UNIVERSIDADE FEDERAL DO RIO GRANDE DO NORTE
FACULDADE DE CIÊNCIAS DA SAÚDE DO TRAIRI
PROGRAMA DE PÓS-GRADUAÇÃO EM SAÚDE COLETIVA

HARYELLE NÁRYMA CONFESSOR FERREIRA

FUNCTIONING AND DISABILITY PROFILE OF CHILDREN WITH MICROCEPHALY ASSOCIATED WITH CONGENITAL ZIKA VIRUS INFECTION

SANTA CRUZ/RN
2018

HARYELLE NÁRYMA CONFESSOR FERREIRA

FUNCTIONING AND DISABILITY PROFILE OF CHILDREN WITH MICROCEPHALY ASSOCIATED WITH CONGENITAL ZIKA VIRUS INFECTION

Dissertação apresentada ao Programa de Pós Graduação em Saúde Coletiva da Faculdade de Ciências da Saúde do Trairi da Universidade Federal do Rio Grande do Norte, como requisito para a obtenção do título de Mestre em Saúde Coletiva.

Área de concentração: Trabalho, educação e a produção social do processo saúde-doença.

Orientadora: Egmar Longo.

SANTA CRUZ/RN
2018

Universidade Federal do Rio Grande do Norte - UFRN
Sistema de Bibliotecas - SISBI
Catalogação de Publicação na Fonte. UFRN - Biblioteca Setorial da Faculdade de Ciências da Saúde do Trairi - FACISA

Ferreira, Haryelle Naryma Confessor.
Functioning and disability profile of children with microcephaly associated with congenital zika virus infection / Haryelle Naryma Confessor Ferreira. - 2018.
27f.: il.

Dissertação (Mestrado) - Universidade Federal do Rio Grande do Norte, Faculdade de Ciências da Saúde do Trairi, Programa de Pós-Graduação em Saúde Coletiva, Santa Cruz, RN, 2018.
Orientador: Egmar Longo.

1. ICF - Dissertação. 2. Public Health - Dissertação. 3. Zika Virus Infection - Dissertação. 4. Microcephaly - Dissertação. 5. Children - Dissertação. I. Longo, Egmar. II. Título.

RN/UF/FACISA CDU 159.922.76-056.313

Elaborado por José Gláucio Brito Tavares de Oliveira - CRB-15/321

“Entrai pelas portas Dele com gratidão, e em seus átrios com louvor; louvai-o, e bendizei o seu nome.” (Salmos 100:4)

FUNCTIONING AND DISABILITY PROFILE OF CHILDREN WITH MICROCEPHALY ASSOCIATED WITH CONGENITAL ZIKA VIRUS INFECTION

Haryelle Náryma Confessor Ferreira, Msc, UFRN-FACISA
Veronica Schiariti, PhD,Professor, Division of Medical Sciences, University of Victoria
Isabelly Cristina. Rodrigues Regalado, Msc, Professor, UFRN
Klayton Galante Sousa, PhD, Professor, UFRN-FACISA
Silvana Alves Pereira, PhD, Professor, UFRN-FACISA
Carla Patrícia Novaes dos Santos Fechine, Msc, UNIPÊ/PB
Egmar Longo, PhD, Professor, UFRN-FACISA

ABSTRACT

Introduction: The increase in the number of cases of microcephaly in Brazil and its association with the Zika virus (ZIKV) is a global public health problem. The International Classification of Functioning Disability and Health (ICF) model is a powerful tool and extremely relevant in managing disability. **Objective:** Describe the functioning profile of children with microcephaly associated with ZIKV in two states of northeastern Brazil. **Methods:** This is a descriptive cross-sectional study. The sociodemographic characteristics, head circumference and other clinical data were collected from medical charts, physical examinations, measuring instruments and interviews with the children and their parents. The Brazilian Portuguese version of the ICF core set for cerebral palsy (CP) was used. Each ICF category was assigned a qualifier, which ranged from 0 to 4 (no disability, mild disability, moderate disability, severe disability and complete disability). For environmental factors, 0 represents no barrier and 4 total barrier; +0, no facilitator +4, total facilitator. **Results:** A total of 34 children with microcephaly caused by ZIKV were recruited (18 girls and 16 boys) at four rehabilitation facilities in Rio Grande do Norte and Paraíba states, Brazil. The average age of the participants was 21 months and head circumference z-scores ranged from 0.92 to -5.51. The functioning profile revealed complete disability in most of the body function categories (b). The activity and participation areas (d) were highly impacted, particularly in mobility-related categories. With respect to environmental factors (e), most of the sample reported a total facilitator for the nuclear family, friends and health services, systems and policies, as well as a total barrier to social attitudes. **Conclusion:** This is the first study that describes the functioning profile of children with

microcephaly associated with ZIKV, using a tool based on the ICF in Brazil. Our findings reinforce the need to maximize health care and access to information – based on the ICF – for multiprofessional teams, administrators, family members and children.

Keywords: ICF. Public Health. Zika Virus Infection. Microcephaly. Children.

Introduction

In late 2015, public health worldwide focused its attention on Brazil due to an outbreak of the Zika Virus (ZIKV) that caused an increase in cases of microcephaly in the northeastern region of the country, which led the Ministry of Health (MS) to declare a public health emergency [1]. In January 2016, 3530 suspected cases of microcephaly had been notified, many of which occurred in children born of women who lived in or visited ZIKV transmission areas [2]. According to epidemiological bulletin no. 29 – Epidemiological Week, no. 22/2016, 113 and 136 confirmed cases of microcephaly after ZIKV infection were reported by the Ministry of Health in the states of Rio Grande do Norte and Paraíba, respectively [3].

The Ministry of Health has developed numerous strategies to combat ZIKV, aimed at providing care to children with microcephaly and their families [2]. With respect to health care, in addition to health education initiatives, the MS broadened sexual and reproductive measures by offering free contraceptives, conducting home visits to educate the population and monitoring women during pregnancy and the postpartum period. Control measures were also implemented, including eliminating possible mosquito breeding grounds, cleaning vacant lots, discarding trash and the proper use of water-bearing containers [4].

Child development depends on both their biology and the environment they are brought up in. The likelihood of developmental problems occurring increases between 90-100% when a child is exposed to a series of 6-7 risk factors including poverty, mental disease in the caregiver, abuse, single parent and low maternal schooling [5]. In fact, there is strong evidence for the association between disability and poverty in low- and middle-income countries, which demands an urgent need for policies and programmatic actions to break this cycle [6]. In this respect, the MS recommends that, in addition to parental monitoring, children with microcephaly after ZIKV infection should also be referred for early stimulation at rehabilitation centers (Specialized Rehabilitation Center, Center for Rehabilitation in Physical Medicine – intermediate level, Intellectual Rehabilitation Service) by pediatric physical therapy, speech therapists or occupational therapists from Basic Care teams or at the Outpatient Facility for the Follow-up of At-risk Newborns [4].

There is still considerable uncertainty about the long-term neurological results and developmental trajectories of children congenically infected with ZIKV [5].

Microcephaly, in turn, does not have a very specific diagnosis, and all reported cases are considered suspect until confirmation by neurological diagnosis using computerized tomography or magnetic resonance. However, understanding and dealing with such an unexpected, extreme and rapidly expanding phenomenon requires the joint efforts of national and international scientific communities, health policy formulators and funding entities [7].

The International Classification of Functioning Disability and Health (ICF) model has emerged as a powerful tool that is extremely important in managing disability. The ICF was published by the World Health Organization (WHO) in 2001, and has been an important instrument in classifying living conditions and promoting social inclusion policies. Its use was recommended since it is a reference framework that best reflects the principles and values of the biopsychosocial and spiritual model, understanding functioning and incapacity as a dynamic interaction between health problems and contextual factors, both personal and environmental [8-10].

A number of strategies have been proposed to incorporate the ICF into public health and rehabilitation services. The use of the core sets provides a group of categories relevant in certain situations for an effective and objective assessment of functioning. The core set for cerebral palsy (CP), for example, was developed by Schiariti et al. in 2014 [11], originally in English, and subsequently translated into several languages, including Brazilian Portuguese.

Trabacca et al. (2012) [12] underscores that the use of core sets operationalizes clinical practice and research, making them more time-efficient. Furthermore, incorporating the influence of environmental and personal factors on functional skills results in endless potential for therapeutic interventions: for example, behavioral motivation interventions and the early introduction of assistive technology [13].

Considering the growing number of children at rehabilitation services with ZIKV-related microcephaly, whose clinical characteristics include spasticity and other signs of pyramidal liberation [2, 14, 15], the abbreviated core set for CP emerges as a valid strategy for its use against this public target. As such, the present study aims to describe the functioning and disability profile of children with microcephaly associated with ZIKV in two states in northeastern Brazil.

Methods

Participants and procedures

This is a descriptive cross-sectional study. The sample consisted of 34 children with ZIKV-associated microcephaly in two states of northeastern Brazil, treated at four pediatric physical therapy rehabilitation services in Paraíba (1) and Rio Grande do Norte states (3). The secondary care rehabilitation centers located in the cities of Natal, Macaíba and Santa Cruz, Rio Grande do Norte, and João Pessoa, Paraíba were invited to participate in the study as treatment centers for children notified by the MS and referred by surveillance service of the municipality. The flowchart of notification, diagnostic confirmation and referral to rehabilitation centers is illustrated in Figure 1.

Each participating center held an ICF and abbreviated core set training workshop for CP. Training was conducted by E. L and H.F. (first and last author) in a 16-hour module aimed at the health professionals involved in the study. The objective was to ensure high inter-rater reliability of the qualifiers in each core set category. Data collection occurred between September 2017 and January 2018.

Assessment Measures

The Portuguese version of the abbreviated ICF core set for CP was used. The instrument contains 25 categories: eight related to body functions (b), one to body structure (s), eight to activity and participation (d), and eight to environmental factors (e). Each ICF category received a qualifier ranging from 0 to 4 (no disability, mild disability, moderate disability, severe disability, complete disability). For environmental factors, 0 represents no barrier and 4 total barrier; +0, no facilitator and +4, total facilitator.

The ICF core set qualifiers were obtained using sensitive and reliable instruments validated in Brazil (Supplementary information 1). Responses (able or unable) on the Pediatric Evaluation of Disability Inventory (PEDI) were converted directly into ICF qualifiers, using a visual response card created by the researchers to facilitate parents' or caregivers' understanding when identifying the degree of difficulty experienced by the children in a category (Supplementary information 2). The following instruments were applied to establish the remaining core set categories: Gross Motor Function Measure (GMFM – 88), Visual Analog Scale (VAS), Infant Sleep Questionnaire (ISQ), and Modified Ashworth Scale and Goniometry. The GMFM

scores, expressed in percentage, were directly converted into ICF qualifiers. The results of goniometry and the Modified Ashworth Scale were also directly converted into qualifiers. With the other instruments, the researchers used the visual response cards with the ICF qualifiers, so that the parents or caregivers could transform the responses given on the assessment instruments into qualifiers, based on the responses given on the assessment instruments.

For the categories that had no available tools, a specific questionnaire was applied to the parents or caregivers, whose responses were converted into ICF qualifiers during the interview, using visual response cards. The sociodemographic characteristics, head circumference and other clinical data were collected from health records, physical examinations, imaging examination reports and interviews with children and their parents.

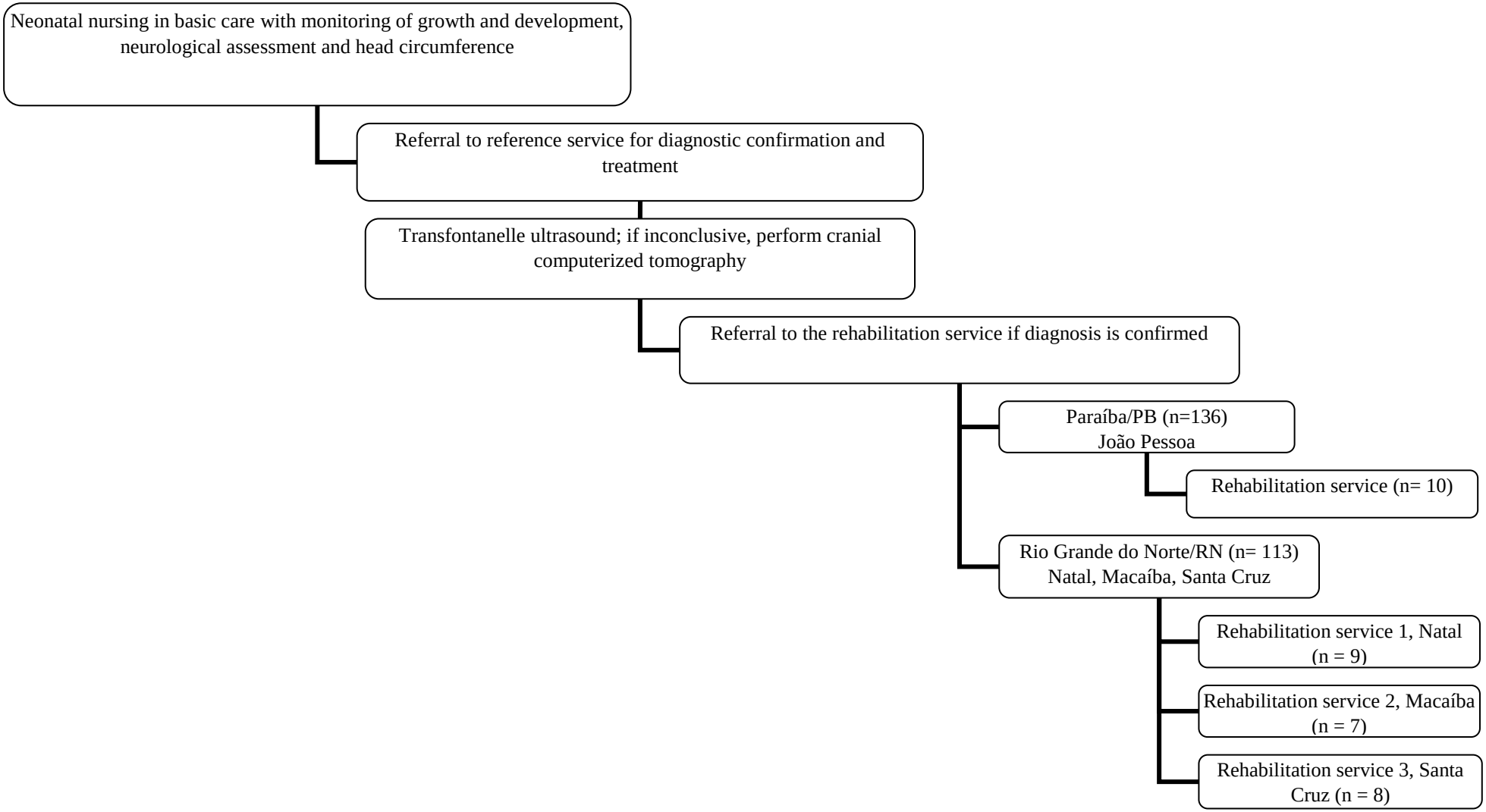
Ethical Principles

The study was approved by the Institutional Research Ethics Committee, under protocol number 2.357.552 and all the parentes/caregivers gave their informed consent.

Statistical Analysis

The quantitative variables were expressed as mean ± standard deviation, and the categorical variables as percentages of the qualifiers, attributed in each category of the ICF core set.

Figure 1. Flowchart of notification of ZIKV-associated microcephaly, diagnostic confirmation, referral to rehabilitation services and sample distribution.



Results

The general characteristics of the sample are shown in Table 1. Most of the children were girls, average age of 21 months and brain circumference with a z-score between 0.92 and -5.51. Around 65% of the parents received a minimum monthly wage (≈USD300.00) as a benefit for their child.

Table 2 illustrates the percentages of disability for each ICF core set category, the function (b) and structure (s) of the body, and activity and participation (d). With respect to body function, the category most affected was b167 (mental functions of language), followed by severe disabilities, as demonstrated by the sample in categories b117 (intellectual functions), b710 (functions related to joint mobility), b735 (functions related to muscle tonus) and b760 (functions related to voluntary muscle control). However, no disability was found in participants for categories b134 (sleep functions) and b280 (pain sensation). In relation to body structure, 55.9% of the sample exhibited moderate disability in s110 (brain structure).

With respect to activity and participation level, 94.1% of participants were unable to perform fine motor hand movements (d440) and 100% to walk (d450); severe difficulty was observed in 55.9% of the sample in category d710 (basic personal interactions), but no difficulty for family relationships (d760).

Table 3 depicts each category of environmental factors identified as facilitator, barrier or neither of the two. Total facilitators considered for the sample were e310 (nuclear family), e320 (friends) and e580 (health services, systems and policies). The only total barrier was category e460 (social attitudes). However, 76.5% of the sample described no facilitator or barrier for e125 (communication products and technology).

Table 1. Sociodemographic and clinical data

Characteristics of the children (n= 34)	
Sex	Male = 47.0% Female = 52.9%
Age (months)	Mean = 21.2 ± 7.3
Height (cm)	43.5 ± 8.3
Weight (kg)	2,773. 1 ± 462.4
1'Apgar	8.2 ± 1.0
5'Apgar	9.0 ± 0.5
Score- Z (Head circumference)	0.92 to -5.51
Use of ventilator support	Yes = 23.5% No = 76.5%
Exclusive breastfeeding	Yes = 47.1% No = 52.9%
Owns baby carriage or wheelchair	Yes = 55.9% No = 44.1%
Characteristics of the mothers (n=34)	
Age (years)	27.0 ± 7.0
Location of residence	100% urban zone
Schooling	Complete elementary education = 17.6% Incomplete elementary education = 14.7% Complete secondary education = 47.1% Incomplete secondary education = 8.8% Incomplete university education = 11.8%
Income	One minimum monthly salary = 64.7% Two to three minimum monthly salaries= 35.3%
Number of pregnancies	1 = 44.1% 2 = 35.3 % 3 = 14.7% 4 = 5.9%
Gestational age (weeks)	37.7 ± 2.6

Type of delivery	Normal = 41.2% Cesarean = 58.8%
Number of prenatal visits	7.7 ± 2.9
Number of ultrasounds	4.8 ± 2.2
Threatened miscarriage	Yes = 23.5% No = 76.5%
Symptoms of ZIKA	Yes = 79.4% No = 20.6 %
Trimester of pregnancy when ZIKA symptoms emerged	None = 20.6% 1st = 47.1% 2nd = 17.6% 3rd = 14.7%
Diagnosis of Zika-virus infection during pregnancy	Yes = 67.6% No = 32.4 %

Table 2. Relative frequency of children with microcephaly by ZIKV in body functions, body structures and activities/participation categories of the brief ICF core set for CP (n=34).

Category	Functions	Qualifier .0 None Problem	Qualifier .1 Slight Problem	Qualifier .2 Moderate Problem	Qualifier .3 Serious Problem	Qualificer .4 Complete Problem
b117	Intellectual functions	2,9	8,8	-	55,9	32,4
b134	Sleep functions	47,1	11,8	11,8	8,8	20,6
b167	Mental functions of language	-	-	-	-	100,0
b210	Seeing functions	32,4	14,7	17,6	29,4	5,9
b280	Sensation of pain	67,6	2,9	5,9	11,8	11,8
b710	Mobility of joint functions	-	8,8	14,7	64,7	11,8
b735	Muscle tone functions	-	5,9	5,9	76,5	11,8
b760	Control of voluntary movement functions	-	5,9	5,9	70,6	17,6
Category	**Body Structures**	**Qualifier .0 None Problem**	**Qualifier .1 Slight Problem**	**Qualifier .2 Moderate Problem**	**Qualifier .3 Serious Problem**	**Qualificer .4 Complete Problem**
s110	Structure of brain	-	-	55,9	44,1	-
Category	**Activities/ Participation**	**Qualifier .0 None Problem**	**Qualifier .1 Slight Problem**	**Qualifier .2 Moderate Problem**	**Qualifier .3 Serious Problem**	**Qualificer .4 Complete Problem**
d415	Maintaining a body position	-	8,8	8,8	64,7	17,6
d440	Fine hand use	-	-	-	5,9	94,1
d450	Walking	-	-	-	-	100,0
d460	Moving around in different locations	2,9	-	11,8	17,6	67,6
d530	Toileting	-	-	-	23,5	76,5
d550	Eating	11,8	2,9	2,9	70,6	11,8
d710	Basic interpersonal interactions	-	-	2,9	55,9	41,2
d760	Family relationships	88,2	2,9	2,9	2,9	2,9

Table 3. Relative frequency of children with microcephaly by ZIKV in environmental factors categories of the brief ICF core set for CP (n=34).

	Category	Mild Barrier 1	Moderate Barrier 2	Severe Barrier 3	Total Barrier 4	No facilitator/No barrier 0	Mild Facilitator +1	Moderate Facilitator +2	Substancial Facilitator +3	Complete Facilitator +4
e115	Products and technology for personal use in daily living	5,9	-	2,9	2,9	50,0	5,9	2,9	17,6	11,8
e120	Products and technology for personal indoor and outdoor mobility and transportation	2,9	20,6	-	-	35,3	-	-	8,8	32,4
e125	Products and technology for communication	-	-	-	8,8	76,5	-	-	-	14,7
e150	Design, construction and building products and technology of buildings for public use	-	-	5,9	14,7	32,4	2,9	2,9	8,8	32,4
e310	Immediate Family	-	-	-	-	5,9	-	-	5,9	85,3
e320	Friends	-	-	-	-	20,6	-	-	20,6	58,8
e460	Societal atitudes	-	2,9	20,6	41,2	35,3	-	-	-	-
e580	Health services, systems and policies	-	-	-	17,6	-	-	-	20,6	61,8

Discussion

This is the first Brazilian study to describe the functioning and disability profile of children with microcephaly caused by ZIKV, using tools based on the ICF. These results reveal the magnitude of disabilities and/or difficulties in function and body structure, activity and participation, as well as barriers and/or facilitators of the environment, which can direct therapeutic strategies and public policies for children with ZIKV-associated microcephaly.

The data indicate that many aspects of functioning showed complete disability, highlighting category b167 (mental functions of language), assessed by the Pediatric Evaluation of Disability Inventory – PEDI, the social function area, where 100% of the sample exhibited complete disability. Changes in language can compromise other functional areas, as demonstrated in a recent study, where children with communication and mobility problems experienced limitations in leisure activities, negatively affecting their long-term development, health and well-being [16].

Nearly 95% of the sample demonstrated extreme difficulty in performing fine hand movements (d440), and were unable to use utensils or drinking vessels, indicating the need for a multidisciplinary approach and possible interventions with assistive technology [17]. The categories d450 (walking) and d530 (care related to excretion processes) exhibited extreme difficulty in 100% and 76.5% of the sample, respectively. However, these results were not entirely unexpected, considering that the average age of the sample was 21 months.

Assessment of gross motor function, conducted by the Gross Motor Function Measure (GMFM- 88), identified severe disability in 70.6% of the participants in category b760 (functions related to voluntary movement control) and in 64.7% of category d415 (maintaining body position). Likewise, Satterfield-Nash et al. (2017) [18] found severe motor impairment, assessed using the Hammersmith Infant Examination (HINE), in nearly 80% of the sample of children with microcephaly caused by ZIKV, including signs consistent with CP.

The repercussions of microcephaly associated with ZIKV in the domains activity and participation revealed severe difficulty in more than 70% of the sample in category d550 (eating). These results were expected since most of the sample were fed a diet of mashed, liquid or strained food, findings similar to those observed in a follow-up of 19 children with ZIKV-related microcephaly where nearly half of the sample also exhibited

eating disorders [18]. By contrast, around 90% of the sample had no difficulty in the family relationships category (d760) and lived harmoniously with their family, including relational and participatory aspects in the therapeutic services [19]. Although the families of children with disability may face challenges that are different from those of families with typically developed offspring, parents recognize that educating disabled children may have a positive impact on the family [20].

The mobility of children with disabilities is commonly one of the main challenges for families and health professionals. In the present study, moving around (d460) was considered extremely difficult by nearly 70% of the sample, which can interfere significantly in a child's interaction with an environment [21]. Indeed, research shows that the premature introduction of electric wheel chairs to children up to 14 months of age improves psychosocial function and the ability to play [22]. In situations of scarce economic resources, such as those of the present study, where monthly income is approximately USD300.00, purchasing mobility aids such as a wheel chair may be unfeasible, and parents are obliged to wait long periods before receiving one from the National Health System, which is guaranteed by the National Plan for the Rights of People with Disability – Living without Limits Plan [23].

The present study found that 47.1% and 67.6% of participants reported no disability in the categories b134 (sleep functions) and b280 (pain sensation), respectively, which may result from the use of medication that acts directly on these problems. Research demonstrates that children with disabilities who develop severe motor impairment are more susceptible to experiencing pain [24, 25]. Although irritability was a symptom seen in the first clinical descriptions of children with ZIKV-related microcephaly in Brazil, none of the data were related to sleep pattern [15, 26].

One of the main points of this study was using the ICF to identify the barriers and facilitators present in the environment, according to the perception of parents and caregivers of children with microcephaly caused by ZIKV, which may reflect the multiple aspects of functioning and disability. While 85.3% of the sample reported category e310 (nuclear family) as a total facilitator, around 60% indicated category e320 (friends). These results reinforce the need for structured family and social support networks, since they are strong facilitators of social inclusion [27, 28].

Access to services, systems and policies can be converted into an important facilitator and indicator of functional results, especially in chronic conditions such as

any childhood disability. In the present study, this point was assessed by category e580 (health services, systems and policies), where more than 60% of the sample reported it as total facilitator. These results may indicate that, despite the problems in regulating and accessing public health services faced by most of the Brazilian population, since microcephaly is a new condition, most of the needs of the children with this disorder enrolled in the study are being met. The MS supports both basic and specialized care to provide better treatment and support for these children and their parents, respectively. The Brazilian National Health System offers basic care, specialized examinations and diagnoses, rehabilitation and hospital services, in addition to orthoses, prostheses and walking aids [4].

It is also important to underscore the effort that most parents make to guarantee adherence to rehabilitation programs, reinforcing the importance of family-centered health care, which gives the families themselves the opportunity to establish their priorities and goals [29, 30]. King and Chiarello (2014) [31] identified three essential factors for family-centered care: (1) respect for children and families, (2) recognition of the family's impact on a child's well-being and (3) family-professional collaboration. Understanding the parents' perspective on therapeutic care is extremely important in enhancing the processes and results of the services [19].

Attitudinal barriers were assessed by category e460 (social attitudes), where more than 40% of parents or caregivers report it as a complete barrier. This finding demonstrates the importance of awareness programs aimed at social inclusion and minimizing prejudice experienced by these families in the community, schools or public services [32, 33]. Studies have highlighted the importance of strengthening interventions in terms of context, since the environment will likely have more potential to change than domains such as body function and structure [34-36].

It is interesting to note that some aspects of the environment that are commonly relevant to children with disability, such as products and technologies for personal daily use (e115) and communication (e125), were reported by more than half the sample as being no barrier or facilitator, which may reflect parents' unawareness of why and how to acquire products and technologies to benefit the functioning of their children. Educating interested parties about the best ways of providing accessible services may minimize attitudinal barriers and facilitate the participation of children with disabilities [37].

The main limitation is the small sample size, because many of the children live in rural areas with a poor public transport system, precluding their appearance at rehabilitation centers during data collection. The next step will be assessing these families during home visits.

Given its relevance, assessments based on the ICF are important in educating professionals about the needs of patients and their families, as well as intervention priorities [13, 38]. Implementing ICF-based changes in clinical practice requires organizational planning by all the professionals of a multidisciplinary team [39]. As such, the use of the abbreviated ICF core set for CP enabled a detailed description of functioning and disability in children with ZIKV-associated microcephaly from four rehabilitation centers. The study also made it possible to train teams in the use of ICF, and identify the needs and intervention goals for this group of children that will guide the rehabilitation program, with a focus on the family and functioning.

Conclusions

Our findings reinforce the need to maximize health care and make access to information universal, based on the ICF, for multiprofessional teams, administrators, family members and children. Health care for the target public should be family-centered, considering modifiable environmental factors and highlighting the functional objectives, in order to ensure optimal levels of participation in domestic, school and community activities in our region.

References

1. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Protocolo de atenção à saúde e resposta à ocorrência de microcefalia [recurso eletrônico] / Ministério da Saúde, Secretaria de Atenção à Saúde. – Brasília: Ministério da Saúde, 2016.

2. Oliveira, K. W.; Cortez-Escalante, J.; De Oliveira W. T. G. H.; Do Carmo, G. M. I., Henriques, C. M. P., Coelho, G. E., De França, G. V. A. (2016) Increase in Reported Prevalence of Microcephaly in Infants Born to Women Living in Areas with Confirmed Zika Virus Transmission During the First Trimester of Pregnancy — Brazil, MMWR, Morb Mortal Wkly Rep. 2015, 65, 242-247.

3. Secretaria de Vigilância em Saúde/ Ministério da Saúde. Informe Epidemiológico Nº 29 – Semana Epidemiológica (Se) 22/2016 (29/05 A 04/06/2016). Monitoramento dos casos de Microcefalia no Brasil. [cited 2017]. Available from: http://combateaedes.saude.gov.br/images/boletins-epidemiologicos/informe_microcefalia_epidemiologico29.pdf

4. Ministério da Saúde. Nova técnica: Brasil adota recomendação da OMS para microcefalia. 2016. http://portalsaude.saude.gov.br/index.php/cidadao/principal/agenciasaude/22553-brasil-adota-recomendacao-da-oms-e-reduz-medida-para-microcefalia. Accessed em 12 de junho de 2017.

5. Leyser M, Olaf K, Mattaa A, Vasconcelosa M, Nascimento O. The International Classification of Functioning Framework in Zika-Related Disabilities. Journal of Paediatric Neurology. 2016, 20:946-947.

6. Banks, L. M., Kuper, H., & Polack, S. Poverty and disability in low- and middleincome countries: A systematic review. Plos One, 2017, 12(12).

7. Teixeira M, Costa M, Oliveira W, Nunes M, Rodrigues L. The Epidemic of Zika Virus–Related Microcephaly in Brazil: Detection, Control, Etiology, and Future Scenarios. Am J Public Health. 2016, 106:601-605.

8. WHO (World Health Organization) (2001). International Classification of Functioning Disability and Health. World Health Organization, Geneva Switzerland.

9. Granlund, M. Participation – challenges in conceptualization, measurement and intervention. Child: Care, Health and Development, 2013, 39, 470-473.

10. Rosenbaum, P. The importance of context: what are our assumptions about childhood disability? [editorial]. Developmental Medicine & Child Neurology, 2015, 57, 1084.

11. Schiariti, V., Selb, M., Cieza, A., O'Donnell, M. International Classification of Functioning, Disability and Health Core Sets for children and youth with

cerebral palsy: a consensus meeting. Developmental Medicine & Child Neurology, 2014, 57, 149-158.

12. Trabacca, A.; Russo, L.; Losito, L.; Rinaldis, M.; Moro, G.; Cacudi, M.; Gennaro, L. The ICF-CY Perspective on the Neurorehabilitation of Cerebral Palsy: A Single Case Study. Journal of Child Neurology, 2012, 27(2) 183-190.

13. Schiariti, V., Tatla, S., Sauve, K., O'Donnell, M. Toolbox of multiple-item measures aligning with the ICF Core Sets for children and youth with Cerebral Palsy. European Journal of Paediatric Neurology, 2017, 21, 252-263.

14. Bastos M, D'Avila P, Umpierre N, Faccini S, Gonçalves R, Harzheim E. Microcephaly and Zika Virus: clinical features and associations. Rev. Bras. Med. Fam Comunidade, 2016, jan-dez, 11(38):1-10.

15. Van der Linden V. Description of 13 infants born during October 2015–January 2016 with congenital Zika virus infection without microcephaly at birth—Brazil. MMWR. Morbidity and Mortality Weekly Report. 2016 ;65.

16. McAnuff, J., Colver, A., Rapley, T., Kolehmainen, N. Improving health in children with disabilities: an intervention-development study to support participation in leisure in 8-12 year olds with communication and mobility limitations. Trials, 2015, 16(2), P5.

17. Oliveira, R., Caldas, C., Riberto, M. Application of the ICF-CY Brief Core Set for cerebral palsy on a school age child. Acta Fisiatr, 2016, 23, 46-50.

18. Satterfield-Nash A, Kotzky K, Allen J, Bertolli J, Moore A, Pereira I, Pessoa A, Melo F. Health and Development at Age 19–24 Months of 19 Children Who Were Born with Microcephaly and Laboratory Evidence of Congenital Zika Virus Infection During the 2015 Zika Virus Outbreak—Brazil, MMWR. Morbidity and Mortality Weekly Report, 2017, dec, 66(49):1347.

19. Nihad A. Almasri, Mihee An & Robert J. Palisano. Parents' Perception of Receiving Family-Centered Care for Their Children with Physical Disabilities: A Meta-Analysis. Physical & Occupational Therapy In Pediatrics, 2017, jul 28, 1-17.

20. Ketelaar M, Bogossian A, Saini M, Visser-Meily A, Lach L. Assessment of the family environment in pediatric neurodisability: a state-of-the-art review. Developmental Medicine & Child Neurology, 2017, mar, 59(3):259-69.

21. Jones MA, McEwen IR, Neas BR. Effects of power wheelchairs on the development and function of young children with severe motor impairments. Pediatric Physical Therapy, 2012, jul, 24(2):131-40.

22. Guerette P, Furumasu J, Tefft D. The positive effects of early powered mobility on children's psychosocial and play skills. Assistive Technology, 2013, mar 1, 25(1):39-48.

23. Brasil. Decreto nº 7612, de 17 de novembro de 2011. Institui o Plano Nacional dos Direitos da Pessoa com Deficiência - Plano Viver sem Limite. Diário Oficial da União, Poder Executivo, Brasília, DF, 18 nov. 2011.

24. Poirot I, Laudy V, Rabilloud M, Roche S, Ginhoux T, Kassaï B, Vuillerot C. Prevalence of pain in 240 non-ambulatory children with severe cerebral palsy. Annals of physical and rehabilitation medicine, 2017, nov, 60(6):371-5.

25. Warlow TA, Hain RD. 'Total Pain' in Children with Severe Neurological Impairment. Children, 2018, jan, 18;5(1):13.

26. Silva A, Ganz S, da Silva Sousa P, Doriqui J, Ribeiro R, Branco D, de Sousa Queiroz C, Pacheco D, da Costa R, de Sousa Silva F, Simões M. Early growth and neurologic outcomes of infants with probable congenital Zika virus syndrome. Emerging Infectious Diseases, 2016, nov; 22(11):1953.

27. Alsem W, Ausems F, Verhoef M, Jongmans J, Meily-Visser M, Ketelaar M. Information seeking by parents of children with physical disabilities: An exploratory qualitative study. Research in Developmental Disabilities, 2017, jan 1; 60:125-34.

28. King G, Williams L, Hahn Goldberg S. Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. Child Care Health Dev. 2017, may, 43(3):334-347.

29. Barbosa M, Balieiro G, Pettengill M. Cuidado centrado na família no contexto da criança com deficiência e sua família: uma análise reflexiva. Texto Contexto Enferm, 2012, jan-mar, 21(1): 194-9.

30. Rosenbaum, P. Family-centred research: what does it mean and can we do it? [editorial]. Developmental Medicine & Child Neurology, 2011, 53, 99–100.

31. King, G., & Chiarello, L. Family-centered care for children with cerebral palsy conceptual and practical considerations to advance care and practice. Journal of Child Neurology, 2014, 29(8), 1046–1054.

32. Armstrong M, Morris C, Abraham C, Tarrant M. Interventions utilising contact with people with disabilities to improve children's attitudes towards disability: A systematic review and meta-analysis. Disability and health jornal, 2017, jan 1;10(1):11-22.

33. Rosenbaum, P. Improving atitudes towards children with disabilities in a school contexto [editorial]. Developmental Medicine & Child Neurology, 2010, 52, 637–43.

34. Anaby D, Law M, Teplicky R, Turner L. Focusing on the environment to improve youth participation: experiences and perspectives of occupational therapists. International Journal of Environmental Research and Public Health, 2015, oct 23, 12(10):13388-98.

35. Anaby D, Mercerat C, Tremblay S. Enhancing Youth Participation Using the PREP Intervention: Parents' Perspectives. International Journal of Environmental Research and Public Health, 2017, sep 2, 14(9):1005.

36. Badia, M., Begona Orgaz, M., Gomez-Vela, M., Verdugo, M., Ullanc, A., Longo, E. Do environmental barriers affect the parent-reported quality of life of children and adolescents with cerebral palsy? Research in Developmental Disabilities, 2016, 16, 312–321.

37. Di Marino, E., Tremblay, S., Khetani, M., & Anaby, D. The effect of child, family and environmental factors on the participation of young children with disabilities. Disability and Health Journal, 2017, 30, 115-2.

38. Gladstone M, Abubakar A, Idro R, Langfitt J, Newton CR. Measuring neurodevelopment in low-resource settings. The Lancet Child & Adolescent Health, 2017, dec 1, 1(4):258-9.

39. Mäenpää H.; Autti-Rämö I.; Varho T.; Forsten W.; Haataja L. Multiprofessional evaluation in clinical practice: establishing a core set of outcome measures for children with cerebral palsy. Dev Med Child Neurol, 2017, mar, 59(3): 322-328.

Supplementary Information 1. Tools used to apply the brief core set for CP

ICF	Descriptor	Tools	
b117	Intellectual functions	Pediatric Evaluation of Disability Inventory (PEDI)	Social function area, items A and B, understanding the meaning of words and complex sentences, respectively
b134	Sleep functions	Infant Sleep Questionnaire (ISQ)	Assesses the perception of parents regarding the child's sleeping behavior
b167	Mental functions of language	PEDI	Social function area, items C and D: functional use of communication and complexity of expressive communication, respectively
b210	Seeing functions	Does the child have problems seeing? Has the child had an eye examination?	Questionnaire applied to the mother in the form of an interview
b280	Sensation of pain	Is the child experiencing pain in any part of the body? Visual Analog Scale (VAS)	Questionnaire applied to the mother in the form of an interview
b710	Mobility of joint functions	Goniometry	Of upper and lower limbs in order to identify possible contractions, movement limitations and joint deformities
b735	Muscle tone functions	Modified Ashworth Scale	Applied manually by the therapist to determine muscle resistance for passive stretching, providing a qualitative measure
b760	Control of voluntary movement functions	Gross Motor Function Measure (GMFM – 88)	Domains A – lying down and rolling and B - sitting
d415	Maintaining a body position	GMFM – 88	Domains A – lying down and rolling and B - sitting
d440	Fine hand use	PEDI	Self-care area, items B and C, using utensils and drinking receptacles, respectively
d450	Walking	GMFM – 88	Domain E – walking, running and jumping
d460	Moving around in different locations	How does the child move around inside and outside the home?	Questionnaire applied to the mother in the form of an interview
d530	Toileting	PEDI	Self-care area, items N and O, urinary and intestinal control, respectively
d550	Eating	PEDI	Self-care area, item A, food texture
d710	Basic interpersonal interactions	PEDI	Social function area, items F and G, interactive social game and interaction with friends, respectively
d760	Family relationships	Who lives with the child? How is your relationship with the child? With the other family members?	Questionnaire applied to the mother in the form of an interview

e115	Products and technology for personal use in daily living	How does equipment for ADL facilitate or hinder the child's life?	Questionnaire applied to the mother in the form of an interview
e120	Products and technology for personal indoor and outdoor mobility and transportation	Does the child need assistive devices to help in locomotion? How much does this help or hinder the child's life?	Questionnaire applied to the mother in the form of an interview
e125	Products and technology for communication	How do communication devices facilitate or hinder the child's life?	Questionnaire applied to the mother in the form of an interview
e150	Design, construction and building products and technology of buildings for public use	Does the child need help to enter or move around public places, such as ramps? Are these adaptations present in health centers and rehabilitation facilities that the child attends?	Questionnaire applied to the mother in the form of an interview
e310	Immediate family	Does the child receive physical or emotional support from parents and siblings? How does this affect their functioning?	Questionnaire applied to the mother in the form of an interview
e320	Friends	Does the child interact with other children? Do these children treat your child well?	Questionnaire applied to the mother in the form of an interview
e460	Social attitudes	Does the child suffer discrimination? Can you describe one of these experiences?	Questionnaire applied to the mother in the form of an interview
e580	Health services, systems and policies	Is the child undergoing rehabilitation? Has the child undergone or waiting to undergo examinations or surgery?	Questionnaire applied to the mother in the form of an interview
s110	Structure of brain	Imaging examination results	Assessed based on imaging examination results - cranial computerized tomography cranioencephalic magnetic resonance, transfontanellar ultrasound and cranial radiography

Supplementary Information 2. Visual response card

CIF				
0	.1	.2	.3	.4
0-4%	5-24%	25-49%	50-95%	96-100%
None Problem	Slight Problem	Moderate Problem	Serious Problem	Complete Problem

ICF – Activities and Participation				
0	.1	.2	.3	.4
0-4%	5-24%	25-49%	50-95%	96-100%
No difficulty- Independent in managing the activity listed at an age appropriate level	**Mild Difficulty –** Requires extra time, verbal prompts or visual reminders to complete the function or activity	**Moderate Difficulty –** Needs physical Assistance or constant verbal prompting to complete the activity or function	**Severe Difficulty –** Needs maximum assistance to perform the task, is aware of the task being performed and can assist by cooperating	**Complete Difficulty** – Fully dependent on caregiver or no awareness of process or complete lack of cooperation

BARRIER					FACILITATOR				
0	.1	.2	.3	.4	0	+1	+2	+3	+4
0-4%	5-24%	25-49%	50-95%	96-100%	0-4%	5-24%	25-49%	50-95%	96-100%
No barrier	Mild Barrier	Moderate Barrier	Severe Barrier	Total Barrier	No facilitator	Mild Facilitator	Moderate Facilitator	Substancial Facilitator	Complete Facilitator