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Zika Virus After Emergency Response: Can the ICF Guide Rehabilitation of Children With Microcephaly?

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The outbreak of Zika in Brazil almost 3 years ago had harmful medical, financial, and social consequences for children and their families. It also significantly increased the statistics of Brazilian children with disabilities being followed up in rehabilitation centers. Actions promoting the use of the International Classification of Functioning, Disability and Health (ICF) framework are encouraged in view of the complex health needs identified in this population, which cover all areas of functioning, and gain special relevance when it comes to a vulnerable context. This perspective article discusses the challenges related to the implementation of the ICF in rehabilitation services for children with congenital syndrome. (*Pediatr Phys Ther* 2019;31:370–372)

Key words: children, congenital Zika syndrome, ICF, rehabilitation

Almost 3 years after the outbreak of Zika virus that brought the global health spotlight to Brazil and led the World Health Organization (WHO) to determine a public health emergency, the situation is now controlled in terms of new cases. Nevertheless, there are 3149 confirmed cases of children with microcephaly and/or other neurological signs due to congenital Zika syndrome (CZS), with another 2795 cases under investigation.¹

The scenario is more concerning in Northeastern Brazil. This region concentrates the majority of cases and is marked by social inequalities, low urban development levels, and weaknesses in training and placement of health care professionals.² Limited access to health services is common in low- and middle-income countries, and may hinder early identification and intervention.³ The efforts of the Ministry of Health in Brazil have shown more concrete progress in controlling the epidemic. However, from the perspective of comprehensive care for children with CZS and their families who are currently living with the condition, less than a third of the confirmed cases had access to the services offered by the national public health system (Sistema Único de Saúde—SUS), including well-baby follow-up, early intervention, and specialized care.¹

In 2016, the Ministry of Health launched an online course to train rehabilitation professionals from Brazil and other Latin American countries on early intervention of children with CZS. The functional assessment module was taught by one of the authors. This was the first concrete effort to introduce the International Classification of Functioning, Disability and Health (ICF) model⁴ in the management of children with microcephaly by CZS. Actions promoting the use of the ICF framework are justified in view of the complex health needs identified in this population, which cover all areas of functioning,^{5,6} and gain special relevance when it comes to a vulnerable context.³

The ICF emphasizes the importance of participation and the role of contextual factors, such as personal and environmental factors, physical, social, and attitudinal environment where people live. These aspects should be considered keys to implementing changes, especially in a low- and middle-income country context.^{3,6} The ICF model has been gaining strength and acceptance among rehabilitation professionals in Brazil, although, due to the continental characteristics of our country, the incorporation of the model proposed by the WHO varies greatly from region to region. The use of the ICF model in children with microcephaly by CZS brings several practical challenges, such as training of professionals, infrastructure in terms of hospitals and equipment, and restructuring of services. An even bigger challenge is the wide application of the medical model in rural areas in Brazil and its excessive impairment-based focus.⁷ It is imperative that a biopsychosocial ICF model is adopted nationwide.

Another challenge for rehabilitation teams in Brazil concerns the clinical presentation of children with microcephaly secondary to CZS. As it is a completely new condition, the teams are using their practical experience based on what is available for

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cerebral palsy (CP). The first publications on the subject showed neurological findings that could fit the definition of CP proposed by Rosenbaum and collaborators published in 2007.⁸ For this reason, caution is necessary, as there is great variability in the provision of services for children with CP in Brazil, which are not always guided by the ICF and the most current evidence available.⁹ Therefore, we must reflect on how to promote an evidence-based, ICF-based rehabilitation practice toward a new health condition such as CZS. Certainly, one of the first steps would be to ensure consistent educational training of health care professionals in rehabilitation centers that provide care for children with microcephaly by CZS.

A pioneering initiative proposed by a collaboration between researchers in Northeast Brazil and Canada used an ICF-based tool specific for children and youth with CP, entitled the Common Brief ICF core set for CP^{5,10,11} to describe the profile of functioning and disability of children with microcephaly secondary to CZS. The first results were recently published,⁵ showing severe effect in not only areas of body functions and structures but also activities and participation. With respect to environmental factors, several factors were identified as facilitators of day-to-day functioning (eg, the immediate family and friends), while societal attitudes were reported as a complete barrier to participation.⁵ This ICF approach was welcomed by professionals and families. The Figure graphs challenges in the implementation of the ICF model in CZS based on the information collected in our pilot study.

In order to standardize the care of children with CZS, we propose to expand this project to other centers following up children with microcephaly by CZS, and to collect national

functional data from all Brazilian children with this condition according to the ICF model. This proposal would bring many contributions to our field and the families we serve. It is expected that evaluation according to the biopsychosocial model would ensure that rehabilitation teams plan their interventions taking all ICF areas into account, rather than focusing only on body functions and structures.

Faced with the challenges of implementing the ICF model, action is needed on several fronts to promote the implementation of best practices. A knowledge translation strategy that can be used is the mapping of rehabilitation interventions offered by Brazilian professionals in children with microcephaly by CZS to determine whether all domains of the ICF are being considered. The knowledge to action process proposed by the knowledge translation framework recommends the identification of current knowledge and gaps in certain practices as the initial phase for the process of change.^{9,12} From this point on, it will be possible to identify critical areas to be addressed in terms of professional training and service delivery.

In summary, we propose steps forward related to CZS:

1. Universal ICF education to all professionals working with children and young adults affected by CZS (open access tools such as the ICF educational e-tool are already available in English and Portuguese, http://learn.phsa.ca/shhc/icfbrasil/story_html5.html);
2. Standardization of data collection based on the ICF;
3. Standardization of assessment and evaluation tools guided by the ICF;
4. Identification of comprehensive evidence-based interventions to be used in CZS.

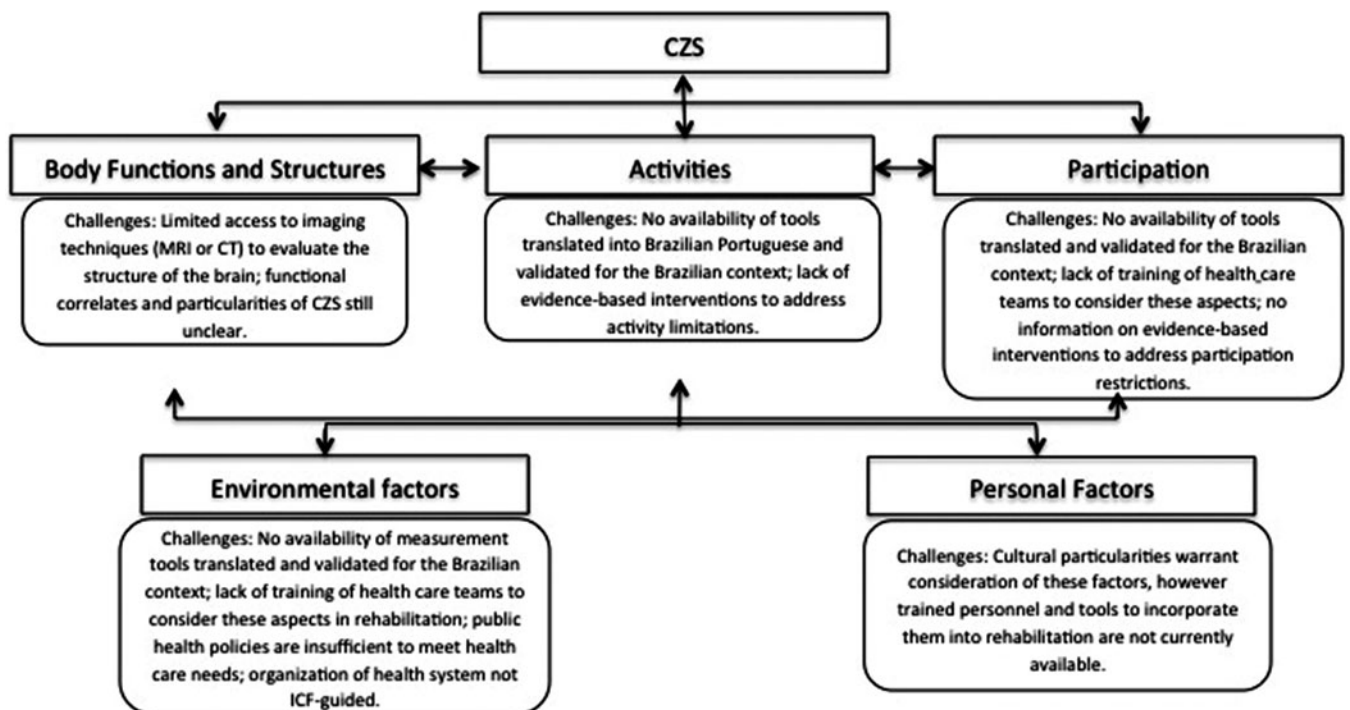


Fig. Challenges in the implementation of the ICF model in CZS. CZS indicates congenital syndrome of Zika; ICF, International Classification of Functioning, Disability and Health.

Finally, applying the ICF and ICF-based tools in CZS may contribute to systematically guide holistic service provision throughout the lifespan for this population. Although the number of new cases is now stabilized, the complex clinical presentation of CZS and its effect on children's developmental trajectories will require both standardized care (guided by ICF-based tools) and individualized care as children mature. It is time to work together, rethink practices, overcome challenges, and move forward toward better health care for children affected by CZS.

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