other neurological disorders notified in Brazil had similarities with the cases described in French Polynesia in 2014, and constituted a public health emergency of international importance due to possible association with the Zika Virus.

The circulation of the disease caused by the Zika virus (ZIKV) was confirmed in February 2015, almost simultaneously in Bahia and São Paulo and, later, in Rio Grande do Norte, Alagoas, Maranhão, Pará and Rio de Janeiro, showing a rapid capacity of dispersion (CAMPOS; BANDEIRA; SARDI, 2015). As of April 2015, the indigenous transmission of fever by ZIKV in the country was confirmed, as well as the notification of pregnant women with an acute rash to ZIKV investigation was recommended. In this context, surveillance of microcephaly and/or changes in the central nervous system (CNS) suggestive of congenital infection was also recommended for the evaluation of newborns with microcephaly associated with ZIKV infection.

Microcephaly is a congenital malformation in which the brain does not develop properly: the newborn's head circumference is less than two standard deviations from the average for age and sex, which can lead to brain changes and problems in neurological development (VARGAS *et al.*, 2016).

There is also another issue that crosses this reality, centered on the complexity of receiving a special child. Families, in general, anxiously await healthy and efficient children (OLIVEIRA; POLETTO, 2015). The fact is that children with special needs demand specific care from the health, education and social sectors, in addition to what is considered normal (ASTOLPHO *et al.*, 2014).

According to Astolpho *et al.* (2014), in the majority of cases in which a special child arrives in the family, the mother becomes the main caregiver due to the specific care instructions needed for that baby, sometimes leaving her job and decreasing income familiar. This routine causes increased stress and anxiety experienced by the person in charge, in addition to isolation and social exclusion of this individual, which can lead to other psychological losses. Therefore, it is necessary to have a care network that extends beyond the parents, who are overwhelmed and helpless, leaving available not only prepared health professionals, but also other family and friends, offering them the appropriate training.

The way in which the disability is interpreted differs between each one, according to their experiences and their way of living. The same occurs with the choice of the healing process, the meanings shared socially by the person influence the reflective processes and choices by the health care systems, and a therapeutic itinerary is built from the experience of the illness experienced (SILVA JUNIOR; GONÇALVES; DEMÉTRIO, 2013).

### **The construction of therapeutic itineraries**

Each individual develops ways of being in society, of relating and developing strategies that allow him to live in community and with quality. The birth of a child with a disability causes a disorder in the family, as the routine ways of dealing with everyday situations and their social relationships become ineffective and, often, impractical to meet the needs of the new situation. According to Alves (1993), in this context, the family is mobilized to impose a certain order on the disturbing experience and transform it into something they can deal with on a daily basis.

The experience of illness is the term used to refer to the means by which individuals or social groups respond to an episode of illness and the Therapeutic Itinerary is the name given

to the set of plans, strategies and projects aimed at solving the problem - the treatment of affliction. For Alves (1993), the construction of the image about a treatment is constituted within the networks of social relations and it is precisely these networks that serve as a reference for individuals, supporting and confirming the image elaborations of certain types of treatment.

Two starting points mobilized the research with mothers of children with microcephaly due to Zika virus: the experience of the disease and the search they undertook when dealing with something new and unknown that mobilized the entire country. In this sense, the concern was to study and unveil the everyday world, in which knowledge is built from experience. For Alves (2015), it is in the everyday world that we acquire a stock of knowledge, formed by our biographical path, by the circumstances that we are enmeshed in and we end up developing a set of strategies and action plans to deal with the world of life.

Therefore, in order to understand IT, an approach is needed to establish relationships between the socio-cultural dimension and the individualized behavior of individuals. The behavior of the patient - illness behavior - is permeated by choices in favor of cost benefit, as there is a search for what is needed to satisfy his needs. Cultural, socioeconomic values, family structure, gender, age and cognitive elements are responsible and determinants in the treatment choice process, assigning a unique therapeutic itinerary to each person (ALVES, 1993).

This study aimed to know the therapeutic itineraries of mothers of children with microcephaly resulting from ZVS, living in a municipality in the Metropolitan Region of Baixada Santista.

## **Methodological procedures**

This is a retrospective study with a qualitative approach that used semi-structured interviews to produce data. The inclusion criterion was that microcephaly was due to Zika Virus and that the child was born from October 2015 to October 2016. From the contact with the Epidemiological Surveillance sector in the municipality, seven cases of live births were found with microcephaly in the period, but only two children were confirmed to be associated with infection caused by the Zika virus during pregnancy.

Both mothers were contacted by telephone and both agreed to participate in the study. A meeting took place, lasting about an hour, with each mother in the place they chose and during this moment the interviews and the application of a sociodemographic questionnaire were carried out. The interviews took place from February to April 2018, as they depended on the availability of the research participants. In both meetings, the interviews were recorded on

two different devices, a tape recorder and a cell phone, all with the consent of the participants who had their identities preserved.

To approve the consent, the volunteers received the Free and Informed Consent Term, being able to read the document and sign it, in order to learn about the ethical principles of the study, which was submitted to the evaluation and approved by the Ethics and Research Committee with Human Beings of the University according to Resolution no. 466/2013, of the National Health Council, under the number 2,317,477, validating their participation and the use of the data informed by them.

The data analysis process was based on the thematic analysis technique proposed by Minayo (2014). This choice was made based on the assumption that the reference values and behavior models, observed in the discourse, are characterized by the presence of certain themes in which the explanation of the meanings contained in the statements, documents or phenomena and the meanings are sought. The material produced was gathered and the themes identified as relevant were grouped into categories elaborated from the objective of the study, described in the presentation of the results.

## **Research scenario**

A study on therapeutic itineraries must lead us to know the context in which the strategies are found, the action plans that individuals develop in search of health care. Offers and access to services, existing resources need to be understood and known.

The municipality where the families live is a city of the Baixada Santista Metropolitan Region with around 421,896 inhabitants, of which about 30.5% have some type of disability (IBGE, 2010). Despite occupying the third position in the Human Development Index (HDI) in the State of São Paulo, the municipality still has regions with high levels of vulnerability. These regions have received a very intense migratory flow in recent decades, which has caused the occupation of the territory, with serious problems in living conditions and local infrastructure.

In relation to health services, these have a coverage in the three levels of care across the municipality. In 2016, the Care Network for People with Disabilities was created, which included the construction of a Specialized Rehabilitation Center (SRC). Parallel to public health, education and social assistance services, the municipality has a considerable number of specialized philanthropic institutions that assist children, young people and adults with disabilities, from early intervention to inclusion in the labor market.

## Results and discussion

A brief presentation will be made of the research participants and an analysis of the statements based on three categories that emerged from the interviews articulated to the national, municipal context and to the authors who dialogue with the theme. The categories discussed will be: moment of diagnosis, search for treatment, social network - family and popular subsystems. The names are fictitious in order to maintain the confidentiality of the participants.

Vanessa is Clara's mother who was born on 11/03/2015. In addition to Clara, she has two other teenage children, a 16-year-old boy and a 14-year-old girl. They all live in the same house in the Rádio Clube neighborhood, located in the Northwest Zone of the municipality of Santos. This region is known for its high social vulnerability and has poor infrastructure. It is a region of stilts, despite not being the case of the research participant. Currently, Vanessa is financially dependent on a pension from Clara's father and does not work. She left her job during pregnancy, when she started to follow up at Hospital das Clínicas, in São Paulo.

Joice is the mother of Letícia who was born on 11/17/2015, lives in the Macuco region in Santos and was diagnosed when at seven months of gestation. She was pregnant with twins, the girl was born with microcephaly and the boy was not. She discovered that it was because of the Zika Virus Syndrome after participating in a study for a university, because at the time she had the fever, she thought it was dengue. She has two more children, in addition to the twins, and lives with her husband, who is a plasterer.

### Moment of diagnosis

For the participants, this moment occurred at different times of pregnancy. Joice portrays the difficulty she had in understanding the news and the lack of support she had on the part of the medical team with whom she performed prenatal care.

*It was thirty-four weeks or so already, they didn't know what it was for sure, you know, there was a doctor who thought it was one thing, then another doctor thought it was another, then they suddenly threw it at me, they took time, they took time to talk, right, then they suddenly said: "look, the baby's skull is not ..", they said: "the baby's skull is not growing. The skull of one of the babies, which is the girl's [...]" (Joice).<sup>4</sup>*

<sup>4</sup> Foi com trinta e quatro semanas mais ou menos já, eles não sabiam o que era ao certo, né, aí passava por uma médica achava que era uma coisa, aí outra médica achou que era outra, aí de repente eles jogaram na minha cara assim, demoraram, demoraram pra falar né, aí de repente eles: "ó, o crânio do bebê não..", eles falaram: "o crânio do bebê não tá crescendo. O crânio de um dos bebês, que é o da menina [...]" (Joice).

For Vanessa, the diagnosis of microcephaly was given during pregnancy, but was later associated with ZVS.

*During pregnancy I had already discovered that she was going to be born with microcephaly. But I had Zika, several symptoms. From four months on, until the third month she was normal, Clara had nothing. After I got the flu and it appeared, the complications appeared, she had it, I did the logical sample, then there was a discrete slide of pericardial effusion (Vanessa).<sup>5</sup>*

Regarding the lack of knowledge about microcephaly, Vanessa says that at first, she did not know about microcephaly and went to look for information on the subject on the internet.

*So it was like that, I said "but what is this doctor?", Then he said "it is a disease that the head does not grow the right size, not that the head will not grow, but it will not grow like ours", [. ..] Actually, I asked, but then I was looking on the famous internet, but it is something that the internet today I do not divulge to any mother, because it gives you positivity and negativity. So it shows you the negative rather than the positive. [I saw] that she was going to be born without a head. Then I said "doctor she will not even have a head, you are lying", then he showed me "look, she has a head, but it is not that" (Vanessa).<sup>6</sup>*

The lack of knowledge about microcephaly is also part of Joice's speech.

*How will it be when you are born? What will she look like, if people would laugh at her when we walk on the street. Then I would say: 'Oh my God, I will have to cover her head, I will have to cover her head'. [...], but after she was born, then I ignored it, I never covered her head (Joice).<sup>7</sup>*

Mothers were diagnosed at the peak of the epidemic and, coincidentally, with the Olympics event in Brazil, gaining international repercussions (TRILLA, 2018). According to the Ministry of Health, the first sign that the Zika virus was not as harmless as it was assured was when the director of Communicable Diseases of the Ministry of Health revealed that the number of cases of Guillian-Barré Syndrome was above the standard and there was a suspicion of a link with the virus. Concomitant to this, in Pernambuco the number of notified cases of

<sup>5</sup> *Na gestação eu já tinha descoberto que ela ia nascer com microcefalia. Mas eu tive a Zika, vários sintomas. Dos quatro meses em diante, até o terceiro mês ela era normal, a Clara não tinha nada. Depois que eu fiquei gripada e apareceu, foi aparecendo as intercorrências, ela teve, eu fiz a amostra lógica, aí apareceu lâmina discreta de derrame pericárdico (Vanessa).*

<sup>6</sup> *Ai foi assim, eu falei "mas o que é isso doutor?", ai ele falou "é uma doença que a cabeça não cresce do tamanho certo, não que a cabeça não vá crescer, mas não vai crescer igual nossa", [...] Na verdade eu perguntei, mas depois fiquei procurando na famosa internet, mas é uma coisa que internet hoje não divulgo pra nenhuma mãe, por que ela te dá positividade e negatividade. Então ela te mostra mais o negativo que o positivo. [Eu via] que ela ia nascer sem cabeça. Aí eu falei "doutor não vai ter nem cabeça, o senhor ta mentindo", daí ele me mostrou "olha, tem cabeça, mas não é aquilo" (Vanessa).*

<sup>7</sup> *Como é que vai ser quando nascer? Qual vai ser a feição dela, se as pessoas iam rir dela quando a gente andasse na rua. Aí eu dizia: 'Ai meu Deus, eu vou ter que cobrir a cabeça dela, eu vou ter que cobrir a cabeça'. [...], mas depois que nasceu, aí relevei de boa, nunca cobri a cabeça dela (Joice).*

microcephaly increased, raising the hypothesis that the phenomenon was associated with the virus (BRASIL, 2017). In the municipality of the survey, notifications of live births with microcephaly increased in the period, but only two confirmed by Zika virus.

The initial moment of news about a child's disability and the support that families need at that moment is what will lead them and direct the search for care for their children. For Astolpho *et al.* (2014), the extensive and heavy demand for care leads the family to reorganize and it is necessary to have a care network that extends beyond the parents, leaving available not only prepared health professionals, but also other family members and friends. According to Barbosa *et al.* (2009), the relationships established and reorganized after the arrival of a child with a disability are configured from the moment the family receives the diagnosis, which can be decisive, even in the way in which this baby is seen and received.

The mothers' search, for trying to understand about microcephaly, involved social, cognitive, subjective (individual) and objective (collective) aspects, which Alves (1993) highlights that are part of the disease experience. For the author, the key question is how to make intelligible the movement by which individual praxis and social generality are constituted among themselves. It is necessary to understand the cognitive and social dimensions incorporated in individual representations. Both mothers sought to know what microcephaly was and why it was affecting their child.

### **The search for treatment**

Unlike the families of children born with microcephaly caused by ZVS in the Northeast, who suffered from the lack of accessible services, information and institutional support, the mothers interviewed traced another path in the search for the care of their children. According to the Ministry of Health, knowledge gaps, challenges for assistance to children and their families - most of them from families of less privileged economic class, from mothers with little education - are still a challenge. The Ministry of Health document emphasizes that despite professional competence, difficulties in accessing health became evident, revealing the absence of the State and making these women and children even more exposed to the aggressive potential of a virus (BRASIL, 2017).

For Freitas *et al.* (2018), the new epidemic was already drawing its social determination linked to poverty, poor housing conditions, lack of planning and development of urbanization and non-existent basic sanitation, transforming child care into a complex and strenuous task. In

the research municipality, only one mother lives in an area of vulnerability and with little infrastructure, but even this one managed to get resources for the treatment of her daughter.

For Vanessa, the medical care and monitoring of her daughter, in addition to research on the causes of Clara's microcephaly, have been carried out by Hospital das Clínicas in São Paulo since pregnancy. The professionals there accompany her regularly and referred her to Clara's rehabilitation process at the specialized institution in the municipality of Santos.

*She [the child] goes through the neuro, phono, endocrine, urologist, pediatrician, nutrology, everything there. Genetics and infectologist. [Goes] Every month. The therapeutic treatment, speech therapist and psychologist initiative was theirs, from Hospital das Clínicas. That, as she has the micro, they are very rigid babies, they indicated to do the therapy. It was the Hospital das Clínicas, the doctors. 2 years and something ago. 2 years and 4 months, why she entered was a month old (Vanessa).<sup>8</sup>*

For Meneses *et al.* (2017), users of health services build real care maps from practical knowledge, using the medical-hospital-outpatient apparatus, depending on their resources. For Vanessa, the fact of obtaining assistance in a large hospital, facilitates Clara's care in many aspects.

*Because we know that you go further. I'm really going, because I'm going to talk about something, I don't stop with Clara. From Monday to Monday I go, I go to São Paulo. I actually go to the Basic Health Unit ... So every month I have a routine appointment. [...] As I said [...] "Look, exams that they [other mothers] are looking to do, trying, I already did, I'll even do it again". It is very difficult here, exams like tomography is time consuming. If you don't have health insurance, it takes time here. One that is quite like that, that they look for a lot, myelogram video with image (Vanessa).<sup>9</sup>*

For Joice, the search for treatment started on her own initiative and was configured as a more complex itinerary. Letícia was born in a public maternity hospital in the municipality and was referred to the neurologist.

*They only sent her to the neuro, but the neuro was on vacation. Then I went to the city hall, went to the pediatrician, the city pediatrician referred me to the*

<sup>8</sup> *Ela [a criança] passa no neuro, fono, endócrino, urologista, pediatra, nutrologia, tudo lá. Genética e infectologista. [Vai] Todo mês. A iniciativa do tratamento terapêutico, de fono, de psicólogo, todo, foi deles, do Hospital das Clínicas. Que, como ela tem a micro, eles são uns bebês muito rígidos, eles indicaram fazer a terapia. Foi o Hospital das Clínicas mesmo, os médicos mesmo. [Há] 2 anos e uns quebrados. 2 anos e quatro meses, por que ela entrou tinha um mês (Vanessa).*

<sup>9</sup> *Porque a gente sabe que você vai além. Eu vou mesmo, porque eu vou falar um negócio, eu não paro com a Clara. De segunda a segunda eu vou, vou pra São Paulo. É que na verdade assim, a Unidade Básica de Saúde eu até passo... Então todo mês eu tenho consulta de rotina. [...] Como eu falei [...] "Olha, exames que elas [outras mães] estão procurando pra fazer, tentando, eu já fiz, já vou até refazer". É bem difícil aqui, exames como tomografia é demorado. Se você não tem plano de saúde é demorado aqui. Um que é bastante assim, que elas procuram bastante, vídeo de mielograma com imagem (Vanessa).*

*doctor there in the northwest area, there in the northwest area she gave me a letter and I took it to Casa da Esperança. It was so. She goes to speech therapist, physio, yes, early stimulation, then she is accompanied by ... a ... I forgot her name, occupational therapist, physiotherapy, speech therapist, then she goes to the orthopedist, she goes to the neuro, which is at Casa X, everything is there, there is a dentist. Only the pediatrician that I spend at the polyclinic, but the rest I spend everything there, she has a nice accompaniment that is in one place, you have the doctor who takes care of the children there (Joice).<sup>10</sup>*

In addition to the rehabilitation services and medical specialties, both mothers report the need for psychological care, especially at the beginning when the news about microcephaly is given to the family.

The process of rehabilitation and medical assistance is constant and extends over long periods, mainly due to the clinical conditions and the children's impairment. Vanessa says that her daughter has associated comorbidities such as epilepsy and West Syndrome, which worsens the child's clinical condition. For Vargas *et al.* (2016), microcephaly does not constitute a disease, but a congenital malformation, therefore, care is constant and begins from the moment the baby is born, concomitantly with medical guidance, which accompanies the baby's development from the moment prenatal.

According to the mothers' testimony, medical care is, since birth, very present in the family's routine, having a strong influence on the actions taken in the face of any problem. The perception that, in this case, the professional subsystem is the most respected is evident. The dominance of this model in our society is, in general, because the field of disabilities is under the domain of medical specialists.

It should be noted that the municipality, since 2016, developed the Care Network for People with Disabilities (RCPD, Portuguese initials). Presented in the heart of the Living Without Limits Plan, RCPD presents itself as a structuring policy for SUS, including all areas of care, from primary care to urgency and emergency, hospital and specialized care, with the strengthening of the articulation between levels and modalities of health care, seeking integrality and equity as prerequisites for its planning and management. Today the municipality has a Specialized Rehabilitation Center (SRC II) that serves people with intellectual disabilities and Autism Spectrum Disorder. In addition, there are a significant number of philanthropic

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<sup>10</sup> *Encaminharam só pro neuro, só que o neuro tava de férias. Aí eu fui na prefeitura, passei no pediatra, o pediatra da prefeitura me encaminhou pra doutora lá na zona noroeste, lá na zona noroeste ela me deu uma cartinha e eu levei pra Casa da Esperança. Foi assim. Ela faz fono, fisio, é, estimulação precoce, aí ela é acompanhada pelo... uma... esqueci o nome, terapeuta ocupacional, fisioterapia, fono, aí ela passa no ortopedista, passa na neuro, que é na Casa X, tudo é lá, tem dentista. Só o pediatra que eu passo na policlínica, mas o resto eu passo tudo lá ela, ela tem assim, um acompanhamento bacana que é num lugar só, você tem a médica que cuida lá das crianças (Joice).*

entities that have agreements with the municipal departments that offer specialized assistance to people with disabilities and carry out the process of rehabilitation and early intervention.

### **Social Network and the family and popular subsystems**

At moments of the interview, Vanessa and Joice were asked if they sought any other type of care, in addition to the care considered formal, and in what situations they found support to deal with difficulties and tensions.

Regarding the support network, Vanessa and Joice said they faced and still face the removal of people from their lives after the diagnoses. In their reports they present family support represented only by the figure of close family members. When asked Joice about her friendships and social ties, she speaks only of the other mothers who, like her, are “special mothers” for having children with microcephaly or the professionals who offer care and help in other issues of Leticia's development. She refers to these mothers as her only friends, as they are able to understand what she goes through in her daily challenges.

*I had a friend of mine, she is my ex-sister-in-law, aunt of my two oldest, has nothing to do with Clara. Nowadays she says that Clara is her niece too. And she gave me a lot of strength because she who lives there in São Paulo, she helped me to go, accompanied her, because Clara's father worked and we weren't together, her father worked, someone had to work, right (Vanessa).<sup>11</sup>*

For Joice, the support network refers to the nuclear family and mothers of the institution that attends.

*I've already been beaten so much in life that when I had her, the moment I had her, I was alone, there was no one. Nobody feels your pain, nobody pities you. So, if you don't have the strength, faith and courage, you will be sad, depressed, discouraged and people will pass by you and laugh at you. [...] Like me when I go to Casa X, when I meet mothers, I feel so good that I say “I really missed you”, I even miss it. My friends are them now, because our subject is the same, it hits. [...] As we learn, they teach us to take care of them. There are already people who say “I don't give a bottle because the baby chokes”, “oh, I don't give it because it might choke” (Joice).<sup>12</sup>*

<sup>11</sup> *Tive uma amiga mesmo minha, ela é minha ex cunhada, tia dos meus dois mais velhos, não tem nada a ver com a Clara. Hoje em dia ela fala que a Clara é a sobrinha dela também. E ela me deu muita força porque ela que mora lá em São Paulo, ela que me ajudou a ir, acompanhou, porque o pai da Clara trabalhava e a gente não estava junto, o pai dela trabalhava, alguém tinha que trabalhar né (Vanessa).*

<sup>12</sup> *Já apanhei tanto na vida que quando eu tive ela, no momento que eu tive ela, eu fiquei sozinha, não tinha ninguém. Ninguém sente sua dor, ninguém tem compaixão de você. Então se você não tiver forças, fé e coragem, você vai ficar ali triste, com depressão, desanimado e as pessoas vão passar por você vão rir de você.[...] Que nem eu quando vou na Casa X, quando eu encontro as mães, eu me sinto tão bem que eu digo “eu senti até saudades de vocês”, eu sinto até falta. Minhas amigas agora são elas, porque o assunto da gente é o mesmo, bate.*

In addition to the family, Joice talks about the formal support of health professionals

*Psychologist is great, I won't lie, you need to talk to psychologist, friends, but the psychology part is very good, it was very effective. The medical team that did my prenatal care, they welcomed me, comforted me, talked to me, never spoke a word that was negative, but also never hid, they said everything, so I think it was what made me feel much more relaxed (Joice).<sup>13</sup>*

In an episode where Clara became ill, Vanessa says that religion helped her to cope.

*He said it right in my face: "with her exams changed as it is here, she won't be able to stand it". So where do we appeal? For faith, right. So I prayed on one side, I called my mother, I said: "look mom, pray there, I'm going to pray, because my religion is Christian, I am Christian, so you there pray to your Nossa Senhora da Aparecida, Nossa Senhora de Fátima, then I pay for everything [laughs] (Vanessa).<sup>14</sup>*

Regarding beliefs and popular knowledge, Joice says she was raised in the evangelical church, but when she feels the need, she moves on to other religions.

*Not even now in the Northeast, she suddenly turned red, then I took her to a "rezadeira" house, then she prayed, and she got well. [...] I believe, well, before I didn't believe in reza, right? After I started to believe, because evangelical and reza doesn't hit much, right? It is more in prayer. But I think it's something, like, it's the same God, asking for what is good. So I try, I looked for the prayers when she stayed, of course I gave the medicine, you know, too [laughs]. Of course, I gave the medicine, but prayed a lot, sang to and there and such (Joice).<sup>15</sup>*

In the strenuous trajectory for coping strategies, families are acquiring the task of finding different ways and possibilities to deal with the adversities and limitations they face. The social, family and even conjugal relationship is often affected due to a daily life full of challenges. The social life of mothers responsible for children with disabilities is sometimes repressed, making these women feel isolated, alone and prevented from having experiences

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*[...] Como que a gente aprende, eles ensinam a gente a cuidar deles. Já tem gente que diz "eu não dou mamadeira por que engasga", "ah, eu não dou isso por que engasga" (Joice).*

<sup>13</sup> *Psicólogo é ótimo, não vou mentir, precisa conversar com psicólogo, amigos, mas a parte da psicologia é muito bom, foi bem efetiva. A equipe médica que fez o meu pré-natal, eles me acolheram, me confortavam, conversavam comigo, nunca falavam uma palavra que fosse negativa, mas também nunca escondiam, eles falavam tudo, então acho que foi o que me deixou bem mais tranquila (Joice).*

<sup>14</sup> *Ele falou bem na minha cara: "com os exames dela alterado como tá aqui, ela não vai aguentar". Então a gente apela pra onde? Pra fé, né. Então eu orei de um lado, liguei pra minha mãe, falei: "olha mãe, reza a senhora aí, eu vou orar, porque a minha religião é cristã, eu sou cristã, então a senhora aí na sua reza pra Nossa Senhora da Aparecida, Nossa Senhora de Fátima, depois eu pago tudinho [risos] (Vanessa).*

<sup>15</sup> *Que nem agora no Nordeste, ela, do nada, ficou toda vermelha, aí levei ela a casa de uma "rezadeira", aí ela rezou, ela ficou boa. [...] Acredito, assim, antes eu não acreditava na reza né? Depois que eu comecei a acreditar, por que evangélica com reza não bate muito né? É mais na oração. Mas eu acho que é uma coisa, tipo assim, é o mesmo Deus, pedindo o que é bom. Então eu tento, procurava as orações quando ela ficava, lógico que eu dava o remédio né, também [risos]. Lógico que eu dava o remédio, mas orava bastante, cantava pra e lá e tal (Joice).*

beyond caring for their babies. The contact with other mothers of the institution favors the exchange of knowledge and experiences, strengthening the perspective that other people also go through similar situations, and making them join a social and support group, in addition to reducing anguish and afflictions that make them feeling helpless (BARBOSA *et al.*, 2009).

### Final considerations

The care of children with microcephaly due to Zika Virus Syndrome is still closely linked to medical knowledge and that of other health professionals, due to the deficiency being detected since pregnancy, thus narrowing these care relationships. The search for other forms of health care, inserted in the popular and family subsystems, is conditioned to the socio-cultural context in which individuals are inserted.

The daily lives of families and the relationships established therein also change with the arrival of a baby with a disability, mainly affecting mothers who, in most cases, take on the responsibility of raising their children. The consequences of this exclusive dedication are exhaustive for women who occupy this role, in addition to the emotional, social and financial burdens that affect their realities and the breaking of expectations that receiving a child with a disability represents for the family (BARBOSA *et al.*, 2009).

In the study it was possible to identify that the disease is not only a state of fragility and suffering, but also a social reality. In this perspective, the lay reference system, which according to Alves (1993) is configured in premises that differ from the biomedical system, has the function of dealing with the various definitions of disease, seeking to contextualize the individuals in their entirety.

**ACKNOWLEDGMENTS:** The São Paulo State Research Support Foundation (FAPESP) for funding this research during the 12-month period.

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### How to quote this article

JURDI, Andrea Perosa Saigh; CHIBANI MAUAD, Luísa, FAGUNDES CINTI, Mariana. Itinerários terapêuticos de mães de crianças com microcefalia decorrente da síndrome do Zika vírus. **Temas em Educ. e Saúde**, Araraquara, v. 15, n. 2, p. 263-276, jul./dez. 2019. e-ISSN 2526-3471. DOI: <https://doi.org/10.26673/tes.v15i2.13078>

**Submitted:** 20/02/2019

**Required revisions:** 05/04/2019

**Approved:** 30/05/2019

**Published:** 30/07/2019