DIAGNOSIS OF CONGENITAL ZIKA VIRUS SYNDROME: I'M A MOTHER, WHAT NOW?

DIAGNÓSTICO DA SÍNDROME CONGÊNITA DO ZIKA VÍRUS: SOU MÃE E AGORA?

DIAGNÓSTICO DEL SÍNDROME CONGÉNITO DEL VIRUS ZIKA: SOY MADRE, ¿Y AHORA QUÉ?

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Abstract: **Aim**: to understand mothers' perceptions about childcare after being diagnosed with congenital Zika virus syndrome. **Method**: qualitative and exploratory study with mothers of children with congenital Zika virus syndrome (CZS) in a Specialized Rehabilitation Center in a city in the interior of Bahia. Semi-structured interviews were conducted and analyzed using thematic analysis, culminating in the construction of a category. Seven mothers of children diagnosed with this syndrome participated in the study. **Results**: Most mothers reported that the diagnosis occurred during childbirth, generating despair and fear. In addition, they received the diagnosis from family members or the local media, and not from the responsible health team, demonstrating ineffective communication between workers and users, revealing a fragility in these relationships that are essential for comprehensive care. It was also noted that there are obstacles that hinder the effectiveness of care coordination and prenatal care for these women. **Conclusion**: The perception of the diagnosis revealed feelings of fear, despair, anguish and uncertainty about the future after discovering SCZ, because most mothers received the diagnosis unexpectedly, due to inadequate communication, exposing flaws in care from prenatal care to care for the pregnant woman. Improving prenatal care and improving communication is essential in the context of difficult diagnoses, which when properly made can change the way situations are faced.

Keywords: Caregivers; prenatal care; microcephaly.

Resumo: Objetivo: compreender a percepção das mães sobre os cuidados com os filhos após serem diagnosticadas com síndrome congênita do Zika Vírus. **Método**: estudo qualitativo e exploratório com mães de crianças com síndrome congênita do Zika Vírus (SCZ) em um Centro Especializado em Reabilitação de uma cidade do interior da Bahia. Foram realizadas entrevistas semiestruturadas, e estas analisadas com análise temática, culminando na construção de uma categoria. Participaram do estudo sete mães de crianças com o diagnóstico desta síndrome. **Resultados**: A maioria das mães relatou que o diagnóstico ocorreu durante o parto, gerando desespero e medo, além disso, receberam o diagnóstico de familiares ou da mídia

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local, e não da equipe de saúde responsável, demonstrando comunicação não efetiva entre os trabalhadores e usuárias, revelando uma fragilidade nessas relações que são imprescindíveis para um cuidado integral. Percebeu-se também que há obstáculos que dificultam a efetivação em relação a coordenação do cuidado e o pré-natal dessas mulheres. **Conclusão**: A percepção do diagnóstico revelou sensações de medo, desespero, angústia e incertezas quanto ao futuro a partir da descoberta da SCZ, isto porque a maior parte das mães obteve o diagnóstico de forma inesperada, por uma inadequada comunicação, expondo falhas na assistência desde o pré-natal até o cuidado à gestante. Aprimorar o cuidado no pré-natal e a qualificação da comunicação é essencial no âmbito de diagnósticos difíceis, que quando adequadamente feitos podem modificar o enfrentamento das situações.

Palavras-chave: Cuidadores; pré-natal; microcefalia.

Resumen: Objetivo: comprender la percepción de las madres sobre el cuidado de sus hijos luego de ser diagnosticadas con síndrome congénito del Virus Zika. **Método**: estudio cualitativo y exploratorio con madres de niños con síndrome congénito del Virus Zika (SCZ) en un Centro de Rehabilitación Especializado de una ciudad del interior de Bahía. Se realizaron entrevistas semiestructuradas, las cuales fueron analizadas con análisis temático, culminando con la construcción de una categoría. En el estudio participaron siete madres de niños diagnosticados con este síndrome. **Resultados**: La mayoría de las madres informaron que el diagnóstico ocurrió durante el parto, generando desesperación y miedo, además, recibieron el diagnóstico de familiares o medios de comunicación locales, y no del equipo de salud responsable, demostrando una comunicación ineficaz entre trabajadores y usuarios, revelando una fragilidad en estas relaciones que son esenciales para la atención integral. También se advirtió que existen obstáculos que dificultan la coordinación de la atención y el control prenatal de estas mujeres. **Conclusión**: La percepción del diagnóstico reveló sentimientos de miedo, desesperación, angustia e incertidumbre sobre el futuro tras el descubrimiento del SCZ, esto se debe a que la mayoría de las madres obtuvieron el diagnóstico de forma inesperada, debido a una comunicación inadecuada, exponiendo falencias en la asistencia desde el control prenatal hasta la atención de la gestante. Mejorar la atención prenatal y la calificación de la comunicación es fundamental en el contexto de diagnósticos difíciles, que, correctamente realizados, pueden modificar el modo de afrontar las situaciones.

Palabras clave: Cuidadores; atención prenatal; microcefalia.

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1 BACKGROUND

A large-scale outbreak of births of children with microcephaly and other congenital malformations occurred between 2015 and 2016 in Brazil, drawing global attention to the infection of pregnant women by the Zika virus (ZIKV)(Lowe et al., 2018).

The congenital Zika virus syndrome (CZS) impairs functional performance due to a set of anomalies (e.g., microcephaly, craniofacial disproportion, irritability, seizures, feeding difficulties, hearing loss, intracranial calcifications, cortical malformation, ventriculomegaly on neuroimaging, and ophthalmological changes leading to reduced visual function) (Freitas et al., 2020; Moore et al., 2017).

Maternal infection in the first and second trimesters of pregnancy may increase the severity and frequency of ZIKV effects on the fetus (Krauer et al., 2017). Although imaging tests can detect brain injuries during the prenatal of pregnant women exposed to ZIKV (Freitas *et al.*, 2020), the extent and impact of the damage and CZS on the life expectancy of children cannot be determined yet (Simas et al., 2020). Thus, families, caregivers, and children with CZS have faced several challenges related to care experiences (Simas et al., 2020).

Care is defined as being or acting with responsibility and sensibility to consider the other as an individual with a personal reality and experience, presuming a continuous relationship among health services, professionals, and users. Also, it must be operationalized within the subjectiveness of human relations, influencing health practices according to the meanings and actions of each individual and not limited to specific techniques and skills (Slomp Junior et al, 2023; Souza et al, 2023).

The mutual trust established among health services, professionals, and caregivers and how the diagnosis of CZS is reported may impact the management of uncertainties and experiences of caregivers in caring for their children (Simas et al., 2020). These uncertainties may be due to doubts related to the specificities of children with disabilities (e.g., child development and access to health and education services) and training of health professionals to report difficult news and support caregivers, which can change their lives (Mendes et al., 2020).

In this sense, identifying and diagnosing CZS may be stressful for mothers depending on how and when it occurs (Mendes *et al.*, 2020). Also, mothers may develop suffering and illnesses (especially when they are the main caregiver) due to the uncertainty on the development of children with CZS and the need for coping with social acceptance, possible family and financial conflicts, and time spent in health services (Pepe et al., 2020; Simas et al., 2020).

Considering mothers of children with CZS as main caregivers, they focus the activities on housework and caring for the children, which may increase the occurrence of depression and anxiety and reduce the quality of life (Duttine et al., 2020; Porter e Mimm, 2016). In this sense, identifying the existing adversities at the diagnosis may contribute to adequate treatment, guidance, and care planning for families of children with CZS (Andrade et al., 2022; Mendes et al., 2020a). Thus, this study aimed to understand the perceptions of mothers about the care of children with CZS from the diagnosis perspective.

2 METHODS

This qualitative and exploratory study was conducted with caregivers of children with CZS assisted at a Specialized Rehabilitation Center (SRC) in Bahia (Brazil). This study was approved by the research ethics committee of the State University of Bahia (no. 52526221.0.0000.0057) and followed the Declaration of Helsinki and Resolution 466/2012. All caregivers signed the informed consent form.

Semi-structured interviews were conducted with the caregivers using a specific script. Inclusion criteria consisted of caregivers of children with CZS assisted at the SRC. Caregivers who could not participate during data collection were excluded.

Caregivers were recruited according to the principle of saturation (i.e., when data from interviews do not provide new elements to the study)(Fontanella et al., 2008). Interviews were scheduled and conducted in person between March and May 2022 with biosafety measures (e.g., masks, hand sanitizer, and a minimum distance of 1.5 meters) to prevent the coronavirus disease 2019 (COVID-19). Interviews lasted from 15 to 20 minutes and were recorded using a voice recorder from a cell phone. The following six topics were addressed: the moment of CZS diagnosis and feelings experienced; therapeutic trajectories before referral to the SCR; changes in routine, family, life, and at home after the diagnosis; difficulties or barriers observed from diagnosis to date; resources available for coping with difficulties; and perception on the care for the child provided by the healthcare service and SCR.

Caregivers were coded as numbers, and the mentioned individuals received fictitious names (Brazilian flowers) to maintain confidentiality. Data were interpreted through thematic analysis (Bardin, 2016). Interviews were fully transcribed, followed by floating reading to familiarize with the data. Units of meaning were extracted and compiled from reports, leading to the conception of the category “perceptions on the diagnosis”.

3 RESULTS

Seven mothers of children with CZS (five boys and two girls) were interviewed. Mothers were aged between 23 and 41 years, and children between two and six years. Although sex was not an inclusion criterion, all caregivers were female, corroborating the historical role of women as main caregivers. Most mothers (4/7) only discovered the CZS diagnosis after delivery, as reported by mothers 2, 5, 6, and 7:

> [...] When the baby was born [...] my mother was the one who told me […] I was still sedated [...] because I underwent a cesarean section [...] an emotion of despair, it was a moment of despair (Mother 2).
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> [...] At birth when, when the doctor entered the room where I underwent a cesarean section, and then he said that he suspected that the baby had microcephaly (Mother 5; 04/04/2022).
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> [...] When I had him! When I took him in my arms, I realized [...] how it would be? What will happen to me, my God? (Mother 6;).
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> [...] I found out on the radio [...] I was still under anesthesia, slow, kind of dizzy, and there was a ward, the room where I stayed was near the ward, and there was a radio on, and then the broadcaster said: “look, guys, before ending the program, we heard that the first case of microcephaly was born in (city A), due to Zika. A boy was born, but the child is doing well, the mother is doing well” [...] then I realized that he was my son (Mother 7).

Three mothers reported discovering the CZS diagnosis during pregnancy and uncertainties related to depressive feelings and fear due to an unexpected and unprecedented disease for families and health professionals,

> [...] It was in the first ultrasound, at five months, that I found out, it was a shock, you know, because I did not expect [...] it was very difficult because, at first, I did not know, I did not know about people with disabilities with microcephaly, I knew about it, but it was not a deep knowledge [...] (Mother 1; 03/23/2022).

> [...] Oh, I found out during pregnancy, you know, at eight months of pregnancy, everything was new, everything was strange, scary [...] I did not know until then, and [...] it was difficult too because I did not know anything about it, everything was [...] the rush to find out, the fear, the fear came too, I was very afraid of losing the baby, I just thought, I, I just wanted to know, I always asked: “is the baby going to die? Is the baby going to die?”. I asked the doctor at the appointments I went to [...] (Mother 3; 04/22/2022).
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> [...] I found out [...] I found out at seven months [...], but at four months, we already had a suspicion of something, that something was altered, you know [...], but an alteration that is normal, right? That happens to many [...] many pregnant women. And then [...] there was that flea in my ear [...] then the news started to appear at that time, you know, about children being born with microcephaly, and then I was desperate, you know [...] I surfed the internet 24 hours a day, researching and crying, I cried, cried [...] I had [...] postpartum depression, but now, people closest to me say that I started developing it as soon as I knew [...] I got deeply depressed [...] my problem is anxiety, and I was like: “my God, how is it going to be?” [...] a difficult phase that when I think that I could get out, I could not, you know, if it was not for God (Mother 4; 04/29/2022).

Also, this uncertainty was aggravated depending on how the diagnosis was reported and who reported it, as shown in the quotes:

> [...] My mother was the one who told me [...] I was still sedated [...] because I underwent a cesarean section (Mother 2).
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> [...] It was so so, you know [...] but my sister was nervous [...] and also, in my pregnancy, that is [...] when they did the ultrasound, it was there, but the doctors did not pay attention at the time [...]. Interviewer: did nobody say anything then? Mother: no, but it was there, in the ultrasound [....] (Mother 5).
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> [...] When I took him in my arms, I realized [...]. Interviewer: was it? So, did nobody tell you? Did you just observe him? Mother: yes, I already felt it, I realized it right away [...] (Mother 6).
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> [...] I delivered C at 39 weeks when I went to the hospital for cervical exams because I was already losing the mucus plug and everything, to find out if it was time to deliver. The doctor asked for an ultrasound, I did it, and at that moment, he saw that the child had it [microcephaly], but he realized that I did not know, so he thought it was better not to tell me [...] then I called the nurse, I said “Alamanda”, the name of the nurse was Alamanda, then I asked her “is this child that has been announced on the radio, born with microcephaly, my son?”, she said “he is your son, did nobody tell you?”. I said “no, Alamanda, they did not tell me” [...] and there was all that fuss, they called a pediatrician to evaluate him, and I said “no, leave him since you did not tell me”. “Oh 7, we had to predict it or other mothers, announce it” [...]. “It does not matter [...] I had to be the first to know, and since I was not, leave my son there, and I will take him home”. Then, I looked over and signed the authorization saying I was leaving, I had a cesarean section, I left the hospital 16 hours after the cesarean section, I came to doctor Y, the pediatrician [...] when the pediatrician confirmed it, I said “doctor, I am going to cry everything I should cry. I am going to cry because it took me by surprise” [...]. I cried, I cried, I cried, and after I cried, I did not cry anymore (Mother 7).

The mothers (2, 5, 6, and 7) narrated moments of failure or lack of communication from the health professional or responsible health team. Relatives and local media of the health unit (i.e., radio) reported part of this information before or shortly after delivery.

4 DISCUSSION

Diagnosing any illness is challenging, especially when it is chronic and may cause sequelae. Studies showed difficulty in early CZS diagnosis, which was often diagnosed only at birth and accompanied by a poor report of the condition and prognosis (Magalhães et al., 2021). The CZS diagnosis changed the life dynamics of all families in this study. For example, factors affecting their lives included the dependence of the child on the caregiver, high financial costs, displacement for attendance at health services, and working arrangements of the caregiver (Sá et al., 2020).

The reports may indicate fragile prenatal care, from access to consultations and tests to the qualification of professionals working in health programs for women and children, resulting in the surprise of the diagnosis at birth. The Unified Health System (UHS) offers assistance and surveillance actions for pregnant women and children infected with ZIKV and other infections. Also, it states that early prenatal care in primary healthcare is essential for the quality of life and to identify changes in fetal growth and development and other factors that may risk the health of the mother and child. These actions also emphasize the participation of the entire health team in providing comprehensive care for pregnant women (Andrade et al., 2022). Peiter et al.(2020) highlighted that the participation of qualified professionals in identifying changes relevant to the CZS might provide an assertive diagnosis and improve the follow-up of suspected cases during the gestational period.

Strategies to overcome fragmented practices with low resolution should stimulate the challenge of providing care and qualifying the health team, valuing the workspace as a learning environment. Also, permanent education mobilizes individuals to think about practices and change attitudes, allowing coordinated care actions that range from early diagnosis to supportive healthcare throughout the process (Alves & Corvino, 2020). According to Silva, Cardoso, et al. (2023) this education stimulates professionals to develop a sense regarding their actions, changing individual learning to an interprofessional scenario. Thus, this approach is a strategic cornerstone for the service dynamics from integrative learning and development of innovative, reflexive, humanized, and ethical practices.

Studies showed controversies regarding the follow-up of pregnant women during the gestational period in primary care according to recommendations for prenatal care . They were demonstrated by the unequal coverage of prenatal care and difficulty accessing diagnostic tools (e.g., ultrasound), especially in small and poorly equipped municipalities that need to direct their users to other cities, requiring long-distance travel (Peiter *et al.*, 2020; Lima & Iriart, 2021).

Reports of the studied mothers reinforced the gaps in health services previously demonstrated (Peiter *et al.*, 2020; Lima & Iriart, 2021)Clique ou toque aqui para inserir o texto.. Also, they corroborated the results of Mendes et al. (2020) which described that several mothers discovered that their children had CZS at birth, which compromised the care of pregnant women and children.

In this sense, Hamad and Souza (2020) argued that prior knowledge (i.e., during pregnancy) has positive and negative factors: positive because it may allow the family to be prepared for the arrival of the child and enhance the acceptance of the CZS. However, prior knowledge may reveal the need to adapt to a new family routine, attendance, and schedules and predispose feelings of worry, anguish, and anxiety that may interfere with the mother-child relationship (Hamad e Souza, 2020; Peiter et al., 2020). The present study corroborated these circumstances, which also may have been enhanced by the simultaneous and intense media exposure of microcephaly and issues related to disabilities during the CZS outbreak (Oliveira et al., 2019).

The diagnosis discovery in this study occurred concomitantly to the first research to elucidate the relationship between ZIKV infection and CZS, enhancing the uncertainties for family members and health professionals regarding the child development and future (Mendes et al., 2020b). Our findings suggested poor appreciation and use of call light technologies, impairing relationships and humanization in healthcare and inducing unprofessional approaches and disrespect for families facing an unprecedented situation. Humanized practices with supportive care must be included in daily work routines by listening and dialoguing as institutional policies. Also, these practices encompass a subjective production of care and prioritize the health needs of users (Silva, Borges, et al., 2023).

According to Cunha et al.(2016) understanding and reframing the moment of diagnosis is closely linked to its report, and a late diagnosis also has the potential to delay or hinder acceptance and treatment when reported improperly. Mendes et al. (2020) suggested reviving the debate on how to report difficult news within SUS, especially because it is a delicate process involving family expectations toward the child birth and development.

Although reporting a diagnosis is mostly attributed to the physician, it should involve different health professionals. This study showed the story of mothers who discovered CZS diagnosis of child from close relatives or other means while in the maternity ward, such as mother 7, who discovered CZS after hearing the news on the radio. Oliveira et al. (Santo et al., 2019) also described a family discovering microcephaly after watching the news, corroborating our study. Thus, an adequate report of the diagnosis with humanized care by the health team may allow the family to cope with the condition and feelings of trust, hope, fear, suffering, and perspectives facing difficult and unexpected news (Cunha et al., 2016).

The notification of a diagnosis of any illness, and especially in conditions characterized by chronicity, as they normally leave important motor and social sequelae, requires a qualified relationship between the health professional and the users, and must be based on the ethics and aesthetics that support in life and living from others. Therefore, investing in meetings as a care tool is essential to enhance the resolution of the care provided, and with the aim of meeting health needs. Furthermore, it allows prioritizing the lives of mothers and children and developing autonomous individuals whose singularities are respected (Rios et al., 2021; Slomp Junior et al. 2023, Souza et al., 2023).

Furthermore, strategies that reach the moral, psychological, social, cultural, economic, political and technical-normative aspects that permeate the act of caring can and should be incorporated into political decisions and viewed from the point of view of social justice (Melo et al., 2023), in order to understand that public policies are as or more effective to the extent that they can get closer to reality - whether through a more cohesive care and support network, groups of mothers or caregivers, activities aimed at care of the caregiver, or even continued training of network professionals - are in fact the way to better face the situations experienced by these mothers, children and their families.

5 CONCLUSIONS

The perception of the diagnosis exposed by the participants in this study reveals a contradictory reality between the regulations established for the care of pregnant women and the practices adopted by professionals and health services. In this research, most mothers of children with SCZ received the news of their children's diagnosis at the time of birth, generating in them feelings of fear, despair, anxiety and concern, as it occurred unexpectedly. Likewise, for mothers who obtained the diagnosis during the gestational period, it was perceived as difficult, triggering the early emergence of uncertainty about the future, fear and anxiety.

These feelings were worsened by the inadequate communication of the news or even the lack of it on the part of the responsible health professionals, with the mothers in some situations being initially informed by close relatives or through local media. In this sense, we believe that the way in which health professionals communicate the diagnosis or when it is transmitted late or omitted by them, implies emotional impacts that can generate important marks in the lives of these families and that has the potential to paralyze them in the face of difficult situations, therefore, clear information combined with a humanized welcome can minimize such impacts, empowering these families to face this condition.

Finally, the findings demonstrate that it is necessary to strengthen the network of care for pregnant women and prenatal care, combined with the redefinition of practices, accountability and creation of bonds, in search of achieving comprehensive care and abolishing the suffering arising from incoherence between what is recommended in this experience, and what has actually been done. We recommend that other studies be conducted, expanding the debate on comprehensive care for children with CZS and their mothers, with designs that allow longitudinal monitoring of this population and that make it possible to evaluate the public policies established and the impact on the lives of their users.

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