Changes in Occupational Roles and Common Mental Disorders in Mothers of Children With Congenital Zika Syndrome

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Importance: The functional limitations and long-term dependence of children with congenital Zika syndrome (CZS) may lead to changes in maternal occupational roles, which can have a negative impact on mothers' well-being and mental health.

Objective: To investigate changes in occupational roles and their effects on the mental health of mothers who have a child with CZS.

Design: Cross-sectional study.

Setting: Rehabilitation centers of the Brazilian Unified Health System in Alagoas, Northeast Brazil.

Participants: Forty mothers of children with CZS.

Outcomes and Measures: The Role Checklist and the Self-Reporting Questionnaire-20 were used to assess the mothers' involvement in occupational roles and common mental disorders (CMDs), respectively. The relationship between changes in occupational roles and CMDs was analyzed using a logistic regression model.

Results: Our study showed that loss of paid work ($p = .026$) is associated with poor mental health of mothers of children with CZS.

Conclusions and Relevance: Strengthening public policies to reduce the economic impact of CZS on families, offering multidisciplinary counseling, and implementing psychoeducational strategies for promoting maternal psychological adjustment are needed.

What This Article Adds: The time and money spent by mothers in daily care activities for children with CZS contribute to a reduction in family income and social well-being and have a negative impact on mothers' mental health.

Brazil recently faced a Zika virus (ZIKV) outbreak, particularly in the Northeast region, that coincided with an unusual increase in cases of microcephaly (de Araújo et al., 2016). After unremitting efforts, the causal association between in utero exposure to ZIKV and microcephaly and other congenital neurological abnormalities was confirmed (Moore et al., 2017); newborns with congenital ZIKV infection demonstrate a range of clinical manifestations, including neurological impairment and hearing and visual dysfunctions (Microcephaly Epidemic Research Group, 2016).

A recent review showed that ZIKV infection differs from other congenital viral infections by presenting five distinct outcomes: severe microcephaly, presence of subcortical calcifications, macular abnormalities, arthrogryposis, and extrapyramidal symptoms (Moore et al., 2017). This spectrum of neurological complications has been termed *congenital Zika syndrome* (CZS; Wheeler, 2018).

The functional limitations and long-term dependence of children with CZS may lead to changes in maternal occupational roles, which can have a negative impact on mothers' well-being and mental health. Occupational roles are defined by daily activity and appropriation of time as well as contributions to society and societal worth (Heard, 1977). *Mental health* is defined as a state of well-being in which a person realizes his or her own potential and can cope with

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the normal stresses of life ([World Health Organization \[WHO\], 2015](#)). Common mental disorders (CMDs) are distress states that manifest with anxiety as well as depressive and unexplained somatic symptoms ([Kagee et al., 2013](#)).

Clinically, a person's role participation becomes the focus of occupational therapy practitioners and other health professionals when disability-related limitations affect his or her capacity to participate in desired and meaningful roles ([Scott et al., 2017](#)). Recently, we reported that mothers of children with CZS have high levels of anxiety and a low quality of life in the first year after birth ([dos Santos Oliveira et al., 2016, 2017](#)). In this study, we examined changes in occupational roles and their relationship to CMDs in mothers of children with CZS.

Method

Study Design and Setting

This was a cross-sectional study conducted in four rehabilitation centers of the Brazilian Unified Health System (SUS) in Alagoas state, Northeast Brazil. Alagoas is one of the poorest states in Brazil with the worst Human Development Index (0.667); it has a population of 3.3 million ([Brazilian Institute of Geography and Statistics, 2012](#)). From 2015 to 2018, 141 CZS cases were confirmed in the state, and 88 were under investigation ([Ministério da Saúde, 2019](#)).

Participants

We enrolled all mothers of children with CZS who were receiving periodic monitoring and treatment in SUS rehabilitation centers in Alagoas state between July 2017 and April 2018. Children with CZS had a head circumference at least 2 standard deviations below the mean for age and sex. They also had typical alterations indicating congenital infection such as intracranial calcifications, cerebral ventricle dilation, or changes in the posterior fossa and other clinical signs, which were found by image diagnostic methods. Laboratory tests were used to identify the ZIKV. A total of 40 mothers (mean age = 25 yr, standard deviation = 6.8) of children with CZS (mean age = 18 mo, standard deviation = 6.4) were included.

Procedure and Measurements

Mothers were interviewed face to face in the health care centers and answered structured questions pertaining to demographic and socioeconomic status, their mental health condition, and their occupational roles before their child's birth and at the time the data were collected.

Mental Health Evaluation.

We used the Self-Reporting Questionnaire with 20 items (SRQ-20; [Harding et al., 1980](#)) to assess CMDs. The SRQ-20 is recommended for epidemiological research in low-income countries and has been validated in Brazil with high sensitivity (83%) and specificity (80%; [Mari & Williams, 1986](#)). Mothers completed the questionnaire in a quiet, private place according to WHO's recommendations ([Beusenbergh & Orley, 1994](#)). When a respondent did not understand the meaning of a question, the interviewer reread the question and did not explain the sentence using other words. SRQ-20 items are scored 0 if answered no (*symptom was absent during past month*) and 1 if answered yes (*symptom was present during past month*). SRQ-20 scores can range from 0 to 20, and a cutoff point of 8 was used as indicative of CMDs.

Occupational Roles Assessment.

The Brazilian Portuguese version of the Role Checklist ([Cordeiro et al., 2007](#)) was used to assess the mothers' involvement in occupational roles. The Role Checklist is a two-part inventory developed within the framework of the Model of Human Occupation ([Kielhofner & Burke, 1980](#)) to identify a person's perceived incumbency (Part 1) and role value (Part 2), along with a temporal continuum (past, present, and future) regarding the following 10 roles: student,

worker, volunteer, caregiver, home maintainer, friend, family member, religious participant, hobbyist/amateur, and participant in organizations (Oakley et al., 1986).

Data Analysis

The relationship between CMDs (outcome) and changes in occupational roles (predictor variables) was analyzed using a standard logistic regression model. Estimates were reported as odds ratios (ORs) and 95% confidence intervals (CIs) and were adjusted for income, schooling, number of children, and marital status. We assessed for multicollinearity using the variance inflation factor (VIF) and analyzed goodness of fit with the Akaike information criterion (AIC) and McFadden's R^2 . The analysis was performed with JASP statistical software (Version 9.1.0; Amsterdam, The Netherlands; <http://jasp-stats.org/>).

Ethical Considerations

The study was approved by the Human Research Ethics Committee of the Federal University of Sergipe (Sergipe, Brazil; CAAE: 65727917.1.0000.5546) and was conducted according to the Declaration of Helsinki. Written informed consent was obtained from the participants. All participants with a score ≥ 8 points on the SRQ-20 were referred to an existing service for people with psychological distress.

Results

Most mothers reported loss of occupational roles as student (−77.8%), paid worker (−76.5%), volunteer (−75.0%), friend (−39.4%), and hobbyist (−35.3%) and increasing their roles as caregiver (+44.4%) and participant in organizations (+150.0%; Table 1). SRQ-20 scores ranged from 0 to 15, with a median of 8 (interquartile range = 6.25). Twenty-three (57.5%) mothers had a high (≥ 8) SRQ-20 score and were positive for CMD symptoms. Logistic regression analysis showed a significant association between CMD and loss of paid work after a child's birth, OR = 7.20, 95% CI [1.26, 41.06], $p = .026$, AIC = 58.2, McFadden's $R^2 = .153$, VIF < 2; Table 2).

Discussion

In this study, we set out to explore the relationship between CMDs and changes in occupational roles in mothers of children with CZS. Our results indicate that loss of paid work was related to an increased risk for CMDs. There is

evidence that the prevalence of mental health problems, particularly depressive disorders, is higher among mothers of children with disabilities than among other mothers (Singer, 2006). In addition, it has been suggested that there is a significant relationship between caregiving time and the level of maternal mental health problems (Sawyer et al., 2011). Our findings are similar to those reported by studies on changes in occupational roles of mothers whose children have severe motor impairment (Brehaut et al., 2004; Ribeiro et al., 2014). The time and money spent by mothers in daily activities of care for children with a major disability (e.g.,

Table 1. Changes in Occupational Roles of Mothers With a Child With Congenital Zika Syndrome ($N = 40$)

Occupational Role	Past Involvement	Present Involvement	Change in Occupational Role, %	Attributed Importance, ^a Mdn (Q1–Q3)
Student	27	6	−77.8	3 (3–3)
Worker	17	4	−76.5	3 (3–3)
Volunteer	8	2	−75.0	3 (2–3)
Caregiver	27	39	+44.4	3 (3–3)
Home maintainer	39	39	—	3 (2–3)
Friend	33	20	−39.4	3 (2–3)
Participant in family activities	29	28	−3.5	3 (3–3)
Religious participant	22	19	−13.6	3 (3–3)
Participant in leisure activities	17	11	−35.3	2 (2–3)
Participant in organizations	4	10	+150.0	2 (1–2)

Note. Mdn = median; Q = quartile; — = not applicable.

^a3-point Likert scale (from *unimportant* to *very important*).

Table 2. Median Self-Reporting Questionnaire–20 Scores

Occupational Role	Mothers Reporting Change in Occupational Role, <i>Mdn</i> (IQR)	Mothers Not Reporting Change in Occupational Role, <i>Mdn</i> (IQR)	<i>p</i> ^a	Adjusted OR ^b [95% CI]	<i>p</i>
Student	8.0 (7.0)	8.0 (6.0)	.989	—	—
Worker	10.0 (4.0)	7.0 (6.5)	.020	7.20 [1.26, 41.06]	.026
Volunteer	9.0 (3.5)	8.0 (7.0)	.612	—	—
Caregiver	8.5 (7.0)	8.0 (5.5)	.813	—	—
Home maintainer ^c	—	8.0 (5.5)	—	—	—
Friend	10.0 (3.0)	7.0 (7.0)	.258	—	—
Participant in family activities	10.0 (5.0)	8.0 (6.0)	.488	—	—
Religious participant	8.0 (3.5)	8.0 (7.0)	.856	—	—
Participant in leisure activities	9.5 (3.3)	7.5 (7.3)	.326	—	—
Participant in organizations	10.0 (3.8)	8.0 (7.0)	.264	—	—

Note. — = not applicable; CI = confidence interval; IQR = interquartile range; *Mdn* = median; OR = odds ratio.

^aUnivariate analysis using Mann–Whitney *U* test. Variables with a *p* < .2 were included in the logistic regression model. ^bAdjusted for income, schooling, number of children, and marital status. ^cOnly 1 mother reported changes as home maintainer.

CZS) contribute to a reduction in family income and social well-being as well as a negative impact on mothers' mental health.

Families with a child with CZS face an immediate set of demands for specialized caregiving and an anticipated lifelong responsibility, but the information on long-term needs of families and societal burden is limited (Bailey & Ventura, 2018). Children with CZS require intensive health care across multiple health disciplines; increased transportation time to urban centers for appointments; and involvement from their primary caregivers, often mothers.

Having a child with a limiting illness can reduce opportunities for mothers to maintain employment and for

unemployed mothers to seek employment (Hope et al., 2017). Besides the obvious financial aspects, employment provides social inclusion and may reduce feelings of isolation and peripherality (Shearn & Todd, 2000). Although the government has made efforts to implement early childhood intervention programs to provide specialized services for children with CZS in Brazil, family-focused support and social and psychological assistance seem to be insufficient. Moreover, the lack of social protection policies and strategies to compensate for maternal unemployment and financial losses may lead to negative outcomes, including poor quality of life and psychological distress.

Because taking care of children with disabilities often leads to social isolation and a high risk of adverse mental health outcomes, active surveillance to identify emerging needs and development of intervention programs to support child health and positive family adaptation are needed (Bailey & Ventura, 2018; Brunoni et al., 2016). Occupational therapy practitioners could potentially assist mothers in developing a realistic plan to develop or regain roles in a manner that minimizes role strain and accentuates role balance (Crowe et al., 1997). In addition, emotional support provided by social ties enhances psychological well-being and reduces the risk of unhealthy behaviors and poor physical health (Umberson & Karas Montez, 2010). Parent-training programs can make a significant contribution to the psychosocial health of mothers by reducing, for example, anxiety, depression, self-esteem, and spouse or marital adjustment (Barlow & Coren, 2004).

Despite the limitations of this study (small sample size and cross-sectional design), our results suggest that loss of paid work is associated with CMDs in mothers with children with CZS. Strengthening mechanisms to ensure the return of mothers to the labor market, providing multidisciplinary counseling, and implementing psychoeducational strategies for promoting maternal psychological adjustment are needed. In addition, it is necessary to adopt institutional protocols to facilitate the collaboration of occupational therapy practitioners with families to determine a system of accommodations to reduce caregiver burden. Public policies should be implemented to ensure access to out-of-home environments that can receive and care for these children while mothers can play occupational roles that they judge to be important.

Implications for Occupational Therapy Practice

The results of this study have the following implications for occupational therapy practice. Occupational therapy practitioners should

- Exercise women's capacity to recover and restructure their occupational roles considering their new context of motherhood.
- Help identify tools that can contribute to the search for alternative work and income generation for women in their community;
- Identify ways of strengthening the family and community support network and promoting parenting skills development among close and extended family members who can collaborate in the care of the child and the mother feels safe sharing care tasks.
- Promote leisure activities, quality of life, and social integration.

Conclusion

Our results indicate that loss of paid work is related to poor mental health in mothers who have children with CZS. ■

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