

## Characteristics of access of children with microcephaly to physical therapy services

## Características do acesso de crianças com microcefalia aos serviços de fisioterapia

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**ABSTRACT | INTRODUCTION:** The "congenital Zika syndrome" comprises a set of signs and symptoms presented by children born to infected mothers during pregnancy. Newborns affected by microcephaly present alterations in their neuropsychomotor development. Therefore, the rehabilitation process becomes essential for the development of children. **OBJECTIVE:** From this perspective, it is necessary to consider access in its broad domain and understand the characteristics of children with microcephaly (born in 2015 and 2016) access to physical therapy services. **METHODS:** This is a cross-sectional study, with a quantitative approach, with a descriptive character. A questionnaire validated by four experts was used, collecting information about the socioeconomic and clinical characteristics, identification of the time between the referral of children, and the characteristics of access to rehabilitation. **RESULTS:** The sample of this study consisted of 103 caregivers of children with microcephaly. It was observed that 93.2% of the children were referred to seek the physiotherapy service and searched for it. However, not all children remained in rehabilitation. Children who had continuous access and those who discontinued care at some point similarly presented themselves concerning the frequency of treatment, physical therapy in more than one service, duration of the session, expenditure of payment for exams, and interference in the professional activity with the child's treatment. **CONCLUSION:** Those who remained in uninterrupted access had better assistance from the municipality for displacement, in addition to the opportunity for help from the caregiver support network, enhancing the maintenance of care.

**KEYWORDS:** Access to health services. Rehabilitation. Microcephaly. Physiotherapy.

**RESUMO | INTRODUÇÃO:** A "síndrome congênita do Zika" compreende um conjunto de sinais e sintomas apresentados por crianças nascidas de mães infectadas durante a gestação. Os RN acometidos por microcefalia apresentam alterações no desenvolvimento neuropsicomotor, assim, o processo de reabilitação torna-se fundamental para o desenvolvimento das crianças. **OBJETIVO:** Nessa perspectiva, faz-se necessário considerar o acesso em seu domínio amplo, e compreender as características do acesso de crianças com microcefalia nascidas nos anos de 2015 e 2016 aos serviços de fisioterapia. **MÉTODOS:** Trata-se de um estudo transversal, de abordagem quantitativa, com caráter descritivo. Utilizou-se um questionário validado por quatro especialistas, coletando informações acerca da caracterização socioeconômica e clínica, identificação do tempo entre o encaminhamento das crianças e sobre as características do acesso à reabilitação. **RESULTADOS:** A amostra deste estudo foi composta por 103 cuidadores de crianças com microcefalia. Observou-se que 93,2% das crianças tiveram encaminhamento para procurar o serviço de fisioterapia e buscaram atendimento, entretanto, nem todas as crianças mantiveram-se em reabilitação. As crianças que tiveram acesso continuado e as que descontinuaram o cuidado em algum momento apresentavam-se de forma semelhante no que diz respeito à frequência de tratamento, realização da fisioterapia em mais de um serviço, tempo de duração da sessão, despendimento de pagamento para exames e interferência na atividade profissional com o tratamento da criança. **CONCLUSÃO:** As que se mantiveram em acesso sem interrupções, possuíam um auxílio maior do município para deslocamento, além da oportunidade de assistência da rede de apoio ao cuidador, potencializando a manutenção do cuidado.

**PALAVRAS-CHAVE:** Acesso aos serviços de saúde. Reabilitação. Microcefalia. Fisioterapia.

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## Introduction

Parting from the Zika virus epidemic in Brazil and the increasing cases of children with microcephaly, in 2015, studies were made to investigate the association of this infection to malformations in newborns above all the microcephaly.<sup>1</sup>

Microcephaly can be diagnosed yet during pregnancy, in the follow-up by pre-birth exams, or by the routine clinical evaluation, the newborns are submitted in the first 24 hours of life. In this case, it is made the scouting of the Cephalic Perimeter (CP), with the measuring of the Occipital Frontal Circumference (OFC), achieving the diagnosis of microcephaly when the value is lower than the expected to the gestational age and sex. Observing an inadequate growth of the skull leads to the conclusion that the brain is found undersized, therefore, showing anatomic-physiological aspects that escape normality.<sup>1</sup>

The epidemic of the “congenital Zika syndrome” comprises a set of signals and symptoms presented by children born to infected mothers during pregnancy, being microcephaly the most marking alteration in the Central Nervous System Associated with the infection by the virus. Newborns affected by microcephaly present alterations in their neuropsychomotor development, possibly presenting intellectual deficiency, epilepsy, brain paralysis, cognitive deficit, motor and speaking compromises. Problems in sight and hearing may also be present.<sup>2</sup>

Since the publication of the Decree 7.692 in 11/17/2011 and the Ordinance 793/2012 that institute the *Plano Nacional da Pessoa com Deficiência – Plano Viver sem Limites* [National Plan of the Person with Deficiency – Living Limitless Plan] and the *Rede de Cuidados à*

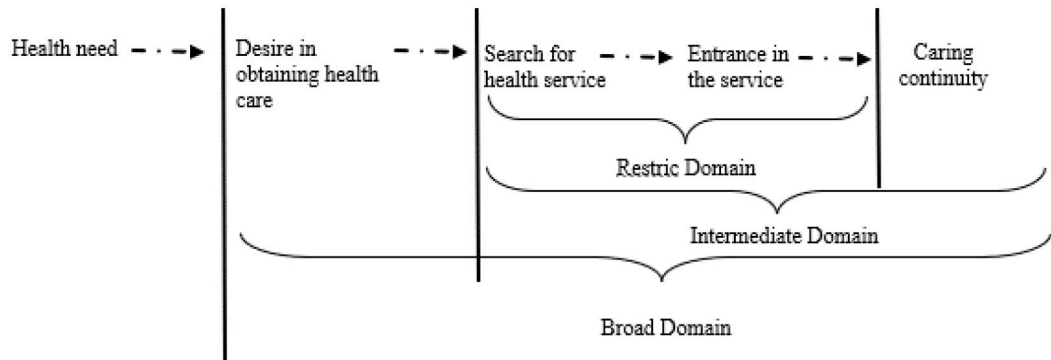
*Pessoa com Deficiência* (RCPCD) [Network of Caring to the People with Deficiency] in the SUS, respectively, there has been the beginning of an expansion movement of rehabilitation services in the country. The new demands arising from the surge of the number of children with microcephaly, in the period mentioned above, demanded a reorganization of the services network, in the sense of attending to the needs of caring imposed by this grievance and the fact that the RCPDC was in expansion was a favorable element, however, the RCPDC, at that moment, was still in the initial phase of implementation. These demands include diagnostic and therapeutic actions, emphasizing the specialized following-up to the development of these children, aiming to prevent and/or minimize sequels arising from this condition.

In this context, the rehabilitation process becomes fundamental to the development of babies and must be initialized as soon as possible, considering the numberless sequels presented arising from the bad brain formation.<sup>3</sup>

Access is defined here as the utilization of service to obtain satisfactory rehabilitation and continuity in the treatment process.<sup>4</sup> More than that, as pointed out by Travassos and Viacava<sup>5</sup>, the access reflects the characteristics of the health system that act increasing or diminishing boundaries to the obtaining of services by the population. These authors advocate, still, that the utilization of health services may be understood as the entrance at them, being a positive expression of the access.

Based on the definition of the flow of events between health needs and the obtaining of caring, three domains are proposed to the access<sup>6</sup>, as diagramed below:

Figure 1. Fluxo de eventos entre necessidades de saúde e a obtenção de cuidados, adaptado de Frenk.<sup>6</sup>



It stands out, thus, that considering the access only for the entrance in the services corresponds to the restricted dimension of the access. In the current study, it will be adopted as a reference, the broadened perspective of the access, which includes the entrance in the service and the continuity of the caring. The choice for this reference is justified by the specificity of the rehabilitation process, which requires a permanence of the person in treatment for long periods, above all when faced with neurological compromises. Thus, the objective of this study is to consider access in its broad domain and understand the access characteristics of children with microcephaly born in the years 2015 and 2016 to the physiotherapy services in a Northeast capital. It is hoped, parting from there, to contribute to improving the Network organization process.

## Method

This is a cross-section study, with a quantitative approach, with a descriptive character. Were included all access data from children diagnosed with microcephaly born between 2015 and 2016, with possible association to the Zika Virus in the state of Paraíba, appearing in the list available by the Secretaria Estadual de Saúde (SES) [Health State Secretariat], parting from notifications registered in the Formulário de Registro de Eventos de Saúde (RESP) [Register Form of Health Events] – Microcephaly, totaling a population of 191 children.

A questionnaire was used, made from an insightful review of the literature, and validated by four specialists, collecting information about the socioeconomic and clinic characterization, identifying the time between the referral of the children, and the rehabilitation access. This instrument was applied to the caregivers of the children with microcephaly.

The data collecting was initiated through the participation of the researchers in the Caravana do Coração [Heart Caravan], a project that was a fruit of the agreement between the Círculo do Coração de Pernambuco [Pernambuco's Heart Circle] and Paraíba State Government, to make screenings, exams, and accompaniment consultations of children in 13 cities in the State of Paraíba. The partnership with this state government project made possible the collecting in all health regions in the State of Paraíba, which occurred in the years 2017 and 2018.

Thereby, the tracking and children's information collecting were made parting from the services of reference for the rehabilitation and were part of the study all the children with the diagnosis of microcephaly, born between the years 2015 and 2016, which the mothers have had historic of Zika Virus infection. Thus, the final sample of this study stayed in 103 children with microcephaly associated with the Zika Virus, of which parents or guardians were interviewed.

## Results

For the presentation of the results referring to the access characterization, was used the descriptive statistic. The study was submitted to the evaluation by the Research Ethics Committee, from the Health Science Center, at Universidade Federal da Paraíba (CAAE: 64800416.9.1001.5188). All participants have signed the *Termo de Consentimento Livre e Esclarecido* [Clarified and Free Consent Term] as rules the resolution 466/12 from *Conselho Nacional de Saúde* [National Health Council].

The sample of this study was composed of 103 caregivers of children with microcephaly. The majority of the mothers of the children in this study were more than 21 years old (82,6%), already in the third or more pregnancy (35,9%), and were referred not to possess a High School degree (96,2%). In addition, an extensive part of the interviewees reported to be inactive (64,1%), and the majority declared to be married or in stable union (69,9%), as can be observed in Table 1.

Most of the children were born with a cephalic perimeter below 31 centimeters (83,4%). The cephalic perimeter of the child at birth was an important variant to verify the late diagnosis. Approximately half of the interviewees (48,5%) have had discovered the diagnosis of the children before birth; more than half (51,5%) have discovered at the birth or post-birth and have not presented and complications during pregnancy (73,8%). The majority reported to make usage of the *Benefício da Prestação Continuada* (BPC) [Continued Provision Benefit] (85,4%) and have family income between one and two minimum wages (99%). Regarding the need for CTI referral at birth, 20,4% of the children were interned and had, as main caregivers, the mothers, 91,3% described in Table 2.

Almost all of the children, 93,2%, have had some referral to seek physiotherapy services. Most of the caregivers, 88,3%, declared to have initialized

the rehabilitation process until eight weeks after the referral, 71,9%. Of these, 74,7% make the physiotherapeutic treatment at the rehabilitation center, and without personal costs, 96,1% are pointed out in Table 3.

In summary, the children were attended, in its majority, at the Specialized Rehabilitation Centers, without costs, between 2 to 3 times a week, with a duration of 40 to 60 minutes, and a large part referred that the treatment process has interfered in their previous professional occupation.

However, it stands out that not all of them have had a continued rehabilitation process (11,7%), which can be evidenced in Table 4.

About the differences between children that have had their treatment interrupted in relation to the ones who have not had an interruption, it is observed that both groups of children presented similarly regarding the treatment frequency, physiotherapy realization in more than one service, duration time of the session, expenses with exams. Furthermore, in dealing with the moving to the realization of the treatment in another city, as well, there was no difference between the children that have had their treatment interrupted and the ones who were kept in their treatment without interruption.

Nonetheless, it was verified that the children kept in access without interruptions had bigger support from the city for moving, contrary to the group that at some moment has interrupted physiotherapy. The difference also happens in what concerns the support/assistance to the caregiver. More than half of the mothers who continued with their children in attendance have had some assistance, and the mothers who have discontinued the rehabilitation process have not obtained any opportunities for assistance.

**Table 1.** Sociodemographic characterization of study subjects

Variable	Characterization of mothers of children with Microcephaly	
	(N)	%
<b>Age</b>		
Up to 20 years old	18	17,5
Between 21 and 30 years old	46	44,7
30 years old or more	39	37,9
<b>Number of pregnancies</b>		
1	30	29,1
2	34	35,0
3 or more	39	35,9
<b>Schooling</b>		
Incomplete Elementary School	34	35,0
Complete Elementary School	63	61,2
High School	3	1,92
University education	3	1,92
<b>Occupation</b>		
Active	39	35,9
Inactive	64	64,1
<b>Stable Union</b>		
Yes	72	69,9
No	31	30,1

Source: Research data, 2019.

**Table 2.** Health, clinical and social needs of the children of the study

Variable	(N)	%
<b>Age</b>		
Up to 24 months	53	51,5
More than 24 months	50	48,5
<b>Cephalic perimeter at birth (cm)</b>		
Between 20 and 28	30	29,1
Between 28 and 31	56	54,3
Above 31	4	3,9
Does not know	13	12,7
<b>Diagnosis</b>		
Before birth	43	41,7
At birth	10	9,7
After birth	50	48,5
<b>Complications during pregnancy</b>		
Yes	27	26,2
No	76	73,8
<b>Support destined to the condition</b>		
Yes	88	85,4
No	15	14,6
<b>Family Income of the child (minimum wages/month)</b>		
Up to one	1	1,0
Between one and two	101	98,0
More than two	1	1,0
<b>Have done prenatal</b>		
Yes	100	98,0
No	3	1,92
<b>CTI referral at birth</b>		
Yes	21	20,4
No	82	79,6

Source: Research data, 2019.

**Table 3.** Access conditions to Physiotherapy: search and entrance in the rehabilitation services

Variable	Health conditions of the child and access to Physiotherapy	
	(N)	%
<b>Referral to the Physiotherapy Service</b>		
Yes	96	93,2
No	7	6,8
<b>Access to the Rehabilitation service</b>		
Yes	92	88,3
Yes, but has interrupted	11	11,7
<b>Time taken for the child to have access to the Physiotherapy service</b>		
Up to 2 weeks	39	37,9
Between 3 and 8 weeks	35	34,0
More than 8 weeks	29	28,2
<b>Place where the treatment is/was made</b>		
Home	2	2,0
Rehabilitation Center	77	74,7
Hospital	5	4,9
School Clinic	19	18,4
<b>The treatment is paid</b>		
Yes	4	3,9
No	99	95,9

Source: Research data, 2019.

**Table 4.** Caring continuity in the Physiotherapy services data

Variable	Continue Access		Discontinue Access	
	N	%	N	%
<b>Making the treatment in the same city of the family home</b>				
Yes	40	44,0	6	54,6
No	42	46,1	3	27,3
In more than one city	9	9,9	2	18,1
<b>Hometown support for moving</b>				
Yes	52	57,1	4	36,4
No	7	7,7	2	18,2
Does not apply	32	35,2	5	45,4
<b>Treatment duration (years)</b>				
Less than 1 year	18	17,5	-	-
More than 2	85	82,5	-	-
<b>Frequency of the treatment (days a week)</b>				
1	17	18,7	3	27,3
2	38	41,7	5	45,4
3	20	22,0	2	18,2
More than 3	16	17,6	1	9,1
<b>If the physiotherapy is done in more than one service</b>				
Yes	54	59,3	1	9,1
No	36	39,6	10	90,9
Does not know	1	1,1	-	-
<b>Duration time of the session (minutes)</b>				
15 to 30	32	35,2	2	18,2
40 to 60	50	54,9	4	36,4
Above 60	8	8,8	2	18,2
Does not know	1	1,1	3	27,3
<b>Payment of Money with diagnostic exams</b>				
Yes	44	48,4	2	18,2
No	46	50,5	8	72,7
Does not know	1	1,1	1	9,1
<b>Interference in the professional activity from the child's treatment</b>				
Yes	65	71,4	6	54,6
No	21	23,1	4	36,4
Did not answer	5	5,5	1	9,1
<b>Offering of some support for the mother</b>				
Yes	50	54,9	4	36,4
No	41	45,1	7	63,6

Source: Research data, 2019.

## Discussion

Concerning the subjects' profiles, it is observed that the maternal age is superior to 21 years old and most of the women do not present complications during labor, in a similar way to what has been found in the study of Marinho and collaborators.<sup>7</sup>

Related to the schooling level, most mothers have studied for less than eight years and, as for the occupation, are dedicated to their homes and self-referred as single mothers. Moreover, most families had family incomes inferior to one minimum wage, and its family nucleus was sustained from the BPC. It was identified, thus, similarity with the findings of the study of Marinho et al.<sup>7</sup> in the predominance of the youngest maternal age group, the schooling, and the family economic condition, in which these authors call attention to the socioeconomic and geographic inequalities of the families of children that present the Congenital Zika Virus Syndrome (CZS).

The Zika epidemic identified in the Brazilian Northeast has reached women of reproductive age. Were more affected mothers who were young, single, with low schooling, and in poverty situation.<sup>7</sup>

It was no observed difference in the prevalence of microcephaly between the sexes in the sample of children in this study. Besides, most of the interviewed caregivers were mothers, evidencing what is already known culturally, the woman is the provider of the family caring, above all when it comes to children caring.<sup>8</sup> The role of the mother in the family context is the provider of care when it comes to the ones that deal with the most adverse conditions, in the example of the deficiencies, which makes them more dependent. Empowered by the feeling involved in the mothership and conscious of their obligations, the mothers do not restrict their caring, possibly, sometimes, abdicating other aspects of their lives.<sup>3</sup>

By evaluating the moment in which the child was diagnosed with microcephaly, it stood out that more than half of the mothers had the diagnosis after the birth.

This way, the child's birth was accompanied by the impact of the news that the child presented a deficiency, and dealing with this casts a feeling of failure and frustration for the loss of the idealized child and breaking of the expectations created by the parents. Furthermore, the deficiency of a child brings together the need to share the obligations referring to the caring among the family members and the planning of new possibilities, including therapeutic, to overcome the adversities.<sup>3</sup>

The study in screen evidence access characteristics to the physiotherapeutic treatment, and regarding the restricted domain access, configured by the search for the service and its entrance.<sup>6</sup> It was identified that almost the totality of the children has had some referral for physiotherapy and achieved access to the rehabilitation service. Nevertheless, other studies refer to difficulties accessing the service with a late entrance, which may harm the individual's health state.<sup>9</sup> It stands out that access to physiotherapy services does not appear to be a situation easily lived.

Analyzing the context of the access to the country's rehabilitation services, in a general way, it was perceived that in the case of the children with microcephaly, there was a differentiation in terms of the supply and the access. Therefore, the SUS amplified the access to healthcare of the Brazilian population, having the Ministry of Health (MS) propose actions facing this issue. Since 2011 with the release of the *Plano Viver Sem Limites* [Living Limitless Plan], later with the RCPCD, there was an expressive expansion of the rehabilitation services. In 2015, with all the repercussions generated by the problem of the Congenital Zika Virus Syndrome (CZS) and strong popular appealing, the MS promoted some actions aiming to attend to the demands of these children and their families and in 2015 released the *Plano Nacional de Enfrentamento à Microcefalia* [National Plan for Facing Microcephaly].<sup>10</sup> In 2016, published the Protocol of attention to the health-related to the Zika Virus infection, as also the Guidelines of early stimulation – for children between zero and three years old with a delay of neuropsychomotor development due to the microcephaly.

The promulgation of the Convention about the Rights of People with Deficiency results from the maturing of society. Along with this process, in 2012 was instituted the Rede de Cuidados à Saúde da Pessoa com Deficiência [Caring Network to the People with Deficiency] at the SUS ambit. The Specialized Rehabilitation Centers (SRC) amplification appears as one of its advances, conceptualized as support services that provide the management of neuromuscular and musculoskeletal diseases that alter the functional state, making clinical, psychosocial, and functional interventions.<sup>11</sup> It was verified, in the current study, that many of the cases were being accompanied at the SRCs, which are preconized as a specialized place for attendance.

The majority of the children have had access to the physiotherapeutic treatment immediately inside the ideal time for the beginning of the intervention, the fact also observed in the study of Santos et al.<sup>12</sup>, in which the studied population has already been doing therapy for an average of nine months, which demonstrates the early beginning of the treatment and the family adhesion.

The late access, that is, in a period larger than 60 days, was identified in a smaller number of answerers. However, early stimulation is essential for post-birth brain development because the communication and connection between the cortical cells in a continuous process chain learning processes, according to each phase, may last the entire life.<sup>13</sup> It is important to mention that the late beginning of the physiotherapeutic intervention may cause the appearance of contractures and deformities, pain, diminishing of muscular strength, and delay in motor learning, making difficult the social reintegration of the patient.<sup>14</sup>

Specialized literature evidence point that rehabilitation is a global and dynamic process. Starting the early treatment potentializes the brain tissue reorganization, maximizing this way the functionality, offering recuperation of physical and psychological health of the person with deficiency.<sup>14</sup> The welcoming, attention, and caring for these children and their families are relevant to accomplishing the biggest functional gaining possible in the first years of life.

Thus, the physiotherapist in the rehabilitation field acts as a functional gains' enhancer, helping in the acquisition of development marks by the children parting from the stimulation of the CNS and other dimensions of organic functioning.<sup>15</sup> The access to quality physiotherapy is, therefore, a reduction of physical complications related to the articular alterations of motor performance, tonus, and strength. The motor activities, symmetry, and amplitude altered dement the initial approach from the physiotherapist, seeking to minimize the impact of the motor sequels related to the CZS, acting to improve their functional independence.<sup>16</sup>

It is known that microcephaly can manifest peculiarly in each newborn, possibly compromising many systems in the organism, generating from the motor to respiratory problems. Therefore, the early and constant following-up also allows monitoring of the child, making specialized referrals, and promoting integral assistance to the health of children with microcephaly.

Given the principle of the assistance integrality of SUS, according to which the access of all levels of attention to healthcare must be guaranteed in a way to attend for the health needs integrally, it is questioned how these services are being offered, once some caregivers referred to have paid for the rehabilitation service at some moment, for having opted for realizing the treatment in more than one service, in public and other private services.

Regarding the broad access domain, in the continuity of the caring question, it was observed that the majority of these children were maintained in treatment without interruptions.

The child with microcephaly must be stimulated and accompanied daily to urge their neuropsychomotor development. Therefore, the family is essential for the maximum development of the child.<sup>13</sup> The research subjects (82,5%) have access to the rehabilitation services for more than 12 months, 41,7% of the ones who maintained access with the frequency of two times a week and 45,4% of those that at any moment have interrupted the treatment.



The constancy with the physiotherapy treatment (88,3%) makes itself important, once the children with microcephaly show delay in the neuropsychomotor development, sight, hearing cognitive, and sensorial alterations, some may have problems in the locomotor apparatus like congenital crooked feet, hip luxation, and arthrogryposis, impacting in the functional independence and the social insertion of this population.<sup>17</sup>

The caring in rehabilitation presents peculiar characteristics that interfere with access, citing the need for treatment after the child's birth, the continuity of the assistance to reach improvements in the functional capacity and life quality. It is important to highlight the specificity of continuous physiotherapeutic caring once the incapacities of these children are related to the presence of motor, sensorial, and cognitive deficits, and that demands time for the optimization of the functionality.<sup>17</sup> This continuous assistance is justified because the neuronal plasticity lasts for different years, which evidences the non-existence of a limited period for the finalization of the treatment of neurological patients in rehabilitation programs.<sup>18</sup>

Nevertheless, on the other hand, prolonged caring may have high physical, financial, and emotional costs that may lead to a discontinuity of access. In this sense, to reflect about "the service abandonment" or the "discontinuity of the physiotherapeutic treatment" (11,7%) implies in analyzing the access to the broad domain proposed by Frenk<sup>6</sup>, which foresees the caring continuity.

The Northeast region, considered one of the poorest in Brazil, possesses a great limitation for the broad access to healthcare services. The users cite as difficulties to access the services: the big wait for the attendance to the specialties, the lack of adequate transportation, the distance of the services, the financial resources limitation, and the architectonic limitations in the public services and users' homes.<sup>19</sup>

It is understood as opportune access to obtain fast scheduling, allowing the user to obtain assistance

for acute conditions. However, continuity is the capacity of the user to access the health professional of reference for the accompaniment, having in mind a long-lasting relation with the professional and, consequently, the caring.<sup>20</sup> However, the need for access to these children finds itself beyond what we have discussed. It is up to here identify, therefore, the definition of adequate access.

Adequate access can be understood as the process of continuous caring, from health conditions, search and entrance at the service, to the creation of bond and adhesion to the service, making possible the longitudinality. Thus, it becomes adequate by looking at the referral flow, the marking, the appointment scheduled hour, emotional and financial, familiar and government support, the organizational and operational structure, material and physical resources, health networks, professional qualification, geographic distribution, and quality of the services, determinant in the conditions for the therapeutic permanence.

Regarding the treatment interruption, in the results shown in the last table, there was no difference in the condition of access supply for it to be interrupted, it is noted, however, some differences between the answers given by the caregivers of children who maintained the access and those who have interrupted it at any moment, among these results, the "treatment being held in another city" and "healthcare network support" stand out.

The transportation difficulties are considered obstacles for the child-caring, for they restrict the transportation to rehabilitation activities. According to Felix and Farias<sup>21</sup>, most cities with Congenital Zika Virus cases do not have specialized service and, for this reason, a pact with other cities; nonetheless, sometimes, there is difficulty maintaining regular transportation for these children for the treatment.

The study of Lima<sup>22</sup> identified that the mothers experienced stress when they needed to move to another city seeking health assistance for their children.

Another important Data verses about the caring network support for caregivers. Brunoni et al.<sup>23</sup>, in their study, identify that the new routine of parents of children with microcephaly reverberates directly in the life quality, besides the accompaniment of the child with microcephaly, it is also necessary to direct special caring for the mothers and other family members. The support can be offered by health professionals, religion, family, and public and private assistance<sup>24</sup>, though a great number of mothers, 63,6%, who have had discontinued access affirmed not having known any assistance.

Besides the expectations of getting better or healing, the families are surrounded by uncertainties about the children's future and the child's condition's inherent anxieties.<sup>25</sup> Adding to this, the daily caring routine, the various day-to-day pressures, in their majority, associated with the financial insecurity, ratify the need for support for the child and the family.

It was seen that the families pass through repercussions of physical, emotional, and financial order, that appear, probably, due to the abandonment of work activities by one of the genitors or both and to the difficulty of the families of maintaining with satisfactory support of government instances or other society instances, and also to the social readjustment of life. So that makes us think that it is important that the public power leans on offering incentive programs focusing on the child's assistance and maintaining the family that cares for the child with microcephaly associated with the Zika Virus.

The study limits itself to presenting a cross-sectional approach. Once the accompaniment of these families, cohort study would be necessary to understand if the broad access was kept during the years.

## Conclusion

The current study identified various potentialities of the services concerning the access of children with microcephaly in Paraíba, which differs from the general context of access studies. Among the difficulties, cases of interruption of the treatment stood out, which may be related to the difficulty of the physiotherapy treatment happening in the same city, to transportation and/or lack of welcoming with the process of health/sickness of the caregiver problems. On the other hand, as potentialities could be perceived from the access characterization, most children with microcephaly have had continuous access to motor rehabilitation, primarily in the SRC, which shows the importance of the ampliation of the RCPCD. However, it is valid to point the necessity for professional qualification and the recognition for the quality service given, independently of the location.

Thereby, the results of this study can corroborate the ampliation of the support for these children and their caregivers, parting from public policies of expansion and action planning aiming for the quality of these services.

## Authors' contributions

Farias DN has participated in the conception, outlining, statistic data analysis of the research, interpretation of the results, and writing the scientific article. Ribeiro KSQS and Nascimento JA have participated in the conception, outlining, search, and statistic data analysis of the research, interpretation of the results, and writing the scientific article. Melo ES, Brito GEG, and Neves RF have participated in the conception, outlining, and interpretation of the results. Melo ES, Lira LDB, and Souza LMG have participated in the research and interpretation data collection. All the authors have participated in the critic review of the article and approval the final version to be published.

## Competing interests

No financial, legal, or political conflict involving a third party (government, enterprises, and private institutions, etc.) was declared for any aspect of the submitted work (including, but not limited to subventions and financings, participation in consultive council, study drawing, manuscript preparation, statistical analysis, etc.).

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