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Stressors and maternal Coping in Congenital Zika virus Syndrome

Estressores e Coping materno no contexto da Síndrome Congênita do vírus Zika

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Abstract

Objective
Congenital Zika virus Syndrome is characterized by a series of neurological changes bearing consequences for child development. In view of the large number of children born with microcephaly and other neurological disorders, this qualitative study sought to understand and review the coping strategies used by 10 mothers of children affected by the syndrome.

Method
A semi-structured interview was applied, which identified four main maternal stressors: diagnosis; childcare routine; child treatment; and development and access to health services.

Results
The most used coping strategies with regard to these stressors were: information-seeking, problem-solving, and delegation.

Conclusion
The implications of such results for the care of this population are discussed within the perspective of expanding the adaptive coping to these stressors and ensuring the necessary support for those families in the long and difficult process of taking care of a child with this syndrome.

Keywords: Coping strategies; Parenting; Zika virus infection.

Resumo

Objetivo
A síndrome congênita do vírus Zika é caracterizada por uma série de alterações neurológicas com consequências para o desenvolvimento da criança. Diante do elevado número de crianças

afetadas pela síndrome, nascidas com microcefalia e outros distúrbios neurológico, este estudo qualitativo buscou compreender e analisar as estratégias de coping utilizadas por 10 mães de crianças afetadas nessa situação.

Método
Foi utilizada uma entrevista semiestruturada, que identificou quatro principais estressores maternos: o diagnóstico; a rotina e os cuidados com a criança; o tratamento e desenvolvimento da criança e a dificuldade de acesso aos serviços de saúde.

Resultado
As estratégias de enfrentamento mais utilizadas para lidar com esses estressores foram: busca de informações, resolução de problemas e delegação.

Conclusão
Discutem-se as implicações desses resultados para o cuidado das mães na perspectiva de ampliar o enfrentamento adaptativo aos estressores e garantir o suporte necessário às famílias no longo e difícil processo de cuidar de uma criança com a Síndrome Congênita do Vírus Zika.

***Palavras-chave*:** *Estratégias de enfrentamento; Maternidade; Síndrome congênita de Zika.*

Between 2015 and 2019, 18,282 cases of babies born with growth and development disorders associated with Zika virus infection and other infectious etiologies were reported in Brazil (Ministério da Saúde, 2019). In addition to microcephaly, those babies presented other clinical conditions associated mainly with the central nervous system, psychomotor development, as well as effects on the osteoarticular system. In this viral infection, it is common to find craniofacial disproportion, spasticity, irritability, brainstem dysfunction, convulsive crises, as well as swallowing problems, limb contractures, auditory, and eye abnormalities (Castro et al., 2018).

Such changes were observed after the identification of the Zika virus in the amniotic fluid of infected pregnant women during the third trimester of pregnancy, based on the finding of a significant reduction in the babies' cranioencephalic pattern, which was smaller than the usual 32 cm (Focosi et al., 2016; Gańczak & Brodowska, 2016; Hills et al., 2017; Ministério da Sáude, 2017a; Robinson et al., 2018). Neuroimaging exams in neonates exposed to the Zika virus during their mothers' pregnancy also showed brain abnormalities (Ministério da Sáude, 2017b; Ministério da Sáude, 2019; Fundo das Nações Unidas, 2018). Despite the variety of signs and symptoms, Teixeira et al. (2020) pointed out three determining elements for the Zika infection syndrome diagnosis, namely: intracranial calcification, ventriculomegaly, and reduced brain volume. Therefore, microcephaly is only one of the detectable signs at a child's birth, or even later, according to the aforementioned authors.

Most cases (2,179 or 56.9% of cases) of Congenital Zika Virus Syndrome (CZVS) were reported in the Northeastern region of Brazil, with 220 of them in the state of Paraíba. This state received the support of the United Nations International Children's Emergency Fund to strengthen the network of health services aimed at this population, given the seriousness of the situation (Fundo das Nações Unidas, 2018; Ministério da Saúde, 2019). In view of the impairment in the development of babies affected by the syndrome, the need for early interventions became evident, thus posing a new burden on public health (Mendes et al., 2019).

Mothers of CZVS babies are faced with the birth of a child with disabilities and with different demands for specialized care involving an intense routine of treatment and home care. Several stressors could affect parents in this situation: the news of the diagnosis, the care routine required, and the impossibility of envisioning a normal development for the child; these are common stressors also for parents of children with other disabilities (Carvalho-Filha et al., 2018). In addition, in the case of CZVS, there is the fear of the baby's imminent death. Caring, therefore, tends to become exhausting, due to the new and continuous demands, which require a support network of relatives (especially parents) to cope with the situation (Barros et al., 2017; Barros et al., 2020; Pinheiro, 2018).

Coping comprises the set of strategies people use to adapt to adverse circumstances and can be understood as efforts made by individuals to deal with a stressor in a particular framework (Skinner, 2007).

Also according to the authors, the coping construct can be analyzed from different theoretical perspectives. A review of parental coping with chronically ill children, for example, found 21 different theories or models used to define and analyze coping (Didericksen et al., 2018).

This study was developed based on the assumptions of the Coping Motivational Theory (CMT), proposed by Skinner and Wellborn (1994), and expanded by Skinner et al. (2003). In this perspective, the concept of coping is based on studies on self-regulation, which consist of the ability to monitor one's behavior in response to different situational demands, considering knowledge of oneself and the environment (Ramos et al., 2015). Thus, coping refers to the individual's ability to adapt and develop strategies to deal with changes that happen in life and that threaten, challenge, or exceed their basic psychological needs – autonomy, relationship, and competence (Skinner, 2007).

The CMT conceives coping from a structural and hierarchical perspective, distinguishing three interrelated levels: (a) coping responses or behaviors; (b) coping strategies; and (c) coping families. At the base of this system are the coping behaviors, which are the individuals' responses (what they do or think) to deal with stressful situations. At a higher level are coping strategies, a categorization of coping behaviors based on their purpose, meaning, or functional value. And, at the very top level, there are coping families, which are classifications of coping strategies that make the connection with adaptive processes and are multidimensional and multifunctional (Skinner et al., 2003). In this theoretical model, 12 coping families were defined, which are organized according to the individual's perception of threat or challenge to the self or to the context: self-confidence, support-seeking, problem-solving, information-seeking, accommodation, and negotiation, which are families considered adaptive in the long term; and delegation, isolation, helplessness, escape, submission and opposition, considered maladaptive (Skinner et al., 2003; Vasconcelos & Nascimento, 2016).

The review by Ramos et al. (2016) pointed out that, in Brazil, research using the theoretical contribution of the CMT has been carried out since 2007, focusing on coping with health stressors in connection with children and adolescents ailments (cancer, sickle cell anemia, diabetes, and pain), for example (Guimarães et al., 2021); also with adults – mainly mothers – in connection with coping of prematurity and low birth weight, Down syndrome, and congenital anomalies of their children; and with health professionals (Reis & Paula, 2018). In addition, studies were also found in the country geared with the coping with stressors in the school and academic framework (Silveira et al., 2014), showing the possibilities of applying CMT in different frameworks and in different age groups (children, adolescents and adults). Only one study on maternal coping with the situation of having a child diagnosed with CZVS was found focusing on child care, carried out in the Southeastern region of Brazil (Cunha et al., 2021). Existing studies on coping in a similar context, with parents of children with disabilities and malformations, focus on the importance of social support (Medeiros et al., 2021; Padua & Junqueira-Marinho, 2021; Silva et al., 2022).

Thus, based on the above picture on CZVS and on the health impairment that it entails, it becomes relevant to understand and review the coping strategies used by mothers of children affected by the virus in order to deal with the consequences of this syndrome in children development and in their lives. The results of such an investigation may be useful for planning interventions with this population, helping to overcome a number of challenges encountered in this scenario.

Method

This article is an excerpt from research on parenting within the framework of CZVS. The study was approved by the Ethics Committee of the *Universidade Estadual da Paraíba* and registered under the number CAAE 75099417.1.0000.5187, protocol nº 4.081.654. It was funded by the *Fundação de Apoio à Pesquisa do Estado da Paraíba* (Fapesq, Research Support Foundation of the State of Paraíba). The ethical standards recommended by Resolution nº 466/12 of the National Health Council, which regulates human research, were complied with (Ministério da Saúde, 2012).

Ten mothers of children diagnosed with CZVS who were assisted in the public service specialized in rehabilitation in the city of Campina Grande, participated in this investigation. They were chosen based on convenience sampling. Before data collection, the investigator explained the survey procedures for obtaining consent, and the mothers who agreed to participate signed the Free and Informed Consent Form. The individual interviews were mostly carried out in the specialized public service or at the participants' homes, and were recorded and subsequently transcribed in full.

The semi-structured interview about coping was based on the script prepared by Vicente (2013), found in Pequeno (2019), which contained questions related to each of the 12 coping families proposed by the CMT and the thematic prevalence (or content repetition) was chosen as a "saturation" criterion; "saturation" usually occurs around the first 12 interviews (Guest et al., 2006). Finally, the analysis of the interviews was carried out based on the principles of categorical thematic content analysis (Bardin, 2016), aiming at identifying and understanding the mothers' coping strategies in the face of the different stressors associated with the CZVS, which were later grouped in the 12 coping categories proposed by the CMT.

Results and Discussion

The data referring to the sociodemographic profile indicated that the participants were aged between 24 and 38 years old. Most considered themselves as brown-skinned, Catholic, and claimed to be married or in common law marriage with the child's parent. Among the ten participants, five had completed High School. Using the Brazilian minimum wage as a reference to classify family income, most participants had an income equal to or greater than one minimum wage, reaching up to two minimum wages. Eight mothers claimed to receive government benefits to supplement their monthly income (Table 1).

Their children were born between the second half of 2015 and the first half of 2016; thus, at the time of the interview, they were between 2 and 3 years old, allowing us to infer that the mothers had been experiencing the syndrome stressors for some time. It is worth mentioning that the diagnosis initially informed to the mothers was microcephaly. Later, clinical researchers indicated that it was a syndrome caused by the Zika virus.

Based on the analysis of the interviews, four main stressors related to the experience of motherhood in connection with CZVS emerged and included: diagnosis; routine and child care; child treatment and development; and difficulty in accessing health services. The strategies used by the mothers, as well as the relevant coping families, will therefore be described, following the listed stressors. The participants were given fictitious names in order to protect their identities.

Table 1
Socio-demographic profile

Participants	Age	Marital status	Education	Race or ethnicity	Religion	Family income
Azaleia	31	C. Law marriage	Incomplete High School	Brown	Catholic	BPC*, *bolsa família*** city hall assistance and partner's income
Camélia	26	Married	Complete High School	Brown	Spiritualist	BPC
Cravo	26	C. Law marriage	Incomplete Higher Education	Brown	Evangelic	BPC and one minimum wage
Girassol	28	C. Law marriage	Complete High School	Brown	Catholic	BPC and one minimum wage
Lírio	24	Married	Incomplete High School	Brown	Catholic	BPC
Margarida	38	C. Law marriage	Incomplete Elementary School	Brown	Catholic	BPC and income less than the minimum wage
Orquídea	26	Married	Complete High School	White	Catholic	BPC and income less than the minimum wage
Rosa	31	Married	Complete High School	Brown	Evangelic	One minimum wage
Tulipa	33	Married	Complete High School	Black	Catholic	BPC and one minimum wage
Violeta	25	C. Law marriage	Incomplete Elementary School	–	Without religion	R$ 700,00

Note: *BPC: *Benefício de Prestação Continuada* (Continuous Cash Benefit) is the benefit paid by social security that aims to ensure a monthly minimum wage for people who do not have the means to provide for their own subsistence or to have it provided by their family. **Government benefit.

Diagnosis

The microcephaly diagnosis was considered one of the main mothers' stressors, and several strategies had been used to face the news, especially those linked to the coping family, such as searching for information – including asking others (*n* = 8) and searching for information on the internet (*n* = 7) – as can be seen in the following report:

> I went to this appointment with the doctor; when I got there I tried to find out. She said very little, that it was microcephaly, which she didn't even know, because it was right at the beginning, right? And in that, information was generated. I tried to find out with other mothers, and in the Whatsapp groups, computer (Camélia, 26 years old).

This family's strategy demonstrates a regulation action associated with the basic need for competence, in which individuals perceive the stressful situation as a challenge to their context and try to learn more about the situation to resolve it or mitigate its effects (Ramos et al., 2015). Considering the little scientific information available about microcephaly and CZVS at the time of children's birth, it is understandable why strategies belonging to the information search category were so recurrent among mothers.

Faced with the diagnostic stressor, although less frequent, other important adaptive strategies were also identified, linked to the "Accommodation" coping family, such as acceptance (*n* = 5), and "Search for support" through the search for comfort (*n* = 4). Although both families relate to the view of the stressful situation as a challenge, the "Accommodation" family refers to a challenge of the self and its strategies imply active attempts to modify the view of the stressful situation, considering the basic need for autonomy (Ramos et al., 2015). The search for support, on the other hand, is linked to the need for a relationship and portrays the individual's attempt to use available social resources to deal with the stressor (Ramos et al., 2015).

In a less adaptive scope, strategies linked to the coping family "Helplessness" were used, including confusion (*n* = 4), cognitive exhaustion (*n* = 2), passivity (*n* = 2), and emotional exhaustion (*n* = 1), as pointed out in the following statements: "At the time (of the diagnosis) I got totally lost; I didn't even look for information like that... I was totally lost; they didn't give me any information at all" (Rosa, 31 years old).

Rumination (*n* = 9), belonging to the "Submission" coping family, was a strategy used by some mothers to face the diagnosis given. Some mothers, for example, questioned the reason for the situation: "I put everything on my mind a lot: "will she walk?", "will she talk?"... And today I learned to conform, be it that God's will is done, if it has to be, it will be, if not... (Camelia, 26 years old). The use of this maladaptive strategy occurs in the face of the impact of the diagnosis given, being abandoned over time, which characterizes a process of assimilation.

The strategies belonging to the "Helplessness" family are associated with a view of the stressor as a threat to the self, specifically with regard to the need for competence. In this case, strategies linked to this family demonstrate the mothers' feeling of helplessness in the face of the diagnosis. The "Submission" family, in turn, also concerns a threat to the self, but in terms of the need for autonomy. In this connection, maternal strategies showed a passive and repetitive focus on the negative aspects of the diagnosis.

Thus, the impact of the diagnosis initially generated intense feelings of fear and helplessness, common to receiving diagnoses of a child's malformations, intellectual disabilities, and developmental disabilities in general, according to the literature on the subject (Coletto & Câmara, 2009; Lai et al., 2015; Li-Tsang et al., 2001; Santos & Pereira-Martins, 2016). At this time, the diagnostic stressor was perceived as a threat to the basic need for competence (Vasconcelos & Nascimento, 2016), being associated with the shock and feeling of helplessness caused by the news in the family system, since mothers expect to have a healthy child. This is also evidenced by the use of strategies linked to the family of "Helplessness", demonstrating that mothers, after the diagnosis, did not feel capable of taking care of the child. Despite this, over time, as the participants reported, these maladaptive strategies are abandoned as the mother adjusts to the situation and learns to deal with it, replacing them with adaptive strategies, as is the case of the strategy "ask others" linked to the coping family "Search for information".

The search for information took place, above all, through the exchange of experiences with other mothers who were facing the same situation. This signals a new understanding of the diagnostic stressor, now seen as a challenge that drives mothers to seek ways to understand and learn to deal with a CZVS child. The exchange of experiences with peers was pointed out by Barros et al. (2017) as one of the main coping strategies used to deal with the daily care of their CZVS children. Obtaining more information from other women who are in the same situation helps develop self-confidence and contributes to the process of building the meaning of this new stressful event thus demonstrating the importance of the interpersonal dimension for the coping process (Didericksen et al., 2018).

Routine and child care

The mothers' routine, which generally involved the CZVS child's daily care, was characterized as a stressor for the participants. To deal with daily life, coping behaviors of the "Problem-solving" family were reported, such as instrumental actions (*n* = 9) and planning strategies (*n* = 3), which shows that mothers were looking for active ways to deal with the stressor, according to the following comments: "take her to the physio, you know, which is more important, to the doctor... take care of her" (Violeta, 25 years old).

Coping strategies associated with the coping family "Search for support" were also observed, with the use of instrumental help strategies (*n* = 3) and contact search (*n* = 1). "When I'm at home, her father always helps me with him, for me, like, cleaning the house, washing clothes, things like that... And my mother always stays with him so I can take care of my things, my sister... stays with him." (Rosa, 31 years old). Strategies associated with the coping family were also identified such as the search for information by asking other people (*n* = 5). However, the presence of strategies associated with the "Helplessness" (*n* = 4) and "Escape" (*n* = 2) families indicated difficulties in dealing with the childcare routine, evidencing the perception of threats from this stressor both to the self and the context.

Therefore, the data show the use, for the most part, of adaptive strategies to face the childcare routine, revealing an active positioning of mothers in this context, mainly related to the use of strategies linked to the coping family "Problem-Solving". In this connection, mothers felt competent to solve the care demands, even though they used coping strategies "Search for support", to trigger their support network, which, in most cases, was formed by the spouse or by the extended family, in order to meet her basic relationship needs.

Given the intensity of the childcare routine, mothers sometimes ended up assuming this role in full, generating overload and stress. This fact can be understood from a sociocultural perspective that also associates motherhood with selflessness and sacrifice. In a study with mothers of children with CZVS, Mendes et al. (2019) also found that women played a key role in child care, being, in most cases, the only caregiver. Assuming this role usually made it impossible for them to carry out a work activity, continue their studies, or even maintain bonds of friendship due to the intense child-caring routine, a common aspect in connection with disabilities (Reis & Paula, 2018). In our study, however, despite the mother being at the core of child care, this task was sometimes shared with the partner and other family members.

Childcare and development

The use of family "Problem solving" coping strategies was frequently identified in the coping process with the treatment and development of the child, especially the instrumental action strategies (*n* = 13) and planning strategies (*n* = 1) observed that include the behaviors of stimulating the child, seeking professional help, seeking health treatments for the child, among others. These data indicate an active coping with the stressor, thus increasing the feeling of competence and favoring the adoption of new actions by mothers (Ramos et al., 2015).

The second most used strategy by mothers in the face of this stressor was associated with the "Accommodation" family, with the use of the cognitive restructuring strategy (*n* = 9), which implies a process of re-signifying the stressor in connection with the psychological need for autonomy. In this connection, the use of the coping behavior "visualizing the child's progress", which appears in the comments of seven of the participants, demonstrates the search to modify perceptions and feelings about the stressor: "I understand the development well, right? It's going well, only if he were calmer it would be better, well, learn faster, but he's fine, he's evolving" (Azaleia, 31 years old).

Regarding the child's development, there are also reports of the use of maladaptive strategies linked to the "Helplessness" family, such as cognitive exhaustion (*n* = 5). In connection with the coping family "Escape", the wishful thinking (*n* = 8) and mental withdrawal (*n* = 2) strategies were observed, as stated by one of the mothers: "I keep thinking if she hadn't been born with a micro, she would be already... walking, at school... with a friend. Sometimes I... I feel sad for her... that you keep thinking... of her wanting to do something and not being able to" (Girassol, 28 years old).

The mother's comments evidence the procedural character of coping. Initially, the coping strategy used was wishful thinking, through the expression of the desire for the child to develop and be a 'normal' child, fitting her idealization. Over time, however, there is an abandonment of this strategy in favor of acceptance, associated with the coping family "Accommodation".

On the other hand, while mothers adapt to the treatment and development of the child and restructure themselves cognitively, some continue to use the wishful thinking strategy, believing that, with the therapies, children will achieve certain goals set by them, such as walking, talking, and develop as a "normal" child. In this connection, God appears as the one capable of changing their children's condition, through a miracle, and such thoughts seem to drive mothers in the search for treatments for their children, averting their abandonment: "My expectation... I think he's going to sit, I even think he's going to walk, I don't know... God knows, but... my expectation of his development is this, that he'll be able to sit, crawl, walk" (Rosa, 31 years old).

In the Brazilian culture, especially in the Northeastern region, where the survey was carried out, there is a strong influence of religiosity in the population. Most participants (n = 9) declared to follow some religious guidelines, which probably influenced the use of religious/spiritual coping strategies. Although the CMT does not address religious coping as a specific category, theorists of this perspective postulate that religious/spiritual coping can facilitate problem-solving, help in seeking comfort, and prevent or alleviate negative emotional consequences in stressful situations (Foch et al., 2017), also allowing acceptance and giving meaning to the situation (Hatun et al., 2016). Thus, on the one hand, faith and hope keep the expectation of progression in the child's development, but on the other hand, it can generate frustration if such expectations are not met (Santos & Pereira-Martins, 2016).

Access to health services

Access to health services was characterized as a stressor in view of the difficulties faced by mothers; it was mainly associated with transport to get to the health service and to return home. Many mothers go to Campina Grande for specialized care for their children, and even those who lived in that municipality do not have their own car to get there. In the Paraíba scenario, Barros et al. (2017) indicated the transport provided by the municipalities as being the greatest difficulty for mothers of CZVS children, which was also verified in this investigation. Another difficulty reported in the mothers' statements was related to the long waiting time at the health institution.

The most used coping strategies were associated with the "Delegation" coping family, such as complaint (n = 9) and lamentation (n = 3); to the family "Helplessness", as cognitive exhaustion (n = 2); "Opposition", as the use of the strategy of blaming others (n = 2); and "Submission", with rumination (n = 1). In the narratives about coping with this stressor, it was noticed that the mothers repeatedly resort to the complaint strategy, mainly in relation to the lack of specialized services in the municipality where they live and in relation to the non-fulfillment of their responsibilities on the part of the public authorities, as mentioned hereafter: "It's an external treatment, it's a better treatment that the municipality doesn't have and they (Municipal Health Department) don't even want to provide a car, we (mothers) feel very bad."(Orquídea, 26 years old).

In this connection, complaints about the lack of specialized services in the municipality where they lived, the lack of adequate transport to travel to the health institution, and the perception of the lack of effective service from public policies generated feelings of exhaustion and impotence. Despite being classified as non-adaptive strategies, when considering the context, the failures of the country's Public Health System are evident; the health system was unable to offer comprehensive care according to the needs of these mothers and their families. Given this scenario, although they acknowledge several difficulties in connection with access to health services, mothers feel gratified for being able to take their children to medical and therapeutic visits, doing the best they can for their children.

In general, the analysis of the coping strategies used by mothers who give birth to a child with CZVS shows that there is an increase in the family's stress levels, with the direct caregiver usually being the most affected family member. In addition, the greater the child's prejudice, the greater the care demands and, consequently, the greater the parents' burden (Reis & Paula, 2018).

In this connection, when a child with CZVS is born, negative feelings are generated, first, because the child has a disability and, second, because it is a clinical condition whose consequences are still poorly known by mothers and even by science (Silva et al., 2016; Vicente et al., 2016). This factor, in addition to the severity of the syndrome, directly influences parents' abilities to deal with the diagnosis (Gomes & Piccinini, 2010).

In this study, the adaptive strategies identified in the mothers' statements were associated with the perception of stressors as challenges to the three basic needs proposed by the CMT. The diagnostic stressor, for example, challenged mothers' competence and relationship needs more, and the most used strategies were context-oriented. On the other hand, in the stressor "Routine and Childcare", challenges to the competence needs appear with greater incidence, revealing more strategies associated with the self. In the case of the stressor "Treatment and development of the child", challenges to competence and autonomy and strategies associated with the self were highlighted.

The maladaptive strategies used by mothers were mainly associated with the perception of stressors as a threat to the basic needs of competence and autonomy. In other words, when mothers used such strategies, it signaled that, at that specific time, they had a perception of low self-efficacy to deal with the situation, either because they did not see possible alternatives to be taken in the face of the threats imposed by the CZVS, or because, although they envisaged alternatives, those alternatives were not available. This occurred, for example, when mothers identified the need for treatment for a particular type of problem resulting from the syndrome, but this treatment was not available or accessible through the municipal health network. The stressor "Access to health services" stands out, considering that, unlike the other stressors, it presented only maladaptive strategies aimed mainly at the self, being considered a threat to the three basic needs: autonomy, competence, and relationship.

Over time, however, about two or three years after the birth of their CZVS child, mothers begin to play a more active role, using mainly adaptive strategies associated with the search for family support. This observation demonstrates the basic role of other people's support in caring for the child, and the importance of social support to these mothers, sympathizing with their feelings. In addition, the use of accommodation strategies, such as acceptance and cognitive restructuring, indicates that, over time, there is a mother's acceptance regarding the situation of raising a child with health problems due to the Zika virus infection.

In this connection, religiosity emerges as a coping facilitating element, giving meaning to the experience of motherhood, mainly because it allows the use of metaphors for having a child with CZVS as something special and a mission (Pinheiro, 2018); this element has been identified in this survey's participants' statements. Coping strategies related to religiosity are often used by mothers and fathers of children with congenital malformations, including CZVS, as indicated in the literature (Félix & Farias, 2018; Mendes et al., 2019; Silva et al., 2016).

Conclusion

This investigation described the main mothers' stressors emerging from having a child with CZVS and identified the main strategies used to face the challenges of having a child in this condition. The data obtained point to the need to consider the interpersonal and contextual dimensions in the coping process, since the strategies adopted were associated with the different actors involved, such as health professionals and family members, who interact in different scenarios, such as public services.

In this framework, despite the mothers' coping with predominantly adaptive strategies, some obstacles negatively impacted the coping process, such as the difficulty in accessing health services and ensuring adequate treatment for the child. Despite the existence of the Network of Attention to Persons with Disabilities at the national level and of a municipal network of intersectoral care of children with CZVS, there are still mothers facing many difficulties with regard to access to health services and the assurance of the best conditions for their child's development. Thus, helping the coping strategies of these mothers also implies authorities' initiatives to provide alternatives in this regard.

The government must, in addition to serving these children, offer interventions for their mothers to expand the coping strategies and helping them overcome the numerous stressors involved in the motherhood of a child with the syndrome. In this connection, creating contexts for therapeutic dialogue among these mothers can help the exchange of experiences, which, in turn, would enhance the development of adaptive strategies, as evidenced by the mothers in our sample, due to the possibility of being heard and understood by other women who share the same anxieties and difficulties. Thus, the results of this investigation, as a whole, indicate the need to enhance public health policies to ensure those children's access to specialized treatments, as well as point out the importance of interventions that help mothers and children's family members to adopt strategies for more adaptive coping in connection with CZVS.

Although our investigation has not used a longitudinal design, it was possible, based on the mothers' reports of what happened at different times of contact with the syndrome, to understand the procedural dimension of coping. Thus, it was found that some strategies, mostly maladaptive, were used at first, soon after the diagnosis news. Therefore, over time, based on the development of certain skills by the mothers, these strategies were abandoned and replaced by more adaptive ones such as acceptance and cognitive restructuring. Further research with this population will be able to assess the long-term effects of mothers' coping on their mental health.

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Contributors

V. C. PEQUENO contributed to the data collection and analysis and writing of the article. S. M. M. BARROS, F. P. RAMOS and C. LEWIS contributed to data analysis and writing of the article.