



# Psychic repercussions in mothers of children with congenital Zika virus syndrome

## Repercussões psíquicas em mães de crianças com Síndrome Congênita do Zika Vírus Repercusiones psíquicas en madres de niños con síndrome congénito por el virus del Zika

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### ABSTRACT

**Objective:** To investigate the psychic repercussions of mothers of children with complications due to Zika Virus Congenital Syndrome. **Method:** Cross-sectional study with a two-step sequential mixed approach conducted in a Health Regional of a Northeast state. Participated in the first stage of the investigation, regarding the application of the Self-Reporting Questionnaire, 15 mothers. In the second stage, interviews were conducted with 13 mothers. The analysis was performed using statistical software (step 1) and the content analysis technique (step 2). **Results:** It was observed that 10 women had a positive result for mental suffering. In the qualitative stage, the following stands out in the reports: the fear of loss/death or non-evolution of the child's condition, physical and psychological exhaustion as a result of continuous care, and the appearance / worsening of conflicts that negatively affect family dynamics. **Conclusion and Implications for practice:** The results point to the need for health education actions in order to enable the exchange of knowledge, practices, and experiences; offering essential psychosocial support and strengthening support networks in the formal and informal health network, aiming to create/expand equipment to assist in self-care and empowerment of these women's identities and potentials.

**Keywords:** Zika Virus; Microcephaly; Mothers; Mental health.

### RESUMO

**Objetivo:** investigar as repercussões psíquicas em mães de crianças com complicações decorrentes da Síndrome Congênita pelo Zika Vírus. **Método:** Estudo transversal com abordagem mista sequencial em duas etapas, realizado em uma Regional de Saúde de um estado do Nordeste. Participaram da primeira etapa da investigação, referente à aplicação do Self-Reporting Questionnaire, 15 mães. Na segunda etapa, foram realizadas entrevistas com 13 mães. A análise se deu por meio de um software estatístico (etapa 1) e pela técnica de análise de conteúdo (etapa 2). **Resultados:** Observou-se que 10 mulheres apresentaram resultado positivo para o sofrimento mental. Na etapa qualitativa, destacaram-se nos relatos: o medo da perda/morte ou não evolução do quadro da criança, a exaustão física e psicológica em decorrência dos cuidados contínuos e o aparecimento/agravamento de conflitos que repercutem negativamente na dinâmica familiar. **Conclusão e implicações para prática:** Os resultados apontam a necessidade de ações de educação em saúde, de modo a viabilizar troca de saberes, práticas e experiências; oferta de apoio psicossocial básico e fortalecimento de redes de apoio no sistema formal e informal de saúde, visando criar/ampliar equipamentos para auxiliar no autocuidado e empoderamento das identidades e potencialidades destas mulheres.

**Palavras-chave:** Zika Vírus; Microcefalia; Mães; Saúde Mental.

### RESUMEN

**Objetivo:** investigar las repercusiones psíquicas de las madres de niños con complicaciones debido al síndrome congénito del virus del Zika. **Método:** Estudio transversal con enfoque mixto secuencial de dos etapas, realizado en una Regional de Salud de un estado del noreste brasileño. En la primera etapa de la investigación, mediante la aplicación de un cuestionario de autoevaluación -Self-Reporting Questionnaire-, participaron 15 madres. En la segunda etapa, se realizaron entrevistas con 13 madres. El análisis se realizó utilizando software estadístico (etapa 1) y la técnica de análisis de contenido (etapa 2). **Resultados:** Se observó que 10 mujeres presentaron resultados positivos ante el sufrimiento mental. En la etapa cualitativa, se destaca lo siguiente en los informes: el miedo a la pérdida / muerte o a la no evolución de la condición del niño, el agotamiento físico y psicológico como resultado de la atención continua y la aparición / empeoramiento de conflictos que afectan negativamente la dinámica familiar. **Conclusión y implicaciones para la práctica:** los resultados apuntan a la necesidad de desarrollar acciones de educación para la salud, a fin permitir el intercambio de conocimientos, prácticas y experiencias; ofreciendo apoyo psicossocial básico y fortaleciendo las redes de apoyo en la red de salud formal e informal, con el objetivo de crear / expandir equipos para ayudar en el autocuidado y el empoderamiento de la identidad de estas mujeres y así contribuir a que puedan desplegar su potencial.

**Palabras clave:** Virus Zika; Microcefalia; Madres; Salud mental.

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## INTRODUCTION

The birth of a baby interferes with family dynamics and interaction and leads to changes in the structure and daily life of families, and may involve a range of feelings, especially anxiety, anguish, insecurity and fear, which may be present since the gestational period. These feelings may intensify when this baby has a disability and trigger repercussions on the life, behavior and emotions of all family members, and may weaken the relationship between the mother/child binomial. Discovering a disability often leads to a true trajectory of difficulties, such as lack of knowledge about caring, feelings of guilt, helplessness and dependence.<sup>1</sup>

As an aggravating factor of this situation, it is clear that the care provided under this circumstance is directed entirely to the child, who becomes the focus of care, with a priority focus on improving their clinical condition. Thus, the psychological aspect of the family, especially the mother, is neglected, leaving only the role of caregiver and executor of the professionals' orders.<sup>2</sup>

Congenital Zika Virus Syndrome (CZS) was considered an unusual event of change in the pattern of occurrence of microcephaly records in newborns in the country, from the year 2015. Due to lack of knowledge, health professionals and family members embark on uncertain paths about the potential of child development and the search for a better quality of life for affected children, but face an uncertain future full of barriers that are still insurmountable.<sup>3-5</sup>

The family that is diagnosed with disability in their child faces great difficulties and battles, since the failure of the idealization of the perfect child can negatively affect the practice of mothering, which is directly related to the affection, care and cherishing developed by the mother when bonding with your baby. In the case of the diagnosis of CZS, children have a multiple disability picture and the impact of this unusual event can generate repercussions with larger proportions and magnitudes, because it is something new in relation to health, to social, social security and emotional.<sup>6</sup>

Therefore, families of children with health complications due to CZS need to be given special attention, considering that they experience realities marked by various obstacles. Given this, it is essential that health teams consider the conditions of these caregivers, in order to provide opportunities to overcome lived adversities and minimize the suffering before the birth of a child with the syndrome.

Given the above, the objective of the study was to investigate the psychic repercussions in mothers of children with complications due to CZS.

In this sense, by addressing such psychic repercussions, this study seeks to promote a broadening of the debate about the need to look differently and integrally to these families, who need differentiated and effective institutional care and resources.

## METHOD

This is an exploratory and descriptive cross-sectional study with a two-step sequential mixed approach. Mixed method studies are characterized as a procedure for collecting, analyzing and

combining quantitative and qualitative research techniques in the same design. It aims to promote the understanding of the phenomenon of choice in a way that would not be obtained with the use of only one approach, and should consider four main aspects: time distribution, weighting, combination and theorizing.<sup>7,8</sup>

The research was conducted in a Health Regional of a Northeastern state, which serves and is a reference for ten cities. The choice of the regional was because it comprises a region in which 80% of its municipalities had cases of Congenital Zika Virus Syndrome, in addition to the need to show the reality of a population living far from large urban centers, thus being a public who find it more difficult due to the scarce availability of services, human resources and materials to provide care to children with CZS.

The study population consisted of all mothers who had children with CZS in the municipalities that make up the referred Regional Health, totaling 16 confirmed cases, according to the health surveillance information of the region. After previous telephone contact to explain the research objectives, 15 mothers were willing to participate, and the day and time were then scheduled to apply the questionnaires.

The participants in this study were between 18 and 30 years old, were mostly married, had, on average, two children, and worked in the care of their children and home activities.

The first phase of the study took place between July and December 2017 and involved the application of a sociodemographic questionnaire and the psychometric instrument *Self-Reporting Questionnaire* (SRQ-20).

The SRQ-20 is an internationally recognized instrument, translated and validated into eight languages and used in many countries with different cultural contexts, achieving acceptable levels of performance regarding sensitivity, specificity and predictive values.<sup>9</sup> The positive aspects of the instrument are satisfactory performance in the analysis of indicators of mental distress, their easy comprehension and rapid application, thus reducing operating costs.<sup>10,11</sup>

The Portuguese version of SRQ adopted the first twenty items of the original scale, subdivided into four domains: "Depressive/anxious mood", "Somatic symptoms", "Decreased vital energy" and "Depressive thoughts". These items allow us to investigate nonpsychotic morbidity, which is confirmed according to the cutoff point if there are seven or more positive statements among the items. It is noteworthy that the instrument helps to detect symptoms suggestive of some mental disorder but does not infer a specific diagnosis of existing disorder.<sup>10</sup>

Data were typed and coded in an electronic spreadsheet and presented by analyzing the absolute and relative frequency of the variables.

As a way to broaden the understanding of primary numerical data and considering that the population was restricted, participants in the first stage were invited to collaborate in a second stage of the study. This stage had a qualitative approach. The interview with a semi-structured script was adopted as a data collection technique to better understand the experience of these mothers

and the repercussions that the routine of continuous care had on their mental health.

Interviews were conducted after telephone contact to schedule location and time according to availability of each participant. At the end, 13 mothers who accepted and were able to participate contributed to this second stage.

Data collection took place from January to June 2018, with interviews being conducted in a private environment, based on the following guiding question: "How did you feel about finding out/knowing that your child has congenital Zika virus syndrome?" To keep the participants anonymous, we gave the name Mother followed by the cardinal sequence number of the interview.

The understanding of the empirical material was conducted by the content analysis technique, which comprised three stages: pre-analysis, material exploration or coding and treatment through inferences and interpretations.<sup>12</sup> This analysis provided

the triangulation of data, from which the analyst interrelates his perceptions, the material produced (*documental corpus*, vital tone and thematic axis) and the pertinent literature, in order to deepen the look on the investigated phenomenon.

The research was approved by the Research Ethics Committee, under approval protocol 2,175,245. Data collection occurred after signing the Informed Consent Form (ICF) by the participants.

## RESULTS

Among the collaborating mothers in this research, the prevalence of mental distress identified by SRQ-20 was 66.7% (n=10), according to the cutoff point adopted in the study (result  $\geq 7$  positive statements).

Table 1 below shows the results of frequency of SRQ-20 responses according to psychiatric symptom groups.

**Table 1.** Distribution of *Self-Reporting Questionnaire* response frequencies allocated by domain. Pernambuco; 2019.

SRQ-20 Questions	Yes		No	
	n	%	n	%
<b>Group 1: Depressive and anxious mood</b>				
Do you feel nervous, tense or worried?	12	80	3	20
Do you get scared easily?	6	40	9	60
Have you been sad lately?	7	46.7	8	53.3
Have you been crying more than usual?	4	26.7	11	73.3
<b>Group 2: Somatic symptoms</b>				
Do you have frequent headaches?	7	46.7	8	53.3
Do you sleep badly?	6	40	9	60
Have unpleasant stomach sensations?	2	13.3	13	86.7
Do you have lack of appetite?	5	33.3	10	66.7
Do you have indigestion?	5	33.3	10	66.7
Do your hands tremble?	3	20	12	80
<b>Group 3: Decreased vital energy</b>				
Do you feel tired easily?	6	40	9	60
Do you find difficult to perform your daily activities with satisfaction?	9	60	6	40
Have trouble making decisions?	11	73.3	4	26.7
Do you have difficulties at your work (is your work painful, does it cause you pain?)	6	40	9	60
Have trouble thinking clearly?	10	66.7	5	33.3
Do you feel tired all the time?	8	53.3	7	46.7
<b>Group 4: Depressive thoughts</b>				
Have you lost interest in things?	4	26.7	11	73.3
Do you feel like a useless, useless person?	3	20	12	80
Have you had any idea of ending life?	5	33.3	10	66.7
Are you incapable of developing a useful role in your life?	2	13.3	13	86.7

Source: Direct Search, 2019.

Considering that the number of participants would not allow a deeper analysis of the data, including associations between the studied variables, but understanding that the mothers of children with CZS presented signs of distress,

we opted for the qualitative analysis, as this provides subsidies for the interpretation of each domain of the scale. Thus, the speeches were categorized by domains in the Chart 1.

**Chart 1.** Speech of study participants allocated according to *Self-Reporting Questionnaire*. Pernambuco; 2019.

Domain	Speeches of the collaborators
Depressive/anxious mood	<p><i>My biggest fear is that she will die, I'm afraid of losing her. I do everything not to think about it (Mother 1). My feeling of mother and woman since I learned of his illness is one of fear, I am very afraid that he will grow up, not talk and do not walk, so I get even sadder (Mother 5). I am still sad, moved because sometimes I get to the health unit and see the same children, of her own age, already walking, and she still in my arm (Mother 12). It's sad you know, because I think we are quite forgotten and to get things we have to go to justice (Mother 4). In my daily life with him sometimes I get very stressed, my husband doesn't help me much, even without being working. I never had any follow-up for me as his mother or with a psychologist, no one ever asked how I was (Mother 2). As a woman, I changed a lot, I developed depression and other things, it all started after she was born, and I found out that she was special. I am accompanied by CRAS, I take controlled medication (Mother 8).</i></p>
Somatic Symptoms	<p><i>Normally, I travel at dawn and don't sleep much because I have to wake up at 3 am to travel at 4 am. Sometimes we are so sleepy, we want to sleep, and we can't (Mother 1). There were days when my husband and I didn't even sleep... just thinking! (Mother 11). ... if we don't give her medicine, she doesn't get better, she can't sleep, she stays up all night, I get to dawn the day without sleeping with her, it hurts me a lot (Mother 8).</i></p>
Decreased Vital Energy	<p><i>... there are times when we get suffocated with so many problems. Sometimes, as I told you, I find myself overwhelmed (Mother 10). Traveling is one of the most difficult times, because it is tiring even when I get home, I still have to do things, sometimes very downhearted, very tired (Mother 1). Time is just for him. I don't have time for anything (Mother 6). One of the difficulties I face is taking care of him alone (Mother 2). This treatment routine is terrible, very bad. I don't receive support from anyone, I always travel alone with my daughter and Jesus (Mother 9). My treatment routine with her is too busy. I go to Recife almost every day, which is far away but I have to go. I'm going in dawn, at four in the morning ã (Mother 7).</i></p>
Depressive thoughts	<p><i>I was very vain and now that whole vanity is over. I think I don't care about myself anymore, I worry about them, my children (Mother 1). My life comes down to taking care of him, I don't see myself as a woman, but as a mother, all the time close to him and for him (Mother 6). My life before her birth was a little different, I worked, went out to have fun, had a normal life, but after she was born everything changed, I see myself today as a mother, I don't have time for myself (Mother 9). Today, I see myself as a mother and not as a woman because I dedicate my life to her alone. I miss the person I was before, because I worked, had my money, I was independent and today I no longer see the possibility of returning to my earlier life (Mother 11). The most intense feeling I had was a very strong desire to die [...] I don't have much patience to take care of her, the feeling I have inside me is sometimes of abandoning her, not taking care anymore of no children (Mother 8).</i></p>

Source: Direct Search, 2019

## DISCUSSION

To deepen and overcome the limitation in relation to the number of study participants, we opted for a mixed approach in which quantitative data are complemented by qualitative data. Despite a restricted sample, it was possible to give voice to the mothers of children with CZS and their suffering regarding childcare.

The frequency of women interviewed in mental distress shows the importance of giving visibility to this condition that they face in the daily care of children affected by the syndrome, as well as sensitizing the health care network so that they can integrate these women into care. The results point to the need to receive these mothers by the multi-professional health team throughout the health care network and the need for a care program to support them to deal with such adverse situations in the care of their children.

It is observed that the frequency of symptoms of decrease in vital energy indicated by women shows that they are in constant physical/psychic exhaustion, which may be a factor promoting the onset/aggravation of mental disorders. It is also emphasized that there was also a prevalence of statements in an item that is part of the depressive/anxious mood symptoms group. It is inferred that this finding is related to a common situation that occurs in people who provide complex and constant care to third parties, such as the investigated population.

It is observed, in the first axis, chronic situations of stress and emotional discomfort were also reported in other studies with caregivers from other populations such as children with cancer, informal from the elderly and from patients with stroke.<sup>13-15</sup>

From the reports, it is found that fear was a frequently present feeling in the daily lives of these women, especially the fear of loss death or non-evolution of the child's condition. Such longing may be related to the fact that, as mentioned by some participating mothers, there would be no "life" beyond the care provided to their child, that is, many of the women interviewed report believing that their occupation is restricted to taking care of their child.

It is emphasized that fear and anxiety are the main characteristics associated with anxiety disorders, where "fear" would be the emotional response to a real imminent or perceived danger and "anxiety" the anticipation of a future threat.<sup>16</sup>

Knowledge and discovery of the physical and/or mental limitations of an individual suffering from a chronic disease has been related to the feeling of sadness, which tends to become more intense as the restrictions worsen. This feeling can lead to disorders both in the personal and in the family, leading to a wear and unbalance of relationships, as well as damage to the attention given to the sick subject.<sup>17,18</sup>

Thus, it is observed that the care routine for a dependent individual is permeated by multiple and ambiguous feelings, love, dedication, anger, sadness, fear and worry. It is worrying that negative feelings, when present for a long period, can cause intense wear on the caregiver's ability to play their role with quality, and it is essential the performance of professionals who value and welcome the wishes presented.<sup>19,20</sup>

The study found that mothers were in physical and mental distress related to difficulties in dealing with the specificities of their child's disability. There are many problems experienced by caregivers of children with CZS, job abandonment, excessive workload with their child, and often lack of family support, resulting in heightened concern, interfering with their daily functioning, triggering the emergence of somatic symptoms, which negatively reflects on the health of these women.

Corroborating the findings of the research, an investigation showed that the diagnosis of children with Congenital Zika Syndrome brings significant changes in the personal and professional lives of women who often quit work, leisure activities and are exhaustively dedicated to the specific care of children's symptoms that make up CZS. Such a conjunction of factors is predictive of the onset of psychological distress and stress.<sup>5,21</sup>

It is inferred that such symptoms evidenced in the study are mainly linked to the burden of tasks directed to these women, who, besides being responsible for the daily care of the child, still face the arduous routes in the therapeutic itineraries demanded by the syndrome treatment and see themselves forced to learn a whole new lexicon, both biomedical and bureaucratic, needing to accept, understand and work with a new dynamic of care with the child.<sup>22</sup>

This extensive and complex routine of activities necessary for the care of the child impairs moments of rest and sleep for some mothers, with some reporting that it was not possible to sleep properly in the night shift due to seizures or constant crying of the child, common characteristics in patients with CZS.<sup>23</sup>

In a study that evaluated the impact of the child with microcephaly on maternity, was possible to identify that changes in family routine occur more significantly in women's routine. Still on this study, the results showed an important burden for these women, who are charged for a role culturally linked to the female gender, making focus on the mother, invisible in her suffering, the duty of self-denial and sacrifice of their tasks to assume fully the care of the chronically ill child. It was also noticed that this reality is aggravated in cases of hospitalizations and outpatient consultations, being these routines common in children with CZS.<sup>24</sup>

Physical and psychological exhaustion are part of the routine of most mothers who spend both day shifts away from home and return at the end of the day to still cope with other domestic duties, other children's school activities, and marital obligations.<sup>22</sup>

In general, no one plans to produce disabled children, so the birth of a special child is a milestone in a woman's life, both because it is a different situation that requires multi-professional work, for comprehensive health care for the child and family, as by reconciling her role as mother with the other attributions of her daily life.<sup>25</sup>

A relevant data in the study was related to the issues inherent in the "Decreased vital energy" symptom group indicating that the investigated women are in constant physical/psychological distress, may being a factor promoting the onset/aggravation of mental disorders. It is inferred that the limitations and dependence of the child leaves them completely dependent on maternal care,

and this factor ends up generating a greater burden for the mother, as it was possible to identify from the reports of this category.

The burden of care for the child, the re-adaptation of the family nucleus and external social relations in view of the limitations imposed by the disease and the conflicts caused by this process, the lack of support, guilt and breaking the idealization of the perfect child and social isolation, can be promoters of the appearance of symptoms of mental suffering. Studies show that the mother, who is often burdened with home and childcare activities, will need help understanding and addressing all these issues.<sup>26,27</sup>

In the statements of the collaborators, it is observed how exhausting and difficult is the process of caring for their children, and they expressed the need for care aimed at them, which are often forgotten in the therapeutic itinerary where care is directed only to the child. It is inferred from the study that mothers assume the provision of alone. Even when this care for the child is alternated with other family members, it is clear that the protagonism of the care process rests with the woman.

It is noteworthy that even child care is often limited and fragmented, and it has already been revealed that the chronic child care production line is weakened, especially in Primary Health Care (PHC), which needs to fulfill their role as care coordinator and be a caregiver source for this family, in order to facilitate their walk through the health care network, which is often lonely.<sup>28</sup>

In the present study, this fragmentation of care was observed when, in the statements of the collaborators, they report that they are forgotten in the network, reporting that the overload and the feeling of loneliness are causing a wear on their physical and mental health.

Much has been discussed in the specialized literature and in the Brazilian media about epidemiology, diagnosis, clinical manifestations and treatment possibilities related to CZS, however, the follow-up of cases, as well as the repercussions beyond the child's health, has always been on the sidelines of debate. The social, financial matter and health care provider's training for this syndrome need to be discussed and adapt to the conditions of these families so that interventions are truly effective in the long term.<sup>29</sup>

Due to the dependence of children with CZS presents, the mother organizes her daily routine around her child's needs, leaving her personal and professional life in the background, as observed in the reports presented in the fourth axis, which is a worrying fact, especially when investigating women who provide constant complex care to third parties, such as the study population.

From the reports of the collaborators, it was observed that the limitations found in children with CZS make them dependent on continuous maternal care, being this a promoter of restrictions in the woman's personal and professional life, which often culminates in a loss of interest in maintaining/starting activities that were once part of your daily life or ambition.

This need for reorganization occurs primarily as a result of the time demand that child care activities need, as seen in a North American study that shows, for example, that caregivers

spend about two hours a week planning their care and about 11 to 12 hours a day in direct home care.<sup>30</sup>

Such dedication to care is, for many mothers, a lonely task. Since, even when the family arrangement allows the division of responsibilities, the woman usually occupies the space of leading figure in the supply of family and home demands, besides the responsibility of execution of the continuous care and therapeutic management to attend the specificities brought by the child's condition, and this accumulation of tasks may be a promoter and/or aggravating physical and emotional instability.<sup>31,32</sup>

The role of primary caregiver plus domestic and other family demands has been studied and this profile, similar to that found in the collaborators of this study, potentiates economic difficulties, marital disorders and predisposes to social isolation and onset of depressive symptoms and overload, being common in this population a compromised quality of life, appearance of somatic symptoms and/or anxiety and depressive psychiatric disorders.<sup>30,33,34</sup>

## **CONCLUSION AND IMPLICATIONS FOR THE PRACTICE**

Research on the psychic repercussions on mothers of children with complications due to Congenital Zika Virus Syndrome showed that motherhood is permeated by an ambivalence of feelings, since these women experienced a sudden and profound transformation in their routines, surrounded by constant suffering situations, needing to deal with feelings of fear, anxiety, impotence, low self-esteem, problems in the transition of their roles, loneliness and personal and social invisibility, abdicating their own care due to the needs of their children. In addition, many are rejected by their partners/family and fight against social prejudice, causing the conjunction of these factors trigger psychological distress in these women.

The results point to the importance of strengthening and planning for the formation of family support networks for children with CZS. The welcoming strategies, conversation circles, therapeutic groups for these mothers will enable them to receive the support and guidance of the entire team, seeking to understand and minimize their doubts, aiming to improve self-care and care with the child, as well as a direction for the emotional impact on quality of life and coping strategies.

These results are expected to contribute to broaden the debate with managers/health workers about the creation/improvement of public policies that seek to offer talk and listening spaces for these caregivers, so that these women see possibilities for self-care and strengthening of their identities and potentialities.

## **AUTHORS' CONTRIBUTIONS**

Study conception and design. Data collection, analysis and interpretation. Results discussion. Content writing and/or critical review: Probation of the final version of the article. Responsibility for all aspects of the content and integrity of the published article: Camilla de Sena Guerra Bulhões.

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Results interpretation. Results discussion. Content writing and/or critical review: Probation of the final version of the article. Responsibility for all aspects of the content and integrity of the published article: Marina Nascimento de Moraes. Altamira Pereira da Silva Reichert. Maria Djair Dias. Ana Maria Almeida.

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## REFERENCES

- Guerra CS, Dias MD, Ferreira Fa MO, Andrade FB, Reichert APS, Araújo VS. From the dream to reality: experience of mothers of children with disabilities. *Texto Contexto Enferm*. 2015;24(2):459-66. <http://dx.doi.org/10.1590/0104-07072015000992014>.
- Gondim KM, Pinheiro PNC, Carvalho ZMF. Participation of mothers in the treatment of the children with cerebral palsy. *Rev Rene [Internet]*; 2009; [citado 2018 maio 5];10(4):136-44. Disponível em: <http://www.periodicos.ufc.br/index.php/rene/article/viewFile/4869/3585>
- Bueno FTC. Health surveillance and response on a regional scale: a preliminary study of the Zika virus fever case. *Cien Saude Colet*. 2017;22(7):2305-14. <http://dx.doi.org/10.1590/1413-81232017227.07012017>. PMID:28724012.
- Teixeira MG, Conceição N, Costa M, Oliveira WK, Nunes ML, Rodrigues LC. The epidemic of Zika virus-related microcephaly in Brazil: detection, control, etiology, and future scenarios. *Am J Public Health*. 2016;106(4):601-5. <http://dx.doi.org/10.2105/AJPH.2016.303113>. PMID:26959259.
- Eickmann SH, Carvalho MDCG, Ramos RCF, Rocha MAW, Linden VVD, Silva PFS. Zika virus congenital syndrome. *Cad Saude Publica*. 2016;32(7):e00047716. PMID:27462846.
- Gradwohl SMO, Osis MJD, Makuch MY. Maternidade e formas de maternagem desde a idade média à atualidade. *Pensando Fam [Internet]*. 2014; [citado 2018 mai 20];18(1):55-62. Disponível em: [http://pepsic.bvsalud.org/scielo.php?script=sci\\_arttext&pid=S1679-494X2014000100006&lng=pt&nrm=iso](http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1679-494X2014000100006&lng=pt&nrm=iso)
- Paranhos R, Figueiredo Filho DB, Rocha EC, Silva Jr JA, Freitas D. Uma introdução aos métodos mistos. *Sociologias*. 2016;18(42):384-411. <http://dx.doi.org/10.1590/15174522-018004221>.
- Santos JLG, Erdmann AL, Meirelles BHS, Lanzoni GMM, Cunha VP, Ross R. Integrating quantitative and qualitative data in mixed methods research. *Texto Contexto Enferm [Internet]*. 2017; [citado 2018 jun 15];26(3):e1590016. Disponível em: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-07072017000300330&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072017000300330&lng=en)
- Mari JJ, Williams P. A validity study of a psychiatric screening questionnaire (SRQ-20) in primary care in the city of São Paulo. *Br J Psychiatry*. 1986;148(1):23-6. <http://dx.doi.org/10.1192/bjp.148.1.23>. PMID:3955316.
- Santosa KOB, Araújo TM, Pinho OS, Silva ACC. Evaluation of an instrument for measuring psychiatric morbidity: a validity study of the self-reporting questionnaire (srq-20). *Rev Bahiana de Saúde Pública [Internet]*. 2010; [citado 2018 abr 18];34(3):544-60. Disponível em: <http://files.bvs.br/upload/S/0100-0233/2010/v34n3/a1881.pdf>
- Guirado GMP, Pereira NMP. Use of the Self-Reporting Questionnaire (SQR-20) for determination of physical and psycho-emotional symptoms in employees of a metallurgical industry located at Vale do Paraíba - Sao Paulo state - Brazil. *Cad Saude Colet*. 2016;24(1):92-8. <http://dx.doi.org/10.1590/1414-462X201600010103>.
- Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.
- Medeiros JRA, Carvalho MAP, Medeiros APG, Dantas GD, Matos ML, Pimentel ERS et al. Common mental disorder among caregivers of children. *Rev Enferm UFPE*. 2018;12(3):651-7. <http://dx.doi.org/10.5205/1981-8963-v12i3a109914p651-657-2018>.
- Morais HC, Soares AM, Oliveira AR, Carvalho CM, Silva MJ, Araújo TL. Burden and modifications in life from the perspective of caregivers for patients after stroke. *Rev Lat Am Enfermagem*. 2012;20(5):944-53. <http://dx.doi.org/10.1590/S0104-11692012000500017>. PMID:23174840.
- Diniz MAA, Melo BRS, Neri KH, Casemiro FG, Figueiredo LC, Gaioli CCLO et al. Comparative study between formal and informal caregivers of older adults. *Cien Saude Colet*. 2018;23(11):3789-98. <http://dx.doi.org/10.1590/1413-812320182311.16932016>. PMID:30427449.
- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition (DSM-V). Arlington: APA; 2014.
- Padovani C, Lopes MCL, Higahashi IH, Pelloso SM, Paiano M, Christophoro R. Being caregiver of people with Parkinson's disease: experienced situations. *Rev Bras Enferm*. 2018;71(Suppl 6):2628-34. <http://dx.doi.org/10.1590/0034-7167-2017-0008>. PMID:30540037.
- Caetano PM, Fernandes JV, Marcon SS, Decesaro MN. Refletindo sobre as relações familiares e os sentimentos aflorados no enfrentamento da doença crônica. *Cienc Cuid Saude*. 2011;10(4):845-52. <http://dx.doi.org/10.4025/ciencuccuidsaude.v10i4.18331>.
- Seima MD, Lenardt MH, Caldas CP. Care relationship between the family caregiver and the elderly with Alzheimer. *Rev Bras Enferm*. 2014;67(2):233-40. <http://dx.doi.org/10.5935/0034-7167.20140031>. PMID:24861066.
- Couto AM, Caldas CP, Castro EAB. Family caregiver of older adults and Cultural Care in Nursing care. *Rev Bras Enferm*. 2018;71(3):959-66. <http://dx.doi.org/10.1590/0034-7167-2017-0105>. PMID:29924161.
- Félix VPSR, Farias AM. Microcephaly and family dynamics: fathers' perceptions of their children's disability. *Cad Saude Publica*. 2018;34(12):e00220316. PMID:30570042.
- Carneiro R, Fleischer, Soraya. "I never expected this, it was a big shock": conception, pregnancy and birth in times of Zika through the eyes of women in Recife, PE, Brazil. *Interface*. 2018;22(66):709-19. <http://dx.doi.org/10.1590/1807-57622017.0857>.
- Barros SMM, Monteiro PAL, Neves MB, Maciel GTS. Fortalecendo a rede de apoio de mães no contexto da síndrome congênita do vírus Zika: relatos de uma intervenção psicossocial e sistêmica. *Nova Perspectiva Sistêmica [Internet]*. 2017; [citado 2019 jan 27];26(58):38-59. Disponível em: [http://pepsic.bvsalud.org/scielo.php?script=sci\\_arttext&pid=S0104-78412017000200004&lng=pt&tlng=pt](http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S0104-78412017000200004&lng=pt&tlng=pt)
- Scott RP, Lira LC, Matos SS, Souza FM, Silva ACR, Quadros MT. Therapeutic paths, care and assistance in the construction of ideas about maternity and childhood in the context of the Zika virus. *Interface*. 2018;22(66):673-84. <http://dx.doi.org/10.1590/1807-57622017.0425>.
- Matsukura TS, Marturano ED, Oishi J, Borasche G. Estresse e suporte social em mães de crianças com necessidades especiais. *Rev Bras Educ Espec*. 2007;13(3):415-28. <http://dx.doi.org/10.1590/S1413-65382007000300008>.
- Costa ES, Bonfim EG, Magalhães RLB, Viana LMM. Mothers' experiences of children with microcephaly. *Rev Rene*. 2018;19:e3453. <http://dx.doi.org/10.15253/2175-6783.2018193453>.
- Silva JB, Soares CCD, Silva PMC, Azevedo EB, Saraiva AM, Ferreira Fa MO. "Suffering in paradise": the difficulties found by mothers in caring for the child with mental distress. *Rev Eletr Enf [Internet]*. 2015; [citado 2019 abr 29]; 17(3):1-10. Disponível em: <https://revistas.ufg.br/fen/article/view/25362/20760>
- Silva MEA, Reichert APS, Souza SAF, Pimenta EAG, Collet N. Chronic disease in childhood and adolescence: family bonds in the healthcare network. *Texto Contexto Enferm*. 2018;27(2):e4460016. <http://dx.doi.org/10.1590/0104-070720180004460016>.
- Brunoni D, Blascovi-Assis SM, Osório AAC, Seabra AG, Amato CAH, Teixeira MCTV et al. Microcephaly and other Zika virus related events: the impact on children, families and health teams. *Cien Saude Colet*. 2016;21(10):3297-302. <http://dx.doi.org/10.1590/1413-812320152110.16832016>. PMID:27783802.
- Pilapil M, Coletti DJ, Rabey C, DeLaet D. Caring for the caregiver: supporting families of youth with special health care needs. *Curr Probl Pediatr Adolesc Health Care*. 2017;47(8):190-9. <http://dx.doi.org/10.1016/j.cppeds.2017.07.003>. PMID:28803827.

31. Okido ACC, Zago MMF, Lima RAG. Care for technology dependent children and their relationship with the health care systems. *Rev Lat Am Enfermagem*. 2015;23(2):291-8. <http://dx.doi.org/10.1590/0104-1169.0258.2554>. PMID:26039300.
32. Figueiredo SV, Sousa ACC, Gomes ILV. Children with special health needs and family: implications for Nursing. *Rev Bras Enferm*. 2016;69(1):88-95. <http://dx.doi.org/10.1590/0034-7167.2016690112i>. PMID:26871220.
33. Romley JA, Shah AK, Chung PJ, Elliott MN, Vestal KD, Schuster MA. Family-provided health care for children with special health care needs. *Pediatrics*. 2017;139(1):e20161287. <http://dx.doi.org/10.1542/peds.2016-1287>.
34. Sampaio LS, Santana OS, Silva MV, Sampaio TSO, Reis LA. Qualidade de vida e depressão em cuidadores de idosos dependentes. *Rev APS*. 2018;21(1):112-21. <http://dx.doi.org/10.34019/1809-8363.2018.v21.16235>.