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Parental Involvement with Children with Congenital Zika Virus Syndrome during the COVID-19 Pandemic

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ABSTRACT – This qualitative, cross-sectional, multiple case study investigated parental involvement with children with Congenital Zika Virus Syndrome during the COVID-19 pandemic. Individual interviews were performed with eight mothers and fathers (four nuclear families). A deductive thematic analysis was conducted, considering components of the concept of parental involvement: interaction, availability, and responsibility. The results revealed that, in some families, mother and father shared interaction activities. In others, however, the mother predominantly performed them. Differences in availability associated with parental work hours were identified, particularly in lower income families, due to the intensification of economic difficulties during the pandemic. Regarding responsibility, a traditional division of gender roles was mostly observed, resulting in maternal overload during COVID-19.

KEYWORDS: parent-child relationships; Congenital Zika Virus Syndrome; COVID-19.

Envolvimento Parental com Crianças com Síndrome Congênita do Zika Vírus Durante a Pandemia de COVID-19

RESUMO – Este estudo de caso múltiplo, qualitativo e transversal investigou o envolvimento parental com crianças com Síndrome Congênita do Zika Vírus durante a pandemia de COVID-19. Realizou-se entrevistas individuais com oito mães e pais (quatro famílias nucleares). Conduziu-se análise temática dedutiva, considerando componentes do conceito de envolvimento parental: interação, disponibilidade e responsabilidade. Os resultados revelaram que, em algumas famílias, mãe e pai compartilhavam as atividades de interação, ao passo que em outras, a mãe predominantemente as realizava. Houve variações na disponibilidade associadas à jornada de trabalho parental, particularmente nas famílias com menor renda, devido à intensificação das dificuldades econômicas na pandemia. Quanto à responsabilidade, observou-se majoritariamente uma divisão tradicional de papéis de gênero, repercutindo em sobrecarga materna durante a COVID-19.

PALAVRAS-CHAVE: relações pais-criança; Síndrome Congênita do Zika Vírus; COVID-19

Historically, literature on childhood and family has emphasized mother-child relationship, to the detriment of father-child relationship (Lamb et al., 1985; Pleck, 2010; Rankin et al., 2019). However, in the last four decades, different studies have begun to investigate paternal involvement, differences and similarities between mother and father behaviors, and how interactional patterns are co-constructed by parents in the family's daily life (Schmidt et al., 2019; Schoppe-Sullivan & Fagan, 2020; Yavorsky et al., 2015).

According to Lamb et al. (1985), three components characterize the concept of paternal involvement: interaction (activities carried out face to face, i.e., in direct contact with the child), availability (being physically and emotionally accessible to the child) and responsibility (ensuring health and providing the necessary resources for the child). Recent research has adopted this conceptual framework to explore paternal involvement in relation to maternal involvement, referring to it as parental involvement (Kotila et al., 2013; Wängqvist et al., 2022).

This more contemporary perspective, which considers the notion of parental involvement, is supported by evidence that both maternal and paternal behaviors are similarly associated with healthy child development (Pleck, 2010; Rankin et al., 2019). In addition, there has been a greater convergence in the way mothers and fathers engage in childcare, particularly in some Western societies (Kotila et al., 2013; Schmidt et al., 2019). However, despite these indications of greater convergence, women remain the primary caregivers in the family (Schoppe-Sullivan & Fagan, 2020; Wängqvist et al., 2022).

Mothers of children with disabilities, in particular, tend to take on the leading role in caring for their children (Ambrogi et al., 2020; Dias et al., 2020), which generates an overload for them (Kuper et al., 2019; Vale et al., 2021; Wyk & Leech, 2016) and, consequently, an increase in the risk of developing common mental disorders (e.g., depression and anxiety) (Rankin et al., 2019; Santos & Farias, 2021). When considering parenting in families of children with congenital Zika virus syndrome (CZVS), the trend seems to be the same (Azevedo et al., 2021; Dias et al., 2020). In fact, most studies on the topic only focus on the mother, who is usually the primary caregiver for the child (Cunha et al., 2022; Matos & Silva, 2020; Santos & Farias, 2021). In an integrative review on CZVS and its impacts on families, Melo et al. (2023) analyzed 31 articles, of which only two investigated aspects related to paternity and, in both, only fathers participated. This finding reveals a gap in studies with the joint participation of mothers and fathers, aiming to understand the particularities of these families' relational dynamics.

The CZVS is a spectrum of congenital abnormalities observed in children as a consequence of maternal infection with the Zika virus (ZV) during the gestational period (Azevedo et al., 2021; Melo et al., 2023). ZV is transmitted mainly through the bite of the female *Aedes aegypti* mosquito (Lesser & Kitron, 2016), but the infection can also occur through vertical transmission (i.e., when the virus crosses the placental barriers, causing congenital disease in the fetus) (Santos & Farias, 2021). For families with children who present more severe clinical conditions, such as microcephaly, seizures, psychomotor, visual and hearing impairments, constant care is required (Santos & Farias, 2021), so that the family's daily routine is shared with several health professionals (Dias et al., 2020; Félix & Farias, 2018; Lima & Souza, 2021).

In Brazil, the Zika epidemic outbreak began in 2015, with a predominance of cases in the Northeast region of the country (Félix & Farias, 2018), especially in the states of Bahia, Pernambuco, and Rio Grande do Norte (Lesser & Kitron, 2016). Although the public health emergency has ended, the repercussions of this period continue to be experienced by children with CZVS and their families (Matos & Silva, 2020). As children grow, new demands arise in different areas, such as inclusion, accessibility, education, and health (Melo et al., 2023). In critical events, such as during a pandemic, these families may face additional challenges related to their fundamental rights, especially the right to health, particularly in the Brazilian context, due to the high prevalence of both CZVS and COVID-19 (Matos & Silva, 2020; Melo et al., 2023; Vale et al., 2021).

Health measures adopted to contain the spread of COVID-19 were associated with the disarticulation of support networks, creating difficulties in accessing health, education, and social assistance services (Matos & Silva, 2020; Silva et al., 2020). In this sense, the fragility of social support seems to have intensified the challenges faced by families of children with CZVS even before the pandemic, causing negative consequences to caregivers' mental health and to parenting (Dias et al., 2020; Lima & Souza, 2021; Vale et al., 2021). Furthermore, other factors triggered by the pandemic affected the relational dynamics of families, such as the remote work arrangements, reduced income, and unemployment (Matos & Silva, 2020; Silva et al., 2020).

Thus, over a period of approximately five years, children with CZVS and their families began to experience a second public health emergency, with exposure to uncertainty, fear, anxiety, impoverishment, and, potentially, illness and death (Ambrogi et al., 2020; Matos & Silva, 2020). Given this context, the aim of the present study is to investigate parental involvement with CZVS children during the COVID-19 pandemic, considering experiences reported by both mothers and fathers.

METHOD

Participants

Eight mothers and fathers of children with CZVS participated in this study, representing four nuclear families. On average, the mothers were 29 years old (SD=5.7), and the fathers were 36 years old (SD=9.2) (additional information about the parents can be found in Table 1). As for the children, at the time of the interviews, they were between 4 and 5 years old (M=4.2; SD=0.4) and lived with their mother and father in the same household, in Salvador/BA (additional information about the children can be found in Table 2).

The families in this study were part of a broader research project entitled "Parenting and Coparenting in Families of Children with Microcephaly: Repercussions of the COVID-19 Pandemic". The inclusion criteria used were: a) families of children with CZVS who, at the time of data collection, were between 3 and 6 years old; b) mothers and fathers aged 18 or over at the time of the child's birth. Furthermore, the following exclusion criteria were applied: a) families that did not have access to the internet allowing contact by video call; b) families that did not permit the interview to be recorded; c) families that did not reside in the Brazilian territory; d) families of children with congenital malformations of the central nervous system, such as microcephaly, not associated with ZV infection. Based on the inclusion and exclusion criteria described above, the number of families participating in this study is in line with that proposed by Stake (2006), who recommends the inclusion of at least four cases in a multiple case study, in order to safeguard the advantages of this research design.

Table 1 *Characterization of Mothers and Fathers*

Cases	Parents	Age	Education	Family income
Case A	Mother	39	Graduate Degree	R$10.000
	Father	43	Bachelor's Degree	
Case B	Mother	25	High School	R$2.000
	Father	25	High School	
Case C	Mother	27	High School	R$1.000
	Father	29	High School	
Case D	Mother	26	High School	R$1.000
	Father	47	High School	

Table 2 *Characterization of Children*

Case	Age	Gender	Weekly consultations	Types of service	School
Case A	4	Female	At home	Physiotherapy, Speech Therapy, Occupational Therapy and Pedagogy	Regular School, carrying out private pedagogical activities
Case B	4	Female	Suspended	Physiotherapy, Speech Therapy	Regular School, with classes suspended
Case C	5	Female	Partially suspended and reduced	Physiotherapy, Speech Therapy, Music Therapy and Equine Therapy	Regular School, with classes suspended
Case D	4	Male	Partially suspended and reduced	Physiotherapy, Speech Therapy, Occupational Therapy, Neurophysiatry and Psychology	Regular School, with classes suspended

Design, Procedures and Ethical Considerations

We adopted a qualitative, narrative, cross-sectional multiple case study to investigate parental involvement with children with CZVS during the COVID-19 pandemic. Qualitative multiple case studies allow for in-depth exploration, based on the analysis of the experiences of different individuals in diverse contexts, providing a greater understanding of the complexity and particularities of the phenomenon of interest (Sehn et al., 2022; Stake, 2006).

Participants were recruited with the support of *Associação aBRAÇO a Microcefalia* (a private nonprofit civil association) that shared on its communication channels an invitation to families of children with CZVS to participate in the study. After the mother or father expressed interest in participating in the study, an initial contact was made via WhatsApp in order to also verify the availability of the other parental figure.

After confirming the families' interest and analyzing the inclusion and exclusion criteria, each participant was called individually to schedule an interview, considering their time availability. The interviews were conducted by a senior undergraduate Psychology student , after receiving training in data collection provided by a PhD in Psychology, expert in family relationships in childhood (both co-authors of this study). Data were collected between October and December 2020, a critical period of the pandemic in Brazil (Silva et al., 2020).

Due to the social distancing measures in force at the time, interviews were conducted via videoconference (Zoom platform). The interviews were structured and conducted in a semi-structured manner, recorded in audio and video, lasting between 57 and 92 minutes (M=72; SD=17.5). In order to preserve privacy and avoid potential conflicts between the mother and father, the interviews were conducted individually (Reczek, 2014).

The broader project from which this study is derived was approved by the Research Ethics Committee of the *Universidade Federal do Rio Grande* (CAAE: 35981220.5.0000.5324; Approval Number: 4.216.349). In compliance with ethical requirements, all participants completed the procedures relating to the Free and Informed Consent Form (FICF).

Instruments

(1) Sociodemographic and Clinical Data Sheet: to collect information about the mother and father (age, residence, occupation, level of education and income), and about the child (age, history of CZVS diagnosis and health condition).

(2) Interview on Child Development and Family Relationships: to collect data on the child's individual characteristics and general information about routine care and family interactions, as well as the repercussions of the COVID-19 pandemic on parenting, among other aspects.

The instruments were developed for the broader research project by one of the co-authors of this study, with expertise in family qualitative studies, and were based on the Family Demographic Data Sheet, the Interview about the Experience of Motherhood and the Interview about the Experience of Fatherhood, adopted in the CRESCI Project and designed by the Childhood and Family Center (*Núcleo de Infância e Família*) at the *Universidade Federal do Rio Grande do Sul* (instruments available in Schmidt, 2018). The instruments were subsequently submitted for assessment by a specialist in rights of people with disabilities. This professional suggested a few adjustments to the instruments, which were made by the investigators prior to submission to the Research Ethics Committee.

Data Analysis

All interviews were recorded and transcribed *verbatim*. In order to conduct this study, individual and in-depth reports of all cases were produced. Subsequently, the verbalizations of mothers and fathers were subjected to thematic analysis (Clarke et al., 2019). A deductive approach was used in the analysis, coding the data according to the three components of the concept of parental involvement (Lamb et al., 1985): interaction, availability and responsibility.

After immersion in the data, the narratives that provided evidence of parental involvement were coded. The data were analyzed at the dyadic level (i.e., considering reports of maternal involvement in relation to reports of paternal involvement, and vice versa), which favored an understanding of the unique dynamics of each family's relational context (Schmidt et al., 2019).

The reports of each single case were composed of maternal and paternal verbalizations about parental involvement, and were written in detail to help readers decide on transferability, i.e., to what extent it is possible to use the findings of this study to understand similar cases in other contexts (Sehn et al., 2022). These procedures enabled cross-case analysis (presented in the Discussion), as proposed by Stake (2006).

RESULTS

In the following, we present each single case report, with emphasis on the particularities of the families with regard to parental involvement. In order to ensure confidentiality and privacy, fictitious names were given to the participants. To indicate maternal and paternal verbalizations, the letters "M" and "P" were included, respectively, at the end of each vignette.

Case A (Mother Adriana; Father André; Child Ana)

Adriana and André lived with their daughter Alice before the birth of their youngest child, Ana, who was 4 years old at the time of data collection and had been diagnosed with

CZVS. Although planned, pregnancy was a turbulent time for the family, due to Adriana's infection with ZV.

Regarding interaction, mother and father participated in face-to-face activities with the child. Both reported working in partnership, sharing care and leisure tasks with their daughters. Due to CZVS, Ana had not developed verbal language, but she used different forms of communication: "She expresses herself a lot by screaming" (M); "She starts moving her legs, arms, and her eyes are alert, so you realize that she [is] interested in something" (F). Part of Ana's care was the responsibility of Adriana before the pandemic: "Therapies, school, I'm always responsible" (M). The father, in turn, took on the sleep routine: "I put her to sleep. When she wakes up at night, I'm the one who stays with her" (F). Both considered that the most rewarding moments of interaction occurred during leisure and play: "Playing with them [daughters] and mainly interacting with them" (M); "Watching a movie, then we watched movies together" (F). With the onset of the pandemic, the couple did not mention changes in the division of their caring tasks, although they did indicate an increase in the time spent interacting with the child: "We started spending more time with her" (M). It is worth noting that neither parent mentioned dissatisfaction with the division of tasks or overload, even though the pandemic changed the routine and required adjustments to the way in which interactions occurred.

Regarding availability, both mother and father were accessible to the child. In this sense, they were dedicated to monitoring and administering the medications that Ana took daily. At the time of the interview, Adriana and André were working predominantly remotely, with flexible hours. In addition, the mother's work hours had been reduced. Thus, greater maternal and paternal availability was identified during the pandemic: "I started to stay more time at home. . . Adriana started to stay more time at home. . . and she was also able to adjust to this way of working remotely" (F). Due to greater time available at home, there was an intensification of involvement in family interactions, which was associated with positive changes in the child's behavior: "[Ana] started to do less therapy. We saw better results . . . She is much more active, she is much more communicative" (M); "I think she is super happy, because we are spending more time at home" (F).

Regarding responsibility, particularly, domestic activities (i.e., cleaning and organizing the house, preparing meals, etc.) were performed by hired employees. Decision-making on topics related to the child was described as a task shared by the couple: "We sit down to talk about different things, to consider the pros and cons" (M); "We work a lot together" (F).

Regarding finances, the father's income was used to the family's sustenance, while the mother's income was set aside for savings. With the pandemic, mother and father were concerned about the possibility of Ana contracting COVID-19. Thus, there were changes in the work and transportation logistics of the employees, in addition to adherence to health protocols, to reduce the possibility of virus transmission: "We were the ones who provided transportation [for the employees], so we took every precaution to ensure that there was as minimal contact as possible" (F). There was also a temporary suspension of some of Ana's health-related services at the beginning of the pandemic, which had already been resumed at the time of data collection and were performed at home by speech therapy, physical therapy, and occupational therapy professionals. In addition, the family hired a private teaching service, because classes at the regular school had been discontinued.

Case B (Mother Brenda; Father Bruno; Child Bia)

Brenda and Bruno had no plans to become parents when they learned about pregnancy. They started living in the same house after Bia was born. When the interviews were conducted, the family was receiving the Assistance Benefit for Persons with Disabilities. Additionally, during the pandemic, they started receiving Emergency Financial Aid (a government benefit granted to guarantee a minimum income to families in situations of social vulnerability during the COVID-19 pandemic). Bia was 4 years old when the study was carried out.

CZVS was discovered in the eighth month of pregnancy. Mother and father reported feelings of fear and insecurity, associated with a lack of knowledge about the possible repercussions of the condition: "I experienced mourning for the idealized child . . . And then we had to reformulate everything, everything we imagined" (M). Throughout the first years of Bia's life, Brenda received psychological support due to Generalized Anxiety Disorder, which was discontinued during the pandemic.

Regarding interaction, the mother was primarily responsible for her daughter's care, as well as for playful moments. The parents mentioned different ways in which their daughter expressed herself during interaction, given that Bia did not verbalize: "I can already tell when she cries to get each thing" (M); "[Bia] starts laughing out loud when she wants to play" (F). The pandemic intensified the maternal overload: "[Bia] had to stay indoors. So, there was a period when she was very irritable, but then I realized that she was also a little anxious . . . So, for me, the workload doubled" (M).

On the other hand, during this same time, the father's more active participation (although in the role of assistant) seemed to be limited to weekends: "I usually helped her [Brenda] on weekends" (F). Bruno seemed to link the division of childcare to paid work-related aspects: "From Monday to Friday I'm working" (F). During the week, at times the father participated in leisure activities: "I play with her, and I really like watching anime [cartoons]" (F).

Concerning availability, the mother reported that when Bia was born, she had to drop out of college to dedicate herself to caring for her daughter. Similarly, the father also interrupted his studies in a vocational training school to dedicate himself to supporting the family financially. Due to the syndrome, the daughter took medication three times a day and was fed through a tube, which required great availability from the caregivers to prepare and administer the medications and the diet. Brenda complained about Bruno's availability: "He comes home tired, wants to lie down, but she's there wanting to play with him and he just goes by" (M). Similarly, Bruno stated that during the week he was not always available: "I don't play with her every day, because there are days when I get home very tired" (F). During the pandemic, the mother had to be more available to her daughter, due to concerns about her change in routine: "It seems like all the external roles we had were transferred to me. I had to be Bia's teacher, her therapist, . . . her doctor, I had to be Bia's mother" (M). On the other hand, there were no indications of changes in paternal availability during the pandemic.

Regarding responsibility, decisions on topics related to the child were predominantly made by the mother, although there was dialogue between the couple: "I have an opinion, but the final decision is always made by Brenda" (F). Both mother and father worked and reported sharing financial responsibilities, although most of the family income came from the father's salary: "We split the bills in a fair manner over here" (F). With respect to care responsibilities during the pandemic, the mother expressed concerns about Bia's social distancing, which required her to be more available to interact with her child: "She started sleeping more . . . I had to start thinking about things to distract her and create a new routine" (M). Responsibilities regarding household chores were also assumed mainly by the mother.

In relation to the child's health care, Bia received home care and had some in-person multidisciplinary care before the pandemic. However, due to the spread of COVID-19, her mother expressed concerns and decided to stop providing external care: "We decided to take a break [referring to care] . . . she has half of her lung affected . . . so she was in a high-risk group" (M). Bia also had her classes suspended, which was related to the mother's feeling of being overwhelmed, affecting parental involvement in the context of COVID-19. It is worth noting, however, that the mothers' reports revealed exhaustion even before the pandemic, due to the busy daily routine, including commuting to school and specialized care: "The pandemic came to give me a little break, like, from my busy routine" (M).

Case C (Mother Carol; Father Caio; Child Clara)

Carol and Caio lived together before Clara was born. However, pregnancy was not planned by the couple and was unwanted by Carol: "I had no plans to have a child in my life, so it was an unwanted pregnancy" (M). The diagnosis of CZVS was discovered in the seventh month of pregnancy. Mother and father described this period as "painful" (M) and "scary" (F). The family was receiving Assistance Benefit for Persons with Disabilities when the interview was conducted. At that time, Clara was 5 years old.

Regarding interaction, mother and father reported that, because their daughter had low vision and had not developed oral communication due to CZVS, they sought ways to interact through hearing: "She doesn't speak, her vision is impaired . . . She has great hearing capability, she listens to voices a lot, like if I talk or play, she laughs" (M); "I interact with her through music . . . Every time I play, she laughs" (F). Both reported weaknesses in paternal involvement, especially in childcare tasks and leisure activities: "Basically I do everything . . . Bathing, I always ask [the father] to give her a bath, but [he] doesn't" (M); "She [Carol] is the one who takes complete care of Clara . . . I rarely take care of Clara" (F). Carol expressed dissatisfaction with the weak paternal involvement, reporting feelings of overload: "It ends up being exhausting for me. I'm afraid it will get to a point in which I can't take it anymore, then I'll have to seek for care for me and for her [Clara]" (M).

In addition, the experience of the pandemic along with concerns about her daughter's health resulted in psychological issues for the mother, who even resorted to self-medication, seeking relief from her symptoms: "I was afraid that she [Clara] could get COVID and die. So, I think that was what triggered my anxiety. I had trouble sleeping, insomnia . . . I started taking medication" (M). The father also reported experiencing symptoms related to his mental health: "I feel some pain, I don't know if it's because of stress . . . Anxiety, I have too much of it" (F). Caio recognized the disparities between maternal and paternal involvement, noting that the latter did not seem to change in the context of the pandemic, and he also mentioned his own dissatisfaction in this regard: "I wouldn't say satisfied. I recognize that I could do something more . . . I believe I could be more present" (F).

Concerning availability, discrepancies were also identified between maternal and paternal involvement, with the mother being the figure with the greatest presence in the child's life. Due to CZVS, Clara used medications regularly and was fed a soft and liquid diet, which required great availability for childcare tasks. Since before the pandemic, the absence of the father was a complaint made by the mother: "If both [father and mother] have free time, both have enough time to take care of her. It doesn't have to be just me" (M). Caio attributed his unavailability to his lack of skills in performing childcare tasks, and also to his paid work situation:

"She [mother] is more skilled in relation to feeding Clara, including because of her training. Because some professionals taught her [in appointments and therapies] how to do it, she knew more than me" (F). With the pandemic, Caio requested to work remotely due to fear of contagion by COVID-19. However, he was terminated after three months. Despite being unemployed, Caio informally performed other paid activities. Although the father spent more time at home during the outbreak, his availability remained limited, which was a source of conflict between the parents.

Regarding responsibility, both mother and father were involved, but in different spheres. The mother assumed exclusive responsibilities related to childcare and was the main person responsible for making decisions on topics related to her daughter: "We [the parents] talk, but what always prevails is what I say" (M); "She [Carol] is the person who controls everything related to Clara" (F). The father, on the other hand, took on the financial support: "There was never lack of food or medicine, you know?" (F). Caio participated in a secondary role, only when asked: "When she [the mother] had some difficulty, when she had to bring some material, then I would go [to appointments and therapies] and help her" (F).

Due to the pandemic, both the mother and father expressed concerns about the child's health. This is because, in relation to multidisciplinary care, there was a significant reduction in the frequency of appointments regarding some therapies, as well as the suspension of others. Additionally, Clara was not attending school. Regarding changes in their daughter's behavior due to the shift in routine, the caregivers reported their perceptions: "She [Clara] is more alert, she is more cheerful, she is interacting more. I believe that before the pandemic, due to the rush, she was more tired" (M); "Before the pandemic, because she [Clara] went out more often, she was more tired, she would fade away. Now, not anymore, she is more alert. I believe that she is also much more stressed" (F).

Case D (Mother Diana; Father Douglas; Child Davi)

When she got pregnant, Diana and Douglas had been together for about three years. Shortly before the pandemic outbreak, the couple had their second child, Danilo, who was born prematurely. At the time of data collection, the family was receiving Assistance Benefit for Persons with Disabilities and Emergency Financial Aid. Diana and Douglas learned of Davi's CZVS diagnosis when she was in her eighth month of pregnancy. Their feelings and reactions to the news were shock, pain, and denial: "It was a terrible shock, I thought I was going to go crazy" (M); "I couldn't believe it . . . I felt really bad too" (F). When the interviews were conducted, Davi was 4 years old.

In relation to interaction, both mother and father were involved with the child, sharing and actively participating in childcare and leisure activities: "He says, 'I'm going to stir the food over there and you feed him' [mother expressing the father's verbalization] . . . When he bathes him, I dry him and brush his teeth, but that's not a rule" (M). Davi had low vision and had not developed oral communication due to SVZC, so the parents mentioned how they communicated with their son during interaction: "When he's upset, he moves his legs a lot and screams . . . We already know his way of saying he's happy" (M); "When we play instruments here, he laughs his head off" (F). The couple did not complain about maternal or paternal overload: "It's not heavy, not at all" (M); "We try to share the tasks so that neither of us feels overwhelmed" (F). During the pandemic, the child became more irritable, possibly due to changes in routine and spending more time at home. Thus, both mother and father sought alternatives for Davi to have contact with the outside world, while taking precautions to avoid the new coronavirus infection: "We live in a condominium. So, we can go in and out quickly, take him out to sunbathe" (M).

The pandemic changed little the availability already established by the parents. With the preterm birth of her second child, Diana decided to resign from her job, for fear of her children contracting COVID-19: "There were two risk groups at home [referring to the children], so I preferred to stay home" (M). On the other hand, Douglas started to spend more time at home, given that he worked in the entertainment sector: "I became more of a homebody, taking care of the child, being closer" (F). The father also reported a closer relationship with his son: "I am 100% close to him, making the most of it . . . It was 90% [before the pandemic], but it is now 100%" (F). At the time of the interview, both mother and father maintained physical and emotional accessibility to the child. Due to CZVS, Davi was taking medication regularly and using a soft diet, which required greater time availability from the caregivers. When asked about which parental figure dedicated more time to childcare, the narratives were similar: "Both of us" (M); "We [mother and father] spend all our time with him [Davi]" (F).

Concerning responsibility, both reported concerns about their son's health, maintained dialogues and shared decisions on topics related to Davi. The family's financial organization was managed exclusively by Diana: "I'm the one who pays the bills" (M). It was noted that responsibilities were shared, so that Diana was responsible for scheduling her son's appointments, while Douglas took him to appointments: "'I'm scheduling a nutritionist office visit for Davi' [mentioning a statement directed at his father]. He already knows that he's the one who's going to take him" (M); "She takes care of everything properly . . . I'm the one who does the practical work: 'I have to take him to the doctor tomorrow at two in the afternoon'. Then I'll take him, you know?" (F). With the onset of the pandemic and the birth of their second child, the couple expressed concerns about ensuring care and preserving the health of their children: "We've become more homely, me and her and our children, because we worry a lot about it [COVID-19]" (F).

Regarding the child's health care, the frequency of specialized care was reduced, which changed the family routine: "Our whole life was full of this [specialized care]. . . Everything was based on this, on stimulating him" (M). In this sense, the mother expressed concerns about Davi's social distancing: "He gets a little stressed [referring to her son], because he's not used to it. He was always going out, and now we stay home all the time" (M). In general, this required greater availability and interaction with the child during the pandemic. Davi was enrolled in school the year the interview took place, but did not attend due to school shut down.

DISCUSSION

Together, the results allow us to highlight similarities and particularities regarding parental involvement in families of children with CZVS during the COVID-19 pandemic. First, to better discuss the experience of these families during the pandemic, it is important to revisit their experiences a few years earlier, when their children were diagnosed with CZVS, and the participants reported reactions of fright, fear, and disbelief, in line with the findings from other studies on the subject (Cunha et al., 2022; Melo et al., 2023; Santos & Farias, 2021; Wyk & Leech, 2016). This suggests that the birth of a child with CZVS requires parents to deal with the real baby, who, in these cases, is even further away from the baby idealized during pregnancy (Santos & Farias, 2021; Wyk & Leech, 2016). Cunha et al. (2022) also discuss that the presence of CZVS has an impact on child development, including social interaction, which can affect parental involvement, as identified in the present study.

With respect to interactions, in families with little or no task sharing (cases B and C), both before and during the pandemic, it was observed that mothers were primarily responsible for childcare, while fathers were more in charge of playful interactions (e.g., playing, watching cartoons, playing instruments). During the pandemic, fathers A and D experienced changes in their paid work hours and reported that they were enjoying more time at home, which may have favored carrying out more face-to-face interaction activities during this period. Likewise, there was a change in the routine of children, who before the pandemic were involved in many specialized care and, with the suspension of these activities, stayed at home, requiring greater interaction and, consequently, availability of caregivers. Thus, the report of greater maternal overload was present in families in which mothers took up these responsibilities with the children (cases B and C), in contrast to families that shared this care (cases A and D).

In this sense, considering the specificity of caring for children with CZVS, several studies indicate that mothers are the ones who mostly perform this function (Cunha et al., 2022; Félix & Farias, 2018; Matos & Silva, 2020; Vale et al., 2021), whereas fathers are perceived as assistants, given that they tend not to take part in childcare tasks (Dias et al., 2020; Silva et al., 2022), despite the importance of their presence for the socioemotional development of children (Cunha et al., 2022). Therefore, women who are exclusively responsible for caring for their children with disabilities may experience increased physical and emotional suffering (Kuper et al., 2019), which was enhanced during the pandemic (Matos & Silva, 2020; Vale et al., 2021) and was observed in our study, especially in case C.

According to Matos and Silva (2020), COVID-19 brought additional concerns to mothers of CZVS children, especially those on low income, such as the need to ensure family's food security, anxiety about possible infection with the virus, and fear of not having priority in case of hospitalization, highlighting the marginalization of people with disabilities in public policies. Furthermore, for Silva et al. (2022), COVID-19 exacerbated and amplified gender hierarchies, because it was women who took on the majority of childcare tasks and household chores.

The greater perception of overload faced with the intersection of two epidemics, namely ZV and COVID-19, may also be associated, as stressed by Vale et al. (2021), with the fact that institutions serving as a support network for families had to suspend, at least face-to-face activities (as seen in schools) or reduce the frequency of care (as seen in health services), which was also identified in current study. Therefore, with the pandemic, families reported the need to redouble their caregiving efforts and develop psychomotor stimulation activities for their children, without being able to count on the usual support network (especially in cases B and D), which tends to be a protective factor for the development of children with CZVS (Lima & Souza, 2021; Santos & Farias, 2021). However, it is important to highlight the particularities of family A. Greater availability of financial resources may allow the hiring of outsourced services (e.g., maid, nanny and teacher), which tends to contribute to preventing the feeling of overload in childcare and injustice in the division of family labor (Schmidt et al., 2019).

Regarding availability for children, the lower paternal involvement was, in part, associated with the father's paid working hours, as identified in other studies with families of children with CZVS (Dias et al., 2020; Félix & Farias, 2018; Melo et al., 2023). According to literature and the parents' reports, this is due, in part, to the crisis caused by the

pandemic in Brazil, which generated significant impacts on the labor sphere (Silva et al., 2020; Vale et al., 2021). Among the repercussions on the work dynamics for the parents in this study, unemployment was observed (case C), as well as reduced working hours and, consequently, income (case D) and, in a more privileged scenario, reduced working hours and adherence to the remote work condition (case A), or the continuation of the work dynamics that existed before the pandemic (case B).

In families in which there was a report of lower paternal availability (cases B and C), fathers also mentioned lack of ability to perform caregiving activities compared to the mother, which contributed to a decrease in their emotional availability. As an example, the father from family C stated difficulty in caring for his daughter when compared to the mother, which is in line with findings from the study by Yavorsky et al. (2015). According to this study, in families with young children, men felt less skilled than their wives to provide childcare. Especially in families with children with disabilities, some mothers also reported feeling insecure about delegating childcare tasks to fathers and to other family members (Wyk & Leech, 2016). Thus, linked to the gender stereotype that women provide childcare more skillfully, fathers tend to be less involved in this kind of interactions (Schmidt et al., 2019), which is especially pronounced in the presence of disability, when the father may be less emotionally available to care for and educate the child (Félix & Farias, 2018; Santos & Farias, 2021).

This can be explained, in part, by the fact that after the birth of a baby, the mother is usually the most present figure at home, whether for biological reasons (puerperium and breastfeeding), the choice of maternal care arrangement (more common than the paternal care arrangement), or the difference in duration between maternity and paternity leave (Schoppe-Sullivan & Fagan, 2020; Yavorsky et al., 2015), particularly in Brazil (Schmidt et al., 2019). Furthermore, the news of a congenital malformation can lead parents to emotionally disengage from the baby, as the idea of a perfect child is disrupted, due to greater presence of risks to child development, as identified by Cunha et al. (2022), which can contribute to paternal withdrawal in terms of availability and interaction with the baby.

It is also worth noting that the pandemic intensified conflicts between parents, particularly in case C, with the most frequent reasons for arguments being the asymmetric division of family labor and the unavailability of the father, who was unemployed, to interact with his daughter. In this sense, there are indications in literature that the father's experience of unemployment affects his identity as a man, reflecting negative effects on the relationship within the family (Souza & Benetti, 2008). These data corroborate the idea that the experience of financial concerns in the family system tends to jeopardize the dyadic father-child relationship (Silva et al., 2020). On the other hand, in cases in which the mother also works outside the home, paternal involvement in terms of availability tends to increase (Lamb et al., 1985), as also observed in the current study (case A).

Concerning responsibility, it was observed that the parents shared parental obligations, either by acting in partnership (cases A and D) or by performing more traditional roles (cases B and C). This dimension included narratives about decision-making on topics related to children, family finances, and health concerns during the pandemic. Regarding financial responsibilities, the predominance of the traditional role of fatherhood was observed, with the father as the family provider. Regarding mothers, in all cases they were responsible for the family's financial management, although they did not have the income (with the exception of cases A and B, in which the mother also contributed to the family income). This finding is in line with other studies on the family context of children with disabilities (Dias et al., 2020; Félix & Farias, 2018).

A similar aspect was observed in the responsibilities for the health and safety of the child, which was primarily attributed to the mothers, whereas the fathers focused on providing for the family. In cases B and C, we noticed a fragility in the sharing of decisions on topics related to children, with the responsibility for carrying out tasks, especially those related to the child's health (e.g., scheduling and attending appointments and therapies), being predominantly maternal. The low frequency of fathers' participation in decisions and activities related to the child's health has already been reported in families of children with disabilities, including in the context of CZVS (Félix & Farias, 2018; Santos & Farias, 2021). One possible explanation for this finding relates to gender stereotypes in family dynamics, in which the management of health care is still considered more congruent with social expectations about the mother's role, when compared to the father's role (Schmidt et al., 2019).

In cases A and D, both mother and father were actively involved in the child's health care, in line with the idea that changes towards greater paternal involvement are also being observed in families of children with disabilities (Félix & Farias, 2018). In these cases, the parental figures worked in partnership, maintained open dialogues, and shared responsibilities for their children's health care. However, the additional challenges to the parental experience that emerge with the birth of a child with a congenital malformation, such as the daily demand for specific health care and the exhausting routine of specialized care (Dias et al., 2020; Matos & Silva, 2020), along with the changes imposed by the pandemic, may hinder and interfere with agreements about parenting, as well as the interaction between caregivers and the child.

FINAL CONSIDERATIONS

This study aimed to investigate parental involvement with children with CZVS during the COVID-19 pandemic, considering the experience reported by both mothers and fathers. The results suggest that whereas some families shared interaction activities, others presented asymmetries, leading to a sense of overload for mothers. This was exacerbated during the pandemic, mainly due to the reduction in interaction with the support network and specialized care for children with CZVS. Regarding availability, there were variations associated with mother's and father's paid work schedules, due to social distancing and the economic crisis resulting from the pandemic, directly reflecting on the availability of families in situations of socioeconomic vulnerability. In terms of responsibilities, mothers and fathers were usually in charge of different spheres (childcare and financial support, respectively), reiterating a traditional gender division. With the pandemic, families began to worry about the potential COVID-19 infection, especially due to greater health vulnerabilities of the child with CZVS.

In general, in the context of CZVS, the emphasis of the health care providers has been directed to the mother-child dyad (Félix & Farias, 2018; Melo et al., 2023). However, the findings of the present study suggest the benefits of including the father figure in these interventions, given that the emotional repercussions due to the diagnosis of CZVS and the continuous demand for multidisciplinary care throughout development were reported by both mothers and fathers. Furthermore, fathers generally considered themselves less skilled than mothers for childcare tasks. Therefore, encouraging them to perform this role can contribute to strengthening the paternal sense of self-efficacy, as well as the quality of interaction and emotional closeness between father and child. Additionally, this can mitigate maternal overload, favoring the general quality of family and marital dynamics, as well as the specific individual development of family members.

Based on the above discussion, it is suggested to implement actions to support families in reaching agreements regarding childcare sharing, with a view to promoting greater paternal involvement. In particular, it is suggested to establish groups for mothers and fathers that encourage and value greater paternal participation in prenatal care and throughout the child's developmental trajectory. This can be done effectively by providing information about the clinical condition of children with CZVS and support for their care. In addition, the creation of groups facilitates opportunities for sharing experiences and mutual support among families.

This study provides pieces of qualitative evidence that supports psychosocial interventions aimed at families with children with CZVS, particularly those in situations of socioeconomic vulnerability, which was potentially exacerbated during the pandemic. Furthermore, the findings of this study are expected to contribute to the promotion of individual and family health care aligned with the demands of the current scenario, considering the ongoing challenges and those arising from the overlap of two important public health emergencies. Thus, it is suggested to conduct longitudinal studies to monitor the repercussions of the COVID-19 pandemic on children with CZVS and their families, considering the different family configurations. Although the present study addressed only nuclear families, it considered maternal and paternal reports, assessing them at a dyadic level, which had been identified as a gap in the literature on the topic (Melo et al., 2023).

We also suggest further research focusing on parental involvement with siblings of children with CZVS, which was not explored in this study as it did not align with the proposed aim. However, it is important to support comprehensive psychosocial interventions focused on families of children with CZVS. Finally, we suggest that future research consider broader samples from other states (e.g., Pernambuco and Rio Grande do Norte, which, along with Bahia, led the number of CZVS cases in Brazil; Lesser & Kitron, 2016). This is relevant because local and regional particularities, such as the availability and functioning of health, education, and social assistance services, may relate to parental involvement with children with CZVS during and after the COVID-19 pandemic.

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Conflict of interest
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