



Supporting Caregivers Affected by Zika

Emerging research shows that caregivers to young children with Congenital Zika Syndrome (CZS) have elevated symptoms of anxiety and depression. Mental health problems can interfere with a caregiver’s ability to offer sensitive and responsive parenting – and sometimes prevent children from getting the services they need – placing them at risk for a range of adverse outcomes, including diminished social competence and emotional and behavioral self-regulatory difficulties.

RESEARCH GOALS

- Gain knowledge around the psychological and support needs of families caring for children with CZS.
- Gather data related to caregivers’ psychological needs, experiences, perceptions of intervention services and social contexts of families.
- Use the data to inform the development of an effective support program to enhance caregivers’ ability to support their children’s development.

WHY IS THIS RESEARCH NEEDED?

More information is needed concerning the mental health and early intervention needs of caregivers to children with CZS beyond infancy, including how caregiving experiences and challenges change over time and are related to factors such as parenting stress, coping strategies and family resources.

This research advances our ability to:

- Identify caregivers and children at risk for poor functioning and developmental outcomes
- Clarify areas of needed support
- Inform the development of interventions aligned with the family’s needs and wishes

COLLABORATORS

University of Nebraska-Lincoln



Natalie A. Williams, Ph.D.
(Principal Investigator)

- Christine Marvin, Ph.D.
- Cody Hollist, Ph.D.
- Holly Hatton-Bowers, Ph.D.

Universidade Federal Rural de Pernambuco



Pompéia Villachan-Lyra, Ph.D.
(Principal Investigator)

- Emmanuelle Chaves, Ph.D.
- Leopoldo Nelson F. Barbosa, Ph.D., Department of Psychology, Faculdade Pernambucana de Saúde

LOCATION

City of Recife, located in the Pernambuco state of Brazil.



RESEARCH SNAPSHOT

50

caregivers to children ages
0-3 years with CZS

10

caregivers (small
subgroup) participated in
home-based interviews

IMIP

Participants recruited via Instituto
de Medicina Integral Professor
Fernando Figueira (IMIP)

RESULTS

- 20% of caregivers reported moderate or severe levels of depression
- 6% of caregivers reported moderate symptoms of anxiety
- 10-24% of caregivers reported high or clinically significant parenting stress
- Caregivers using more coping strategies had lower depression scores.
- Existing intervention services focus on working directly with the child rather than helping the caregiver to support their child's development.
- Parenting stress scores were significantly higher for caregivers who reported a low level of involvement in their child's intervention program.
- Personal distress contributed to overall parenting stress more than attributes of the child or the parent-child relationship.
- Greater use of family-centered intervention practices was associated with lower parenting stress via its association with increased parental coping strategy use.

RECOMMENDATIONS

- Prioritize mental health concerns, specifically depression and parenting stress, in caregivers of children with CZS who reside in low-income homes.
- Integrate caregiver mental health support services into existing early intervention programs targeting children with CZS.
- Consider the role of family coping and resources in the development of new programs designed to help caregivers of children with CZS.
- Train practitioners on family coping strategies that will support a caregiver's psychological resilience in caring for a child with CZS.
- Raise awareness among public and governmental agencies on how CZS affects families and reflect on how best to meet the needs of families as well as children in home and school contexts.
- Develop social service programs that increase resources to support families of children with CZS.

What's next?

- Complete data analysis and report results for qualitative and quantitative data collection.
- Code interview transcripts to shed light on the specific challenges in caregiving experienced by families of children with CZS in the home.
- Explore future projects to support well-being among teachers who support children with CZS in early childhood care and education settings.

Our team will continue to build on our existing research programs in Brazil and the U.S. We plan to initiate research with the University of São Paulo where nursing faculty have expressed an interest in collaborating to optimize care for children and families in hospital settings to improve child health outcomes and parent well-being. Funding is needed to begin this work.

