

Congenital Zika virus syndrome in infants: repercussions for the promotion of families' mental health

Síndrome congênita do Zika vírus em lactentes: repercussões na promoção da saúde mental das famílias

Síndrome congénito por el virus Zika en lactantes: repercusiones en la promoción de la salud mental de las familias

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doi: 10.1590/0102-311X00176217

Abstract

This article aims to discuss the impacts of the promotion of families' mental health following the diagnosis of Zika virus infection in the pregnant woman and/or congenital Zika virus syndrome (CZVS) in the infant. The study also aims to foster reflection on mother-infant bonding in this context. The study is relevant not only because there is still so much to learn about CZVS, with its enormous capacity for dispersion and many doubts as to the physical consequences and psychological impacts, but also due to the urgent need to provide families and/or caregivers with guidelines for care and alternatives for dealing with the illness. The study was conducted in an outpatient clinic specifically providing care to children with CZVS at the Unit for Infectious Diseases in Pediatrics in a tertiary hospital of the Brazilian Unified National Health System (SUS) in Rio de Janeiro, Brazil. The team is multidisciplinary, and each member conducts an assessment based on their specific field of knowledge. This qualitative study drew on participant observation, and the data analysis showed that the use of virtual social networks, which function (independently of the medicine approaches) as channels for communication and collective discussion of the different experiences, in order to share strategies to overcome the diagnosed impossibilities.

Zika Virus; Mental Health; Infant; Family Relations

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Introduction

The description of a new and serious congenital infection, the congenital Zika virus syndrome (CZVS), in Brazil in late 2015 triggered large mobilization of the technical and scientific apparatus, society, and the media. The unprecedented nature of the disease raised doubts and expectations in the population. Fear and anxiety became part of the daily lives of pregnant women and their families.

Based on the notion of comprehensiveness in the principles of the Brazilian Unified National Health System (SUS), there was a need to respond to this suffering by adopting measures for the promotion of the families' mental health. Thus, the concept of Mental Health used in the study is linked to the vision of the human being, and as discussed by Dimenstein ¹, it is possible to view the individual as a whole, acknowledging and respecting biopsychosocial aspects. Thus, understanding the suffering triggered by the illness in the patients and their families contributes to care and attention for them in health services ².

In this setting, the study is relevant not only because so much still remains to be learned about CZVS, with its enormous capacity for dispersion and many doubts as to the physical consequences and psychological impacts, but also due to the urgent need to provide families and/or caregivers with guidelines for care and alternatives for dealing with the illness. Thus, an attentive ear to the complaints, fears, anxieties, and doubts generated by CZVS should be emphasized in the work by mental health professionals, expanding their view beyond the concern over the physical illness per se. Bezerra Júnior ³ (p. 154) thus states that *"there is a hidden meaning in the symptom, and treating means to unveil this hidden reason of the illness and thus allow patients to find more adequate solutions to their conflicts"*.

Further, given the lack of an available cure for CZVS, a chronic health condition sets in, as defined by Barsaglini ⁴. From this perspective, chronic illnesses can bring psychological and social consequences, since the continuous need for care and periodic visits to health services tend to disrupt the family's routine and require learning to live with the condition.

In light of the above, the article aims to discuss the impacts of the promotion of families' mental health following diagnosis of Zika virus infection in the pregnant woman and/or presence of CZVS in the infant.

Method

The qualitative study was based on participant observation, a technique which according to Haguette ⁵ seeks the meanings (more than the appearances) of human actions.

The study was conducted in an outpatient clinic specifically caring for children with CZVS at the Unit for Infectious Diseases in Pediatrics at a tertiary hospital of the SUS in Rio de Janeiro, Brazil. The team is multidisciplinary, and each member conducts an assessment based on their specific field of knowledge.

Thus, from April to July 2016, the clinic received 20 families with infants ranging from two to eight months of age (12 females and eight males). Nine of the mothers were accompanied by the infants' fathers, ten came with other relatives (their mothers, aunts, or sisters) or friends, and one mother came to the appointment alone with her infant. Of these families, ten participated once, three had two appointments, another three had three meetings, and four families attended more than four team consultations.

Importantly, some of the families included in this study had already been interviewed by television, radio, and newspapers on how they deal with the adverse impacts of CZVS. Some of these families are known throughout their communities, and their children are known as "the children of Zika", so great is the media exposure caused by the epidemic, as reported previously by Diniz ⁶.

Data on mental health were collected during the visits, recorded in a field diary, and linked to the collaborative consultations with other health professionals. The conversations during visits also allowed families to connect to significant areas of their own experiences, which Fernando Rey ⁷ has defined as "Conversational Dynamics", allowing the expression of subjects' needs and conflicts, facilitating the emergence of new symbolic processes based on the emotions that surface.

Data analysis was conducted according to Qualitative Epistemology, defined by Rey⁷ as the meeting of three principles: constructive-interpretative knowledge, singularity, and dialogue. The dynamic of these principles, combined with participant observation, allowed the researcher to interpret the subjects' discourses, resulting in configurations. Convergence of the latter resulted in Units of Meaning.

The study complies with Brazilian National Health Council *Resolution n. 466/2012*. It is a sub-project of the study *Vertical Exposure to Zika Virus and its Consequences for Infant Neurodevelopment*, approved by the Institutional Review Board of the National Institution of Women, Children and Adolescents Health Fernandes Figueira, Oswaldo Cruz Foundation, under case review CAE 52675616.0.0000.5269.

Results

The configurations emerging as expressions of subjectivity in families of CZVS patients were:

- (1) Divine mission: feelings of punishment for having received the child, as well as the idea of having been chosen by God to deal with such an enormous sacrifice. The religious experience as a mission of faith and redemption;
- (2) Family participation: the possibility (or impossibility) of relying on help from the immediate or expanded family in caring for the affected child;
- (3) Prejudice: discrimination against the child due to the syndrome, and refusal to accept any negative opinions from others;
- (4) Parent-child relations: dealing with the child based on manifestations of fear, sadness, and uncertainty vis-à-vis the diagnosis;
- (5) Daily routine and economic and financial interference: changes in the family's routine, impacts on the couple's relationship, obstacles to social benefits, and sometimes the need to quit work to care for the child, leading to difficulties in covering the expenses;
- (6) Media impacts: immense use of virtual social networks as a medium for support and exchange of information on the children's development and references for treatment and social benefits.

The "units of meaning" built on the basis of these configurations allowed reflections on the individual and collective possibilities for families to deal with the children's illness. Although the definitions are quite succinct, items 1, 2, 3, 4, and 5 do not differ from similar scenarios in experiences with other chronically ill children. What is new and specific to these experiences is the use of virtual social networks (item 6). In addition to acting as a means of communication between the families and the collective discussion of their different experiences, they serve to share strategies to overcome difficulties. The promotion of the families' mental health was thus not limited to specific care in the team consultations, but also included the support provided by the virtual social networks.

Research aspects

This article aimed to present the initial reflections pertaining to the field of mental health that emerged during conversations with caregivers of children with CZVS. In addition to familiar issues like prejudice, parental relations, and changes in the routine, the families voiced the importance of the media and social networks. At first, the families felt supported by the great interest in the mass media, favoring the creation of a network of health care for children with CZVS. However, as the media interest waned, the families felt abandoned and began to face the difficulties involved in a chronic illness. Still, they found support and references in the virtual social networks to deal with the daily challenges over time.

In this sense, the parents see themselves as a community of victims of the epidemic, and many of them have to be with the child fulltime. Due to the exhausting routine of appointments and tests, many parents have sacrificed major parts of their workday or even lost their jobs. This new family condition interferes in the couple's relationship in their subjectivities and marital life.

Another observation was that the parents assimilated medical language to describe their children's seizures, malformations, and clinical condition. This may suggest the parents' difficulty in establishing

an emotional bond with the child, a relationship with the infant other than in terms of the disease, putting medical care in first place and relegating their own parental attitudes such as hugging, kissing, and playing with the child. This stance may stem from the difficulty in accepting the child's limitations and their perception of the infant's different development, directly impacting the establishment of a healthy parent-child relationship. "Acceptance of the baby" by the parent/caregiver is a fundamental issue that cannot be neglected, since this process is the starting point for affective bonding.

Although this is a preliminary study that merits more in-depth development in future research, it shows the crucial importance of a public policy to meet the various demands from CZVS, including mental health, with the promotion of measures to favor the child's development.

Contributors

I. M. Freire contributed with the conception and study design, data collection, data analysis and interpretation, manuscript writing and critical revision regarding methodological aspects and intellectual content. S. M. Pone contributed with the writing of the manuscript and critical revision regarding methodological aspects and intellectual content. M. C. Ribeiro contributed to data collection and data analysis and interpretation. M. S. Aibe contributed with the data analysis and interpretation and writing of the manuscript. M. V. S. Pone contributed with the conception and study design and critical revision regarding methodological aspects and intellectual content. M. E. L. Moreira contributed to the conception and study design. L. Dupret contributed with the data analysis and interpretation and critical revision regarding methodological aspects and intellectual content. All authors have approved the final version of the text to be published.

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Resumo

Este artigo tem como objetivo discutir os impactos na promoção da saúde mental nas famílias a partir do diagnóstico de infecção pelo vírus Zika na gestante e/ou a presença da síndrome congênita do Zika vírus (SCZV) na criança. Busca ainda favorecer uma reflexão a respeito da construção do vínculo mãe-bebê nesse cenário. A relevância do estudo se dá não somente pelo fato de a SCZV ser ainda pouco conhecida, com uma enorme capacidade de dispersão e com muitas dúvidas quanto às consequências físicas e ao impacto psíquico causado, como também pela urgência em ser dada às famílias e/ou cuidadores diretrizes de acolhimento e alternativas para lidar com a doença. O estudo foi desenvolvido em ambulatório específico para o cuidado de crianças com SCZV da Unidade de Doenças Infecciosas em Pediatria de um hospital terciário do Sistema Único de Saúde (SUS) no Rio de Janeiro, Brasil. A equipe é caracterizada como multiprofissional e cada um de seus integrantes faz uma avaliação com base no campo de saber específico. A pesquisa de cunho qualitativo foi realizada valendo-se da observação participante, e a análise dos dados revelou que a utilização das redes sociais virtuais, as quais independentemente dos caminhos seguidos pela medicina, funcionam como veículo de comunicação e discussão coletiva de diferentes vivências, no intuito de compartilhar estratégias para a superação de impossibilidades diagnosticadas.

Zika Vírus; Saúde Mental; Lactente; Relações Familiares

Resumen

El objetivo de este artículo es discutir impactos en la promoción de la salud mental dentro de las familias a cuyas gestantes se les ha diagnosticado infección por el virus Zika, y/o la presencia del síndrome congénito del virus Zika (SCZV, por sus siglas en portugués) en el niño. También pretende favorecer la reflexión respecto a la construcción del vínculo madre-bebé en este escenario. La relevancia del estudio se produce no solamente por el hecho de que el SCZV sea todavía poco conocido, con una enorme capacidad de dispersión, y con muchas dudas respecto a las consecuencias físicas y el impacto psíquico causado, sino también por la urgencia en proporcionar a las familias y/o cuidadores directrices de acogida y alternativas para enfrentarse a esta enfermedad. El estudio se desarrolló en un ambulatorio específico para el cuidado de niños con SCZV de la Unidad de Enfermedades Infecciosas en Pediatría de un hospital terciario del Sistema Único de Salud (SUS) en Río de Janeiro, Brasil. El equipo estaba caracterizado como multiprofesional y cada uno de sus integrantes realizó una evaluación a partir de un campo de saber específico. La investigación de cunho cualitativo se realizó a partir de la observación participante. El análisis de datos reveló que la utilización de las redes sociales virtuales, independientemente de los caminos seguidos por la medicina, funciona como un vehículo de comunicación y discusión colectiva sobre diferentes vivencias, con el fin de compartir estrategias para la superación de las imposibilidades diagnosticadas.

Virus Zika; Salud Mental; Lactante; Relaciones Familiares

Submitted on 07/Oct/2017

Final version resubmitted on 26/Apr/2018

Approved on 30/May/2018