

Stigma perceived by mothers of children with congenital Zika virus syndrome*

Estigma percebido por mães de crianças com síndrome congênita do Zika vírus

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ABSTRACT

Objective: to build care gerontotechnologies to help family caregivers with the difficulties experienced in the context of elderly people with Alzheimer’s disease. **Methods:** strategic action research carried out with seven family caregivers of elderly people with Alzheimer’s disease and 12 health academics from a university. Data was gathered from the family caregivers using a semi-structured interview. Three focus groups were held with the academics. The data was submitted to the discursive textual analysis technique. **Results:** eight difficulties experienced by family caregivers emerged, corresponding to cognitive aspects, Activities of Daily Living and issues relating to family care. It was possible to construct 14 care gerontotechnologies in product form. **Conclusion:** gerontotechnologies were built to help family caregivers with the difficulties experienced by elderly people living with Alzheimer’s disease. **Contributions to practice:** the gerontotechnologies developed have the potential to contribute to the care process, since they can be used by family caregivers on a daily basis and can be adapted to each reality, based on the unique needs of each elderly person.

Descriptors: Aged; Family Relations; Geriatrics; Alzheimer Disease; Technology.

RESUMO

Objetivo: apreender as experiências do estigma percebido por mães de crianças com síndrome congênita do Zika vírus e suas repercussões. **Métodos:** estudo qualitativo desenvolvido com 12 mães respondentes às entrevistas semiestruturadas. Foram procedidas a Análise Fatorial de Correspondência e Classificação Hierárquica Descendente por meio do Software IRaMuTeQ. **Resultados:** emergiram quatro classes que abordam a experiência com a percepção do estigma: Percebendo a discriminação do público; Comportamentos estigmatizadores e suas repercussões; Sentindo-se culpada e adotando estratégias de enfrentamento; Vivenciando a Rejeição do pai, dos outros e sentimento de Solidão. **Conclusão:** o estigma é percebido por mães de crianças com síndrome congênita do Zika vírus em interações afetivas, familiares e sociais, expressas através da rejeição, afastamento e exclusão resultantes em sofrimento às mães, as quais adotam como estratégias de enfrentamento ocultar a criança e o autoisolamento. **Contribuições para a prática:** à Enfermagem cabe identificar sinais de isolamento social, tristeza profunda e estresse relacionado ao estigma em ser mãe de uma criança com síndrome congênita do Zika vírus e elaborar planos de cuidados para prevenção do adoecimento materno.

Descritores: Estigma Social; Infecção por Zika Vírus; Anormalidades Congênicas; Bem-Estar Materno; Serviços de Saúde Materno-Infantil.

Introduction

Congenital Zika Virus Syndrome (CZS) emerged in 2016, following the Zika virus (ZIKV) epidemic declared by the World Health Organization as a public health emergency of international concern⁽¹⁾. It is characterized by physical deformities and neurological disorders, including eye problems, hearing problems, craniofacial disproportion, changes in joints and limbs, irritability, and seizures, especially microcephaly⁽¹⁾. Microcephaly produces body patterns that diverge from the notion of "corporeality", relating the body to the ability to produce value⁽²⁾. Otherwise, injuries and impediments result in prejudice, discrimination and stereotypes directed at children, making them "marked", as well as those involved in their care, such as mothers.

Stigma is a strongly derogatory sign used to separate an individual or a group of people with characteristics that deviate from socially acceptable standards, which leads to rejection, discrimination, and exclusion. Complimentary stigma is expressed when people living with stigmatized individuals become disapproved of and rejected for maintaining a close relationship with the stigmatized individual⁽³⁾. Caring for a child with CZS requires changes in family dynamics, which trigger physical, psycho-emotional, and financial burdens, and interfere with sociability and quality of life, especially for those involved in direct care, such as the mother. The mother accompanies the child in public spaces and therefore perceives and suffers from prejudice and discriminatory comments⁽⁴⁾.

The disapproval and rejection suffered by the mother-child dyad with CZS can be manifested by indiscreet attitudes for third parties, from looks, comments, speeches, and unpleasant emotions. On the other hand, mothers develop coping strategies to minimize the stress generated by stigmatization and its repercussions. These strategies can include social isolation, attempts to hide the child with CZS to avoid negative experiences, as well as hostile responses and looks when faced with episodes of prejudice and

discrimination⁽⁵⁾. Despite the countless scientific findings about children's neuropsychomotor skills, their clinical and epidemiological conditions, there is a lack of research into the negative social interactions that cause mothers to become ill⁽⁴⁾. This is a relevant morbidity, with worldwide magnitude due to the high incidence of arboviruses in tropical countries, the recent epidemic in Iran and the likelihood of new epidemic waves in the next five years⁽⁶⁾.

This study aims to fill a scientific gap, as research into the stigma perceived by mothers of children with CZS makes it possible to learn about their social, psychological, and emotional experiences and vulnerabilities to define interventions and implement care practices in health services. In addition to complying with the principle of intersectionality for the development of health education activities to deconstruct the stigma directed at this specific public.

This study could also help to strengthen the health care network for these mothers in line with the Sustainable Development Goals - Agenda 2030 – set as a target by the Member States of the United Nations. Considering the above, the following question arises: What experiences of stigma are perceived by mothers of children with congenital Zika virus syndrome? To answer this question, the objective was to understand the experiences of stigma perceived by mothers of children with congenital Zika virus syndrome and its repercussions.

Methods

This was a qualitative study based on the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ), carried out at the Municipal Infectious Diseases Outpatient Clinic and the Association of Parents and Friends of the Exceptional of from the city of Feira de Santana, Bahia, Brazil. At the time, both the clinic and the association served approximately 25 mothers each, offering multi-professional care for their children.

Twenty-two mothers (n=22) found at Muni-

pal Infectious Diseases Outpatient Clinic and Association of Parents and Friends of the Exceptional during the research were invited to take part in the study. Of these, 12 participants were included who met the following criteria: being over 18 years of age, having at least one child with CZS and participating in the care of this child. To enable broad participation, considering all the mothers' experiences to be valuable, there were no exclusion criteria, ensuring the homogeneity of the sample by meeting all the inclusion criteria. The mothers who refused to participate justified their refusal for reasons such as the unavailability of transportation from the city hall (n=6) or the short time available (n=4) for the interviews.

The data was collected between December 2019 and February 2020. The number of participants was established based on the criterion of theoretical-empirical data saturation, when new data collected was like that collected previously, with no substantial contribution to the phenomenon under investigation⁽⁷⁾. To validate the achievement of this criterion, the authors independently judged all the data collected, ending the collection when two authors converged on theoretical-empirical saturation.

To gather data, semi-structured interviews were conducted with closed questions to collect sociodemographic data and open questions, such as: "Have you ever experienced prejudice or discrimination against your daughter or son? Could you please tell us about this situation?" The interview script was piloted with one mother, and modifications to the instrument were deemed unnecessary. The interviews were carried out in the private office of the healthcare establishment, in the presence of the first author, the participant (mother) and the child with CZS and lasted an average of 15:28 minutes. The transcription was carried out by the interviewer herself and then presented to the participants to read for them to approve, remove or add information.

The empirical material was submitted to Factorial Correspondence Analysis (FCA) and analysis using Reinert's method using the software interface

de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRaMuTeQ). Before submitting the data to the software, the corpus of the study was prepared and organized, with the first author adjusting it according to the orthographic rules of the Portuguese language, deleting symbols, spaces and punctuation that generate inconsistencies if submitted to IRaMuTeQ.

Among the possibilities for categorizing the interviews, we opted for FCA, which produces graphic representations of the data, indicating the proximity between the classes or words, arranged in quadrants, after calculating the frequency of the words and the Chi-square correlation of each word in the corpus. Reinert's method results in the Descending Hierarchical Classification (DHC), which organizes the text segments according to their respective vocabularies, with the aim of obtaining classes of text segments which, at the same time, have similar vocabularies to each other and are different from the text segments in the other classes⁽⁸⁾.

In this study, word classes were formed by considering the words with the highest frequency and the significant association between them: nouns, verbs, and adverbs. At the same time, the software performs the Chi-square (χ^2) test to check the associative strength of the words with the class they belong to, grouping them according to their significance⁽⁸⁾.

After forming the DHC, the authors read the text segments of each class and assigned titles to each one to represent the main theme, enabling subjective interpretation of the textual material. The results were analyzed in the light of sociological contributions to stigma and health⁽³⁾.

This study complied with the norms and guidelines of Resolutions No. 466/2012 and No. 510/2016 of the National Health Council, with approval from the Research Ethics Committee under opinion No. 3,740,211/2019 and Certificate of Presentation for Ethical Appreciation: 22750719.3.0000.0053. All participants signed an informed consent form and freely chose fictitious names to ensure anonymity and confidentiality.

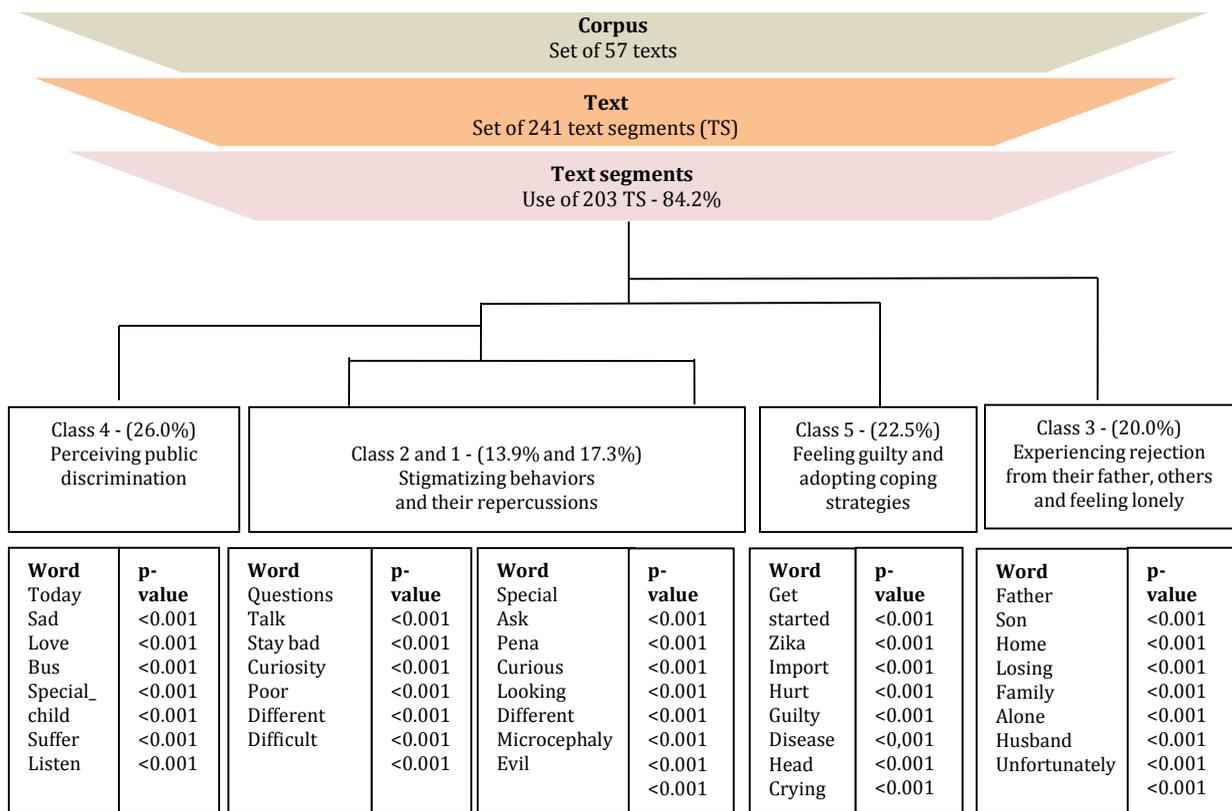


Figure 2 – Dendrogram representing the Descending Hierarchical Classification of words organized by classes, in relation to the stigmas experienced by mothers of children with CZS. Feira de Santana, BA, Brazil, 2020

Realizing public discrimination

Among the most frequent words are “today”, “sad” and “strong”, but it is important to emphasize the following words that also make up this class: “love”, “special child” and “suffer”.

The mothers’ experiences are permeated by feelings such as sadness because their child is “special” and because of the stigmatizing looks and comments directed at them. Below, Rita states that the stigmatizing mark is in the shape/size of her son’s head, while Paula cites the judgment of incapacity issued by society in relation to the child’s body: *Very sad comments, once a woman said, “the body is cute, but the head is so strange” ... Before, I cried, I felt sad about the situation, I didn’t want to go out anymore, ...but not today (Rita). ... It’s happened to me waiting for the bus, when a girl arrives, someone to take me and all, “ You have a special child, take the bus, I’ll take you, it doesn’t cost me anything” (Paula).*

Stigmatizing behavior and its repercussions

Curious questions about the development of the child with CZS, which required imprecise answers, made the mothers uncomfortable, as Marina says: *They asked if the child was sick, if he would walk or talk. I felt bad (Marina).*

The mothers also noticed looks and intonations in the speeches that denoted sarcasm, prejudice, pity and aversion to the child, especially because of the shape/size of the head, resulting in the stigmatizer moving away because of aversion to the child’s image, as the testimonies exemplify: *There are others who look on with contempt, or pity, even prejudice (Julieta). When you have a special child, it’s not easy! People’s looks, judgment (Maria). People just move away, they become afraid to get close, I don’t know, they just move away (Paula).*

Feeling guilty and adopting coping strategies

This category brings together mothers' memories of the beginning of the CZS epidemic and the spread of infection prevention among pregnant women. Although there was a time gap between the first births of children with CZS and the discovery of the cause of the syndrome, with the spread of prevention intensifying afterward, these accounts are permeated by a feeling of guilt for the mother, as if she were the one most responsible for what happened because she didn't prevent herself and didn't take care of her health: *But in a way, the mother feels a little more guilty* (Marina). *We feel guilty, you know? As if it were my fault that he was born with micro* (Carla). *Sometimes you feel, I don't know, like you allowed it, you feel guilty, I could have been more careful, you have many things on your mind* (Rita).

Also, noteworthy are the words "head", which due to microcephaly is the main stigmatizing mark of CZS, and "hurting", which is related to the suffering caused by the perception of the child's anomaly and disabilities recalled by the image of the skull. There are judgments from third parties directed at the mother, as if the CZS was caused intentionally by her, as Carla quotes: *A woman came up to me and said, "why did you let the mosquito bite you?", then I said, "I didn't let a mosquito bite me, when I saw it, I already had Zika"... some people think we're to blame, but it's not my fault at all that my son was born with micro* (Carla).

Still in Class 5, the participants mentioned how they dealt with such judgments, raising their level of concern based on what they did and spoke. Over the course of the experience, the mothers began to ignore prejudiced comments and discriminatory behavior as a way of coping.

Staying away is also a coping strategy for the mother, moving away from the stigmatizer as a way of protecting her child, as the statement below shows: *They stare, like they want to ask something, they intend to say something, but when I see these negative energies, I get away. I prefer them not to say anything* (Júlia).

However, the mothers stressed that there were people who treated them with esteem and generosi-

ty, as if their children were "normal children", so that "being normal" was a condition for being accepted and well-liked: *Thank God I'm treated well, like a mother of a normal child because even in the places I go, he's well received, accepted, well-liked by people* (Amanda).

Experiencing rejection from the father, others and feeling lonely

The most frequent words in this class were "father", "son", "home", "lose" and "fight", contextualizing the stigma associated with the rejection of the child by the parent, the abandonment of the family due to the father leaving home, making it one of the moments of great loss for the woman, not only due to the abandonment of the parent, but also of friends and family, when they had to gather the strength to overcome this situation and fight for the child's well-being.

Rejection and loneliness can be seen in their accounts: *... If it's in terms of family, friends, these things that we also lose, I don't know what happens after having a special child because we lose friends, family ...and lately, I feel alone, I'm alone, me and my children alone* (Paula). *My family didn't want the child, the father's family didn't want him, so I felt that my son was being rejected* (Marise).

Discussion

This is the first study in the Brazilian context that sought to understand the experiences of stigma perceived by mothers of children with CZS and its repercussions, showing that mothers live with courtesy stigma. The results of this study point to the need for health professionals to encourage strategies to tackle stigma and develop care for mothers of children with CZS, helping Brazil to achieve the Sustainable Development Goals approved as a target by the Member States of the United Nations, such as the goals: 3 - Health and well-being; 5 - Gender equality; and 10 - Reducing inequalities.

Although the stigmatizing experience is the subject of this study, it is necessary to produce an

analysis that goes beyond corponormativity, highlighting the subaltern “social marks” imposed on mothers, such as being a woman, brown or black, from the Northeast, single, a housewife, with low schooling and low income⁽⁴⁾. The phenomenon discussed brings together intersectional social aspects based on socio-historical structures of patriarchy, heteronormativity, whiteness, xenophobia, classism, and education.

The mother of the child with CZS is stigmatized for courteously giving birth to the child with a disability, so both are rejected. These women, sometimes with broken relationships with the child’s genitor and/or family members, embark on a lonely journey, taking the lead in caring for the child and maintaining responsibility for household chores⁽⁹⁾. Loneliness is permanently present in the daily lives of the mothers of children with CZS, pointing to the neglect of several fathers towards the family and to affective abandonment⁽¹⁰⁾. In addition, there is the isolation imposed by the excessive responsibilities associated with caring for these women, a similar scenario experienced by Chinese mothers of children with Autism Spectrum Disorder⁽¹¹⁾ and mothers of children with developmental deficits in Ethiopia, where they also showed stigma towards the siblings of children with disabilities and social isolation behaviors⁽¹²⁾.

The causality of the social phenomenon experienced by mothers lies in the social structure of patriarchy, which sustains sexist behavior and imposes on women responsibility for the health and education of their children, care for the domestic environment, compliance with the standards of corponormativity and acceptance of their partner’s wishes⁽⁹⁾. In this way, the mother of a child with CZS accepts the stigma and becomes her own tormentor, in other words, she is aware of the stigma attributed to her and the child, but even so, she keeps the negative consequences of the syndrome’s stereotypes within herself, as if accepting the justification for this phenomenon⁽⁴⁾. Self-stigma can manifest from the correspondence between the perceptions of others (social identity) and the subjective and reflective perceptions of the indi-

vidual themselves, culminating in the constitution of ego identity⁽³⁾.

Prejudiced comments and discriminatory behavior were evidenced by mean-spirited questions or just to satisfy curiosities, in the form of comments and looks permeated with sarcasm, rejection, aversion, pity or pity, or with comments permeated with criticism and judgments against the mother. Such stigmatizing actions cause discomfort in the mothers of children with CZS, increasing the desire for seclusion, withdrawal from society and resulting in psychological suffering⁽⁹⁾.

People’s varied behaviors are related to the collective fantasy of the dominant group, those who oppress people for their socially unacceptable marks and labels, the “inferiors”⁽¹³⁾. In this way, the main bodily mark of CZS, the shape/size of the head, becomes the symbol of the child’s inferiority, also diminishing the mother out of courtesy, summing them up in the mark of stigma. Therefore, CZS has a negative social construction, in other words, it is not stigmatized in itself, but by society^(3,13).

When talking about the rejection of the genitor, friends and family, the reports indicated that people with very close ties, such as the father figure, also positioned themselves as stigmatizers. Associated with the birth of the non-idealized child, the parent assumes the condition of being discredited, when they are attributed the cause of that characteristic that is publicly evident to society⁽³⁾. However, the parent and mother of a child with CZS have different ways of coping with the stigma of courtesy; the parent expresses hatred, aggression, and contempt on discovering that the child was born with limitations and will have repercussions throughout life. The abandonment of a child with CZS, in this case, is surrounded by stigma, in which the stigmatizing parent in a privileged and dominant position feels their moral identity affected by witnessing the disability in their offspring, resulting in the rejection of the child^(10,14) and family abandonment as a way of escaping reality⁽¹⁵⁾.

Paternal abandonment in the group with CZS

is significantly higher when compared to the group without the syndrome, reaching up to 70% of cases, also demonstrating that renunciation of the child can happen even during the woman's pregnancy after the discovery of the disease through prenatal examinations⁽¹⁶⁾. Stigma from people with close ties has a destructive impact on daily tasks, can reduce a woman's sense of well-being and make her ill, due to the overload of responsibilities and suffering caused by contempt and belittlement. In this context, instead of really being a support network, family and friends become a barrier to social interaction, making it difficult to welcome the child with CZS and their mother, making it a lonely experience^(5,17).

In addition to the stigmatizing thoughts emitted by family members and the social support network worsening the mothers' health situation, it is known that the level of disability is directly proportional to the intensity of the stigma, resulting in greater social exclusion⁽¹⁸⁾. With a weakened support network, mothers are sometimes blamed for the syndrome in their children, being judged for displaying highly vulnerable behaviors, such as not having used repellent or not having worn long clothes to avoid being bitten by the mosquito that transmits the Zika virus, which can be considered by people to be negligent attitudes that justify the birth of the child with malformations⁽¹⁹⁾. On the other hand, some family members choose to welcome the mother and child with respect, regardless of the cause of the CZS, which enhances coping with the stigma, reduces the risk of internalizing the stigma and the consequent maternal illness⁽¹²⁾.

As for self-blame (self-criticism), when it occurs in a hostile circle permeated by stigmas, it may indicate an effort by the woman to defend herself against another who is certainly dominant (the stigmatizer) and, in this way, it may be an attempt to minimize or stop the probable damage to the belittling⁽²⁰⁾. The weakening of the social support network results in the intensification of suffering and causes feelings of low self-esteem, self-blame, and self-reproach⁽³⁾, internalizing the stigma (self-stigma) and assuming behaviors of social isolation⁽¹²⁾.

Breaking away from oppressive situations like this requires problematizing reality, raising awareness of existing power relations and collective organization⁽²¹⁾ to foster coping strategies in favor of maternal empowerment. At the same time, cognitive-behavioral techniques such as self-compassion have protective effects on mental health and should be encouraged in the care of mothers of children with CZS. Self-compassion implies looking closely at oneself, recognizing one's limitations as a human condition, learning to live with difficulties and handling kind practices for oneself⁽²²⁾. It is up to the nurses to plan care that integrates the three properties of self-compassion: self-kindness, common humanity, and mindfulness.

The mothers' testimonies indicate strategies for coping with stigma, such as attempts to ignore people who looked at and asked questions with curiosity and/or aversion to the child; hostile reactions to these looks and comments; withdrawing when they realized they were being or would be stigmatized; attempts to hide the child, especially the head, which because of microcephaly, carries the main mark of stigma; among others. Coping, also known as coping strategy, is the set of strategies to overcome something that poses a threat to the individual, given that this threat appears as a burden on cognitive and behavioral capacities⁽²³⁾.

Positive coping strategies can be summarized as: talking about the stigma; spending time with family and friends; discussing problems with someone you trust; doing activities that help you relax; exercising, and so on. Accepting and coping with stigma can put the mother in an uncomfortable position, handling the stigmatizing characteristic to neutralize it. In association, the stigmatized may raise the pitch of her voice and utter harsh words as a means of coping with the stigma⁽³⁾. Positive behavior provokes feelings of social value, raises self-esteem and conveys a sense of security, support and comfort to mothers, so it is important to implement unique care actions considering the specific health needs⁽³⁾ of mothers, including respect for the principle of popular participation and the inclusion of mothers' groups in decision-making

spaces such as councils and management collegiate bodies⁽²⁴⁾. Ensuring fundamental rights to life, as well as the exercise of solidarity practices, such as sharing information and successful experiences, and donating resources, are kind, acceptable and relevant actions that promote health for mothers.

On the other hand, negative coping strategies should be discouraged, such as absence of leisure and relaxation time; isolation from friends and family; and neglect of self-care⁽²⁵⁾. Such behaviors may indicate the mothers' acceptance of stigmatization and the incorporation of stigmatizing thoughts into their belief system, which is known as self-stigma⁽²²⁾. Mothers and fathers of children with autism spectrum disorder in Poland who live with self-stigma develop high levels of stress, anxiety and depression⁽²²⁾.

Stigma coping strategies are also unconsciously determined by the oppressive power of the social structure. In the case of the mother of a child with dyslexia, self-stigma resulted in maternal overload, calling herself an agentive mother, who participates in associations, goes through complex therapeutic itineraries and takes part in the inclusive school model in favor of the child's development⁽²⁶⁾; but, at the same time, to correspond to moral values and respond to social judgments.

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Study limitations

The study did not assess the strengths and weaknesses of the mothers' social support network before the diagnosis of CZS, nor did it identify the type

and intensity of the congenital anomaly, aspects which may particularize the stigmatizing experiences and restrict the generalization of the results. Future studies are advised to assess family structure and functioning and support networks to better understand experiences before and after the diagnosis of congenital disability.

Contributions to practice

Aware that mothers of children with CZS experience stigma in a complimentary way, it is up to nurses, as well as other health professionals, to notice signs of social isolation, deep sadness, anxiety and stress in mothers, in addition to encouraging discourse on coping with stigma. It is essential for nursing professionals to be willing to maintain bonds of trust with these mothers, to establish sensitive listening and to be able to understand them, giving them support so that they can overcome stressful situations, identifying those who need unique care, so that the Systematization of Nursing Care is expanded and comprehensive.

It is worth highlighting the contribution of this study to understanding the phenomenon of social stigma in the Northeast of Brazil, offering an important diagnosis for the development of technological innovations in health in favor of the well-being of mothers of children with congenital anomalies.

Conclusion

The stigmas perceived by mothers of children with CZS point to exclusionary behaviors that generate suffering for mothers and are learned by them from social interactions, showing judgments and attitudes of withdrawing or rejecting contact with their child.

Authors' contribution

Conception and design or data analysis and interpretation: Alves DV, Vale PRLF, Carvalho ESS.

Writing of the manuscript or relevant critical review of the intellectual content, Final approval of the version to be published and Responsibility for all aspects of the text in ensuring the accuracy and integrity of any part of the manuscript: Alves DV, Vale PRLF, Cerqueira SSB, Suto CSS, Morais AC, Carvalho ESS.

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