

# Child-mothers with congenital Zika syndrome: daily rites for the prevention of COVID-19



*Mães-crianças com síndrome congênita do Zika: ritos quotidianos para prevenção da COVID-19*

*Madres-infantiles con síndrome congénito de Zika: ritos diarios para la prevención del COVID-19*

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## ABSTRACT

**Objective:** To comprehend the daily rites of child-mothers with congenital Zika virus syndrome for the prevention of COVID-19 during the pandemic.

**Method:** Study with a qualitative-exploratory approach, in the light on the comprehensive sociology of Michel Maffesoli, carried out in WhatsApp groups of associations of families of children with the syndrome. 44 mothers answered the online questionnaire between April and May 2020. Lexical and similarity analyzes were used through IRaMuTeQ.

**Results:** Mothers encourage exercises for child development and help the children's school activities, watch television, sew, cook, support other mothers on social networks and find satisfaction in not meeting previously established schedules. To prevent COVID-19, mothers adopt physical distance, try to consume healthy foods and intensify hygiene measures.

**Final considerations:** Child-mothers experience, in physical distance being closer to their children and other mothers through the networks, and adopt preventive care to COVID-19, with care overload.

**Keywords:** Coronavirus infections. Zika virus. Disabled children. Postmodernism. Mother-child relations. Covid-19.

## RESUMO

**Objetivo:** Compreender os ritos quotidianos de mães-crianças com síndrome congênita do vírus Zika para prevenção da COVID-19 durante a pandemia.

**Método:** Estudo de abordagem qualitativo-exploratória, à luz da sociologia compreensiva de Michel Maffesoli, realizado em grupos de WhatsApp de associações das famílias de crianças com a síndrome. Responderam ao questionário online 44 mães entre abril e maio de 2020. Foram utilizadas análises lexical e de similitude através do IRaMuTeQ.

**Resultados:** As mães estimulam exercícios para o desenvolvimento infantil e auxiliam as atividades escolares das crianças, assistem à televisão, costuram, cozinham, apoiam outras mães nas redes sociais e encontram satisfação em descumprir horários estabelecidos anteriormente. Para prevenir a COVID-19, as mães adotam o distanciamento físico, procuram consumir alimentos saudáveis e intensificam medidas de higiene.

**Considerações finais:** As mães-crianças experienciam, no distanciamento físico, estarem mais próximas dos filhos e de outras mães pelas redes e adotam cuidados de prevenção à COVID-19 com sobrecarga de cuidado.

**Palavras-chave:** Infecções por coronavírus. Zika vírus. Crianças com deficiência. Pós-modernismo. Relações mãe-filho. Covid-19.

## RESUMEN

**Objetivo:** Comprender los ritos cotidianos de madres-infantiles con síndrome congénito del virus del zika para la prevención del COVID-19 durante una pandemia.

**Método:** Estudio con enfoque exploratorio cualitativo, a la luz de la sociología integral de Michel Maffesoli, realizado en grupos de WhatsApp de asociaciones de familias de niños con síndrome. 44 madres respondieron el cuestionario en línea entre abril y mayo de 2020. Se utilizaron análisis léxico y de similitud a través de IRaMuTeQ.

**Resultados:** Las madres fomentan ejercicios para el desarrollo infantil y ayudan en las actividades escolares de los niños, ven televisión, cosen, cocinan, apoyan a otras madres en las redes sociales y encuentran satisfacción en no cumplir con los horarios previamente establecidos. Para prevenir el COVID-19, las madres adoptan la distancia física, intentan consumir alimentos saludables e intensifican las medidas de higiene.

**Consideraciones finales:** Las madres-hijos experimentan la distancia física al estar más cerca de sus hijos y otras madres a través de las redes, más atención preventiva al COVID-19, con sobrecarga de cuidados.

**Palabras clave:** Infecciones por coronavirus. Virus Zika. Niños con discapacidad. Posmodernismo. Relaciones madre-hijo. Covid-19.

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## INTRODUCTION

The daily life of mothers of children with congenital Zika virus syndrome (CZS) involves dedicating themselves entirely to the child<sup>(1)</sup>, going through complex therapeutic itineraries, performing stimulation in the home environment and performing care attitudes, such as lulling, playing, feeding and cleaning, in addition to home care and other family members<sup>(2)</sup>.

This routine is carried out in the midst of financial difficulties, breaking ties with the child's parent, the absence of a personal life project and facing prejudiced comments in public spaces<sup>(2)</sup>. This reverberates in high levels of depression, anxiety<sup>(3)</sup> and caregiver burden<sup>(2)</sup> in addition to poor sleep quality<sup>(3)</sup>.

Mother and child build an intimate biological, social and psychological relationship, which regulates the interaction between both and determines efforts for the better development of the child<sup>(4)</sup>. Thus, due to the child's total dependence on the mother and based on the assumption that taking care of someone promotes benefits to self-care<sup>(4)</sup>, it is adopted, in this study, the name of the child-mother dyad.

CZS is defined as craniofacial disproportion, muscle contractures, spasticity, seizures, auditory and visual abnormalities and brain anomalies, identified by neuroimaging and related to infection by the Zika virus during pregnancy<sup>(5)</sup>. The CZS epidemic emerged in 2015, with 19,072 suspected cases of CZS reported by June 24, 2020. From these, 3,535 (18.5%) are confirmed. In 2020 alone, until the date previously informed, another 468 new cases were reported, 13 (2.8%) of which were confirmed. In other words, despite the end of the public health emergency period, children with CZS continue to be born<sup>(6)</sup> and new mothers may suffer psychosocial repercussions typical of being a mother of a child with CZS.

The COVID-19 pandemic, as well as the CZS epidemic at the time, generates fear in society due to the lack of scientific knowledge, the absence of effective therapy that promotes a cure in a short period of time and uncertain prognosis<sup>(7)</sup>. In this context, the effective measures to delay the rapid transmission of the SARS-COV-2 virus, which causes COVID-19, were to reduce contact between people and maintain frequent hygiene actions, such as hand washing, in addition to disseminating information to the population about the relevance of these measures<sup>(8)</sup>.

The Comprehensive and Everyday Sociology seeks to analyze behavior in everyday life. For Michel Maffesoli, a postmodernist sociologist, daily life is the locus where the (re)construction of social bonds and the conservation of individuals and species take place. The daily life expresses the relationships, beliefs, emotions, values, symbols and

imaginary, which shape routine attitudes<sup>(9)</sup> and can be constituted as rites. This term is conceived as rules of conduct so relevant, which hold sacred and emotional value, functioning as acts that unite people<sup>(10)</sup>.

Given the diversity of activities carried out by mothers before the pandemic, and considering children belonging to the group of people susceptible to clinical complications due to COVID-19, the need to maintain physical distance, the suspension of in-person rehabilitation care for the child and the relevance from the nursing team on the front line of the pandemic, the following guiding question emerged from this study: how are the daily rites of child-mothers with CZS expressed to prevention of COVID-19?

For these reasons, the objective of the study is to understand the daily rites of child-mothers with CZS for the prevention of COVID-19.

## METHOD

It is a qualitative-exploratory study, written according to the 32 items of the Consolidated criteria for reporting qualitative research (Coreq) for qualifying the writing of qualitative studies<sup>(11)</sup>. 44 mothers of children with CZS participated in the study, who met the following selection criteria: being a mother of a child with CZS and being 18 years of age or older. There were no exclusion criteria.

The theoretical-empirical saturation determined the number of participants, when all possibilities for new discussions from the collected data were exhausted, with no need for other mothers to respond to the data collection instrument. To find saturation, one researcher (doctoral student) and two researchers (postdoctoral researchers) independently performed the initial data analysis, in order to define the nuclei of meanings that emerged from the collected data. Upon finding convergence between two researchers, the data collection stage was ended.

The empirical field of the investigation was the WhatsApp groups of the Parents of Angels of Bahia Association (*Associação de Pais de Anjos da Bahia - APAB*) (263 mothers) and the Embrace Microcephaly Association (*Associação aBRAÇO a Microcefalia*) (234 mothers), Bahia, a space used by several mothers of children with CZS. Both Associations are not for profit, are based in the city of Salvador, Bahia, Brazil, and were founded in 2017 and 2016, respectively, with the objective of promoting support, reception and defense of the rights of children with CZS and their family. It is noteworthy that the researchers did not participate in the WhatsApp groups mentioned. Thus, the first author asked the Associations to share the invitation to participate in the research and the online questionnaire (<https://forms.gle/Ztuu8x1gHgXeC38K6>)

in each WhatsApp group. The period for answering the questionnaire was between April and May 2020, being the only data collection instrument used.

The online questionnaire was built by the researchers using the Google Forms tool and organized in two parts: the first, reserved for filling in personal, social, and economic identification data; and the second, with open questions related to the daily life of the child-mother during the pandemic and care for the prevention of COVID-19: did anything change in your daily life after the coronavirus pandemic? What has changed? What did you do before and don't do now because of the coronavirus? What are you doing more now than before the coronavirus? Is there anything you didn't do before the pandemic and are you doing it now? How has the child been treated during the coronavirus pandemic? What did you think/feel when you learned that the child's school would no longer function because of the coronavirus pandemic? Do you take any specific care to prevent the child from getting the coronavirus? If so, which ones? Do you take any specific precautions to prevent you from getting the coronavirus? If so, which ones?

The Respondent Driven Sampling technique<sup>(12)</sup> was used after posting the link to the electronic questionnaire in WhatsApp groups. This technique allows study participants to freely direct the reach of data collection techniques, which is why it is indicated for research with groups of people with difficult access<sup>(12)</sup>. Due to the physical distance established in Brazil during the pandemic, she was eligible for this study. Therefore, respondent mothers were asked to share the link with other mothers of children with CZS who they knew.

As for ethical aspects, it is worth mentioning that the study was approved by the National Research Ethics Committee and by the Research Ethics Committee of the *Universidade Estadual de Feira de Santana* (CAAE: 30757920.6.0000.0053), statement No.3,990,246, allowing consent of participants via electronic platforms according to the guidelines of the National Research Ethics Commission. Upon accessing the electronic questionnaire link, the participants found on the first page the Free and Informed Consent Term (FICT). After reading the Term in full, there were two options for free choice: "I want to participate in the research" and "I don't want to participate in the research".

Participants who chose the first option accessed the questionnaire in its entirety, while the questionnaire was closed immediately for mothers who refused to participate in the research. After agreeing to participate, the mothers chose the best way to receive the informed consent form signed by the main author and by the guiding teacher,

choosing between e-mail or WhatsApp and offering the necessary information for sending the informed consent form by the first author. The principles of autonomy and confidentiality were respected, recommending the choice of fictitious names by the participants themselves to name themselves and children, and in compliance with Resolutions No. 466/12 and No. 510/16 of the National Health Council.

When completing the questionnaire, automatically the responses of the participants were sent to the email [sindromecongenitaz@gmail.com](mailto:sindromecongenitaz@gmail.com) administered by the first author. Therefore, all data collected and analyzes performed will remain stored for five years in Google Drive of the specific email account. To proceed with the analysis, a first stage of organization and preparation of the corpus. Then, the two data analysis techniques were used: lexical and similarity, performed in the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ), version 0.7, alpha 2.

The analyzes were conducted by the first author, starting with the identification and grouping of excerpts from individual responses, which addressed the daily lives of child-mothers, maintaining 44 individual texts. Then, the treatment of each text was carried out to constitute the *corpus* of the research to be submitted to analysis by IRaMuTeQ. Such stage consists in the suppression of grammatical symbols, editing of abbreviations or acronyms and standardization of words so that the spelling and grammatical rules of the Portuguese language were respected.

For further analysis, the *corpus* was submitted to lexical analysis, explored by the Reinert method, and to similarity analysis. The lexical analysis results in the Descending Hierarchical Classification (DHC), which analyzes the frequency of words in the *corpus* and the significant association between them according to the p value ( $p \leq 0.001$ ). From then on, the software uses the chi-square test ( $\chi^2$ ) to check the association of words with a certain class, grouping them according to their significance. The similarity analysis uses the lexical form to identify the relationship between the mentioned words, generating a tree-shaped graph, where the most frequent words form nuclei that derive branches with subfrequent words, which have connectivity in the reports.

After the construction of the classes by the software, the main author accessed the text segments of each class and prepared the respective titles. Such results were interpreted in the light of comprehensive sociology using the theoretical and sensitivity assumptions proposed by the French sociologist Michel Maffesoli<sup>(9,13)</sup>.

## ■ RESULTS

Among the 44 study participants, 38.7% were between 18 and 25 years old and 88.6% of the children were aged between four and five years old. As for religion and skin color, 38.6% are evangelical, 45.5% brown and 45.5% black. Unemployed numbered 9.3%, 58.3% declared to be housewives, while 27.3% lived with two people in the house, the same amount for three and four residents, including the mother; and 90.8% of mothers lived in the state of Bahia, 4.6% in Amazonas and 4.6% in Paraíba.

From the DHC, the lexical analysis took advantage of 80.20% from the text segments of the *corpus*, allowing the construction of the dendrogram shown in Figure 1.

Classes 1, 4 and 6 constitute the category entitled "Daily rites of child-mothers with CZS during the COVID-19 pandemic", while classes 2, 3 and 5 comprise the category "Care for prevention of COVID-19". It is reaffirmed that the formation of classes occurs automatically by the software, while the categories were organized and titled by the authors representing the main thematic.

The similarity tree 1 (Figure 2) illustrates the centrality of the verb "leave" in the participants' responses, indicating the daily life of leaving home before the pandemic and being at home during the pandemic, while in the similarity tree 2, the frequency of the word "home", emphasizing hygiene and cleaning care with this space and when arriving at it.

### Daily rites of child-mothers with CZS during the COVID-19 pandemic

The daily routine of child-mothers with CZS was modified during the pandemic, as the health measures to prevent contagion by SARS-COV-2 imposed conditions for the behavior of child-mothers with CZS. Before the pandemic, the routine was mainly filled with therapeutic itineraries and complex access to health facilities, seeking therapeutic resources capable of enhancing the child's development. This change can be identified in the following narratives:

*Everything has changed in my life. We traveled a lot because his treatment [child with CZS] was in another city. (Maria).*

*I had a very hectic life because of my son's treatments and it stopped. It was an everyday routine to take him somewhere for treatment. (Joicy).*

With the physical distance imposed by the pandemic, the rehabilitation services that depended on close contact between professional and child were suspended, as well

as school activities. In this way, mothers were concerned with the discontinuity and disruption of the rite, so they sought to alleviate possible delays in the child's development by adapting stimulation exercises and school activities at home.

*I try to stimulate at home in our own way. (Alice).*

*Lara is at an advanced stage in cognitive. Getting her out of school was worrying. (Thais).*

*I do school activities with him. The 'pro' sends me and I'm doing it with him. Then, I return it. (Carmen).*

The discontinuity of the rite can be identified not only in the interruption of the children's treatments, but also in the act of leaving home for a walk, going to the rehabilitation services, beach, market, school, shopping, and church, making visits to family and friends, and participate in courses.

*I went out for a walk, to go to therapies, to be with family and friends. (Nalva).*

*We went to physiotherapy, market, school, tours, and trips. (Jade).*

*Did courses, went to the beach, visited friends and family. (Giovana).*

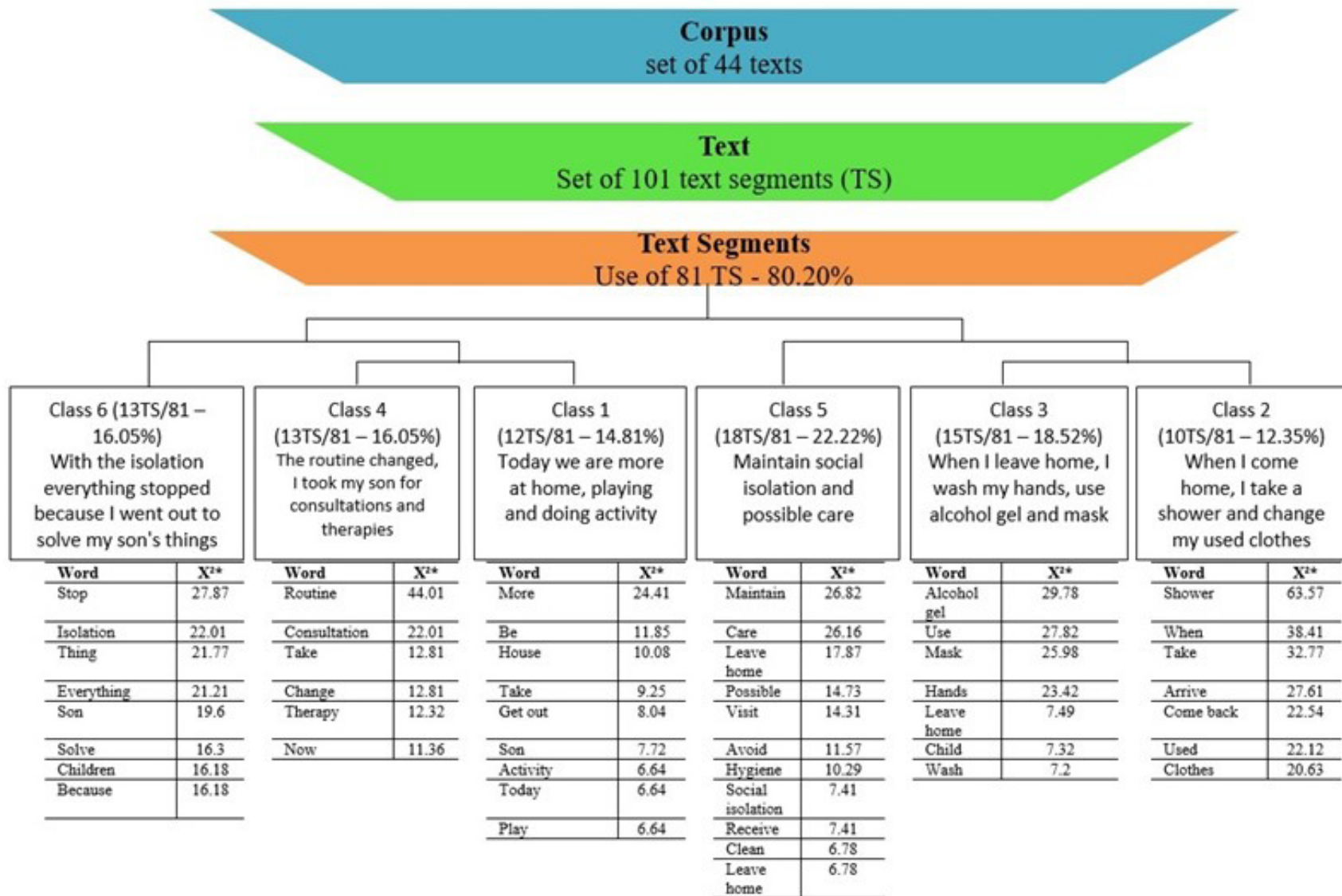
*I can no longer take my daughter on birthday, shopping, and beach. (Rodrigues).*

When meeting the recommendations of health authorities and facing the suspension of professional rehabilitation services, child-mothers felt more isolated than before and immersed in new difficulties. For Joicy, there was a transgression of the isolation stage established by CZS and lived previously, to a more restricted isolation stage aggravated by COVID-19.

*In fact, we were already experiencing social isolation because of the fragile health of our children with disabilities. We became even more isolated and everything became more difficult. (Joicy).*

Besides the situation of isolation and interruption of children's therapeutic activities, unemployment was also a concern for some mothers during this period, as reported by Isadora and Laís. Mothers filled their daily lives by watching television programs, sewing, using the Internet more, talking and helping other mothers with financial difficulties.

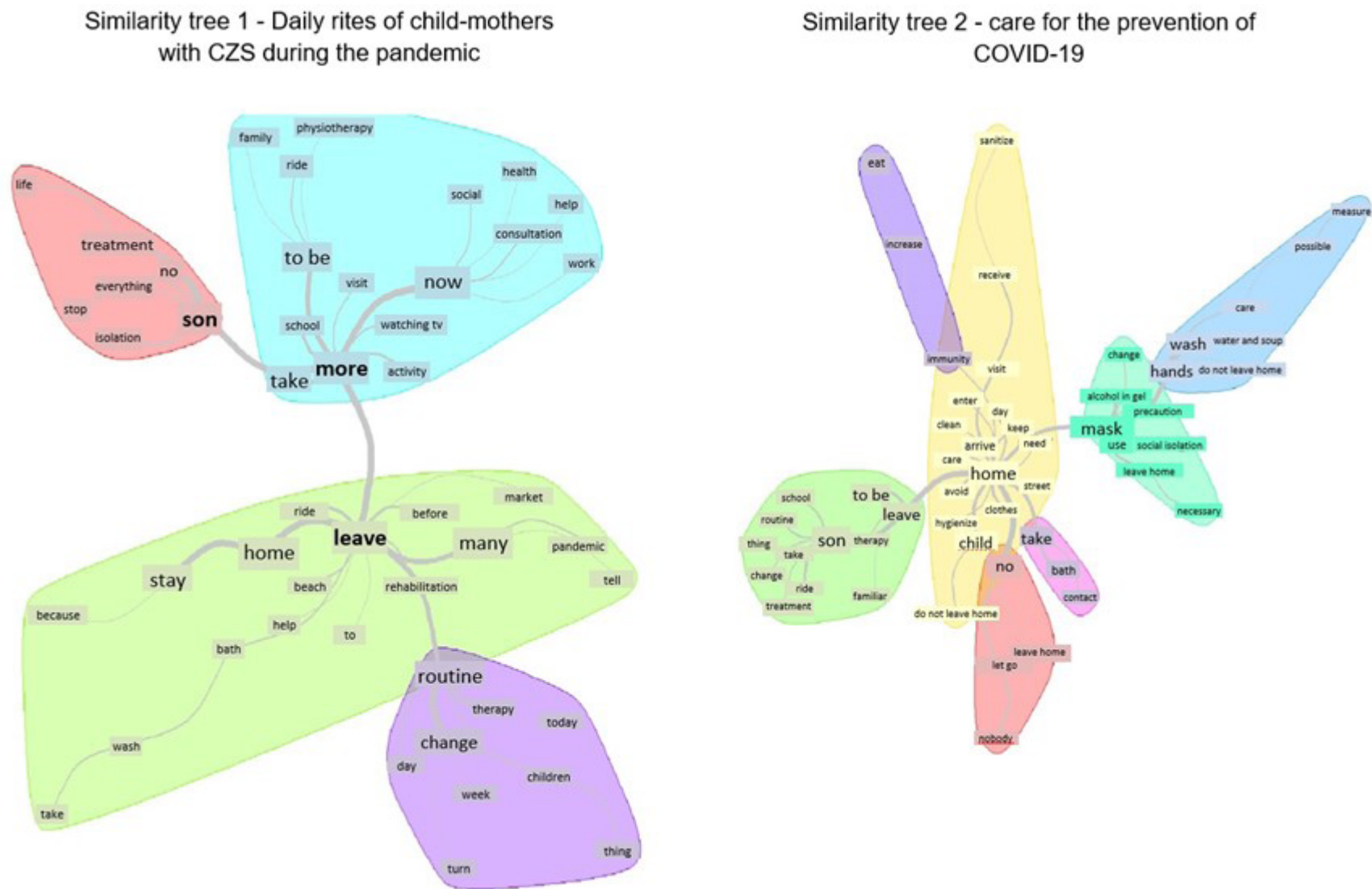
*Now, I am unable to work and in total isolation at home. (Isadora).*



**Figure 1** – Thematic structure of the research *corpus* according to the Descending Hierarchical Classification.

Source: Research data.

Note: X<sup>2\*</sup>: statistically significant chi-square values (p<0.01).



**Figure 2** – Daily rites of child-mothers with CZS during the pandemic and care for the prevention of COVID-19.  
Source: Research data.

*I am without work, without leaving. We stopped everything.* (Laís).

*Now I'm watching more television.* (Alice).

*I'm sewing and using the internet more to solve everything (...) including talking to other mothers* (Marília).

*I try to help other mothers who, due to the pandemic, have gone out of work and need to help with family income. So, they go through a lot of need.* (Joicy).

Cooking also emerges as an activity developed during this period of physical distance. They created and executed recipes in the kitchen as well as believed they were eating more.

*I spend more time cooking.* (Fernanda).

*I'm eating a lot now. Very anxious.* (Heloara).

The changes in daily rites have some aspects that seem beneficial according to the mothers' reports; for example, the lack of compliance with the schedules established by health services, the unconcern with the time to wake up and the better recognition of the child's development.

*Enjoying more of my little girl at home, because since she was born, she is concerned about physiotherapy hours.* (Lara II).

*Waking up later without worrying about my daughter's school schedule and physiotherapies.* (Lara).

*I have been paying much more attention to my daughter's development.* (Laura).

The mothers sought to adapt to the conditions of physical distance by adjusting their daily rites. However, they were concerned with the development of children's physical and cognitive functions. They identified as positive aspects: the possibility of waking up later due to non-compliance with previously mandatory schedules, being closer to their sons/daughters, helping other mothers and reinventing themselves in the face of domestic activities in their daily lives.

### Care for the prevention of COVID-19

The participants adopted collective care, such as maintaining physical distance and cleaning the domestic environment (class 5), and individual care, such as washing hands, wearing a mask, alcohol, and gloves (class 3), bathing and changing used clothes away from home (class 2).

When asked about the activities carried out on a daily basis, the mothers mentioned care taken to prevent the

contagion of the child by COVID-19, often describing the words "house, masks, hands, take, leave and no".

The similarity analysis illustrates the centrality of maternal care at home. Mothers avoided leaving home and only did so in extreme cases of need without the presence of the child.

*I only leave the house if it is very necessary.* (Heloara).

*We go out of extreme need, but the child does not leave home.* (Lais).

In the similitude tree 2, the term "wash" is often linked to "water and soap" and "hands", as well as it is related to wearing a mask, alcohol gel and social isolation, these being the main maternal care attitudes. They were also dedicated to maintaining social isolation. However, when leaving home, they adhered to the use of the mask, alcohol gel, water, soap and gloves.

*The main thing is total social isolation. Then comes hygiene.* (Thais).

*When I go out, I wear a mask and glove.* (Heloara).

*If I leave home, it is with a mask, glove, I use alcohol gel and I wash my hands with soap and water.* (Rani).

In view of the rigor to comply with the physical distance and the protection of the child against the new coronavirus, an unprecedented daily family life was established, such as the eligibility of a member to perform activities outside the home. The father was chosen according to Vanessa.

*We maintain total social isolation. Only the father goes out to buy food or something necessary, but taking all possible precautions.* (Vanessa).

Collective preventive care required greater dedication to cleaning and hygiene in the home environment. For Lara II, the frequency of house cleaning was conditioned to the number of times that residents or other people accessed her house.

*I sterilize the house twice a day.* (Edna).

*I always leave the house clean. I pass sodium hypochlorite, clean the furniture with alcohol.* (Rodrigues).

*I wipe the floor three times a day, depending on who enters and leaves the house or if we leave and come back a lot from the street.* (Lara II).

They described taking all possible preventive care to go to the market and return home. Others said they improve

family food by offering and ingesting more liquids, greens, fruits, and vegetables as a way to strengthen their immune system and that of the child.

*When I get home, I wash my hands, I go to bathe, and I take off my used clothes on the street. The products I buy in the market, I wash with water and soap or detergent. (Maria José).*

*If I have to go to the market, as soon as I get back, I go straight to the bathroom to wash my hands and take shower. (Rodrigues).*

*Food has changed too. We eat a lot of vegetables, fruits, greens and vitamins to increase immunity. (Joicy).*

*I drink a lot of water and juice. I eat greens, vegetables and fruits. (Lara II).*

The direct care for the child involved: not allowing him to leave the house, forbidding contact with people who do not live in the same house, washing her hands frequently, putting on her mask and washing her hands and nose in addition to changing her clothes before having contact with the child.

*The child does not leave the house at any moment. I don't let anyone take the child. (Ajuda).*

*The child has no contact with other people. (Patrícia).*

*I wash the child's hands before and after everything he does. (Maria).*

*I wash my nose before having contact with the child. (Edna).*

*When I take care of the child I always put on the mask and change clothes. (Laura).*

Part of the mothers did not allow people to visit their home, cleaned it frequently and changed clothes and used shoes before entering the house.

*I do not receive visits at my home. We try to keep everything clean and sanitized. (Joicy).*

*I don't let anyone enter at home to visit the child. (Laura).*

*I get home, leave the sandal on the front door, and go straight to shower and wash the clothes I used. (Vitória).*

The maternal care for children during the pandemic involved constant vigilance and the establishment of new rites considered essential for the protection of the whole family. These rites are related to the environment, family dynamics, body hygiene and the strengthening of the immune system.

## ■ DISCUSSION

Organic solidarity and the satisfaction with pleasurable activities make up the daily rites of child-mothers with CZS participating in this study. They are based on the notions of formism, sociality, dynamic rooting, presenteeism and raciovitalism.

As occurred in various segments of the population in general, physical distance was the main health measure that resulted in changes in the daily lives of child-mothers with CZS, leading them to avoid leaving home and suspending visits from family and friends. However, conspiracy theories, or mothers' movements, were not cited in the sense of denying the existence of the pandemic, contradicting or refusing to assimilate care-oriented attitudes of prevention of COVID-19, accepting them as such and acting according to the concept of formism Maffesolian, little questioning the meaning of events<sup>(13)</sup>.

With the pandemic scenario, mothers cannot leave home with the children to go to health services, relatives home, beach, shopping and market. However, study<sup>(1)</sup> indicates that some mothers previously used social isolation as a strategy to cope with the stigma and prejudices they experienced.

Therefore, there seems to be a group of mothers who lived together in "social isolation" before the pandemic, avoiding public and unknown spaces due to prejudice and discrimination<sup>(1)</sup> or because they believe that children have health conditions that are vulnerable to illness. Other mothers may have overcome such conceptions by adopting a libertarian understanding of the child's illness process and its repercussions on the family. As a result, they were less isolated before the pandemic. Regardless of belonging to such groups, the physical distance due to the COVID-19 pandemic affects the daily lives of child-mothers with CZS and all rites starts to be defined according to compliance with the distance rules.

Despite the changes in daily rites caused by physical distance, it allows the accomplishment of tasks that were not feasible before. Thus, the time spent on routine trips to health units is now used to create and execute recipes, use the internet, wake up without a predefined schedule and notice the progress in the child's development. These are attitudes that can generate satisfaction, pleasure and well-being. Thus, such tasks can conceive of orgasm in the midst of a pandemic - actions driven by libido, enjoyment, affection and pleasure to maintain life - in everyday life that seems tragic<sup>(13)</sup>.

From the physical distance and other health measures, mothers build, through the internet, tactics to socialize the condition of being a child-mother with CZS during



the pandemic and collaborate to supply the need of other mothers. Thus, despite adhering to physical distance, mothers belong to the tribe - a micro group of people with common interests<sup>(13)</sup> - called "mothers of micro", who exercised care over the internet to maintain, during isolation, the relationship between them more restricted at home and offer solutions to mitigate the effects of unemployment.

The results of this study identified the exercise of organic solidarity mediated by the internet. Such tactic is common among mothers of micro<sup>(2)</sup>, privileging the sharing of information about treatment, therapeutic itineraries, judicialization of health needs and access to benefits among family members of the child with CZS<sup>(2)</sup>.

The organic solidarity seen in the daily lives of micro mothers privileges the affection, the sociality of life and the well-being of the members of this tribe<sup>(14)</sup>, allowing for dynamic rooting, a notion of strengthening common goals that can be modified<sup>(15)</sup>. These movements of each member, seeking different trajectories based on the presenteeist phenomenon, can change from the pandemic.

The mothers of micro take root with the objective to achieve the well-being of the child and the family. However, these objectives are dynamized, modified and replaced with the advancement of the child's growth and development, resulting in different health needs over time<sup>(2)</sup>. In summary, the pandemic phenomenon may have contributed to the strengthening of dynamic rooting and sociality - collective based experience, which values the solidarity between relationships<sup>(9)</sup> - of mothers of children with CZS.

Thus, the condition of being at home may not represent the tragic situation for mothers, as it causes orgasm and enhances dynamic rooting and sociality. On the other hand, the conception of tragedy may reside in the interruption of rehabilitation services and suspension of school activities, since these events require adaptation of activities that were carried out by health professionals and educators, respectively. In addition, mothers are concerned about the possibility of stagnation or delay in psychomotor development and the loss of the child's sociability.

Similar to that found in this study, rehabilitation services for people with disabilities were also suspended in the United States of America and Italy during the pandemic. These were decisions made exclusively by health professionals<sup>(16)</sup>, which made it impossible for people with disabilities, caregivers and professionals to dialogue. This condition reaffirms the understanding of the lower value of life and the invisibility of people with disabilities<sup>(16)</sup>, aggravated by the characteristic of being a non-white woman in 91% of the participants in this study.

The daily life of child-mothers with CZS during the pandemic shows the lack of activities that stimulates the child's sociability. Even though mothers use the internet to strengthen their tribe's sociability, sociability with educators, schoolmates, health professionals and other family members did not find substitute or other activities that would alleviate such loss. Even if the child interacts with the residents of their home, the concept of sociability of postmodernity considers that any and all experiences and interactions, the more diversified and intense, contribute to the formation of the subject, overcoming dichotomous understandings of norms and predefined cultural meanings<sup>(9,15)</sup>.

The abrupt modification of the daily rites of children with CZS can result in difficulties in restoring or creating affective bonds favorable to the child's interaction in the post-pandemic period. It is important to state that, during physical distance, the child lives in a protected environment, with people, objects and known spaces, requiring, after the pandemic, patience, time, kindness and dedication of family members, professionals, and educators in favor of resuming their social interactions.

The outcomes of this study point out to the need for health professionals, responsible for the child's rehabilitation, to practice the notion of sensitive reason. The sensitive reason emphasizes compatibility between previously dichotomous pairs, such as reason and emotion, subjective and objective<sup>(9,13)</sup>. Therefore, it is also important that health professionals seek to know the daily life, thoughts, emotions, feelings and plans of the mothers at the same time that they put scientific knowledge into practice through professional care.

Faced with the tragic postmodern, people tend to provide orgasm and intensify daily actions, valuing presenteeism - present time - and limiting themselves to thinking or planning for the future<sup>(9)</sup>. Thus, the uncertainties generated by the pandemic cause the intensification of life, of daily actions, resulting in mothers who need to act like the "teacher" and provide health care "of professionals" even though unmotivated and unprepared.

This daily life can be more burdensome for 45.4% of mothers living with four or even seven residents, requiring more frequent hygiene and cleaning care. The accumulation of these tasks can raise the levels of depression, anxiety<sup>(3)</sup> and care overload<sup>(2)</sup>, affect the quality of sleep and generate feelings of insecurity and abandonment<sup>(3)</sup>.

Despite valuing presenteeism, the intensification of life in the present can be driven by thoughts about the past, such as the acceptance of maternal guilt for the illness of CZS<sup>(2)</sup>. Thus, the perception of CZS's causality drives mothers to dedicate themselves to the maximum to prevent a new

and unknown viral disease, such as COVID-19, from reaching their child and other family members.

On the other hand, it is recognized that unemployment and the decrease in family income are some of the repercussions of the pandemic on society, a worse condition for women who are the first to lose their jobs<sup>(17)</sup>. In this study, 67.6% of mothers are unemployed or housewives, occupations that must be overcome or chosen based on self-interest, avoiding their social imposition as women's activities.

In this study, there is only one report that indicates the social support of a family member for the mother, pointing out to the absence of a social support network or the impossibility of activating it in view of the suspension of home visits and other tactics adopted for prevention of COVID-19. During the COVID-19 pandemic, international studies showed a decrease or loss of social support for people with disabilities<sup>(18-19)</sup> and high levels of mental health problems in informal caregivers<sup>(19)</sup>.

Although preventive care does not differ from the measures recommended for the world population, adding them to everyday life contributes to the accumulation of tasks in mothers, which can result in levels of care overload and negative repercussions on mental health and satisfaction with life, aggravated by the lack of social support, which is a protective factor for mothers' mental health<sup>(20)</sup>. Therefore, it is recommended that the home care and prevention of COVID-19 is not exclusively attributed to mothers, but a commitment and task for everyone who lives in the same environment, including the parent.

The daily lives of mothers of children with CZS are based on the notion of raciovitalism, understood by the inventive flexibility and the rationalism of the being based on human organicity and the conditions of life. Thus, although mothers exercise all the recommendations of the health authorities (reason), they perform the control of the rites in different ways and choose who should leave the house, who enters, what substances to use and the frequency of hygiene and cleaning of the house, attitudes defined from the adversities of life, vitalism<sup>(21)</sup>.

## ■ FINAL CONSIDERATIONS

The child-mothers experience a dynamic daily rite, involving exercises to stimulate child development, adaptations for the continuity of school activities, exercise of organic solidarity with "mothers of micro", satisfaction with activities that emanate pleasure and adherence to recommended care by health authorities for the prevention of COVID-19; as examples: maintaining physical distance, cleaning the domestic environment, washing hands, wearing mask, alcohol

and gloves, taking a shower and changing clothes used outside the home.

Although innovative care attitudes were not verified in this study, its results point to the need for the look of Nursing at mothers and children in chronic situations and disabilities, considering the risk of contagion to COVID-19, the abrupt change in daily life and measures of interaction based on remote resources.

In the Nursing field, the experiences of the pandemic, portrayed in this study, show the potential of groups constituted in virtual social networks as a space for building bonds, interaction, and exchange of knowledges. These can be used to socialize knowledge and ways of caring for vulnerable groups, especially women positioned as mothers of children in chronic conditions beyond pandemic times. It is important that the nursing team performs family care in order to assist in restructuring and activating the social support network of child-mothers through remote virtual devices and the sharing of tasks between residents of the same home environment.

In summary, it is recommended surveillance by the Nursing team to: identify groups in vulnerability that experience serious and/or chronic consequences in epidemic or pandemic situations; articulate with education and social assistance sectors to mitigate the repercussions of the loss of sociability of children with disabilities and the burden of care for informal caregiving mothers during physical distance measures; as well as innovating in nursing consulting practices, considering the use of interactive technologies between professional and person to be cared.

The study's limitation lies in the impossibility of using other data collection techniques conditioned by physical distance. At this juncture, it was not possible to direct the open questions according to the objective of the study, nor to encourage the participants to construct testimonies with a wealth of details.

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