



## FIELD REPORT

Research Team: Universidade Federal de Pernambuco – FAGES

Project Number: APQ-0553/2016 FACEPE-Newton Fund

### **Action Ethnography on Care, Disability and Health Policy and Administration of Public Service for Women and Caretakers of Zika virus affected Children in Pernambuco, Brazil**

Period: March 1, 2017 to February 28, 2019, with extension of activities to October 30, 2019

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Research done in Association to Research Support for Call 14 of 2016 – CNPQ-CAPES-DECIT (440411/2016-5) (**Etnografando Cuidados e Pensando Políticas de Saúde e Gestão de Serviços para Mulheres e Seus Filhos com Distúrbios Neurológicos Relacionados com Zika em Pernambuco, Brasil**)

## **DESCRIPTIVE SUMMARY OF RESEARCH**

In Brazil, the Zika epidemic, a national and public health emergency declared in 2015, and in effect until early 2016, caused severe neurological damage to over three thousand newborn children (3.179 confirmed cases up to the fifteenth week of 2018), of which, by the same date, 451 were from the state of Pernambuco. The newborn evidenced microcephaly at birth based originally on observations from Pernambuco and Paraíba, were discovered to be part of a still uncharted conjuncture of symptoms which came to be known as the Congenital Syndrome of Zika Virus (CSZV) mobilizing mothers and their networks, health and social service professionals and workers, and researchers from diverse disciplines to find ways to understand, treat, alleviate and prevent the Syndrome. Since March of 2017 we have continued our CNPq research (begun in October of 2016), reinforced and made more widely applicable with the Newton Institutional Links grant. Our research team accompanied daily therapeutic itineraries of mothers with Zika-affected children, and observed different institutional therapeutic spaces.

At all times the ethnographic practice of constant interaction and sharing of experiences in multiple frames was favored, and registered by way of fieldnotes, images and collection of documents. That information was complemented by approximately 190 formal and informal interviews (110 with mothers and Family, 80 with health and social service professionals and workers), research on at least 60 institutions, and participation in associations and numerous events and networks protagonizing and discussing knowledge and action concerning CSZV, and social communication networks. With this information the questions of the social burdens of Zika for caretakers and family; the social, economic and cultural factors related to the spread of the epidemic, factors informing the institutional organization of treatment and care, the effects on citizen-state relations, and the real and potential dialogue between caretakers and families and those institutionally responsible for the delivery of services and discovery of information about the syndrome and forms of prevention. Special attention was systematically given to the novelty of the Public Emergency Condition of a previously unknown disease in a country with an active sector of health researchers. Besides dozens of presentations and papers read and discussed at congresses of health and of anthropology, articles published (5) and in preparation for academic journals, many professionals in formation prepared and presented ongoing research reports and final course monographs at BA, MA and, in the future, PhD levels.

The focus on anthropological procedures of research demonstrates strong emotional ties between mothers and the SCZV children, rearrangement of living and mobility patterns in accordance with therapeutic itineraries used to deal with rehabilitation, numerous innovations and numerous barriers in the articulation between domestic care domains, institutional care domains, and researchers' care with obtention of knowledge about Zika, the intensive focus of health organization to deal with a disease that tested the cumbersome elements of fragmented public and private health systems, and the intense use of exceptional specialized webs to stimulate mutual communication in response to the challenges of SCZV. The importance of associations protagonizing caretakers, both at the level of immediate demands, and at the level of widening of the scope to deal with rare disease and other disabled populations catalyzed participation of caretakers, dialogue with the legal system in search of the respect for rights, more agile

practices and attention to the caretakers, and not only to their SCZV children. A group of mothers participated in a replicable course, entitled Mother's tell their stories, learning basic audiovisual techniques, defining themes they judge important about the experience of being a Zika caretakers, producing and narrating videos to be discussed with professionals and workers to value the caretakers' perspectives in the exchange ideas about best practices.

## **OBJECTIVES SOUGHT AND OBTAINED**

### General Objective:

To develop institutional links for strengthening interdisciplinary research to contribute to socially effective and acceptable response measures to diminish the burden of social suffering of vulnerable populations affected by the Zika virus.

[The research done by FAGES is ethnographic principally on two fronts: 1) participating in and documenting mothers' itineraries and uses of networks; 2) participating in therapeutic spaces, seeing services and planning. Ample use of taped interviews complements this information and efforts have been, and are being, made to favor encounters between both. Institutional links include activities between research and service institutions, as well as associations representing mothers and the mothers themselves]

### Specific Objectives:

1. To co-construct innovative methodological approaches, bringing together UK and Brazilian expertise in anthropology, development studies and policy analysis [emphasis in Newton-FACEPE Project]
  - The discussion of activities with UK researchers brought methodological suggestions that were adopted by Brazilian teams, and the presence of a UK trained master's level field researcher in short field experiences, afforded dialogues. The FAGES Brazilian team provided long-term participatory research that, given the emergency situation, is difficult to occur among field researchers, providing a privileged look to complement other data collection instruments – our own and of other researchers – and participation in collective forms of sharing information and action stimulated by the same emergency situation, provided opportunities to monitor and influence actions and perspectives]
2. To apply these approaches to ethnographic description of therapeutic and care practices of Zika virus affected families and communities and related public health and social service responses
  - [Very clearly done as evidenced in numerous publications that specify how work was done with families, service institutions and other researchers]
3. To articulate collaboration between populations and service providers and co-produce public response agendas based on families' and communities' own priorities.
  - [Much collaboration was being done by diverse institutional spaces which involved attention to Zika affected family demands, and our presence frequently reinforced and legitimated the families' viewpoints that might otherwise not have been as clearly understood. These actions continue.]

4. To develop research outputs which broaden national and international knowledge of Zika-related care needs and responses and replicable training resources for researchers and practitioners
  - [Articles, Chapters, Academic Title Monographs, Papers and Participation at Congresses and other events, Multiple-agent Situation Rooms, Meetings of Zika Network and Research Call participants, Events promoted by FAGES, Activities of Associations, Production and Course of Videos about Zika experience, Internal Workshop to Develop these products and development of outline of course for professionals and practitioners, collaboration with diverse protagonistic activities]

It is very important to recognize that the themes identified in the CNPQ/CAPES/DECIT (Doing Ethnography on Care..) (440411/2016-5) which include ethnographic work with families and service planners and administrators with identification of social burdens, social and cultural determinants, and understanding of the establishment of relations between the State and the idea of citizenship, all in order to promote more effective dialogue between sectors, were present invariably behind all activities done, We also decided to include special attention to the general category of “researchers” as a separate and very influential group in activities done.

## FINDINGS AND THEMES HIGHLIGHTED

To be most respectful of the process of production of these findings, this section is first organized relating them to the objectives of the CNPQ 440411/2016-5 project which contributed strongly to our perspective, and second highlighting how these findings relate more directly to the APQ-0553/2016 project emphasis (objectives 1 and 4 of the previous page). The themes and findings are organized according to their relation to four overall themes, the first three from project CNPQ 440411/2016-5, and the fourth (researchers) that came directly from fieldwork.

What are the social burdens, vulnerabilities, and experiences of daily care and health and social service care furnished by the State and others.

- *Full-time daily attention of mothers provoking abandonment/limitations of other activities.*
- *Super-emphasis on the value of maternity for mothers.*
- *Strong emotional*
- *Formation of female-centered care networks and much male absenteeism and separations.*
- *Extreme difficulties in mobility between dispersed treatment centers, and migration of entire families or parts of families to new residences nearer treatment*
- *Majority of families low-income, non-white, from urban periphery*
- *Difficulties in caring for siblings of the children with the Syndrome*
- *Varied implications for family planning and pregnancy protective measures*
- *Processes of innovation and adaptation of technically-based means of treatment that are inaccessible to low-income families*
- *Questioning of effectiveness of chemical-pharmaceutical products for alleviating convulsions and other symptoms*

What are the social and political determinants of the State-Citizen relationship related to the effects of vulnerability to the Zika Virus and to the efforts of prevention and response to it?

- *Approximation of mothers and caretakers to those responsible for services as relevant for access to services*
- *The creation of special treatment and attention for the segment by means of special supporters and planning*
- *Continued fragmentation and indefiniteness of general policies for treatment of Zika and other disease that require intensive rehabilitation*
- *Continuation of discourse of family/ individual responsibility underemphasizes social inequalities in environmental factors*
- *Wealthier patients with access to more efficient therapies*
- *Lack of day-care centers and difficulties of social interaction when they exist*

What are the implications for the construction of more confidence and engagement with State systems which may lead to more effective control and preparation for future outbreaks?

- *Need for more guarantee of access of families to results of exams*
- *Mainstream treatment to avoid feelings of being valued only because they are providers of information about the illness*
- *Associations as very effective vehicles to pressure for more and better attention*
- *Inclusion of Zika victims in interests of the larger category of disabled contributes to more visibility of the needs of both*
- *Increase in, but still very limited, channels of communication between families, service providers and researchers,*
- *Termination of treatment without solutions diminishes credibility of services and over-burdens mothers in name of institutional efficiency*

*What does the State of Emergency of Public Health effect relations between the care domains of everyday life, of institutional services, and of researchers?*

- The intensity and visibility of the Zika Syndrome permits more volume of care than in other situations of less visibility
- The solution of the problem is dealt with as a point of pride for researchers and for geopolitical entities (state and nation) leading to more attention
- Researchers funding and desire for access to information lead to intensive and non-continuous support and treatment
- Access to results of exams, even though more are done, is very difficult
- A constant and often precarious articulation between everyday care demands, formal service care demands with little intersectoral dialogue, and researcher information care about the characteristics of the hitherto unknown pathology lead to conflicting aims as well as to new collaborations

As stated in the FACEPE-NEWTON Project, we continued our emphasis on two axes: mothers and affected children, and policy makers and administrators of treatment, adding a third: researchers, because of their relevance in the particular scene of an epidemic of a little-known disease.

The focus remained on practices and emotions concerning care, health and social assistance, and the therapeutic itineraries and healthcare available. We worked with many more than the four different social networks, most of which are composed of census declared black/brown population, but the color/racial element had limited influence on the organization of family networking and itineraries. Nonetheless we accompanied discussion groups of the black movement (Fernanda Meira) and, identified an indigenous mother who abandoned her native territory home to reside and have access to the city-based, non-ethnic treatment. In one other territory, despite the lack of confirmed cases of Zika, we did research on specialized treatment of arboviruses for indigenous groups, including an emphasis on a group with a reported, yet unconfirmed, case.

Ethnographic research and interviews in clinics and therapeutic units with policy makers, professionals and workers, were fundamental for the understanding of real and idealized paths for intersectoral therapeutic care for populations.

Our research team participated in fieldwork and discussion of research activities in Recife, Rio and Brasília at different levels of health, social service, welfare, education and other services, but the bulk of fieldwork on these institutional settings was done by the collaborating partners. This permitted a view of local, statewide, regional and national levels.

## **RECOMMENDATIONS TO PROFESSIONALS AND RESEARCHERS**

Need for Attention to clearer and better Intersectorality (diverse health-service institutions, education, welfare, day-care centers, transportation, social work)

Demands made more visible by Zika should be extended to other disabled groups and to people with rare diseases, going beyond the limits associated to emergency status

Better communication/integration between basic health professionals and rehabilitation centres.

More R4 Rehabilitation Centres distant from capital cities

More sensitive policies of provision of transport for children and for caretakers.

Maintenance of special flow of attention to Zika syndrome patients even after the end of the declaration of Public Health Emergency

Presence of more varied specialists at basic health units, capable of doing more integrated care. This includes respiratory therapy, motor and cognitive evolution therapies, animal-assisted therapies

Diminish the waiting time for treatment since hours are spent waiting for sometimes short sessions.

Adaptation of transport vehicles

Remove the prohibition on use of Canabiol which has positive effects on alleviation of convulsions and spasticity.



## PUBLISHED AND FORTHCOMING PUBLICATIONS, IMAGENS E LINKS

SCOTT, Russell Parry; QUADROS, Marion Teodósio; RODRIGUES SILVA, Ana Cláudia; LIRA, Luciana Campelo de; MATTOS, Silvana Sobreira de; MEIRA, Fernanda, SARAIVA, Jeíza. A Epidemia de Zika e as Articulações das Mães num Campo Tensionado entre Feminismo, Deficiência e Cuidados - do Dossiê Zika da Revista Gênero e Diversidade UFBA. Vol 03, N. 02 - Mai. - Ago., 2017, pp 73-91.

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Projeto “Disseminando informações sobre impactos sociais da epidemia do zika vírus em escolas de Pernambuco”.: Jeíza das Chagas Saraiva (UFPE) (2017)

Oficina de audiovisual “Mulheres contam suas Histórias”, coordenado por Russell Parry Scott, Luciana Campelo de Lira e Fernanda Meira. (2018-2019)

Produção de 5 vídeos com mães que participaram da pesquisa e da oficina.

#### **APOIO:**

