



Factors Related to Adherence to Pediatric Services for Congenital Zika Virus Infection in Puerto Rico

Julie H. Levison^{1,2}, Lourdes García Frago³, Ines E. García García³, Paola del Cueto^{1,2}, Leticia Gely³, Maria F Levis⁴, Miguel Valencia⁵, Dharma E. Cortés^{2,6}

¹Massachusetts General Hospital; ²Harvard Medical School; ³University of Puerto Rico School of Medicine; ⁴Impactivo; ⁵Puerto Rico Department of Health; ⁶Cambridge Health Alliance

Contact: jlevison@partners.org

Background and Objective

- Over 3,000 children in Puerto Rico were potentially exposed to Zika virus infection during pregnancy in the 2016 Zika virus epidemic. This congenital exposure is an established risk factor for birth defects and neurodevelopmental abnormalities, which may appear after birth.
- Puerto Rico's guidelines require consistent pediatric monitoring for early identification and intervention of children up to age five.
- Our objective was to assess factors that influence caregiver adherence to Zika-related follow-up pediatric services in Puerto Rico.

Methods: Study setting and Population

- Qualitative semi-structured focus groups and individual interviews with 57 individuals, including 35 caregivers and 22 healthcare providers or service coordinators.
- **Caregiver eligibility:** Aged ≥18 years and a primary caregiver for a child with laboratory evidence of confirmed or possible Zika virus infection during pregnancy. **Provider eligibility:** Aged ≥18 years service coordinator or health care provider of pediatric Zika services.

Methods

Quantitative data: Participants responded to a brief pre-interview demographic questionnaire. Caregivers reported on clinical characteristics of the child with congenital Zika infection as well as pediatric appointment attendance. Non-adherence to pediatric follow-up was calculated as 2 or more missed pediatric follow-up appointments without prior warning or greater than a 6-month gap in pediatric appointments, in the last 12 months.

Qualitative Interviews:

- In February 2020, Spanish-speaking research staff conducted 13 semi-structured interviews: 8 focus groups with caregivers, 2 focus groups and 3 individual interviews with providers. Interviews lasted ~1 hour.
- Interviews explored participants' views on barriers to Zika-related pediatric services and suggestions for improving appointment attendance.
- Interviews were recorded, transcribed, and translated from Spanish to English.

Analytic methods:

- In this preliminary analysis, we developed and applied a coding scheme based on barriers and facilitators from the Andersen Model of Health Care Utilization and Katz Model for Adolescent Vaccine Adherence (a multi-step process influenced by adolescent and caregiver factors).
- We also used a deductive analytic approach to identify themes that expanded upon the conceptual model.

Results

Factors influencing adherence to Zika-related pediatric follow up

1) Clinic location, availability and costs associated with transportation, and physical requirements to transport child or multiple children influence ability to get to appointments:

"Parking time, which is very expensive. And because it [the appointment] lasts so long, sometimes I pay up to \$10 or \$15 for parking. And sometimes I can't come because I don't have money for parking. Sometimes I have to call to have my appointment changed."
- Caregiver

"In my case, I have a car, but transportation also has an influence, like the public bus. There are many mothers who, if they do not have a car, have to carry a stroller, a diaper bag, the baby."
-Caregiver

"If they have other children sometimes it is a bit difficult, coming with all the children to appointments and sometimes finding someone to take care of the other children is a bit difficult and sometimes they bring them all." - Provider

"Sometimes they don't have money to come, and here the parking is very expensive. I mean, if they have a car, then being here for an appointment is super expensive. And usually we try to give them several appointments on the same day so that you take advantage, but it is very expensive."
-Provider

2) Caregivers encounter complex requirements for follow-up appointments:

"There is no specific place for these children with microcephaly. There is no specific place, where one calls where one looks for information. It is very difficult. Because I go to the clinics and as of today, I still don't know if my daughter sees clearly. She has been seen by a retinologist. Now I have to take her to an ophthalmologist... she's one year and five months old and I'm still in limbo."
-Caregiver

"You have to come personally to make the appointment. But look, I live an hour or so away. How can you not make the appointment for the child? Oh, and you have to come with all the documentation. Okay. If the appointment was for two months, then, I have to renew everything that the medical plan, authorization and such."
- Caregiver

"They (caregivers) say they have to wait one, two years to see a specialist."
- Provider

3) Caregivers experience burdens that are emotional, social and time-dependent:

"This is just beginning, because she is one year and five months old. This is just beginning. And I say, I am I the one who is with her 24/7. Dad comes home and sees her bathed, he already sees her fed, he sees everything, but all that load and all those things I carry."
- Caregiver

"The baby's father I told him, get out and go because I can't. I can not. I tell him: you do not understand that I need patience and understanding for what I live day by day...My days off, as I say, are Saturday and Sunday. But Saturday and Sunday I take care of my son, because my mother works on weekends, so she cannot say I stay a little bit with the baby."
-Caregiver

"Many of them [mothers/caregivers] say, 'I'm not going. Not because I don't want the services. I just started a new job, and my boss gives me the excuse for one day. But several dates, he won't give it to me.'"
- Provider

	Total Cohort n=57
Caregiver Sociodemographic Characteristics	n=35 (%)
Female	35 (100)
Relationship to child	
Mother	32 (91)
Grandmother	3 (9)
Caregiver Age, mean years [SD ± years]	33.5 [±10.5]
Child Age, mean months [SD ± months]	26 [±11]
Annual income	
No annual income	16 (46)
<\$10,000	13 (37)
>\$10,000	5 (14)
Not reported	1 (3)
Child Clinical Characteristic	
Trimester of congenital Zika infection (caregiver self-report)	
First trimester	3 (8.5)
Second trimester	16 (46)
Third trimester	13 (37)
Unknown	3 (8.5)
Congenital abnormality possibly related to Zika (caregiver self-report)	
≥ 1 abnormality	14 (40)
No abnormalities	17 (49)
Unknown	4 (11)
Pediatric Follow-Up Adherence last 12 months	
Non-adherence	23 (66)
Provider Position	N=22 (%)
Social worker	4 (18)
Patient navigator	8 (36)
Physician	4 (18)
Nurse	1 (5)
Allied health professionals	
Occupational/Physical therapist	2 (9)
Speech/language pathologist	3 (14)

SD= standard deviation

Conclusions

- Barriers to Zika-related pediatric follow-up care in Puerto Rico are complex and multi-level.
- Core intervention targets should include caregiver burden, health system navigation, and coaching caregivers in communication with pediatric providers.
- Use of a caregiver-delivered manualized intervention led by community health workers seems appropriate to achieve these goals.