

Congenital zika syndrome from theoretician Betty Neuman's perspective: family stressors

Síndrome congênita do Zika à luz da teórica Betty Neuman: estressores familiares
Síndrome congénito del Zika de acuerdo con la teórica Betty Neuman: estresores familiares

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Abstract

Objective: To learn the family stressors involved in the context of the congenital Zika syndrome from Betty Neuman's systems model theory perspective.

Methods: Qualitative and exploratory study with 13 mothers of children affected by the disease. Individual semi-structured interviews were conducted in the outpatient clinic of a public hospital that is part of Pernambuco's state health network. Data were analyzed using IRAMUTEQ software and applying the descending hierarchical classification technique, which originated a dendrogram. Betty Neuman's systems model theory was used as a framework for discussing the data.

Results: The dendrogram originated five classes: family routine, care provided by health services, changes in lifestyle, support network, and social consequences of care for the family context.

Conclusion: The changes in family dynamics led to the identification of a family system characterized by multiple interactions with stressors. Recognizing the effects caused by these stressors is the main mechanism for adopting coping measures, which could provide family members with a stable system.

Resumo

Objetivo: Desvelar os estressores familiares no contexto da Síndrome Congênita do Zika Vírus à luz da Teoria do Modelo de Sistemas de Betty Neuman.

Métodos: Pesquisa qualitativa, exploratória, realizada com 13 mães de crianças acometidas pelo agravo. Foram realizadas entrevistas semiestruturadas individuais no ambulatório de um hospital público da rede estadual de saúde de Pernambuco. Os dados foram analisados pelo software IRAMUTEQ por meio da técnica da Classificação Hierárquica Descendente, a qual originou um dendograma. Ademais, foram discutidos à luz da Teoria do Modelo de Sistemas de Betty Neuman.

Resultados: O dendograma deu origem a cinco classes, a saber: Rotina Familiar, Assistência do Serviço de Saúde, Mudanças no Estilo de Vida, Rede de Apoio e Repercussões Sociais do Cuidado para o Contexto Familiar.

Conclusão: As mudanças ocorridas na dinâmica das famílias proporcionam a identificação de um sistema familiar repleto de interações com estressores. O reconhecimento dos efeitos causados pelos estressores é o principal mecanismo para que medidas de enfrentamento sejam adotadas, possibilitando aos membros da família um sistema em estabilidade.

Resumen

Objetivo: Desvelar los estresores familiares en el contexto del síndrome congénito por el virus del Zika de acuerdo con la teoría del modelo de sistemas de Betty Neuman.

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Conflicts of interest: none to declare.

Métodos: Investigación cualitativa, exploratoria, realizada con 13 madres de niños acometidos por agravamiento. Se realizaron entrevistas semiestructuradas individuales en los consultorios externos de un hospital público de la red de salud del estado de Pernambuco. El software IRAMUTEQ analizó los datos por medio de la técnica de Clasificación Jerárquica Descendiente, que originó un dendrograma. Además, fueron discutidos de acuerdo con la teoría del modelo de sistemas de Betty Neuman.

Resultados: El dendrograma originó cinco clases, a saber: Rutina Familiar, Atención del Servicio de Salud, Cambios en el Estilo de Vida, Red de Apoyo y Repercusiones Sociales sobre el Cuidado para el Contexto Familiar.

Conclusión: Los cambios ocurridos en la dinámica de las familias proporcionan la identificación de un sistema familiar lleno de interacciones con estresores. El reconocimiento de los efectos causados por los estresores es el principal mecanismo para que se adopten medidas de enfrentamiento, posibilitándole a los miembros de la familia un sistema en estabilidad.

Introduction

The arrival of a baby and the relationships that develop between it and the family members are followed by countless projections and expectations. Any malformation in the baby may cause a huge impact on family life. This new circumstance makes family members experience care overload in face of the demands.^(1,2)

Congenital zika virus syndrome (CZVS) stands out as a possible cause of neurologic malformation in which the brain does not develop properly.⁽³⁾ Although its occurrence is considered rare, there was an increase in the number of cases in 2015, with most reports in the Northeast region of Brazil and the state of Pernambuco showing a high concentration of cases.⁽⁴⁾

In face of the problem, studies were initiated to identify the possible causes of the malformation. In the same year, the World Health Organization and the Brazilian Ministry of Health confirmed the causal link between the observed microcephaly and zika virus.⁽⁵⁾ In addition to microcephaly, CZVS can also lead to severe global hypertonia with hyperreflexia, irritability, hyperexcitability, excessive crying, and seizures, among other problems.⁽⁶⁾

The relationships between the family members of a child with CZVS are extremely meaningful and accompanied by positive or negative reactions. The new demand for specific care makes the family routine disorganized, which modifies the family dynamics. This situation requires an adaptation to the new reality, a process that originates stress.^(1,7)

The systems model theory proposed by Betty Neuman is based on stressors and reactions to them. In this model, families are seen as an open system that interacts with the environment, is under the action of several environmental stressors, and must

seek stability by means of interventions that aim at ideal well-being.⁽⁸⁾

Stressors are classified into three types according to their nature: intrapersonal (those that occur within the boundaries of the system, such as an autoimmune response); interpersonal (those that take place outside the boundaries of the system, as exemplified by role expectations); and extrapersonal (those beyond the system and acting at a larger extent, such as social policies).⁽⁸⁾

Stressful situations experienced by families with children with CZVS can lead to system unbalance.⁽⁹⁾ By understanding the dynamics in affected families and finding out the possible stressors that compromise the stability of the family system, health professionals, especially nurses, can offer tools to cope with these stressors more satisfactorily and propose a care plan oriented toward comprehensive care.

The objective of the present study was finding out what family stressors were involved in the context of the congenital zika syndrome from Betty Neuman's systems model theory perspective.

Methods

This was a qualitative and exploratory study carried out in the outpatient clinic of a public hospital in the city of Recife, and which is part of Pernambuco's state health network. Participants were 13 mothers of children with CZVS who met the following inclusion criteria: providing direct and informal care to a child with CZVS, being 18 years old or older, and accompanying the child during medical appointments.

Data were collected from February to April 2017 by means of individual semi-structured in-

interviews. These were oriented by a data collection script with five guiding questions: 1) How is the child's care routine?; 2) What has changed in your life and in the family's life after the child was born?; 3) What are the main sources of support you have received or still receive to look after the child?; 4) How is the child care support offered by health professionals?; and 5) Can you express your questions and needs related to the child to health professionals?.

The theoretical saturation criterion was used to determine the number of interviews.⁽¹⁰⁾ Overall, theoretical saturation of data occurred in the tenth interview, which provided no information that could be considered new or relevant to the study. However, the authors opted to conduct three more interviews to secure a safety margin.

The steps to organize, analyze, and interpret data were recording the interviews, transcribing them, and organizing them into a single corpus using IRAMUTEQ software, which has resources that help perform textual analysis.⁽¹¹⁾

Descending hierarchical classification (DHC) was applied. This technique consists of organizing and categorizing text segments (TS) with their vocabularies as a starting point and producing a dendrogram that shows the relationships between

the classes. The data were then analyzed and discussed from Betty Neuman's systems model theory perspective.

The present study followed the recommendations in National Health Council Resolutions no. 466/2012 and no. 510/2016, and its proposal was approved by a research ethics committee as per report no. 1,928,540 and Certificate of Presentation for Ethical Evaluation no. 63485617.9.0000.5208.

Results

All the participants were mothers of children affected by CZVS. The data extracted from the interviews originated the textual corpus, which was analyzed by applying DHC. The corpus was split into 371 TS containing 1,691 words that were present 13,211 times in total. Descending hierarchical classification kept 81.40% of all TS and originated five classes made up of 302 elementary context units (ECU). The corpus was divided into two sub-corpora, the left and right ones. The latter gave rise to class 2. Part of the left subcorpus was split into three divisions, with classes 3 and 4 differing from class 1, and class 5 distinguishing itself from these three (Figure 1).

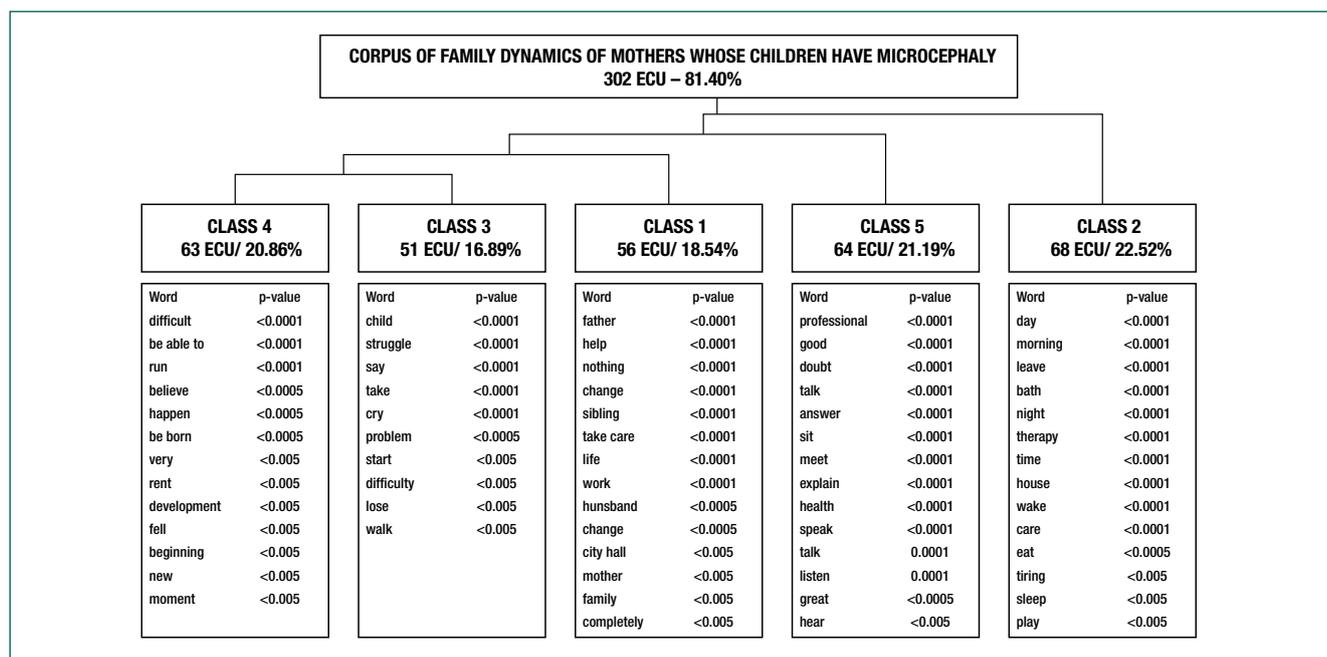


Figure 1. Dendrogram resulting from DHC of the textual corpus

After the dendrogram was analyzed and the TS were read, the classes were named: family routine (class 2), care provided by health services (class 5), changes in lifestyle (class 4), support network (class 1), and social consequences of care for the family context (class 3). Class 2 accounted for 22.52% of the ECU. By experiencing a new reality imposed by the specific care demand resulting from the child's condition, families initiated a process of routine readjustment.

My everyday life is really busy. Some days she sleeps a lot, some days she does not sleep at all. It is very complicated. (Participant 01)

It is a hassle. I have to wake up early. It is really stressful to have to take the bus every day, it is tiring. (Participant 03)

Class 5, entitled care provided by health services, accounted for 21.19% of the ECU. Although the established relationships and care quality in health institutions are indispensable for successfully treating children affected by CZVS, some mothers reported that the relationship with health professionals became difficult.

There is this doctor who is slightly anxious. He does not explain things well, mixes all information, and wants to drive me crazier than I already am. (Participant 01)

If you want to say something after the appointment or ask a question, you are going to have a hard time. The relationship is definitely not good. They give you their phone number, but do not pick up the phone if you call. (Participant 12)

With 20.86% of the ECU, class 4 was entitled changes in lifestyle and was directly related to the alterations in the family lifestyle, especially the mother's, who stood out in the present study as the main caregiver of children affected by CZVS.

When he was born, I saw myself living a life I had never imagined living. I had never seen myself as the mother of a special child. (Participant 02)

It was a huge surprise, so I have been through several stressful situations. (Participant 04)

The accounts of the mothers indicated that the arrival of a child with limitations brought about great changes and that the family began experiencing feelings such as sadness, frustration, and difficulty accepting the diagnosis.

My life went from heaven to a very dark period. I cannot say hell because it is not really what it is. The point is: I wanted to be a mother, and when I achieved my goal, I had this disappointment. (Participant 04)

I feel comfortable to speak about her care now. It was frustrating some time ago. In the beginning, it was like the ground fell out from under my feet. (Participant 13)

Another factor that originated changes in lifestyle was the need for parents to stop working or studying to dedicate themselves to providing the child with care. This fact brought up internal conflicts caused by intrapersonal stressors.

Before she was born, I was an undergraduate in a nutrition course. I had to ask for enrollment withdrawal because I was no longer able to attend college. (Participant 06)

I used to work before he was born. His father had to quit his job, and now he is very dependent. My current work is being his slave. (Participant 07)

The need to leave the work environment gave rise to financial problems in the family, which originated interpersonal stress. Not receiving the government's Welfare Benefit to Disabled People is an extrapersonal stressor.

We did not get the money from her welfare benefit yet, and the expenses with her are very high, we have no income at all. There are a lot of costs now, and we cannot afford. (Participant 03)

I have no income. I am petitioning the court for her right. A right that many mothers already enjoy and was denied to me. (Participant 04)

Situations such as lack of time for themselves, exclusive dedication to care for the child, and stopping interacting with friends, neighbors, and even family members were also intra and interpersonal stressors identified in the accounts of the participants.

Before it happened, I still had some "me time", some time to go to my neighbor's house, a relative's. Sometimes the family gets together, and I am not there. (Participant 01)

After she was born, all I think about is her. I no longer think about myself, my health. We had some time to rest, go out, but today we avoid going out. (Participant 12)

Another interpersonal stressor was the change in the relationship with the partner after the arrival of a child with special needs.

It is just me and the father looking after her. We cannot go out anymore, we just stay home with her. We cannot go out just the two of us, really live as a couple. (Participant 13)

One of the participants declared that the need to engage in providing one child with care made her grow apart from her oldest daughter, which caused the latter to develop health problems.

In an attempt to spare my eldest, I began dropping her at my mother's place quite often, and all this process resulted in her developing childhood depression. She is taking an antidepressant, and she is only 13. (Participant 05)

Most participants quit their jobs. However, one of them informed that, despite all difficulties, she managed to keep working after adjustments in her working hours.

I am still working, but it is much harder now because I have just the morning to produce what was due to an entire day. Then there is this whole thing of waking up early, leaving her at home, going to work, coming back home, taking her to therapy. This routine is quite stressful. (Participant 13)

Support network, in class 1, encompassed the characteristics related to the support received by mothers and/or relatives by family members, friends, neighbors, and governmental institutions and entities regarding child care. This class accounted for 18.54% of the ECU.

It is just me looking after her. I get no help, either from my family or someone else. (Participant 03)

The person who provides care is myself. I have support from no one to do that. (Participant 10)

Even experiencing social vulnerability and having gone through an unexpected situation, these families also have to deal with the lack of support by governmental entities, which is characterized as an extrapersonal stressor.

I have not received a food parcel from the municipal government in three months. (Participant 02)

I feel completely abandoned by public administration. (Participant 04)

Class 3, which accounted for 16.89% of the ECU, was entitled social consequences of care for the family context and expressed how daily care of the child interfered with the family well-being.

My daughter cried a lot. When I attended a therapy session and then came back home, I never did what they told me to do. It was very tiring. (Participant 03)

Bedtime is a whole ritual. There is this medication... It is really complicated. (Participant 06)

The participants reported that daily care is pervaded by intrapersonal stressors, such as questions and uncertainties related to the child's development progression, which originates a feeling of helplessness regarding the future.

We are still in this situation of not knowing if he is going to walk. We fight for something we do not know he is going to be able to do in the future. (Participant 02)

In addition to everyday difficulties involved in providing the child with care, other stressors, including episodes of public embarrassment and prejudice, can promote inter and extrapersonal stress.

The world is stressful. Looking daggers at us and pointing a finger to criticize... This kind of prejudice is stressful. (Participant 07)

Discussion

The present study had limitations related to the authors' subjectivity in the interpretation of the accounts. Nevertheless, the findings are relevant for nursing, since they allow nurses to know the family stressors involved in the context of CZVS from Betty Neuman's systems model theory, and consequently, minimize or eliminate them.

The mother figure stood out as the main caregiver of children who developed microcephaly as a consequence of CZVS. Other studies have similarly shown that the child care process is often associated with mothers, who usually have no one with whom to share this responsibility and end up overburdened.^(12,13)

The arrival of a child with special health needs deeply impacts family dynamics. However, most of the time, only mothers restructure their lives in face of the new obligations and constant demands.^(13,14) The new family routine holds them back from external activities and forces them to dedicate exclusively to the care of their children.^(15,16)

Two participants reported that their partners also had to quit their jobs to help look after the

child. This demonstrated the need for fathers to adapt their routine as a consequence of having a child with CZVS, a result also described in other studies.^(1,17)

The impact of having a child with special needs leads to the modification of previous family projects, which originates internal conflicts triggered by intra and interpersonal stressors that affect the family system and cause instability between its members.^(18,19)

The account of the participant who kept working after having a child with CZVS brought up her overload as a negative aspect of this decision. A study showed that mothers' health and life are the most affected, because the majority takes over household chores and meets the child's needs regarding activities of daily living.⁽²⁾ In these families, the income is severely compromised.⁽²⁰⁾

The unexpected experience of providing specific care to a child imposes limitations to social life. For some families, this process is a source of stressors. Looking after a child with special needs leads to physical and psychological alterations in most people.⁽²¹⁾

Betty Neuman addressed stressors as stimuli that cause tensions and system destabilization. It is in the interaction with the environment that the basic structure identified as family with a child affected by CZVS is under the action of stressors that originate mutual exchanges.^(8,9)

A study showed that these families receive multiprofessional attention, which provides parents with guidance and allows children to have a better quality of life, although there are still issues in the received orientations and the relationship with professionals.⁽²⁰⁾

Changes in families' lifestyles originate difficulties in terms of accepting the new reality triggered by intrapersonal stressors, such as feelings of sadness and frustration and barriers and hurdles to deal with the diagnosis. Other stressors involved in these changes were expressed in the participants' accounts as lack of time for themselves and distancing from friends, neighbors, and relatives.

The arrival of a baby with a malformation is an event that can disrupt family balance. Because of the exclusive dedication to the child, the caregiver's pos-

sibilities of carrying out other activities end up nullified as a result of either tiredness or lack of time.⁽⁷⁾

The full-time dedication to the daughter with CZVS caused the oldest daughter of one of the participants to develop childhood depression. It is necessary to consider the mechanisms of response to stress by construing each family as a system and taking into account that, when a member has a health problem, the previous order is destabilized.⁽²²⁾

As illustrated by the report of a participant, marital relationship is an aspect of family life that is negatively impacted. A study showed that caregivers mentioned changes in their marriage after the child was born.⁽²³⁾

Another problem cited by mothers is the consequences of the diagnosis, including concerns about the changes in activities of daily living and success and social acceptance of their children.⁽²⁾

Episodes of public embarrassment and prejudice are inter and extrapersonal stressors, respectively. Exposing a child to contact with society provokes reactions that affect the family system. Most parents of a child with malformation face social stigma and discrimination at some point in everyday life.^(2,24)

The findings related to support network indicated that not all families received structured help to look after the child, a problem that originated stressors, especially interpersonal ones. A deficient and limited support network is a difficulty that is commonly reported by families with children with malformation.^(2,9)

In most cases, mothers can rely only on the support provided by their husbands, parents, other children, and godparents. Consequently, the physical and emotional distress experienced by the main caregiver is patent and can lead to physical and psychological disorders.⁽²⁵⁾

Another extrapersonal stressor was limited or inexistent support by governmental entities. Families that participated in another study informed that getting help was indispensable for improving the child's quality of life.⁽²⁶⁾

Conclusion

The changes in family dynamics after a child with CZVS is born allowed to identify a system full of

interactions pervaded by stressors. By treating the data from Betty Neuman's theory perspective, it was possible to recognize intra, inter, and extrapersonal stressors that cause unbalance and can lead to the sickening of the family system. It is suggested that other studies be carried out in order to better discuss family stressors in the context of CZVS, especially those related to family health promotion and prevention of this disease.

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Contributions

Lima LHSS, Mendes RCMG, Monteiro EMLM, Marinus MWLC, Linhares FMP, and Cavalcanti AMTS declare that they contributed to the study conception, data analysis and interpretation, article writing, and critical review of the intellectual content. All authors approved the final version to be published.

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