

# Therapeutic Journeys of family members of children with Congenital Zika Syndrome in the metropolitan region of Salvador/Bahia

Itinerários Terapêuticos de familiares de crianças com Síndrome Congênita pelo Zika Vírus de uma cidade da região metropolitana de Salvador/Bahia

Rutas terapéuticas de familiares de niños con síndrome congénito por el virus Zika en una ciudad de la zona metropolitana de Salvador/Bahia

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## Abstract

**Introduction:** The living and health conditions of children with Congenital Zika Syndrome (CZS) are an important public health issue. Neurodevelopment changes impact family life and imply multi and interdisciplinary care. Therefore, studies on the therapeutic journeys of family members in search for health care and education are needed. **Objective:** To investigate the therapeutic journeys of family members of children with SCZV in the metropolitan region of Salvador/Bahia. **Methods:** Descriptive and cross-sectional study with a qualitative approach, including recording, transcribing and analyzing videos of interviews with eight family members. The following thematic axes were defined: knowledge and impact of diagnosis, search and support in healthcare and educational inclusion. **Results:** Most family members became aware of the diagnosis of CZS only after the birth. All received guidance and

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### Authors' contributions:

ACG: data collection and analysis, article writing.

PMPP: critical review and final organization of the article.

RYSC: conception and orientation of the study in all phases, critical review and follow-up of the article construction.

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referrals, mainly from public health professionals. The children were referred to different specializations and received priority assistance. Some participants reported anguish receiving the diagnosis, changes in dynamics and family life, long waiting for a wheelchair, difficulties to access specialized institutions due to distance and lack of transportation, and problems in educational inclusion due to the lack of classroom assistants. Most family members reported having support from relatives and friends. **Conclusion:** The findings show the impacts of therapeutic journeys on the lives of these families and the difficulties faced due to the effects on the neurodevelopment of children in search for assistance. The results suggest the need to formulate public policies in line with the needs of these children.

**Keywords:** Zika Virus Infection; Microcephaly; Delivery of Health Care.

## Resumo

**Introdução:** As condições de vida e saúde de crianças com Síndrome Congênita pelo Zika vírus (SCZV) constituem importante questão de Saúde Pública. As alterações no neurodesenvolvimento impactam na vida familiar e implicam cuidados multi e interdisciplinares. São necessários estudos de itinerários terapêuticos dos familiares em busca de assistência à saúde e educação. **Objetivo:** Conhecer os itinerários terapêuticos de familiares de crianças com SCZV de uma cidade da região metropolitana de Salvador/Bahia. **Método:** Estudo descritivo e transversal de abordagem qualitativa. Foram gravados, transcritos e analisados vídeos de entrevistas com oito familiares. Estabeleceram-se eixos temáticos: conhecimento e impacto do diagnóstico, busca e suporte no cuidado em saúde e inclusão educacional. **Resultados:** O conhecimento do diagnóstico da SCZV ocorreu depois do parto, para maioria dos familiares. Todos receberam orientação e encaminhamentos, principalmente, de profissionais da rede pública de saúde. As crianças foram encaminhadas para diferentes especialidades. Receberam prioridade em atendimento emergencial. Algumas participantes referiram angústia ao receber o diagnóstico, mudanças na dinâmica e vida familiar, longa espera para cadeira de rodas, dificuldades de acesso às instituições especializadas pela distância e falta de transporte e problemas na inclusão educacional por falta de auxiliares de sala. A maioria apontou o apoio de parentes e amigos. **Conclusão:** Os achados evidenciam os impactos dos itinerários terapêuticos na vida dessas famílias e as dificuldades enfrentadas pelas repercussões no neurodesenvolvimento das crianças na busca pela assistência. Os resultados contribuem para formulações de políticas públicas consonantes às necessidades dessas crianças.

**Palavras-chave:** Infecção por Zika vírus; Microcefalia; Atenção à Saúde.

## Resumen

**Introducción:** Las condiciones de vida y de salud de los niños con síndrome congénito por el virus Zika congénito (SCZV) son un importante problema de salud pública. Los cambios del neurodesarrollo impactan la vida familiar y implican cuidados multidisciplinarios e interdisciplinarios. Son necesarios estudios sobre rutas terapéuticas de los familiares en busca de atención sanitaria y educación. **Objetivo:** Conocer las rutas terapéuticas de familiares de niños con SCZV en una ciudad de la zona metropolitana de Salvador/Bahia. **Métodos:** Estudio descriptivo y transversal con abordaje cualitativo. Las entrevistas de ocho familiares fueron videograbadas, transcritas y analizadas. Se establecieron ejes temáticos: conocimiento e impacto del diagnóstico, búsqueda y apoyo en salud y educación inclusiva. **Resultados:** El conocimiento del diagnóstico de SCZV ocurrió después del parto para la mayoría de los familiares. Todos recibieron orientación y derivaciones, principalmente de profesionales de salud pública. Los niños referidos a diferentes especialidades. Recibieron prioridad en la atención. Algunos participantes refirieron angustia al recibir el diagnóstico, cambios en la dinámica y la vida familiar, larga espera por silla de ruedas, dificultades para acceder a instituciones especializadas por la distancia y falta de transporte e educación inclusiva por falta del maestro asistente. La mayoría señaló el apoyo de familiares y amigos. **Conclusión:** Hallazgos muestran lo impacto en las rutas terapéuticas en la vida de estas familias y las dificultades frente las repercusiones del neurodesarrollo infantil en la búsqueda de cuidados. Los resultados contribuyen a la formulación de políticas públicas para atender las necesidades de estos niños.

**Palabras clave:** Infección por el Virus Zika; Microcefalia; Atención a la Salud.

## Introduction

As a key component for families within the context of chronic health conditions<sup>1</sup>, social support impacts the adherence of families to therapies and health monitoring. It also depends on the health care alternatives offered to these families, the way in which these options are offered by different professionals in the network and the services offered by the Brazilian Unified Health System (SUS), as well as the emotional and psychological conditions of individuals<sup>2,3</sup>. As this article aims to show, this situation becomes even more complex for families within the context of impacts resulting from microcephaly associated with Zika virus (ZV) infection.

It is known that ZV infection resulting from the bite of the *Aedes aegypti* or *Aedes albopictus*<sup>4</sup>, can cause low-grade fever, spots on the skin, arthralgia, myalgia, headache, conjunctivitis, dry cough and gastrointestinal changes<sup>5</sup>. In addition, ZV infection can also occur through sexual contact, secretion, blood transfusion and vertical transmission<sup>4,6</sup>. In turn, vertical transmission can lead to fetal microcephaly, which is a congenital malformation characterized by the occurrence of head circumference lower than expected for the baby's age and sex<sup>5</sup>. Therefore, the clinical condition of children with microcephaly associated with ZV concerns the sequelae arising from the infection of their mothers to the virus, which define what is known today as Congenital Zika virus syndrome (CZS)<sup>4,7,8</sup>.

As this group demands the need for early intervention actions, multidisciplinary follow-up is essential to address the multiple risks for global neurodevelopmental alterations that they have with a high impact on their adaptive functioning<sup>1,9</sup>.

As shown by several studies, families go through different processes of financial readjustment and day-to-day dynamics due to the growing need for health services, the resulting expenses and the stigmas of society, which, in turn, can result in low levels of mental health<sup>10,11,12</sup>. Some authors claim that the mental health status of the family has a great impact on the therapeutic journey of this population group<sup>2</sup>.

The therapeutic journey concerns the paths taken by individuals in search of health care and/or treatment of an affliction/disease, which are not restricted to the medical field, but also reflect the subjectivity of the individuals<sup>13</sup>.

Researchers<sup>14</sup> report that guardians, especially mothers, are the protagonists in the therapeutic journey of children with CZS, and that they suffer the consequences of the follow-up on their children's health. Due to media attention at the end of 2015, which resulted in many promises at the time when there was an increase in cases of ZV infection in the Northeast region, families initially received good care from health institutions<sup>14,15</sup>. However, these authors also report that with the end of the State Emergency Public Health Decree for Zika in May 2017<sup>16</sup> and with the decrease in confirmed cases of infections and the prevalence of live births with microcephaly, there was a also decrease in media attention and children were "forgotten"<sup>14</sup>.

As addressed by ZikaLab<sup>3</sup>, this work is justified by the need to care for the children and, particularly, their family. It should be noted that the biopsychosocial conditions of the family will directly reflect on the choices and adherence to health therapies and treatments, which can help health professionals to understand the different issues and particularities of these individuals, even more in the context of a health condition that lacks literature, due to recent confirmed cases of the epidemic. It is also evident that "*as this field is totally unknown in all spheres, health professionals need to find ways to link research on the Zika virus to the quality of care for mothers, babies and families*"<sup>3</sup>.

In this context, many studies aim to describe CZS, as well as the symptoms of virus infection, explain the relationship between the infection of parents with microcephaly in fetuses and describe the phenotype of affected children<sup>4,6,17</sup>. Although this knowledge helps and guides the care of affected children, this knowledge is still far from the daily reality of these families, as this study will discuss later.

Therefore, this study aims to understand the therapeutic journeys of families with children with CZS-associated microcephaly.

## Method

This is a descriptive and cross-sectional study with a qualitative approach, linked to a Brazil-US international cooperation research called «Brazil in Emergency in Public Health of National Importance (ESPIN): Comprehensive Care, Rehabilitation, Accessibility and Inclusion of Children with Microcephaly associated with Zika virus»,

approved by the Research Ethics Committee of the University where this investigation was carried out.

As reported by Turato<sup>18</sup>:

[...] the [qualitative] researcher's interest is focused on the search for the meaning of things, because this meaning plays an organizing role in human beings. What the 'things' (phenomena, manifestations, occurrences, facts, events, experiences, ideas, feelings, and subjects) represent, shapes people's lives. (p. 510)

The sample consisted of participants from eight families of children with CZS, of both genders, who are their legal guardians and who live in a city in the metropolitan region of Salvador/Bahia. Participants were recruited with the help of a member of the research group, who was the physiotherapist responsible for the local care of these children. Inclusion criteria included family members of children born in the end of 2015 to 2016, whose mothers had ZV infection and the children had Zika virus-associated microcephaly. In turn, the exclusion criteria included participants who withdrew from participating throughout the study or who had health or other impairments at the time of data collection.

Data were collected from the database of the research linked to this study, collected through a semi-structured interview with family members,

in their hometown, which was carried out by a speech-language pathologist who was one of the researchers. The interviews were videotaped after introducing the study and obtaining the consent of the participants by signing the Informed Consent Form (ICF), following the ethical resolutions of research with human beings. Only the interviewer and the participant were present at the time of the interview, which was carried out at the place of physical therapy assistance and at the time of their convenience during the period in which the researchers were in the city.

## Results

### 1. From the sociodemographic profile of family members and their children

The socioeconomic and demographic characteristics of the family members who participated in the research (FM1 to FM8) were recorded, such as the family relationship with the child with CZS, educational level, occupation, religion, housing, Benefit of Continuing Provision (BPC) and family income. This information is relevant for analyzing the therapeutic journey of the population group involved in this study. At the time of data collection, the BPC corresponded to the value of one minimum wage (BRL 998.00)<sup>19</sup>.

**Chart 1.** Socioeconomic and demographic characteristics of the participants.

Family Member	Family relationship	Educational level	Profession	Religion	Housing	BPC	Household income*
FM1	Mother	Complete higher education	Civil Engineer	Catholic	Rented	Yes	2.5
FM2	Mother	Complete high school	Nursing Technician	Evangelic	Rented	Yes	1
FM3	Mother	Ongoing higher education	Student of physiotherapy	Evangelic	MCMV** Housing Program	Yes	2.4
FM4	Mother	Complete high school	Homemaker	Evangelic	Rented	Yes	2
FM5	Grandmother	Complete primary school	Homemaker	Evangelic	Rented	Yes	***
FM6	Mother	Complete high school	Homemaker	None	MCMV Housing Program	Yes	1
FM7	Mother	Complete primary school	Homemaker	Evangelic	Own	Yes	1.5
FM8	Mother	Complete high school	Homemaker	None	Own	Yes	2

\* Number of minimum wages

\*\* *Minha Casa, Minha Vida* Housing Program

\*\*\* Participant was unable to inform

Chart 2 shows the sociodemographic characteristics of the children in terms of gender, date of birth, age of the mother at birth and members of the family nucleus. In order to guarantee the con-

fidentiality of children and participants, each child was identified with an acronym (C1 to C8) with the number corresponding to the person interviewed and the family relationship.

**Chart 2.** Characteristics of children in terms of sex, date of birth, mother's age at birth and family members.

Child	Gender	Date of birth	Mother's age at birth	Number of family members at the same house
C1	Male	11/30/2015	34	Mother, father and two brothers
C2	Male	12/12/2015	18	Mother
C3	Male	11/15/2015	19	Mother, father and brother
C4	Female	8/9/2015	23	Mother, father and sister
C5	Male	11/12/2015	18	Mother and brother
C6	Female	9/26/2015	22	Mother, father and brother
C7	Female	7/23/2015	34	Mother, father and two sisters
C8	Female	1/1/2016	27	Mother, father and sister

## 2. From interviews with family members

Below are interview results by category of analysis.

A. Moment when they became aware of the diagnosis

Chart 3 shows the moment in which they became aware of the diagnosis of CZS, as well as the guidance and conduct in the perception of the family members. In addition, the Chart includes the child's date of birth, due to the association of the diagnostic hypothesis (HD) of microcephaly and ZV having occurred at the end of 2015 in Brazil.

**Chart 3.** Diagnosis of congenital Zika virus syndrome regarding knowledge, guidance and conduct.\* Date of Birth

Family Member	DoB* of the child	Time when the HD** of microcephaly was informed Microcephaly	Zika virus-associated microcephaly	Guidance with regard to diagnosis	Awareness about the outbreak	Professional who guided
FM1	11/30/2015	Pregnancy (7th month)	Yes	Yes	No	Prenatal Doctor (SUS)***
FM2	12/12/2015	At birth	Yes	No	No	None
FM3	11/15/2015	Pregnancy (9th month)	Yes	Yes	Yes	Prenatal Doctor (SUS)*** and from private clinic
FM4	8/9/2015	After birth (3 months)	Yes	Yes	No	Neurologist from the Hospital
FM5	11/12/2015	At birth	Yes	Yes	No	Prenatal Doctor (SUS)***
FM6	9/26/2015	At birth	Yes	Yes	Yes	Doctors from the Maternity Ward
FM7	7/23/2015	Pregnancy (9th month)	No	No	No	None
FM8	1/1/2016	After birth (2 months)	Yes	Yes	Yes	Neurologist from private clinic

\*\* Diagnostic Hypothesis

\*\*\* Unified Health System

Regarding the guidance received at the time of diagnosis, in the case of family member FM2, the nurse at the health center referred the child to undergo tests at the hospital in Salvador after reaching the diagnosis, thus, the family did not receive guidance at the time of diagnosis. As for family member FM7, with the onset of the outbreak, the hospital contacted her to make referrals to Speech-Language Pathology, Physiotherapy, Infectology and Neurology. However, the mother had difficulties in finding care to be guided before that.

As shown in Chart 3, FM7's report is different from the others, which may be related to the fact that the child was born (July 2015) when the relationship between the outbreak of microcephaly associated with ZV had not yet been established. However, after the increase in media attention and in the number of cases in the Northeast, the hospital contacted FM7 in order to offer the necessary guidance, as shown in the following report:

*FM7: When the outbreak started, people began to associate Zika and microcephaly. There were a lot of children being born with microcephaly, so, at that time, there was concern from professionals and the people... And the hospital then began to call people and get in touch. The hospital set up a team here and a group, and they called me to physiotherapy, speech-language pathology, neurology, etc. And they began to explain the things that we would be entitled to.*

Almost all family members (n=7) were informed about the association with ZV at the time of diagnosis of microcephaly. The difference is precisely the time of diagnosis, which was mostly after delivery (for five family members - three at birth, and two 3 and 2 months later), while the three remaining family members received the diagnosis during pregnancy.

In turn, although the child of FM8 was born in January 2016, when there was already a causal link between microcephaly and ZV, the family received the diagnosis of microcephaly only when the child was 2 months old.

Six of the eight family members were guided by the physicians about microcephaly and ZV at the time of diagnosis, and only three family members reported being aware of the outbreak at the time of the child's birth.

As reported by the interviewees, the health care provided by the public network prevailed in these cases, with the reference hospital in Salvador standing out as the most cited by them:

*FM1: I was doing prenatal care here with the physician from SUS and when I was informed about the diagnosis, she immediately referred me to the reference hospital, where there were already other cases. So, there was already a team being formed to address this issue of the outbreak, right? Everyone was surprised by the situation.*

## B. Impact of diagnosis

**Table 1.** Impact of the diagnosis on the perception of family members.

Characteristic		Number of participants (n=8)
Feeling	Anguish	5
	Peace of mind	3
Grief	Acceptance	8
	Denial	0

Regarding the impact of the diagnosis on the lives of family members, Table 1 shows that the majority (n=5) of the participants reported feeling anguish due to uncertainties and fears about the disease. However, all family members reported acceptance after the initial impact of being informed about the diagnosis, as shown in the report of FM7:

*FM7: "At first, I was a little sad when I actually learned about the causes, but then that feeling passed".*

*Interviewer: Why were you sad?*

*FM7: In fact, there was a fear of not being able to do anything. Not being able to walk or speak... And the seizures made me really sad. Even today, the seizures make me really, really sad.*

Among the results, the report of FM4 stands out, who is the mother of one of the children and who felt negatively affected, mainly because of the way she received the information:

FM4: *Well, I felt so bad for the way the doctor told me and not for the microcephaly itself. When she was born, the doctor told me that she would not be able to walk, speak, or have any development, that*

*she could stay in a vegetative state in a bed, and that I could even take her home, but that I wouldn't see my daughter grow up. He said that my daughter would not speak, see, or walk.*

#### C. Search and support in health care

Chart 4 shows the distribution of referrals that the interviewees received after being diagnosed with microcephaly.

**Chart 4.** Distribution of professional referrals after microcephaly diagnosis according to family members.

Family Member	Physiot.	SLP	OT	Visual rehab.	Neuro.	Infec.	Gastro.	Nutri.	Ped.	Social Ass.	Psycho.	CHA	Nurs.
FM1	X	X	-	X	X	X	-	X	X	X	X	-	-
FM2	X	-	-	-	-	-	-	-	-	-	-	-	X
FM3	X	-	X	-	-	-	-	-	-	X	-	X	X
FM4	X	-	-	X	X	-	X	-	X	X	X	-	-
FM5	X	-	-	-	-	-	-	X	-	X	X	X	-
FM6	X	-	-	-	X	-	-	-	-	X	X	-	-
FM7	X	X	-	-	X	X	-	-	-	X	X	-	-
FM8	X	X	-	-	X	-	-	-	-	-	-	-	-

Abbreviation: Physiot.=Physiotherapy; SLP=Speech-language pathology; OT=Occupational Therapy; Visual rehab.=Visual Rehabilitation; Neuro.=Neurology; Infec.=Infectology; Gastro.=Gastroenterology; Nutri.=Nutrition; Ped.=Pediatrics; Social Ass.=Social Assistance; Psycho.=Psychology; CHA=Community Health Agent; Nurs.=Nursery.

Most of the family members were referred for care with a physiotherapist from the municipal network at the time of diagnosis and, according to the reports, this professional assumed a leading role in the organization and guidance of the care that children and family members should undergo.

In this context, FM1 and FM4 were referred for visual rehabilitation at a reference institution in Salvador. The community health agents and/or nurses who provided care for FM2, FM3 and FM5 worked at the reference health center that the participants attended. In addition to the information shown in the Table, FM3 and FM8 reported that

they accessed private services to perform tests and receive guidance soon after the child's birth.

It is also noteworthy that, according to the participants, most medical referrals, such as for the areas of Neurology, Infectology, Pediatrics and Gastroenterology, and also for Social Assistance received by family members, were to professionals at the reference hospital in Salvador.

Chart 5 follows the distribution of care by specialization received by the children at the time of the interview, according to the reports of the interviewees.

**Chart 5.** Distribution of child care by specialty at the time of the interview.

Family Member	Physiot.	SLP	OT	Visual rehab.	Neuro.	Infec.	Gastro.	Nutri.	Ped.	Psycho.
FM1	X	X	-	X	X	X	-	-	X	-
FM2	X	X	-	-	X	-	-	-	X	-
FM3	X	X	-	-	X	-	-	-	-	-
FM4	X	X	-	-	X	X	X	-	X	-
FM5	X	-	-	-	X	-	-	-	-	-
FM6	X	X	-	-	-	-	-	-	X	-
FM7	X	X	-	X	-	-	-	-	-	-
FM8	X	X	X	-	X	-	-	-	-	-

Abbreviation: Physiot.=Physiotherapy; SLP=Speech-language pathology; OT=Occupational Therapy; Visual rehab.=Visual Rehabilitation; Neuro.=Neurology; Infec.=Infectology; Gastro.=Gastroenterology; Nutri.=Nutrition; Ped.=Pediatrics; Psycho.=Psychology.

Children were around 3 years of age at the time of data collection. All participants also reported that they received care from the physiotherapist in the municipality where they lived. As the place where most family members receive support, guidance and exchange experiences, and where children undergo speech-language pathology care, the NGO in Salvador also has an important role. All children who have undergone, or are undergoing, visual

rehabilitation receive assistance from the institute specializing in care for the visually impaired in Salvador. In addition, some family members reported that the reference Health Center team was essential for guidance and referrals.

Chart 6 presents the results regarding the pros and cons in the journey of families in seeking and supporting the follow-up of their children's health care.

**Chart 6.** Pros and cons in seeking health care according to the perception of family members.

Family Member	PROS		CONS	
	Public and/or social assistance	Access to private services	Reported difficulties	Waiting for
FM1	Not addressed	Ultrasonography	Not addressed	Not addressed
FM2	Health Department; NGO	Not addressed	Not addressed	Wheelchair
FM3	Transportation of the Municipal Government; Home care by the HC nurse	Ultrasonography; Specific guidelines	Lack of professional guidance;	Classroom assistant at school;
			Availability of municipal transport	OT Care
FM4	Transportation of the Municipal Government; Support group	Not addressed	Lack of professional guidance	Classroom Assistant at school; wheelchair
FM5	Support group	Not addressed	Not addressed	Not addressed
FM6	Transportation of the Municipal Government; Mother's Group	Not addressed	Lack of professional guidance;	Classroom Assistant at school
			Availability of municipal transport	
FM7	Transportation of the Municipal Government; Care institution; Support group	Not addressed	Difficulty in accessing care	Classroom Assistant at school; wheelchair;
				OT Care
FM8	Transportation of the Municipal Government; Family member who is a councilman	Neurologist and pediatrician;	Loss of health insurance;	Not addressed
		Ultrasonography and blood test	Child's symptomatic condition	

Abbreviation: NGO=Non-governmental organization; HC=Health Center; OT=Occupational Therapy



Based on the participants' reports, the findings presented in Chart 6 show that the services offered by the Municipal Governments were important in the search for health care, especially regarding the provision of transport to the state capital. In addition, most family members sought care through information exchange with other families in the same situation, such as in the support group.

Three participants (FM1, FM3 and FM8) reported that they used private services both before and after childbirth for exams and specialized care. In turn, four family members (FM3, FM4, FM6 and FM7) were waiting for the arrival of a classroom assistant so that the child could start attending school, while three family members (FM2, FM4 and FM7) reported that they were waiting for the wheelchair for the child.

As an important positive aspect, some participants (FM2, FM3 and FM6) reported receiving priority care in the emergency and outpatient services needed by their children. They also reported that the professionals at the institutions gave priority to the care of the family when they became aware that it was a child with CZS, as shown in the report of the family member FM3:

*FM3: When we arrived with a referral and informed that we had a case of microcephaly, the institutions responded quickly because they were giving priority to children who were born with microcephaly.*

Although participant FM3 reported the transport provided by the Municipal Government as a positive aspect at the beginning, she also reported that she stopped using this service due to related difficulties, when explaining the child's reasons for interrupting occupational therapy (OT) visits, as follows:

*FM3: Due to the distance and transport provided by the Municipal Government as well. He also had follow-up with two OTs in Salvador. We interrupted this service because it was very difficult to take him out in the Municipal Government's car. Many times we stayed there at the institution because the car wouldn't pick us up, so I decided to take him out for this reason. The last time they dropped me off in Salvador I was without my cell phone, and they didn't tell me who was going to pick me up or anything. Many hours later and no one had come to get me. Finally, the institution's physiotherapist lent me money so I could go home, and I arrived home late at night, with my son in my arms. Therefore, that*

*day was the last straw for me and, as a result, I took him away from all the services that were provided in Salvador. As we depended on the Municipal Government car to go to Salvador, I decided it wasn't worth it and I took him out of therapy in Salvador for this reason. Thus, he receives all medical care here in the city; everything is done here where we live.*

Another participant (FM4) reported the lack of specialized professional guidance as a con, and also stated that she left the maternity ward after delivery, believing that her child had no changes. However, months later a professional told her that her daughter would never develop as a normal child.

Participant FM8 reported that she feared putting the child in school due to the symptomatic history, since she had episodes of feeling sick and demanding the exclusive attention of the family.

In turn, participant FM6 addressed different difficulties, such as diagnosis and access to specialized care for the child. This participant reported that she received controversial medical information during prenatal care regarding gestation time and head circumference measurement. Therefore, the mother reported that the professionals would have discarded the diagnostic hypothesis of microcephaly.

*FM6: I received opposite information on every appointment I went to. Some professionals said that I was 5 months pregnant, while others said it was 4 months. I thought these people were kind of crazy, since each one said something different. When I was there (in Ceará), I went to an appointment and the doctor said I was 6 months pregnant, then I went to another appointment and the doctor said I was 5 months pregnant and I didn't understand why. Maybe this difference in the answers occurred because they couldn't explain it either due to the size of the head, but they never explained it to me. Perhaps it was also due to the fact that it was always a different doctor and I was never seen by the same doctor. So, I was seen by another doctor and this new doctor used to say something like 'the other doctor made a mistake when measuring'. This may be the reason, but no one has ever said anything (about microcephaly).*

In addition, this mother also added that, after the birth of the child, there was great difficulty in accessing care due to the delay in transport time by the Municipal Government and the fatigue resulting from travel.

#### D. Effect on children's development and inclusion

This category aimed to list the differences in the lives of the eight family members after the

child's arrival and with the inclusion of health care in their routine. However, many participants did not address some aspects, as shown in Table 2.

**Table 2.** Effects on family dynamics regarding child health care and the support received.

Characteristic		Number of participants (n=8)
Work	Interruption	3
	Did not address the topic	5
Home routine	Changes were made due to the child's condition	3
	Did not address the topic	5
Support received	from relatives	6
	Did not address the topic	2

Three participants (FM1, FM2 and FM4) reported that they had to stop working, while three participants (FM1, FM2 and FM5) reported that the family routine schedule changed with the child's arrival, based on the child's needs. Six participants reported that other relatives helped with the child's care and with visits to health care services, as shown in the following report:

*FM2: My mother stopped working and his father also stopped working, due to the care he requires. The change occurred because I lived alone with my husband, my ex-husband, so I had to go back to my mother's house to be able to take care of my son. Because I needed to go out a lot for visits and she accompanied me.*

## Discussion

The findings show many important issues, such as women's role in child care, low family income, lack of clear information, difficulties in accessing services, in addition to changes in family dynamics. These questions show how the presence of a child with disabilities at home proves the precariousness resulting from social inequalities and the lack of full exercise of public policies. And this can be related to previous studies found in the literature.

Some authors<sup>20</sup> published a study of the sociodemographic profile of 25 mothers of children with CZS in the State of Espírito Santo, including 19 non-white mothers, 9 single, 13 who did not complete high school, 12 who had an income between USD 0.00 and USD 61.72, 17 who lived in peripheral areas and 12 of the 16 mothers who had an employment before pregnancy were fired

or resigned after the baby was born. In view of these findings, the authors conclude that the health condition is influenced by social and economic conditions, with the distribution of the disease being a result of social organization, which is in line with the findings of this study.

Gender issues also characterize the outbreak of Zika in the country, in addition to the fact that the BPC proves to be insufficient, as expenditure on child care exceeds the value of this benefit. All family members in this study were women and played a major role in caring for the children. They also reported great dependence on the services and assistance offered by the SUS, which must provide comprehensive care and universal access. However, these social inequalities must be addressed through efficient public policies, which still do not provide adequate support to these families<sup>20</sup>.

Both these social and economic issues and the vulnerable situation of the child and their family members directly and indirectly affect the therapeutic journey of the families participating in the study, since the paths from the prenatal period and awareness of the diagnosis to specialized health care and education depend on the meaning that subjects give to the search for health care and their subjectivity. From this perspective, some authors<sup>21</sup> discuss vulnerability in their work and how it configures itself in a dynamic of reciprocal interdependencies that express biological, existential and social values:

*A situation of vulnerability restricts the relational capacities of affirmation in the world, including forms of social agency, resulting in weakening. [...] Capturing this complexity is a challenge both because of the practical implications in the clinical or*



public health sphere and because of the challenges surrounding the general criticism of contemporary social institutions [...]”<sup>21</sup>. (p.246)

The findings show that children attend a large number of services and professionals in their therapeutic journeys. These results are in line with findings in the literature that report that, in view of the high risk of alterations suffered by children with CZS, it is necessary to permanently monitor their growth and development. Therefore, multidisciplinary care is essential, as shown by the findings.

However, the care of these children still requires greater attention so that their therapeutic journeys are not only characterized by travels to institutions, without a common bond between the services. In this context, some authors<sup>22</sup> report that, under the SUS framework, the fragmentation of the care process and the movements of users between professionals and services without an integral approach may have ineffective and inefficient results, as shown in the findings.

Although family members report referrals and assistance to different specializations, the families do not seem to be directly involved or assisted. In a review of the care provided to children with CZS, researchers<sup>23</sup> warned that practices in Brazil are often aimed at stimulating skills, with a focus on the rehabilitation of the child’s difficulty, through clinical approaches that limit family participation.

The results show a weakness in the health care of children with SCZV, which is possibly also found in other Brazilian regions, but which is different from the international context. According to these authors, other countries carry out monitoring of child development through early intervention, including strong support for families. However, these authors report that the difficulty of establishing trans and interdisciplinary work is a factor that compromises this family support in Brazil<sup>23</sup>. In addition, the findings show that the participants bring issues and impacts on the lives of children with CZS and their families that go beyond health care in the perspective of treating and rehabilitating children..

Among the difficulties encountered by family members in their search for health care, there is a lack of guidance, which makes some mothers search alone on the internet when receiving the

diagnosis of CZS. Along this path, children often receive priority in emergency care. It should be noted that participants report that children receive more attention, especially from professionals at the reference hospital in Salvador and from the physiotherapist in their municipality.

The findings show the anguish of the participants due to the uncertainties and fears facing CZS, which was not typical of those who had no knowledge about the virus outbreak. However, after the initial impact of the diagnosis, all family members reported having accepted the diagnosis, and showed resilience even after suffering, which is also in line with the findings in the literature<sup>10</sup>. In a study of the mental health of parents of children with CZS, these authors report that the presence of the child’s health condition is an important factor for the development of stress, as a result of uncertainties about the future of the child and of the family itself, as shown in the following report:

[...] in addition to all the health services that should be offered to children with CZS, the parents of these children, especially the mothers, need a closer look by health professionals, especially psychologists, in the sense of thinking about intervention strategies that focus on the way these individuals perceive their life experiences and their feelings. In addition, taking care of the parents implies necessarily taking care of the children, since psychologically healthy parents will be in better physical and psychological condition to take care of their children.<sup>10</sup> (p.9)

The Humaniza SUS document that addresses the Singular Therapeutic Project emphasizes that “to specify the Therapeutic Projects is to look for the right way and the right proposal for each person or group, according to their preferences and history”<sup>24</sup>. Therefore, therapeutic journeys must be adjusted to family life, given the different types of health care and the implications of their search, as this will greatly influence adherence to services, motivation to seek improvement and continuity of care even in the face of difficulties, as shown by the results of this study from the perspective of family members.

## Conclusion

The results show that the children received the necessary assistance at the time of diagnosis, even though this initial stage of the therapeutic journey was often not ideal. In addition, participants reported positive aspects, such as availability of transport by the Municipal Government, and support from family members and health professionals.

On the other hand, the findings also show negative aspects based on the perception of family members, such as access to specialized health care services and to equipment, such as a wheelchair, in addition to changes in family dynamics and access to early childhood education by the child, which could be solved by the full exercise of rights conferred by existing laws and public policies.

The findings show the paths taken, as well as the pros and cons, in the therapeutic journeys of these families, which are essential for the formulation of new public policies or to guarantee the existing ones in order to meet the health and education needs of this population group and that bring to light the importance of comprehensive care for these children and families, who have been impacted since 2015 and who still need more attention.

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