Psychosocial Adaptation of Caregivers to Children with Congenital Zika Virus Syndrome

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INTRODUCTION

2016: World Health Organization declared an international public health emergency in response to the proliferation of the Zika virus.

Brazil has been most affected by Zika, where widespread transmission of this disease has been recognized since 2014.

While most people infected by the Zika virus are asymptomatic or experience only mild symptoms, intrauterine infection can have devastating consequences for fetal development.

Zika infection during particular periods of pregnancy is associated with the occurrence of Congenital Zika Virus Syndrome (CZVS), a pattern of congenital anomalies that includes microcephaly and other serious brain abnormalities and sensory impairments.

Early monitoring and identification of developmental delays is critical to ensure that children receive appropriate subspecialty care.

Parents and other primary caregivers should take an active role in the care and developmental monitoring of children with CZVS.

Psychological distress, particularly symptoms of anxiety and depression, has been shown to compromise parents’ coping resources, diminish parent-child relationship quality, and adversely affect parents’ ability to problem-solve to meet their child’s needs.

Gap: empirical data describing the psychological functioning of caregivers is currently insufficient and family interventions are lacking.

AIMS

The purpose of this project is to obtain critical information needed to develop an ecologically valid and responsive intervention to enhance the ability of caregivers to promote optimal development for their young children with CZVS. A mixed methods approach is used to understand the psychological adjustment, caregiving experiences, and available supports among Brazilian caregivers.

Aim 1: To evaluate psychological distress in caregivers of infants with CZVS.

Aim 2: To identify psychosocial and contextual correlates of caregiver psychological distress.

Aim 3: To describe family routines, caretaking demands, and desired supports and intervention outcomes among caregivers reporting severe anxiety and/or depression.

Aim 4: To describe the ecological context in which caregivers live and interact, in order to identify available and needed informal and formal sources of support.

METHODS

PARTICIPANTS

This project includes caregivers of young children with CZVS who are receiving treatment at a public hospital in Recife, Brazil. Participants are the primary caregivers to children between the ages of birth to two years who have been diagnosed with CZVS and are receiving weekly rehabilitation services at the hospital.

MEASURES

PHASE 1: QUANTITATIVE

1. Child Diagnoses and Treatments
2. Child and Family Background Information Questionnaire
3. Beck Depression Inventory-II
4. Beck Anxiety Inventory
5. Parenting Stress Index
6. Family Crisis Oriented Personal Scales
7. Family Resource Scale-Revised
8. Parenting Experiences Scale

PHASE 2: QUALITATIVE

1. Routines-Based Interview
2. Family Eco-Map

DATA COLLECTION AND PRELIMINARY ANALYSIS

Data collection for this study began in late January 2018. At the time of this submission, 33 mothers of toddlers with CZVS have participated. Descriptive statistics for the measures of psychological distress, coping strategies, and family resources were examined.

4.18% (SD = 4.55) of the participants in the sample reported severe anxiety symptoms (total BAI score ≥ 26), 10.8% (SD = 8.39) reported clinically significant symptoms of depression (total BDI score ≥ 29).

IMPLICATIONS FOR PRACTICE IN EARLY CHILDHOOD

Support
Identifying family stressors, as well as needed and available supports, for a subpopulation of Brazilian families.

Intervention
Providing the basis for developing, implementing, and evaluating a targeted intervention.

Vulnerable
Promoting an optimal developmental outcomes for this vulnerable population.

Public Policy
Informing policymakers in how to establish a large public policy program in Brazilian public health system.

New Scales
The culturally-sensitive translation will permit further analyses of the psychometric properties of each scale.

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