

ORAL HISTORY OF MOTHERS OF CHILDREN WITH CONGENITAL ZIKA VIRUS SYNDROME

Camilla de Sena Guerra Bulhões¹ 

Ana Maria de Almeida² 

Altamira Pereira da Silva Reichert¹ 

Paula Daniella de Abreu² 

Maria Djair Dias¹ 

¹Universidade Federal da Paraíba, Programa de Pós-graduação de Enfermagem. João Pessoa, Paraíba, Brasil.

²Universidade de São Paulo, Programa de Pós-graduação Enfermagem em Saúde Pública. Ribeirão Preto, São Paulo, Brasil.

ABSTRACT

Objective: qualitative, exploratory study, based on the Oral History theoretical methodological framework, conducted in a Health Regional of Goiana, Pernambuco, Brazil. Data collection occurred from October 2017 to May 2018, with 13 mothers through individual interviews.

Method: qualitative, exploratory study, based on the Oral History theoretical methodological framework, conducted in a Health Regional of Goiana, Pernambuco, Brazil. Data collection occurred from October 2017 to May 2018, with 13 mothers through individual interviews. The data were processed in a software using the similitude analysis method, which identified the most frequent terms and resulted in the interpretation of *the corpus* through the words in the light of the reference.

Results: the interpretation of the corpus highlights the maternal experiences regarding the discovery of the Congenital Zika Virus Syndrome, of the forced paths implying changes in lifestyle and of the coping strategies used to care for the child.

Conclusion: the stories of mothers of children with the syndrome allowed reflection on the challenges related to disability and their children's need for daily care. The context of the syndrome, associated with low socioeconomic conditions, revealed the magnitude and peculiarities of the problem that permeate the limits to dignity, compromising quality of life and showing the precariousness of the lives of women neglected by the State and society.

DESCRIPTORS: Congenital abnormalities. Mothers. Child. Comprehensive health care. Nursing.

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HISTÓRIA ORAL DE MÃES DE CRIANÇAS COM A SÍNDROME CONGÊNITA DO ZIKA VÍRUS

RESUMO

Objetivo: compreender as histórias e vivências das mães que tiveram filhos com a Síndrome Congênita pelo Zika Vírus.

Método: estudo qualitativo, exploratório, fundamentado no referencial teórico metodológico História Oral Temática, realizado em uma Regional de Saúde de Goiana, Pernambuco, Brasil. A coleta de dados ocorreu no período de outubro de 2017 a maio de 2018, com 13 mães por meio de entrevistas individuais. Os dados foram processados em um software pelo método da Análise de Similitude, o que permitiu identificar os termos mais frequentes e possibilitou a interpretação do *corpus* por meio das palavras à luz do referencial.

Resultados: a interpretação do *corpus* aponta para as vivências maternas frente à descoberta da Síndrome Congênita Zika Vírus, para os caminhos forçados implicando nas mudanças do estilo de vida e para as estratégias de enfrentamento para cuidar do filho.

Conclusão: a compreensão das histórias das mães de crianças com a síndrome possibilitou a reflexão sobre os desafios relacionados a deficiência e dependência dos seus filhos por cuidados diários. O contexto da síndrome, associada às baixas condições socioeconômicas, revelaram a magnitude e peculiaridades da problemática que permeiam os limites à dignidade, comprometendo a qualidade de vida e mostrando a precariedade da vida de mulheres negligenciadas pelo Estado e sociedade.

DESCRITORES: Anormalidades congênicas. Mães. Criança. Assistência integral à saúde. Enfermagem.

HISTORIA ORAL DE MADRES DE NIÑOS CON SÍNDROME CONGÉNITO DEL VIRUS ZIKA

RESUMEN

Objetivo: comprender las historias y experiencias de madres que tuvieron hijos con el síndrome congénito del virus del Zika.

Método: estudio cualitativo, exploratorio, basado en el referencial metodológico teórico de Historia Oral Temática, realizado en una Región de Salud de Goiana, Pernambuco, Brasil. La recolección de datos ocurrió de octubre de 2017 a mayo de 2018, con 13 madres a través de entrevistas individuales. Los datos se procesaron en software mediante el método de Análisis de Similitud, que permitió identificar los términos más frecuentes y permitió la interpretación del *corpus* a través de palabras a la luz del referencial.

Resultados: la interpretación del *corpus* apunta a las vivencias maternas ante el descubrimiento del Síndrome del Virus Congénito del Zika, a los caminos forçados que implican cambios en el estilo de vida y a las estrategias de afrontamiento para el cuidado del niño.

Conclusión: la comprensión de las historias de madres de niños con síndrome permitió reflexionar sobre los desafíos relacionados con la discapacidad y dependencia de sus hijos para el cuidado diario. El contexto del síndrome, asociado a las bajas condiciones socioeconómicas, reveló la magnitud y peculiaridades del problema que permea los límites de la dignidad, comprometiendo la calidad de vida y mostrando la precaria vida de las mujeres desatendidas por el Estado y la sociedad.

DESCRIPTORES: Anomalías congénitas. Madres. Niño. Atención integral de salud. Enfermería.

INTRODUCTION

The gestational cycle is a complex period comprising pregnancy, childbirth and puerperium. In this phase, the influence of biopsychosocial factors on the maternal social network related to the birth and arrival of a new being is highlighted. It is known, however, that motherhood has great social repercussions and results in changes in lifestyle, feelings and expectations that involve, above all, the mother and child binomial. Therefore, the possible diagnosis related to the child's development impairment can lead to the breaking of a dream, and physical and emotional overload.¹

The construction and deconstruction of expectations related to the birth of the child causes conflicts and feelings, such as fear and insecurity, which can affect motherhood. This is related to the care provided to the child in order to meet their basic needs, but also physical and emotional support in an environment favorable to the construction of a mother-child bond.² The birth and presence of a child with developmental disabilities often induces stress and poses challenges for the whole family. These families experience economic difficulties in caring for children with disabilities, in addition to dealing with the needs and expectations of other family members.³ Therefore, motherhood may be affected by unexpected events in the child's development, such as the impairment that occurs in congenital Zika Virus Syndrome (CZVS).

The CZVS is characterized by a situation of multiple deficiencies and, the impact of this unusual event, from the year 2015, generated repercussions of great proportion and magnitude in relation to the health, social, social security and emotions of families that had children with this diagnosis.

Diagnosis is painful for the family and becomes more difficult, depending on the approach of professional uses when breaking the news. The unpreparedness of professionals when communicating the diagnosis to mothers of children with disabilities, as well as not offering to clarify information or give guidance on how to act and how to care for the child can cause feelings of denial, anger and guilt and anger, negatively influencing the process of assimilation/acceptance process of the family.⁴

In the case of mothers of children with CZVS, after diagnosis, they face the challenges of caring for their children who present several changes in their development and growth on a daily basis and, in addition to microcephaly, have other important changes in vision, hearing and motor development. Given the unexpected diagnosis and the complexity of the care these children need, mothers begin to deal with limitations in their daily lives, with complete change of routine and feelings of fear and insecurity, in addition to multiple emotions such as non-acceptance, frustration and hope.⁵⁻⁶ Mothers who had children with CZVS also have an idealized feeling of guilt and carry the ideation of incapability and responsibility for their child's disability.⁷

Understanding the life histories of these mothers, who are generally the main caregivers and are particularly exposed and vulnerable to various stressors and, face the challenges that this condition has imposed on them, can be a fundamental strategy for the organization of health services that meet this demand that is recent but has specific needs.

Thus, it is believed that this study has the potential to increase the visibility of the problem of CZVS, since it is an unusual event with high social impact. It is expected to offer theoretical and scientific support to health practices, family self-care and professional care.

In view of the above, the question was: what are the stories and experiences of mothers who had children with CZVS? The study aimed to understand the stories and experiences of mothers who had children with CZVS.

METHOD

This is a qualitative and exploratory study which used oral history as a methodological theoretical framework, more specifically, thematic oral history (OH), whose objective is to clarify the narrator's opinion on some specific theme. Oral history is a conceptualized research method that uses social experiences, allowing people to retell their stories according to their own points of view.⁸

The research was carried out in a Health Regional of the State Health Department of Pernambuco, which is a reference for 10 municipalities. The choice of regional was due to the fact that it comprises a region in which 80% of its municipalities were affected by the CZVS, as well as the need to highlight the reality of a population that lives away from large urban centers and, a public that encounters difficulties due to the limited availability of services, human and material resources to provide care to children with CZVS. The health care network in this region is composed of a Regional hospital, maternal and child reference and rehabilitation for all municipalities. The other municipalities have small hospitals and polyclinics in addition to the Basic Health Units (UBS) and the Family Health Support Center (NASF).

The fundamental concepts for the proper operationalization of OH were adopted in order to provide direction to the study.⁸The target community consisted of 121 mothers who had children with suspected CZVS in the municipalities of the Regional Health Region, the study participants were mothers who had children with confirmed CZVS in these municipalities, totaling 15 confirmed cases, according to information from the state health surveillance and the network was made up of 13 mothers of children with CZVS who met the prerequisites established for the research. Two mothers did not participate in the research, one of them due to having moved and another due to lack of availability, since she commuted to the state capital every day for son's treatment and rehabilitation.

The data collection period took place from October 2017 to May 2018. A semi-structured interview was used for data collection, which was recorded and performed in the mothers' homes and in the UBS, according to the availability of each one, after signing the Informed Consent Form (ICF). In the interview, a previous script was used, with questions about the identification of the participant and directed by the guide question: "Tell me how you felt since you discovered that your son had Congenital Zika Virus Syndrome?".

The treatment of empirical material, the documentary corpus went through the stage of transcription, textualization and transcreation. The transcription corresponded to the process of changing the stage from oral recording to written code. In textualization, any questions that, incorporated in the answers, overcome their importance and it is at this stage that the vital tone of the interview was identified. The transcreation corresponded to the recreation of the text in its entirety, which was redone several times, removing or adding words and phrases that were legitimized by the collaborators.⁸

Thus, an initial reading of the stories was performed, which lead to the construction of the corpus, which consisted of a systematized and organized document, which was confirmed by the participants. In this phase it is necessary to understand the representativeness of the content, homogeneity, pertinence and completeness of the information.

Next, the textual corpus was analyzed with the help of *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ). Concerning analysis, the following steps were followed: organization of the material in a single text *file*, in the OpenOffice software; separation of each interview by command lines (asterisks), correction of spelling errors and revision of the file with the standardization of similar terms.⁹

The software is an important resource for qualitative studies, especially for extensive corpus analysis, since it enables lexical analysis with greater methodological rigor. The Similitude Analysis

allowed the illustrative visualization of the corpus through the presentation, in a network, of associations. This technique is based on graph theory, which provides a set of words in a network of connectivity.⁹

From the analysis of empirical data on the oral history of mothers with CZVS, the connections between the words verbalized by mothers of children with CZVS were evidenced, as presented in the like-for-like tree in Figure 1

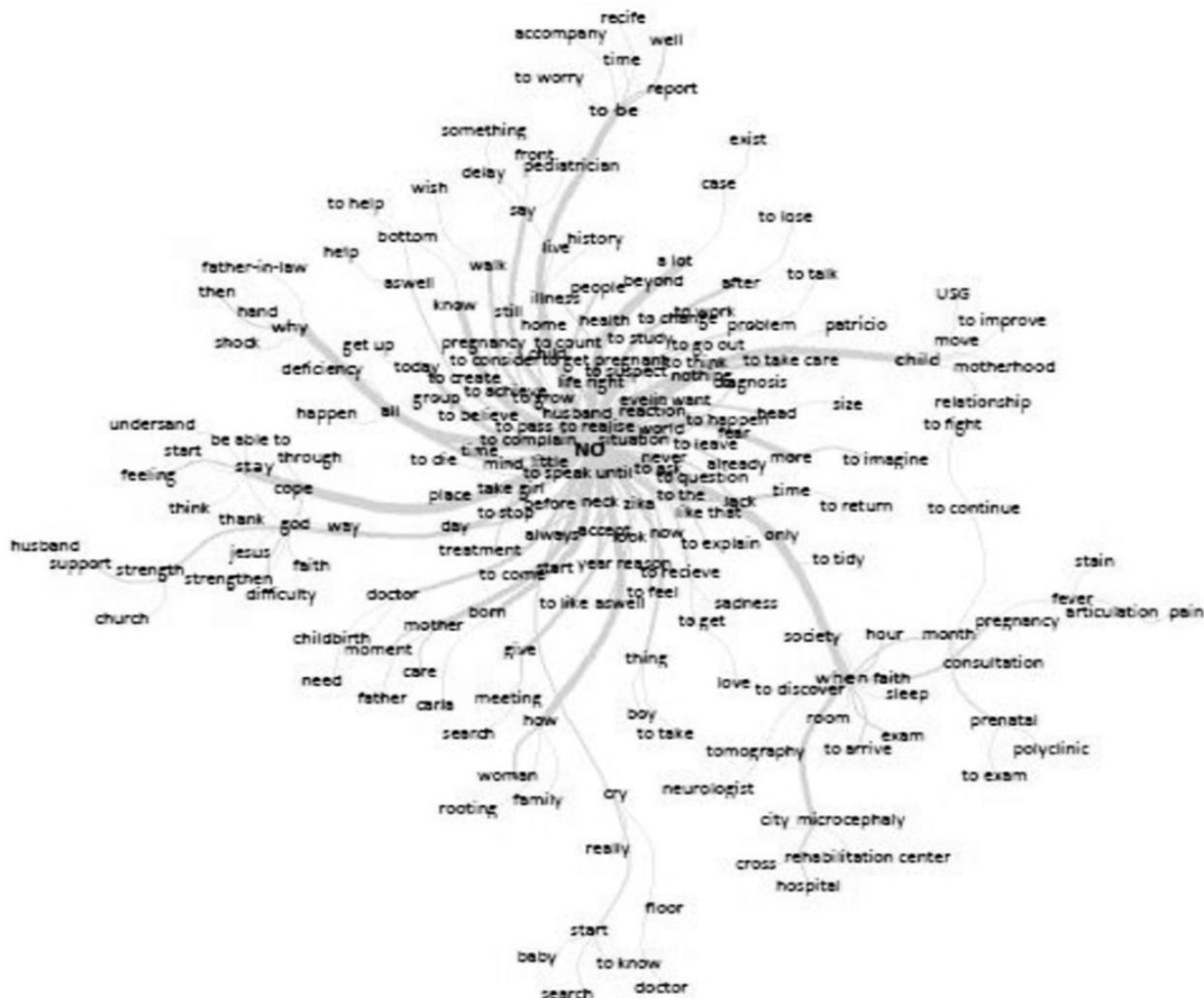


Figure 1 – Illustrative tree of the similitude analysis referring to the textual corpus of the interviews conducted with the mothers of children with CZVS. Pernambuco, Brazil, 2019.

The similarity analysis can be visualized in the co-occurrence tree, which represents the connections between the most frequent words in the statements of mothers of children with CZVS.

In this analysis, the relationships between words are observed. The words that were most frequent are presented prominently in the figure, followed by the words associated with them. Thus, the Similitude Tree represents the textual *corpus*, making it possible to visualize the words and their connections for interpretation and the construction of thematic categories. It is important to highlight that the illustration refers to the textual *corpus* referring to the history of mothers and the context experienced by them and, thus, express the ideas of the studied group.

Thus, it was possible to identify the most frequent terms and interpret the *corpus* through words in the light of the reference, together with the emergence of the thematic categories presented in Figure 2.

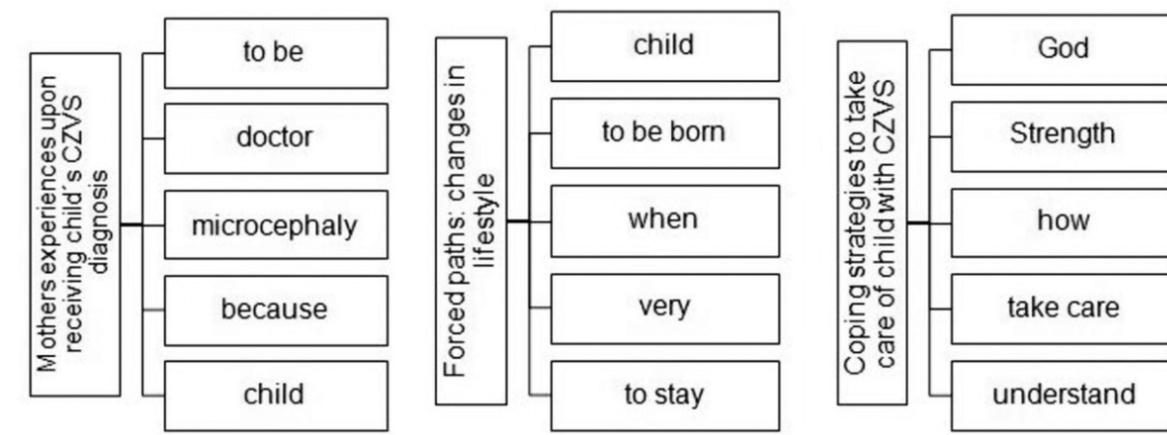


Figure 2 – Categorization of the textual corpus of the interviews conducted with the mothers of children with CZVS. Pernambuco, Brazil, 2019.

The entire study was guided by the ethical standards in force in Brazil, with approval from the Research Ethics Committee involving human beings of the institution.

RESULTS

The study collaborators were between 19 and 47 years old. Regarding marital status, seven reported living in a civil union, one was married, four were single and one was divorced. They lived with their companions and children and, in some cases, with other family members. They were housewives, with a financial income between one and two minimum wages and most had incomplete elementary school.

Maternal experiences upon the discovery of CZVS

The mothers received the news about CZVS at various times: during prenatal care, postpartum, in the maternity hospital, or even months after the child's birth.

Regarding the time of the children's diagnosis and about how they received the news, four mothers reported that they received the diagnosis when they were still pregnant and the others reported that it occurred during the postpartum period and in some cases a few months later.

[...] *when I discovered the diagnosis, I was eight months pregnant* (Mother 02).

[...] *I just found out that my daughter had microcephaly when she was born* (Mother 07).

[...] *I discovered that my son was special at the time of delivery* (Mother 01).

[...] *I found that my daughter had microcephaly at five months of gestation, when I went to do the private morphological ultrasound here in the municipality* (Mother 06).

[...] *the doctor was suspicious, but she never said anything because she wasn't sure what he had, when he was 11 months old, it was confirmed. I noticed myself the things he didn't do in relation to children his age, then at his monthly visit, I asked the nurse for a referral to a pediatrician* (Mother 04).

The lack of information and lack of knowledge of health professionals about the syndrome led mothers to become nervous and anxious. These feelings were exacerbated by the information transmitted by television and by people's prejudice, factors that increased their insecurity regarding the birth of the baby, without knowing what their child would be like, as well as the future of the baby.

[...] the pediatrician looked at her, talked to me, explained the problem that was happening and said they could not explain what and why this was happening, nor how it would be. They didn't know anything, but I wanted an explanation and no one had one to give, which it was, no one could explain it (Mother 07).

The doctor said he had a small head but did not say he had microcephaly[...]all the professionals that saw him only said he had a small head (Mother 08).

[...] in the middle of it all, the doctors said that children who were born with microcephaly due to ZIKA virus, were not going to last long, it was an uncertain thing [...]At the time she was born the doctors suspected, in my I heart already knew, due to so much news that was on television [...] (Mother 13).

Regarding the feelings they experienced when they received the diagnosis, it was possible to identify feelings of shock, sadness, pain, anger, anguish, fear, doubt, despair, disappointment, prejudice, guilt and impotence.

[...] I didn't want to believe it. It was unacceptable because during prenatal care, I performed all the consultations, tests, medications, had nothing different was everything apparently normal (Mother 09).

[...] for me to receive this diagnosis, it was very difficult, I did not believe it, I still came to think that it was a lie and that it was just a mistake. I imagined several things and one of them is that they had taken my healthy girl and left a sick one in her place [...]but of all, I consider that the most intense feeling I had was a very great desire to die, not to see it like this, I wanted to disappear from the world (Mother 03).

[...] mother, she really has microcephaly, at that moment my world collapsed, I started crying [...]my feeling was of despair, I was desperate, I did not know exactly what the disease was, I did not think of myself, but I thought about society too, how society would react, my family or my husband's family or people they knew when they saw my different daughter (Mother 13).

Forced paths: lifestyle changes

The mothers reported that caring for their child led to several changes in their daily life routine after the discovery of CZVS: changes in lifestyle, in the habits and customs of daily life, differentiated care in relation to other healthy children, family or social support. Their statements show these changes and manifest that they are unable to lead a life like the one they had before their child's arrival, with the knowledge that these health demands of the child will extend throughout their life. In this sense, the priorities of their lives move to this care, making them invisible in their entirety, prioritizing the demands of their children in relation to their own.

[...] sometimes I miss the old woman I was [...]. I don't have time for myself. I think I don't care about myself anymore [...] (Mother 04).

[...] I dedicate my whole time to her and i can't find time to take care of myself(Mother 10).

[...] the woman inside me is forgotten because I dedicate my life only to my daughter. I miss the woman I was before, because before I worked, Had my money, was more independent, not today!(Mother 06).

This detachment in relation to oneself and the care itself, coupled with an overwork and exhaustion due to daily demands, trigger conflicts and a distance in relation to the functions of wife. Some women reported that their husbands are jealous and demand attention and care:

[...] I forget a little about me, because I see myself just to take care of her and my other son. My husband even distances himself away a little, we have fights, but out of jealousy [...] (Mother 12).

[...] I just see myself as a mother, I don't feel like a woman anymore, sometimes I have joy in getting dressed. Sexual intercourse with my husband, only sometimes [...] (Mother 03).

[...] *I see myself more as a mother than as a woman. There are moments that the husband asks me, to be more than a mother, to be a wife, have time to have our intimacy [...]* (Mother 05).

Coping strategies to take care of the child diagnosed with CZVS

Concerning the difficulties in daily life with the child with CZVS, the mothers refer to spirituality as a way to deal with the difficulties and, affirm that the acceptance of the child with disabilities comes from God and, if He chose it is because they are worthy of caring and loving. It is evident that these mothers would not be able to cope if it were not for faith.

[...] *and I find the strength to face all this in God, it is He who gives me strength.* (Mother 04).

[...] *In the beginning I thought so, as I was going to take care of a special child and today I see that God gave me her to take care and have this ability to take care of her and I take care very well* (Mother 12).

[...] *to face all this, it is God who gives me strength. I ask god a lot and I go ahead [...]* (Mother 02).

[...] *I got this strength to face the difficulties and see life differently, through my faith in God!* (Mother 05).

[...] the family is another source of support that these women have to help them accept and overcome all difficulties and, they say:

[...] *I have the support of my husband, I feel safe leaving her with him, I can share her care with him*" (Mother 06).

[...] *Most of the time, I take care of her alone, but the father, my mother and mother-in-law also help me to take care of her* (Mother 11).

[...] *I get support from my daughter, who helps me a lot to take care of her [...]* (Mother 10).

Participation in therapeutic groups proved to be a space for welcoming, sharing and learning for the mothers. It is possible to identify in the statements the importance of a therapeutic environment to work on the psychological suffering of these collaborators:

[...] *I have participated in two support groups with psychologists there at AACD. These groups helped me a lot. Because we were in groups, we met the mothers and the children too, so each one had its own story. And we exchange experiences, sharing our stories of care and sharing helps us a lot. I come out very strengthened after these encounters [...]* (Mother 06).

[...] *that therapy I did there on Mother's Day I really liked, I loved it, because I managed to open up, I said what I was feeling, I liked it a lot. I think it is very important that this moment of being able to take care of us and to be able to talk about difficulties, of one mother listening to another and wanted her to have more times [...]* (Mother 10).

[...] *today I see myself as another woman and the therapy helped me a lot in this acceptance process and another moment that helped me and marked my life was the Mother's Day meeting that was held that therapy wheel made me feel that I was not the only mother who was going through problems, and listening to the life stories of the other mothers, I realized that they had more delicate situations than mine, and in that meeting, I met the other mothers that I hadn't met before [...]* (Mother 13).

DISCUSSION

The understanding of the experiences of women who are mothers of children with CZVS explains the repercussions caused after receiving the diagnosis, not only in the lives of the children, but also in the lives of family members and health services. Through the narratives of the participants, it was possible to perceive that this moment is associated with the rupture of idealized dreams and

the emergence of fear, insecurity, abdication and, above all, the need to adapt to the new challenges presented in the face of the child's disability.

Most confirmed cases of this syndrome are among poor women in the Northeast and, in this study, all were low-income employees, with low educational levels and performed household activities. A study on the socioeconomic aspects of parents of children with Microcephaly related to Zika Virus corroborates these data, in which housewives predominated (43.90%) and unemployed (31.71%), with a monthly income of up to one minimum wage (65.85%). Another aggravating factor is that many have stopped working or performing paid activities to care for their children.¹⁰ In view of this, the involvement of the CZVS reveals the denial of rights and precariousness of women's lives in the context of social vulnerability.¹¹

The mothers, upon receiving the diagnosis that their child has the syndrome, initially experience the feeling of loss of the idealized child and experience "mourning". This situation may also be tied to the initial difficulty in dealing with the feelings and conflicts experienced when faced with the reality of the birth of the child with some disability. This loss causes internal conflicts in these women, leading them to have to abandon their work activities, as well as their social life in order to meet the demands of their child's care.¹²

The diagnosis of a disability brings significant changes to the family, mainly altering the mother's routine. These women undergo a process of restructuring after the birth of their child with disabilities, presenting a higher level of stress and it is possible to detect repercussions and feelings of mourning, sadness and guilt associated with the impact of the diagnosis.¹³

The early diagnosis of Zika virus infection is essential for the referral of children with microcephaly and its prognosis, with regard to the neurological development of affected children.¹⁴ However, the lack of information among health professionals regarding the syndrome was present in the statements of the participants of this study, who also mentioned anxiety and fear in relation to social reactions of prejudice.

A child with CZS requires specific complex care due to their fragile health condition, which in addition to microcephaly, have intracranial calcifications, other brain, ocular, auditory, motor anomalies, arthrogyriposis, convulsions among others. They need increased attention which causes changes in every family context, and it is extremely important that health professionals are prepared to deal with this fragile family, implementing an active and humanized listening in their clinical care practices.¹⁵

Health professionals are unprepared and do not clearly communicate the diagnosis of a disabled child to parents. Moreover, they do not promote a reception to mothers, thus hindering the adaptation and acceptance of the new reality.¹⁶

It is emphasized that good quality consultations performed by health professionals, which promote humanized care, as well as the transmission of information and clarification of doubts, improve access and support to the necessary services, in addition to self-confidence, psychological support and intensification of parental empowerment, in the process of overcoming the impact of the diagnosis of a child with disabilities.¹³⁻¹⁷

Lack of attention and support to deal with the demands of illnesses related to the burden of care are reported by mothers of children with intellectual disabilities. They report that the care provided by health professionals is directed only to the child. One mother in the study reported the need to use medications to deal with the psychological suffering. The recognition of this situation reinforces the importance of family care, especially the figure of the mother, as well as humanized, integral and effective care, which includes guidance, psychological and social support actions for these mothers.¹⁸

Studies reveal that mothers, in most cases, become the main caregivers of children with disabilities, and this is an arduous task that involves a set of actions and many hours of care, the supervision of daily needs, the promotion of an adequate environment, financial issues, requiring

readaptation in family daily life, in addition to often requiring selflessness regarding social life and exclusive dedication.^{19–20}

This centralization regarding the maternal figure's responsibility for care may be related to a gender condition, since it is still considered an eminently feminine task. It is still very present in society that women are the ones who give up their professional activities and life habits to dedicate themselves exclusively to the care of children who have some commitment in their development, in addition to being responsible for domestic activities.²¹

In other conditions regarding child disability, the man was responsible for supporting the family and being the financial provider for the family and the mothers had to reorganize themselves to meet the demands of care for the child and, due to the complexity and dedication of care, had to move away from their work activities to dedicate themselves exclusively to the care of the child and the house.²²

Unequal relationships in the performance of social roles burden women, especially with activities of the domestic sphere, making them feel obliged to give up their social and professional life to comply with the legacy of the moral obligation that society imposes. Moreover, they often experience situations of oppression that trigger stress, compromising their physical and psychological well-being.^{23–24}

It is noteworthy that a child with neuropsychomotor developmental disability is a permanent condition, whose future is not desirable in the ideal of motherhood and becomes a stress factor for parents/family members due to daily obligations such as medical treatments in the health network and at home, with no time for personal interests or leisure activities.¹⁵

This condition, in another study, led to the abandonment by the parent of the mother and child soon after the diagnosis of microcephaly.¹³ In the present study, this was not a reality among the participants, however, they report that by fully assuming the role of care for children with disabilities, they end up forgetting to take care of themselves and also how to exercise their role as wife, causing their husbands to be dissatisfied and who complain about their absence.

Regarding the coping strategies concerning the difficulties experienced in daily life with the child with the CZVS, in the presence of the child's syndrome and the demands arising from it, faith in God was the driving force for mothers to accept the child's disability. Spirituality was a resource used as a coping mechanism and all mothers reported that the strength to face the difficulties and acceptance of the disabled child came from God and believed that if God chose them to be the mother of a disabled child, it is because they were worthy to care and love for the child.

As in other similar studies^{25–26}, it was evidenced that many mothers referred to spiritual/religious issues as a foundation for support regarding the experienced reality, because it was determined by a supreme being. In this perspective, these women presented resignation as a form of renunciation of a grace from a higher being, to have the strength to overcome and accept the diagnosis of CZVS.

The spiritual dimension of caring for children with disabilities was taken as a way of coping with hopelessness, adversity and the impossibility of healing. The search for the divine and the transcendental offers emotional support and demonstrates the hope inherent to the human being, even when medicine denies the possibility of cure. This reconstruction of thinking is based not only on religious dogmas, but, above all, on spirituality, because there is a change, not only in their acts but mainly in their hearts, and are able to open new fields of experience and deepening.²⁷

In addition to spirituality, other coping strategies that allowed study participants to overcome the barriers and difficulties of day-to-day life were family support and participation in a therapeutic group.

In the study, it was observed that CZVS causes repercussions not only on the lives of children with disabilities, but also on the lives of family members. Given this condition, studies show that it is extremely important to provide adequate support, such as educational strategies, to help families experience totally new situations and restructure this family environment. It was noticed that they are satisfied with the educational practice and the approach of the professional offering them safety

and strengthening a relationship of trust, providing favorable conditions for the child's development and their well-being.²⁸

Another coping strategy reported by the mothers was affective family bonds. In this study, mothers who received support from their families felt safer and stronger to face difficulties, because they received the emotional support they needed from their own family. The family enters this context as an inseparable and indispensable link in the life of these children and in the rehabilitation of their child with disabilities.

The human being is born and lives in a network of relationships represented by family, school, community, work, among others. The social support network is a set of systems and significant people, which make up the relationship links received and perceived by the individual.

Long-lasting social bonds are important because they provide help in times of need, and help coping and overcoming moments of crisis. Therefore, this support needs to be continuous and include family, friends, neighbors, the health team, health institutions, NGOs, in other words, the entire social circle that surrounds this woman. In this study, all mothers reported that it was through the support network that they were able to face difficulties and challenges, and highlighted the family and therapeutic spaces as essential supports for acceptance and adaptation.²⁰⁻²⁵

The mothers reported that in these support groups they their voices were heard and they felt strengthened as they shared their stories and listened to the stories of the other mothers. These groups are considered spaces for sharing and socializing the knowledge produced in life experiences, providing these mothers with the awakening of possibilities of change. The study participants showed characteristics of strong and female fighters, and that, often, suffering is the bond which can be the thread that weaves the social support network.

A study on the use of a conversation wheel as a strategy of health education in the preparation of hospital discharge of family members of children with technological devices, showed that this care strategy favored the exchange of knowledge, and is well accepted by family members, who approved the resources used, in addition to having favoring the dialogue established among the participants of the group, through reflection and critical awareness, in order to develop safe and quality home care for their children.²⁹

These therapeutic spaces contribute to the improvement of the quality of life of these mothers and, allow them to be protagonists of their own lives and in the care of themselves and their child. The collaborators were then able to develop a sense of pertinence, especially when they were able to express their feelings in the group, changing the way they relate and communicate with the other, thus triggering acceptance, autonomy, increased self-esteem and especially empowerment.

A child with CZVS needs therapeutic support and lifelong care, thus health care network professionals must should be prepared to provide qualified and humanized care for the child and family. Among these professionals, nursing professionals stands out, because it is a profession in which the care of life is the essence of the profession and which has an important role in helping the adaptation of families to new demands. In situations related to CZVS, both the mother and the child need care and the professional needs scientific knowledge to meet the needs that may occur in the course of the disease.³⁰

The experiences of mothers of children with disabilities highlight the need for a differentiated look, because it was observed that care is aimed mainly at children with CZVS. It is imperative that health care network professionals have knowledge about the repercussions and coping mechanisms of these women, as it will allow reflection and decision-making about the main needs, in addition to directing the construction of quality care and the strengthening of the mother-child bond.

Among the limitations of the study, it is considered the fact that the participants are in a single scenario and are a cross-sectional section of the studied condition, in addition to the type of study

that does not allow generalizations. However, it is emphasized that it allows to understand the context and verbalizations of the research members with rigor and depth, without compromising the quality of the findings and discussions. Cohort studies which monitor the development of these children and the physical and mental health conditions of mothers, may bring important contributions on the theme.

CONCLUSION

The stories of mothers of children with CZVS allowed reflection on the challenges linked to disability, marked by emotional overload and physical exhaustion in the care of the child and in the activities of daily routines of life. In addition to uncovering the feelings of shock, sadness, pain, anger, anguish, fear, doubt, despair, disappointment, prejudice, guilt and impotence after the discovery of the diagnosis of the child. The context of the syndrome, associated with low socioeconomic conditions, revealed the magnitude and specific characteristics of the problem that permeates the limits to dignity, not only in the quality of life of mothers of children with CZS, but in the precariousness of the lives of women neglected by the State and society.

Studies with this scope provide a basis for the consolidation of a care practice aimed at the mother, with multidisciplinary actions for personal strengthening and autonomy in caring for the child. It is relevant for nursing to step into life histories and coping mechanisms in order to identify new care strategies, which allows a reflection on the main needs of these women, in addition to directing the practice of comprehensive care and overcoming adversities.

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NOTES

ORIGIN OF THE ARTICLE

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CONTRIBUTION OF AUTHORITY

Study design: Bulhões CSG, Almeida AM, Reichert APS, Abreu PD, Dias MD.

Data collection: Bulhões CSG, Almeida AM, Reichert APS, Abreu PD, Dias MD.

Data analysis and interpretation: Bulhões CSG, Almeida AM, Reichert APS, Abreu PD, Dias MD.

Discussion of the results: Bulhões CSG, Almeida AM, Reichert APS, Abreu PD, Dias MD.

Writing and/or critical review of the content: Bulhões CSG, Almeida AM, Reichert APS, Abreu PD, Dias MD.

Review and final approval of the final version: Bulhões CSG, Almeida AM, Reichert APS, Abreu PD, Dias MD.

APPROVAL OF ETHICS COMMITTEE IN RESEARCH

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CONFLICT OF INTEREST

There is no conflict of interest.

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CORRESPONDING AUTHOR

Camilla de Sena Guerra Bulhões
camilla_sena_@hotmail.com