

Stigmas of congenital Zika syndrome: family perspectives

Estigmas da síndrome da Zika congênita:
perspectivas das famílias

Estigmas del síndrome Zika congénito:
perspectivas familiares

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Abstract

This article uses a socio-anthropological framework to explore the stigmas around interactions with children born with congenital Zika syndrome caused by the Zika virus epidemic in two Brazilian municipalities. Semi-structured interviews were conducted with parents and other relatives. We reflected on the search for meaning when having a baby with unexpected body marks, the moral suffering, the societal ableism, the burden of care, and the need for support networks. We concluded that public policies, especially social policies (health, education, and social assistance), are essential for compensatory mechanisms, recognition, and social inclusion of these children and their families.

Zika Virus; Family; Social Stigma

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Introduction

Congenital Zika syndrome (CZS) is characterized by a set of signs and symptoms – gathered in a several diagnoses –, including a head proportionally smaller than expected, with expressions of missing parts, and developmental disabilities (language, motor, visual, eating habits, physical, etc.). Between 2015 and 2016, an unexpected epidemic increased cases of this previously unknown illness. Its most unknown outcome were newborn babies with significant changes in head measurements and intracranial structural alterations, discovered by imaging testing. The occurrence was therefore extraordinary, unexpected, and surprising, showing that ideal expectations of normality and social standards must be discussed since these create stereotypes and prejudice ¹.

This universe of children affected by CZS intrigued social and human sciences and epidemiological, clinical, and experimental areas, which received national and international investments to produce knowledge, increase visibility and create research agendas. These areas were mostly interested on the health emergency of the epidemic, in which the State organized a coping plan in an environment of “public commotion” ², uncommon to other rare chronic health conditions and disabilities. The epidemic crisis can create a permanent and chronic movement not announced as acute, obscuring other conditions. CZS gave visibility to children with similar disabilities who were previously invisible, including children with other dysmorphias. Its public dimension attracted looks from different directions, including that of researchers, working as a total social fact ^{3,4,5,6,7,8}.

We can cite some similarities and differences between the social configurations of children with chronic, rare, and complex health conditions and of the emerging group of children with CZS. The former have greater visibility in specialized care environments such as tertiary hospitals and rehabilitation clinics, eventually receiving home care. On the other hand, children with CZS emerged unexpectedly from a public health event, the Zika virus epidemic, which affected the health of pregnant women and their children.

The first group of children can be diagnosed using genetic markers and fetal medicine and may develop complex chronic diseases from accidents in the first years of life; children born with CZS denounce the violence of the State’s lack of commitment towards public health, sanitation actions, combat of vectors, and milestones of health inequities at the base.

Symbolic interactionism promotes a situated perspective of the issues herein investigated, focusing not on adverse outcomes but on who is spoken about, how the subject is discussed, who starts the discussion, and how the speaker elaborates about the shared moral experience. Newborn children are the main subject, providing perspectives, questions, interpretations, and care as parents manage the infant’s health and assess normality or abnormality. Regarding infants born with CZS marks, families, society, and professionals often ask: “what is going on here?”. Goffman ⁹ (p. 10) explains “frame” as “a group of definitions of situations that govern social events and our subjective involvement in them”. The author ^{9,10,11} also recalls the “face value” and social experience frames, which situate all analyses; that is, interactions must be read within the social situations in which they occur. Nothing exists outside the established relationships expressed in each frame. The experiences of the real world also organize the interpretation and the intersection between what unfolds in them. Two concepts guided this study from the perspective of interactions and social frameworks: stigma and moral experience. Discrimination deals with the mark itself, whereas stigmas are negative stereotypes related to it. The mark represents distinction and difference, and those affected face discrimination, exclusion, and avoidance.

Moral experience ^{12,13,14} is an essential concept that considers perception and experience inaccuracies, viewing essentialism as inherent truths. This process affects how scholars work with research data, especially since they become examples of weakly debated thoughts with low levels of reflection. Perception is a cognitive and physiological act with personal mediation, interacting with experience and authority in one’s life that may not necessarily be shared. We risk losing the dialogue between society, culture, and humanity by restricting ourselves to focusing on perceptions, erasing our hybrid scope of shared cultural symbols. Perception lies between something beyond us and that surpasses us, dialogically requiring support, anchoring sense, and meaning between the assigned and what diachronically traverses us. The qualifying moral experience thus crosses the collective and shared dimension.

From an analytical perspective, the experience of mothers and family caregivers of children with CZS shows that the stigma in children results in discrimination and social exclusion of caregiver in primary family environments. This study is therefore supported by a set of arguments.

Firstly, children born with CZS marks are close to many other children with disabilities and other rare diseases unrecognized by the State and society; they are discriminated because of body normativity, which classifies their stigmas as tragedy which needs correction. They stand out because their stigmas of “microcephaly” result from an epidemic that the State could not control with equity. Zika syndrome “microcephaly” marks refer to the absent state that allows for an avoidable epidemic. The State must take responsibility and be charged for the permanence of the “humanitarian emergency”¹⁵. For “other children” with microcephaly, hydrocephalus, or anencephaly – invisible children with little-known syndromes who are sent to family care or medium and high complexity health care –, the State must demand permanent care, sustain stigma, and combat prejudice by encouraging resignifications.

Secondly, we revisited Goffman’s view of stigma as a mark that distinguishes bodies with the “birthmark”, not as a stereotype. When a child is born with a syndrome with visible body marks, at least two stigmas are permanently negotiated^{16,17,18,19}: (a) a curse, searching for a cause in material explanations (a medicine taken, a fall, domestic violence, the pregnancy onset) (b) a divine blessing, exalting the children without blaming them. This is because stigma as a mark of the unexpected and beyond the norm represents a moral experience. In the case of CZS – whose vector is the mosquito –, this is caused by the Zika epidemic. As for the State, its violence of structural inequality as responsibility is also common to other syndromes, not guaranteeing health care as a policy⁶.

Thirdly, Zika syndrome’s epidemic caused by a non-human vector marks an externality. Unlike rare genetic diseases²⁰ – including congenital or late-onset anomalies, intellectual disability, inborn errors of metabolism, or non-genetic origin from infections, inflammation, and autoimmune diseases –, the CZS mobilizes national and international health emergency actors, creating a collective experience. For other rare diseases and syndromes, the collective movement happens differently²¹, when someone finds their peers in the waiting rooms of health services, in the associations of people with rare diseases, and in public events while exchanging experiences; that is, in groups that bring together only those interested, including family members, patients, researchers, and health professionals.

This article emphasizes the stigma and moral experience on newborn children with CZS from the perspective of social interactions, as reported by their caregivers.

Methods

This study analyzed part of the research collection to assess the social and economic effects of the Zika virus in Recife (Pernambuco State) and Rio de Janeiro²². The research was approved by the Ethics Research Committees of the Fernandes Figueira National Institute of Health for Women, Children and Adolescents, Oswaldo Cruz Foundation and the Aggeu Magalhães Institute, Oswaldo Cruz Foundation, and all informants signed an Informed Consent Form.

In total, 59 interviews were conducted with mothers and other caregivers (i.e.: father, grandmother) of children with CZS identified in the health services they were referred to. All interviews were conducted from May to September 2017 and audio recorded. Topics included setbacks in pregnancy, tests, search for health system, relationships with little-known diagnoses, and interactions with family members, acquaintances, and strangers. Following systematic readings, data were organized by specific categories of explanation and understandings of CZS and its marks.

Boxes 1 and 2 shows the interviewees’ profile and their children’s ages, considering that infants or children in their first three years of life were the study’s main subject.

Data collection is characterized by diversity, strengthening qualitative research and prioritizing the possibility of increasing similarities and differences. Answers differ because of different health networks frameworks, local state response, and associative organization of families in the two research fields²³.

Box 1

Profile of children with information about relatives, shared care, and care reference in Recife, Pernambuco State, Brazil.

CHILD	CHILD'S AGE (MONTHS)	CHILD'S GENDER	INTERVIEWEE	INTERVIEWEE AGE (YEARS)	INTERVIEWEE RACE/ ETHNICITY	MOTHER'S SCHOOLING LEVEL
C1	20	F	Mother	20	Mixed-race	Incomplete high school
C2	19	F	Mother	36	Mixed-race	Complete high school
C3	20	F	Mother	18	White	Complete high school
C4	19	F	Two adoptive mothers	42 and 19	Mixed-race	Incomplete high school
C5	15	M	Mother	34	Mixed-race	Complete high school
C6	22	F	Mother	W/I	Black	Incomplete high school
C7	22	F	Mother	31	Mixed-race	Incomplete high school
C8	19	M	Mother	39	White	Complete higher education
C9	18	F	Mother	27	Mixed-race	Incomplete high school
C10	22	M	Mother	W/I	White	Incomplete high school
C11	20	M	Mother	23	Mixed-race	Complete high school
C12	19	M	Mother	35	Mixed-race	Complete high school
C13	20	M	Mother	23	Mixed-race	Incomplete elementary school
C14	21	F	Mother	28	Mixed-race	Incomplete high school
C15	22	M	Mother	35	Mixed-race	Complete higher education
C16	23	M	Mother	33	Mixed-race	Incomplete high school
C17	24	M	Father	38	Mixed-race	Incomplete elementary school
C18	20	F	Father	26	W/I	W/I
C19	21	M	Father	33	W/I	Complete high school
C20	20	F	Father	37	White	Complete high school
C21	21	F	Grandfather	47	Mixed-race	Incomplete elementary school
C22	22	F	Father	W/I	White	W/I
C23	23	F	Mother and grandmother	21 and 63	Mixed-race Mixed-race	Incomplete elementary school
C24	24	F	Grandmother	50	Mixed-race	Incomplete elementary school
C25	18	F	Aunt	22	White	Complete high school
C26	Missing	F	Mother	W/I	W/I	W/I
C27	11	F	Mother	42	White	Complete high school
C28	23	M	Aunt	18	White	Complete elementary school

F: female; M: male; W/I: without information.

Box 2

Profile of children with information about relatives, shared care, and care reference in Rio de Janeiro State, Brazil.

CHILD	CHILD'S AGE (MONTHS)	CHILD'S GENDER	INTERVIEWEE	INTERVIEWEE AGE (YEARS)	INTERVIEWEE RACE/ ETHNICITY	MOTHER'S SCHOOLING LEVEL
C1	7	F	Mother	33	White	Complete high-school
C2	15	M	Mother and grandmother	31 and 60	Mixed-race	Incomplete higher education
C3	16	M	Mother	23	White	Complete high school
C4	10	F	Mother	33	White	Complete high-school
C5	18	F	Mother and grandmother	23 and 37	Mixed-race	Incomplete high-school
C6	12	F	Mother	27	Mixed-race	W/I
C7	9	M	Mother and grandmother	23 and 51	Mixed-race	Complete high school
C8	16	M	Mother and father	32 and W/I	White	Complete high school
C9	9	F	Mother and father	23 and 26	White	Complete high school
C10	7	F	Mother	34 and 33	White	Complete elementary school
C11	9	F	Mother	W/I and W/I	Mixed-race	Complete high school
C12	9	F	Mother	34	Mixed-race	Incomplete higher education
C13	5	F	Mother	18	Mixed-race	Complete high school
C14	4	F	Mother	W/I	White	W/I
C15	10	M	Mother	28	White	Incomplete high school
C16	19	F	Grandmother	43	W/I	Incomplete higher education
C17	10	F	Grandmother	47	W/I	W/I
C18	13	M	Father	21	W/I	W/I
C19	21	M	Father	29	W/I	W/I
C20	18	M	Father	29	W/I	Complete high school
C21	15	M	Grandmother	49	W/I	W/I
C22	22	M	Aunt	19	W/I	W/I

F: female; M: male; W/I: without information.

Based on the perspective of stigma and moral experience, considering the statement excerpts from the interaction with marked children is strategic, for these can be minimized or maximized and answer the cause: a virus-and-mosquito-related syndrome.

Results and discussion

The association between stigma and moral experience is caused by living experience, an elaboration requiring assessments, search for references, and attribution of value in a set that evokes morals.

From an exercise of designating other vocabulary to refer to their children, mothers of children with CZS, who support the analysis by Scott et al. 4, react to the claims of "sick, sick, poor thing" that arise in interactions with their children. They refuse this sickness identity and use the term "special", the same term that activist mothers of disabled children no longer use, preferring the term "atypical" even to name their family. The term "special" was banned from the vocabulary of the disabled persons social movement for perpetuating stereotypes.

Morality is an attribution of meaning, in which suffering appears as a reference for authors who trigger the dimensions of moral experience with chronic illnesses. Chronicity is a category that, over time, can make a disease permanent²⁴, emphasizing the importance of discussing the temporality, duration, and permanence of a health condition^{21,25}. Scott et al.'s⁴ analysis of therapeutic itineraries in the context of Zika virus and Alves & Fleischer's²⁶ recognition of time as an organizer of the existence of mothers of CZS children consider chronicity as something that "kills" those affected, in the exhausting agendas of health services, displacements, and struggles to guarantee rights.

Stigma, scare and the search for meaning

The empirical category "scare" is recurrent in analyses of rare, complex, and little-known diagnoses when families turn to less specialized healthcare sectors¹⁸. This category was also present in the research by Carneiro & Fleischer⁵. Valuing emic categories, they emphasize "social diagnosis" as "*broader than the relationship between cause and consequence or vector-disease-disability. It can go through childbirth, personal stories, vaccines, or it can still be unknown or inexplicable*"⁵ (p. 715). In the *Introdução*⁷ of *Micro: Contribuições da Antropologia*, Fleischer takes the expression micro – derived from microcephaly – as a metonymy that synthesizes meanings and stories.

During pregnancy, individuals expect to have a typical baby; however, imaging and neonatal screening tests can reveal an exception to normal standards, and this unexpected path may be rough. We noticed the difference between "accepting" and "getting used to" terms and their intrinsic relationship with the discussion on stigma. Both concern interaction, accepting someone/something, and getting used to someone/something. The test announcement of identifiable or unidentifiable malformations brings "despair" to the respondent (a mother) and "scares" others, who will need to accept and then get used to the condition. Families experienced (1) accepting the baby's difference regarding its abnormality, (2) going through despair, and (3) recalling the possibility of getting information, knowing, recognizing, and getting used to it. This process is first experienced alone, as one learns more about the diagnosis and meets children in similar cases.

The "scare" comes with suffering and recognizing the Zika virus as a "poison". From this perspective, something from outside invades and materializes in the body with convulsions, portraying suffering. Recognizing the virus' effects on the life of a child distorts the typical image of childhood. The image of a suffering child does not match the redescribed concept of childhood. In normalized situations, families think about genetics, not from a natural history of disease perspective, but from a family history perspective related to the child's difference looking for signs of heredity and not abnormality.

This search for meaning is a strategy of normalizing difference, seeking to do what is mentioned in the following quote: "to believe in the supernatural of God". In other words, the difference can be justified by (1) family genetics, not as a disease, but as something hereditary in people, or (2) divine capacity, viewing the difference as something that will encourage learning and redemption from a messianic perspective where the child's and the family's situation results from an unknown plan that transcends them.

The label of "angel" removes the child's humanity, putting them in a divine condition as someone who brings divine messages, offers protection, perseveres, and teaches lessons²⁶. Being an angel does not justify the estrangement of body marks, rational expressions, and reactions. This "noise" is the strange, the weird, and the surprising difference. Alves & Fleischer²⁷ suggest in their collection that the angel of activist mothers in Recife becomes a divine gift that supports the fight for their children's rights.

If this expected/unexpected condition occurs, negotiation processes with the news are offered, often accompanied by inadequate handling of the clinical scene which reverberates in the memory of parents and relatives. By resorting to the idea of stigma as a distinction mark, often associated with a curse, Goffman¹⁰ shows that many symbolic components reside in social interactions. In interpreting it as a blessing, a gift from God, the child is considered as an angel.

Moral distress, super parent, suffering, and stigma

Blaming reactions are justification responses to what appears to be unexpected. When someone is blamed, they become unable to avoid the event. Women who give birth to children with CZS are blamed as if those children and the responsibilities during pregnancy were theirs only. The stigma of the marks of a child born atypical accuses “someone” of being “guilty” of this evil.

Working as mediators, these symbols build images, reveal interactions, and prepare those involved to face and to respond to marks/stigmas, addressing social discrimination. Discrimination is a response to the difference, seen as inferior. The response to this inferiority changes when the one affected is close regarding familiarity, protection, and care.

Moreover, children are under the judgment of adults, who will either encourage positive actions, strengthening, and investment or discrimination, refusal, and distance, triggering suffering and justification to create a protection circle. Goffman¹⁰ says that this “enchanted” circle protects one from the glances, putting up a guard and distancing them from the public, all for protection. This conduct assumes that “exposure” removes the protection of an “enchanted” family circle against public scrutiny. Privacy and publicity, protecting and preserving, and offering the child to science to benefit other mothers. Das et al.¹² characterize this unexpected, painful experience as “moral distress”, that is, when something that appears catastrophic somehow unfolds after being reread and presented publicly to exchange experiences, knowledge, and even comfort.

Some reflections on stigma and suffering in this collection are secondary reflections. That is, if someone cannot identify signs of suffering in the baby, they might delegitimize or lessen its pain. In other words, recognizing that the stigma experience first occurs in the child, requires a fine and delicate reading.

On having the child or not if the choice had been given, the child’s birth is attributed beauty and happiness, idealized and justified transcendently as “time of God”. The so-called “time of God”, which establishes a temporality for development and divine support for the difference, is not exclusive to mothers of children with CZS. This is because the meanings around stigmas of children with disabilities can span generations. The Zika virus epidemic, in which several infants had physical marks mainly related to microcephaly, restored myths of the hero/heroine, of being special, of overcoming, of the divine desire.

Another important aspect is the attribution of masculinity and the admiration of a heroic character. The mother highlights the infant’s happiness for existing and captivating paternal love, whereas the father who becomes a heroic figure for loving someone with a different development. The “super dad” (or the hero) indicates a widespread surprise at a father’s affective capacity^{28,29}. Even mothers considered “super moms/warriors” admire fathers who treat the baby as “normal” and children who can stir paternal affections, for this is seen as a special quality. Men continue to be perceived as distant from the world of care, especially concerning children with disabilities. Furthermore, father abandonment is the most expected outcome in these situations³⁰.

“...When I found out about microcephaly, and I saw the cases happening on television of men abandoning women because of their child, I thought about that too. I said, ‘He’s going to leave me. (...) He will reject this child!’. But no [the child] was also showing another behavior, improving day by day. He’s crazy about the boy!” (REC_M_16).

Expected and actualized fatherhood differ concerning abandonment. The saying “crazy about him” indicates true affection instead of absence, surprising for fathers, therefore depicting this father as a hero. The hero figure dehumanizes and idealizes parents, so they cannot understand the social forces at stake in the construction of parenting and care expectations. Atypical mothers reject the label of “heroic, resilient mother” precisely because it reinforces idealizations that do not criticize ableism, that is, the discrimination against people with disabilities³¹. Criticizing a society that does not recognize the obstacles of diverse lives combats prejudice.

The suffering around stigmas is still used to justify hoping to achieve the developmental marks of an expected “normal” development.

“Then I would go into despair and say, ‘My God’. Then something crosses my mind: Will he walk? Will he speak?” (RIO_C_08).

“Someone said, ‘You cry. You keep crying, you are rejecting your daughter.’ I said, ‘It is not rejection, it is because every mother wants a ‘normal’ child’ (...) Then I see that the other children, doing everything, the same age as her, that she can’t, that she doesn’t” (RIO_M_10).

Searching for bases of comparison with other children of similar ages is insufficient to dialogue with the future, which seems to only be answered using “God’s will”.

This process can help children be recognized as worthy of existence.

“So, in the beginning, she had a hard time accepting that it was a disease, and said, ‘Oh, no, this boy is normal,’ and we kept saying, ‘No, mom, he has a condition, you have to accept it.’ The first step is to accept that he has a condition, and as much as he looks like a normal child, he needs some care” (RIO_C_15).

The expression “he has a condition” represents realizing that one is faced with a challenge that must be recognized, accepted, and embraced. Such challenges can lead to discussions of health conditions. International agencies³² refer to chronic conditions as a broad category that emphasizes what prevails in life, generates coexistence, and indicates non-transmissibility, deviating from the concept of “disease”.

*Micro: Contribuições da Antropologia*³³ shows other clues that match our discussion about interactions with children with CZS and its stigmas. Learning with the child – not only to make it intelligible for health professionals, through the discovery of their characteristics – but also with the achievements of mothers who become public personas, who must move around the city, living their life “for them [the child]”³³ (p. 41). Other studies on children with complex chronic health conditions³⁴ include the idea that mothers translate their children’s characteristics for professionals.

Ableism and stigma

Honneth³⁵ shows the fundamental and loving action of respecting the other with reciprocity during dialogue. Children with disabilities bring up the imagery of protection, which is however associated with inferiority. One must justify their existence and show signs of a full life to be respected and not be threatened by symbols of prejudice and social discrimination. Short- and long-term repercussions include the socially unjustified abandonment and isolation of children with disabilities.

Attributing feelings to children with disabilities gives them humanity. Children with disabilities face ableism, which is defined as prejudice against people with disabilities. Ableism dialogues with prejudice and reassesses prejudiced individuals as rightful subjects of law.

Adult-centered and ableist social interactions discriminate children using stereotypes. The more children interact with environments with symbols of social discrimination based on prejudice, the more they are affected by them, experiencing withdrawal and rejection.

“Children are not prejudiced; adults are. There [at the nursery], the children love them [children with disabilities] and the mothers as well, from what I can see. Others talk a lot about him at home. (...) One even said, ‘I don’t know why I send him to school if he does not learn” (RIO_C_01).

“Then she’s looking. We are mothers. We feel that they are talking about our [children] (...) like, ‘There, man, poor boy, he has microcephaly’ (...) She was so embarrassed, and I left. (...) They are not animals, they are children, and they have microcephaly. (...) But the child is perfect to me, regardless of his problem” (RIO_M_03).

“People who looked with affectionate eyes at our children because they were not monsters. They are babies. They are beautiful and helpless” (REC_M_02).

Strangeness can make children with a disability feel like monsters, showing what the ableism can mean in its extreme. The responses of abandonment and objectification deprive children of their humanity, distancing them from recognizing their inherent difference.

“Is it better to put the child up for adoption than to do something like that with the child? If we, as adults, get crazy when we are locked at home. Think about a child! A unique child, regardless of age, but they are always children. The child does not have our mentality” (REC_M_07).

Abandonment has two dimensions: (1) living “hidden at home” due to shame, being a young woman with a disability, and wondering if it would be better to “give up” than to hide; and (2) being associated with the father’s place, as an expected and strengthened perspective in the media. In both dimensions, women’s place must be explored. On the one hand, a mother does not abandon her child but is ashamed of them and hides them at home. On the other hand, as reported in the media, a father’s abandonment is a rejection of the child. The intensity of these reports contrasts the patriarchal para-

digm with the ableism ³¹. Ableism and other race, color, and gender prejudices against people with disabilities must be confronted while also questioning men's ability to be a caregiver, seeking to affirm the child's difference.

The phrase *"the child does not have our mentality"* (REC_M_07) shows that stereotypes and discrimination are a part of the adults' world, of the expanded society where an instrumental, body normative, and little inclusive rationality predominates. The dissemination of information, flags of struggle, and affirmation of the children are strategies against discrimination. Regarding the construction of social networks in health, Goffman ¹⁰, based on Moreira & Souza ¹⁶, shows that a relationship between equals – people with disabilities – and those informed – those who share the stigma or who live intimately and technically with these people – is a virtuous circuit of social inclusion.

Housework distribution and the burden of caring for a child with a disability emphasizes stigma as a moral experience, especially for those without family and community support.

"[What is different about caring for this child?] Dependence. Today, I can't do anything. (...) And I'm afraid to go to the stove with him in my arms. I'm afraid. I prefer not to because an accident could happen" (REC_M16).

"...Because it was going to be a daycare center just for these children with microcephaly. They said they were going to put this daycare center to help mothers work, mothers who did not finish school, and all that" (REC_M_03).

"[Who helps you? How is this helpful?] ...My husband, my mother-in-law (...) stay with him, so I can do something and wash clothes. They stay and play with him so that I can finish other things" (REC_M_11).

When a child with a disability is born, support systems based on familiarity and neighborhood networks could change and weaken or have to endure increments, causing fear, insecurity, and concerns. In circles of sociability, these children could feel unable to be cared for since they require "special care". The mother's burden can become unbearable if these structures fail, destabilizing positive bonding relationships with the child.

"I'm afraid to leave her in the hands of others. (...) That's why I take her with me everywhere I go. I don't leave her with anyone else..." (REC_M_05).

Communities should consider the structures of daycare centers and schools where children with disabilities can enjoy other networks, allowing families to rebuild and recharge. The State should also provide specialized services for these children. This possibility of giving children the right to an education network could rebuild the relationship with difference positively and inclusively.

"We just wanted more collaboration from the government, from hospitals. (...) Less prejudice" (REC_M_02).

This support network can be associated with blood ties, in which older siblings are called upon to be caregivers despite being children themselves.

"You are the eldest. You have to help your sister. What you see, you tell mom. (...) If something is going wrong, speak to mom" (REC_M_13).

"He requires special care. It is not just for a part of life, it is for life. This affects us, our lives, and everyone's structure" (REC_M_12).

Child born atypical have a special place; in this case, the holy place, in which they deserve to be helped, cared for, protected, and preserved to gain strength.

Moreira & Souza ¹⁶ and Moreira & Macedo ^{17,19} have discussed the stigma related to children with hydrocephalus and microcephaly, exploring the symbolic dimensions of the mark of a "bigger and with a valve" head in social interactions and life projects. "A problem in the head" leads to discrimination, making children seem incapable of education, work, and happiness. This is because the social convention assumes that the head centralizes reason and control, tasks, and intentionality, which refers to prejudice from looks, evaluations, and discriminations.

The stigma associated with microcephaly/hydrocephalus or other body dysmorphias precedes the social production of prejudices and stereotypes. Stigma is a brand, an attribute that mobilizes classifications, apprehensions of meaning, interpretations, and assessments judgmental toward the body.

Conclusions

The reactions to the stigmas of children born with CZS can be interpreted differently based on the interpreter's position. Strangers who do not belong to an informed circle of family members, professionals, or researchers have more permanent reactions toward bodies with disabilities.

Zika virus' public image as a causal and exogenous factor for children with CZS operates differently concerning the stigmas of bodies with disabilities. The public interactions of its health emergency mobilized the media and knowledge, distinguishing CZS from other rare syndromes and chronic and complex health conditions. This difference brought by the epidemic is essential to distinguish between the moral experiences of mothers of children with Zika syndrome and mothers of children with other syndromes. For CZS, the State is charged as the cause and must take responsibility in the course of life. For other rare syndromes, the State is not charged as the cause, but as a maintainer which guarantees access to treatments, medicines, and visibility of rights, except for "the rare expensive patient".

Contributors

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Additional informations

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Resumo

O artigo adota um referencial socioantropológico para explorar os estigmas subjacentes às interações com crianças que nascem com a síndrome congênita do vírus Zika provocada pela epidemia de Zika em duas cidades brasileiras. Foram realizadas entrevistas semiestruturadas com os pais e outros familiares. Os autores refletem sobre a busca de sentido ao ter um filho com marcas corporais inesperadas, sofrimento moral, capacitismo, o fardo pesado dos cuidados e a necessidade de redes de apoio. Concluem que políticas públicas, principalmente sociais (saúde, educação e assistência social) são essenciais para produzir mecanismos compensatórios, reconhecimento e inclusão social dessas crianças e de suas famílias.

Zika Vírus; Família; Estigma Social

Resumen

Este artículo adopta un marco socioantropológico para investigar los estigmas subyacentes a las interacciones con niños, nacidos con el síndrome congénito del virus Zika, causado por la epidemia de Zika en dos ciudades brasileñas. Se realizaron entrevistas semiestructuradas con padres y otros parientes. Reflejamos en la investigación el significado de tener un bebé con marcas corporales inesperadas, sufrimiento moral, razón de la discapacidad social y carga de cuidado, así como la necesidad de redes de apoyo. Concluimos que las políticas públicas, especialmente las políticas sociales (salud, educación, y asistencia social), son cruciales produciendo mecanismos compensatorios, reconocimiento e inclusión social de estos niños y sus familias.

Virus Zika; Familia; Estigma Social

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