


Professional approach in times of pandemic: what have we learned from the Zika virus?

Abordagem profissional em tempos de pandemia: o que aprendemos com o Zika vírus? (resumo: p. 16)

Abordaje profesional en tiempos de pandemia: ¿qué aprendemos con el Zika virus? (resumen: p. 16)

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The bonding between families of children with Zika Congenital Syndrome and health professionals is a *sine qua non* for the development of the affected children. This study aims to know the perspective of mothers of children with ZCS regarding the professional approach, forming bonds in the health care process during the Zika Virus epidemic. It is a qualitative, descriptive-exploratory research, with interview of 25 mothers. The results reveal that health professionals had practices of dehumanizing care and committed obstetric violence. In contrast to dehumanization, there have also been sporadic cases of humanized practices with bonding. The results of this study point to the need for strategies and interventions for better care for pregnant women with a diagnosis of congenital malformation and adequate management in addressing emerging diseases and pandemics.

Keywords: Zika virus. Zika virus infection. Professional practice. Humanization of care. Women's health.



Introduction

The circulation of the Zika virus in Brazil was first identified in April 2015, through numerous cases of a exanthematous disease. In October of the same year, an alert was issued about an epidemic of microcephaly in Pernambuco, with radiological changes suggestive of congenital infection. Then, the Zika Congenital Syndrome (ZCS) emerged, a new condition, described for the first time based on the outbreak occurred in Brazil¹.

The unprecedented causal association between Zika virus and congenital malformations, coupled with the fragility of the initial clinical protocols and the insufficiency of information² may have affected health care - understood here as the encounter between health workers and users - , being the result of professional work developed daily within health systems and services^{3,4}. In this sense, the health emergency condition generated by the Zika virus may have expanded characteristics that already occupy the daily work, influencing the production of care and the humanization of the therapeutic encounter³ between health professionals and women, mothers of children with ZCS.

Thus, the formation of bonds between families of children with ZCS and professionals is a *sine qua non* condition for the development of the affected children, given that the Ministry of Health (MH) recommended that care for these children should be produced in the multidisciplinary space, for a long period and intensely⁵.

Few studies discuss the approach of health workers, and in what capacity the construction and/or (de) construction of a care bond⁶ took place with the families affected by ZCS. It is important to know the role of these health professionals in these meetings/mismatches with users of the Unified Health System (SUS), in the face of epidemics and emergency pandemics, such as ZCS. The purpose is to provoke the reflection and guidance of these conducts with regard to the production of care, bond formation, embracement, referral and mitigation of the suffering of the affected families.

The increase in the frequency of public health emergencies challenges attitudes, professional practices and the production of health care, and brings to the fore a (carelessness)/care that turn people into a thing and trivializes relationships built in the health field. This fact highlights the need to recover the value of social solidarity, in search of overcoming an individualistic view of human actions⁴. In this sense, the proposed study aimed to give voice and know the perspective of mothers of children with ZCS about the professional approach, forming bonds in the health care process, in times of Zika virus.

Method

This is a descriptive-exploratory research with a qualitative approach, part of a broader research entitled "Public health policies in emergency situations: the Zika virus outbreak". In it, health managers and mothers of children with ZCS were interviewed to understand the perception of these actors about the outbreak.



The present study was carried out in Brazil, in the state of Espírito Santo, with 25 women who had children with ZCS. Initially, the researchers went to the Microcephaly Committee of the Secretary of State for Health of Espírito Santo, to survey the cases, which occurred, from November 2015 to December 2016, 49 newborns confirmed for ZCS, including 10 abortions or stillbirths⁷. All 39 mothers of babies born alive were invited to participate in the research.

Of the 39 eligible, the following did not participate in the survey: 4 women who moved from the state in search of better health care for their babies; 2 underage mothers, who did not obtain parental authorization; 1 homeless mother who was not found; 1 mother who delivered the child to a shelter without the power of a father; 2 mothers who lost their babies in 2017, due to ZCS complications; 1 mother whose baby was admitted to the Pediatric Intensive Care Unit; and 3 mothers who did not want to give an interview.

For data collection, interviews were conducted with a semi-structured script, and open and closed questions. The interviews were conducted in 2017, individually, recorded through audio recording. The field diary was also used for notes of observations, made during sessions with the women.

All interviews were transcribed verbatim and analyzed according to the content analysis technique, thematic modality. Thematic Content Analysis is a subtype of content analysis. It is important to clarify that it is linked to the notion of theme, which can be graphically presented by means of a word, a phrase, and an abstract. Thematic analysis follows a trajectory that consists of: categorization, inference, description and interpretation. The categorization demands, from the researcher, great knowledge in discovering an adequate classification plan. The inference is made when one deduces, logically, some of the content being analyzed. The description is defined as an enumeration of the text's characteristics, summarized after analytical treatment; and interpretation is the meaning given to those characteristics that were enumerated during the description⁸.

The results and discussion of the data were organized into empirical analytical categories, that is, categories that emerged from the data and were not defined *a priori*, in order to facilitate the analysis and observance of the nuances of the object under study. Categories were grouped into two dichotomous themes, namely: The dehumanization of care and the loss of the caring dimension and the humanization of care and the (re)constructive potential in the formation of care bonds.

The research project was approved by the Research Ethics Committee under Protocol number 1,730,231/2016, fully respecting Resolution number 466/2012, and also by the International Ethics Committee (PAHOERC), under Opinion PAHO-2017-02-0013. Informed Consent Terms were presented to all participants in this research, identified by the letter M and the respective numbers referring to the sequence of the transcription of the interviews.



Results and discussion

The dehumanization of care and the loss of the caring dimension

Health work centered on instrumental logic as a producer of (lack of) care

During the ZCS outbreak, there was still not enough information to support the work process of health professionals. Many pregnant women with symptoms suggestive of Zika virus infection were treated for other pathologies, without an epidemiological clinical investigation and qualified listening⁹. It is believed that these pregnant women, when accessing the health service, wanted a clinical practice centered on them. The technical insecurity of health workers should be shared with these women, creating protagonism and co-responsibility, principles rooted in Humanization in health¹⁰.

I only learned about his microcephaly when he was born... At about four months of gestation, I had felt some pain in my back and noticed the appearance of red spots, but I went to the hospital and my doctor gave me anti-allergic pills only. (M7)

In the first cases diagnosed, women and babies, in the immediate postpartum period, were subjected to precautionary and isolation measures, with suspicion on the part of professionals that ZCS was infectious. This practice, in addition to not finding comparison in scientific literature, increased the feeling of helplessness among women.

I asked the nurse why they took me to isolation, right after the cesarean section. She told me it was because I had Zika, and that this virus was still in the person's body for a long time. (M1)

It should be noted that light-hard and hard technologies¹¹, through robust protocols and manuals, are not sufficient in dealing with the complexity of the relationships that involve the Zika virus health-disease-care process. The micropolitical dimension, which mobilizes creativity, critical adaptation to reality, reactions in the interaction with others and with subjective processes, is necessary in the tangle of health production. In this sense, the integral care of these women requires time, and initially, these professionals and users relationship was very fragile, causing strangeness and producing a little autonomous care for these women.

The absence of robust protocols and manuals contributed to the advent of professionals afraid of the adopted behaviors, which, added to the disease-centered practice, the medical-hegemonic model and the work focused on instrumental logic¹², brought fragmentation of the mothers' care and suffering.



My daughter was admitted to the hospital just to be researched. To see if it was because of Zika. (M4)

My son was born at the worst moment of Zika, but they didn't even ask for an examination of the placenta... the doctors were not prepared. (M6)

In the social ideal of the “know-it-all” health worker, it must be admitted that this place of “not knowing”, for many workers, involves a sense of a certain professional failure. However, this feeling may be linked to health education with a focus on instrumental and little relational work, which are insufficient for the production of health care^{6,13}.

It is necessary to leave a position of supposed knowledge, and understand that, in health work, we learn from each other continuously. Valuing the moment of encounter with the users, listening their stories and experiences, recognizing that everyone creates solutions to answer complex questions of daily life¹⁴.

It is assumed that, in the midst of a troubled scenario, professionals did not want to take the responsibility of closing the diagnosis of ZCS, which needed delicacy in its approach due to its implications¹⁵.

I only learned about his microcephaly when he was born..., and even then, in the documents, they put it on suspicion. (M3)

[...] in the last ultrasound I did, the doctor said that she thought her head was smaller than normal, but that she would not diagnose it as microcephaly. (M4)

One of the research participants also reports the absence of the health team in family preparation for the child's arrival, as shown below:

With the passing of the ultrasounds, we saw that he had a congenital clubfoot, a shortened femur, cardiomegaly, ascites ... Only, yet, no one prepared me to have a special child! Regardless of whether the doctors knew whether it was because of Zika or not, they knew what would happen... For example, a child who has malformation of the cerebellum, what are the consequences? That was more or less what they came to tell us when he was born, but why didn't they say it before? We thought clubfoot would be the biggest trouble we would have with him! We were not looking for what this or that was, we expected to hear from our doctor! We trusted him. (M6)



An important strategy for family preparation is the participation in therapeutic groups, since they provide a space for sharing experiences and reflection¹⁶. It is at the meeting - especially in the relational dimension of the health worker with these users - that the power of the bond could have reorganized the work processes as a production of care practice. In this sense, the bond is a powerful indicator of positivity in care relationships. Despite something that can be built, but that can also be deconstructed - or never achieved - and that, therefore, such a bond needs to be taken care of^{6,17}.

Ineffective communication that produces dehumanizing practices

Humanized care is an indispensable practice in health services¹⁸. The importance of technical-scientific knowledge is undeniable; however, without the addition of empathy, listening and dialogue, users tend not to experience the service as satisfactory¹⁹. Reception, as a device of the National Humanization Policy (NHP), must be present as the core in the relationship between teams/services and users/populations. With a qualified listening offered by workers to the users' needs, it is possible to guarantee timely access to the technologies appropriate to their needs, increasing the effectiveness of health practices²⁰.

In contrast to the NHP, a frequent disrespectful practice against the user is to talk about the child's health situation in her presence, as if she were not there, revealing the total annulment of the other as a subject²¹. Dehumanization of care practices permeated the women's speeches, with reports of being ignored while health professionals discussed the case of children in her presence, as if the mother were invisible:

"There's a strange thing here", then he said to his secretary: "Call the other doctor"; she called the other doctor, he came, then when I look, three doctors inside the room... I said: "Mercy!". I started to get scared... Then he said: "You do not need to be scared, you can be calm!"; then the other doctor went and said: There is no way! You can put microcephaly there at the conclusion of the exam". Then I took it and looked like this... Then he said: "Good luck!" (M23)

Nobody explained anything. And, that's when the doctor arrived with a series of academics there and then, the doctor there, you know: Oh, this is a child, probably from congenital Zika, she has microcephaly, I don't know what'. It was when I looked, kind of, kind of. Then I said: Doctor, just a minute, it was confirmed? Microcephaly? She said: Yes. Nobody arrived: Look, mother [...]. That's how I heard it. They were there, talking to each other there, she explaining each case, for them to learn. Then she simply spoke like that. This is a child, with microcephaly, it has malformation, calcification, congenital Zika, such and such. Then I looked, kind of, then, kind of, oh my God. [...] There, at that moment and I wanted to scream, I wanted to somehow put it out. M2



This corroborates, in view of the invisibility of these mothers, the biomedical armor of denying listening, originating from the pattern of professional training in health, which, since its origins, has produced “holders of knowledge” that dominate the validity of practices. It is known that this discourse annulled the listening - at least the listening of intensity -, because the important thing was the diagnosis of the disease and the prescription of treatment, regardless of the singularity that brings together the trajectory of each user. In order to break this model, permanent health education aims to foster, bring about changes in work, giving space to reflective, critical and creative thinking²².

In this sense, effective communication during every meeting with the user is a powerful device for the bond to be established. In addition, it is essential in communicating the diagnosis of a disability. Adherence to treatment and the production of autonomous care are directly related to adequate communication between users and health professionals³.

Often, the less empathetic professionals permeated the (dis) meetings using coarse and rude communications:

He turned and said: He will be like this forever, his brain is all damaged. He has no brain; and I didn't say anything, I kept quiet. It felt like this, as if I had swallowed a stone. (M18)

At the hospital, a neurologist asked my husband if he knew that our daughter had microcephaly with hydrocephalus, and he said that because of that she would not be able to move from the neck down. He said it just like that! (M4)

The doctor next to me saying: Do you know that your daughter has microcephaly? I said: No, I didn't know. Like, I was expecting hydrocephalus until then. Then she said: Yeah, she has it. I said: Wow, but it doesn't look like. It does look like, her head is small, she turned her back and left. Like this. So, at the time I didn't know if I would cry, because I wasn't expecting it, or if I would fly on her neck. It's like, she could have been a little more delicate, because it was a difficult moment. She turned her back and left, I stayed there. (M14)

In the survey conducted by Human Rights Watch²³, women who received the news of an anomaly in the development of their children, at the time of delivery, and the experience they had in the way health professionals treated them, had a profound psychosocial impact. Many of them did not receive information about the diagnosis, nor psychological support or counseling to help them deal with the harsh news. Other studies have also shown the professionals' unpreparedness for the moment of disclosing the diagnosis of ZCS²⁴.

Another complaint was the lack of prestige in the family's participation in the treatment. Some interviewees pointed out the difficulty in participating in early stimulation services in their respective municipalities.



They won't let us in to accompany the physical therapy and the speech therapy. (M4)

They do not let us follow the sessions [...]. We even had a disagreement with the speech therapist. (M7)

It is necessary to understand that the production of comprehensive care will only occur if there is autonomy for the families, including their participation in all meetings between health workers and children with ZCS.

Because they are children who require routine monitoring by several health professionals, the bond between the family and the health service ends up being established by the very coexistence, and promotes the possibility of carrying out the care offered through parents' education. Family support can be decisive for obtaining the child's development, as, when well instructed, family members can continue stimulation at home²⁵.

Obstetric violence

Another form of dehumanization of care, found in this study, was obstetric violence. This terminology was proposed for the identification of any act of violence directed at the pregnant woman, parturient or puerperal woman, or her baby, practiced during professional assistance, which means disrespect to her autonomy, physical and mental integrity, her feelings, options and preferences²⁶. If the practice of obstetric violence is serious in itself, it is even greater when it occurs against women like the mothers of babies with disabilities.

Based on the assumption that the disrespect for the pregnant woman's autonomy is obstetric violence, in this study there was withholding information from the professional towards the mother, in an attempt to dominate the woman's body, making it impossible for her to make autonomous decisions about her body and her life.

When it was this year that I took the baby to the medical center, I asked her: Doctor, why didn't you tell me the truth? She spoke like this, she was afraid that I would abort the girl. Was I going to abort a four month old child in my belly, the child moving already? So, since the beginning of my pregnancy there was already the problem of microcephaly, but she did not guide me at all. (M16)

With regard to the right to abortion - a practice, as a rule, criminalized in Brazil -, the United Nations recommendations for countries that faced and face the Zika virus epidemic were to ensure full access to family planning and to carry out review of punitive laws in relation to legal abortion²⁶.

Another conduct that can be considered obstetric violence is to infantilize women through diminutives, in which the hierarchical relationship between the professional and the user is closely associated with the objectification of the other²⁷.



The doctor arrived at the reception and asked: where is the little mother who is suffering? (M1)

At times, the woman was ignored and treated harshly, and her role not being respected:

He: Look, I'm going to assist this birth, but I have two things to say. He said: Look, this baby, either he will be born dead or he will only live two hours, it will not be more than two hours, he will live. Just like this. I said: Is that right? You assist my birth. When this boy came out of my belly, I remember it as if it were today, that boy cried so much, and his head was born normal. He cried like a normal baby. (M17)

I remember that when the doctor took it out, she said: It's really microcephaly. It was the only thing I heard her say. After that she left and even left another doctor to sew me. (M1)

When he was born, I heard the doctor saying that his head was small, but my doctor said: "No! How small?! But they didn't explain anything to me. (M7)

Recent studies^{28,29} have revealed obstetric violence during delivery of babies with ZCS, and have had serious impacts on women's mental health.

There is still a shortage, in the scientific field, regarding the delivery of women with children with disabilities. A study with these women demonstrated a different tactile experience with their children in the moments after delivery, due to the behavior shown by health professionals. Usually, when a child is born typical, it is celebrated and handed over to the mother with satisfaction; however, when there is a suspicion that the child has a disability, it is left beside the mother, as if the professional were embarrassed to hand her over³⁰.

Humanization of assistance and (re)constructive potentialities in the formation of care bonds

The concept of humanization is polysemic, and the Ministry of Health has strained humanization practices in care since the implementation of the NHP. In this sense, the humanization of health is understood as a movement that seeks to improve care and a favorable environment for the development of care. In humanization practices, the valuation of the subjective dimension and the rights of users are established; also their autonomy and protagonism, the construction of cooperative and solidary networks of health production³¹.



There were reports of humanizing practices and (re) building bonds with a health professional: the neuro-pediatrician who took care of children with ZCS. Affections were mentioned, including the careful and gentle way of providing information about symptoms, zeal for the child, future complications and attention to the mothers' health:

Ah, she is a very special person. She is that kind of professional that never let you down. She is a professional who makes you see the horizon, she makes you see that everything is possible. (M6)

I was nervous at the first consultation, I was very nervous, like that. Then she calmed me down a lot, she talked to me. Kind of, she said: if you need anything, I am here on Tuesdays and Fridays, you can call me anytime. (M17)

The doctor is wonderful. We have nothing to complain about her. She's very attentive, she's a model doctor, like that, you know? That kind of professional you see who loves what she does? (M15)

The way that the health professionals develop the first contacts with the families, is undoubtedly a moment of greater sensitivity in the relationship between the health professionals and the mothers/families. The bond will occur from that encounter, and it is closely related to the ability to find support.

In this encounter³, the care produced will not only be care conduct, but a practice in the exercise of health care based on integrality, a caring practice³², through which relational technologies produce integral and autonomous care - autonomy understood as freedom to act and to decide of the individual according to his values, priorities, desires, beliefs and self-determination. This autonomous care must be built on the relationship between health professionals and user, with an axis in listening as a producer of autonomy^{33,34}.

Qualified listening is paramount in comfort and help for mothers, as it helps to avoid the apprehension of anxieties, fears and traumas, contributing to the consolidation of a process in which the family needs to be valued, because only in this way is it possible to transmit esteem and confidence to parents³⁰. Acceptance and adaptation can be defined based on the sensitivity of the health professionals, making them essential for empowerment and family balance³⁵.

A common fact reported is the proximity and ease of access to the care of this professional, either by phone or in person at the office. The affection given to mothers and children is also emphasized, describing her as an angel in the lives of these families.



Wow, she's a woman, she's a perfect neurologist. I only have compliments for her, because she is very attentive. She helps me, I send the baby's photo, I send everything any little evolution I send and she is following up. Right now, this month, I went to see her three times, she made the electrocardiogram, she accompanied the electrogram". (M21)

She, in my view, she is an angel of God. And that God sent her, because a woman like that, my daughter ... everybody speaks well about her, and she treats her patients so well, right? And both the companions. And she's too great. That woman is gold. (M1)

She is the kind of doctor you come you don't go with her baby to the office. My baby, she comes with him in her lap. I take the bag. She is very affectionate. I am even speechless to praise her for being so good that she is for me. She is a doctor who, if the mother does not show up at the appointment, she calls. (M18)

Doctor x, ah, she is an angel, that woman. Wow, she sent me to the Disability Reference Center. And I won, they wrote me there already, to win a chair, for her, for her neck, little feet. It was all for my baby. She was the one who put everything in front of me, for me. Ah, she helped me a lot. The drugs my baby took, clonazepam she takes. There is another one. I had no money to buy it, so she gave it to me. She gave me the money to buy the medicine. (M8)

The mothers, until then helpless, uninformed, had a singular "encounter" with a health professional, who used the guiding axes of humanized care - such as the ability to welcome and listen -, which is a differential component in the production of comprehensive care and autonomy. A recent study³⁵ also found humanized practices of health professionals towards mothers who had children with microcephaly, including reports of qualified listening and understanding of the psychic process experienced.

There were also reports of good encounters with other professionals, as part of the daily care of babies, as noted in the statements below:

I have received the benefit since he was born. For me, it was the social worker. She helped me a lot! Guided me in everything! There are great people taking care of him. And his neuro pediatrician?! She was the one who gave me a light! (M1)

I love his physical therapist! She is very attentive, very good! (M3)

It was the neuro pediatrician who opened opportunities for us! She is the one who sends my daughter to everything that is a medical attention. She's my daughter's godmother! (M4)



In this context, the interprofessional team plays an important role in the availability of clear information and in the recognition of the social support network accessible to the mother and her family, to improve the quality of life and the understanding of these mothers about the ZCS²⁸.

A humanized professional, who treats the individual in an individualized, empathetic and ethical way, goes beyond technical knowledge and adds to this the ability to differentiate themselves through the development of listening and welcoming, basing quality practices recognized by users of the health service³⁶.

Final considerations

This study demonstrated, from the perspective of the mothers of children with ZCS, the importance of providing care and the formation of bonds in the health care process. Through the voice of these women, from the perspective of the people who use the services, the crises between knowledge and practice have become visible in the health work process, reinforcing the importance of permanent health education as a potent inducer of changes in the respective services.

Acts of (re)construction of care were revealed through effective communication, bonding, qualified listening and humanization of care; and acts of (carelessness) care occurred due to dehumanized, disrespectful practices and even configuration of obstetric violence with these women. The intensity of their testimonies was an evaluative marker of the (lack of) care received and the quality of the clinical care that was offered by the professionals, and the results showed that listening to health service users in the country should be encouraged.

In this sense, health work - as care production, as learning in/through daily work, as professional training, as teamwork and as an inter-sector collaborative work, for the most part - did not meet the expectation of care and neither did need of these women. This result, which screams in the speech of the women in this study, reveals a serious crisis of an insufficiency that is found in the daily work. This crisis is related to training centered on the biomedical model, in a fragmented health care model, hindering comprehensive care.

To break with this logic, it is necessary to tension health education in the country, aiming at a critical, reflective and human formation, which culminates in the effective improvement of care in the face of the manifestation of new epidemics and pandemics.

The results of this study call our attention to the need for new strategies and interventions that aim for better care for pregnant women with a diagnosis of congenital malformation, and also an adequate management in the approach of emerging diseases and pandemics.

Thus, it becomes necessary to rethink and reframe the process of training health professionals, articulating their relationship not only with aspects of the disease - technical-scientific and instrumental -, but also with health, life, happiness, the affection and the production of care that fosters citizenship, solidarity and inclusion of the actors involved.

Authors' contributions

All authors actively participated in all stages of the preparation of the manuscript.

Funding

This study was funded by the Pan American Health Organization - PAHO, through the call for proposals Joint Program HRP/TDR/PAHO for small grants for research into the outbreak of the Zika virus in the Americas.

Acknowledgment

We thank the women, the mothers of children with ZCS, who opened their homes and their hearts to the researchers.

Conflict of interest

The authors have no conflict of interest to declare.

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Translator

Carmela Carolina Alves de Carvalho

Submitted on

06/25/20

Approved on

10/27/20

References

1. Eickmann SH, Carvalho MD, Ramos RC, Rocha MA, Linden V, Silva PF. Síndrome da infecção congênita pelo vírus Zika. *Cad Saude Publica*. 2016; 32(7):e00047716. Doi: <https://doi.org/10.1590/0102-311X00047716>.
2. Victora CG, Schuler-Faccini L, Matijasevich A, Ribeiro E, Pessoa A, Barros FC. Microcephaly in Brazil: how to interpret reported numbers? *Lancet*. 2016; 387(10019):621-4. Doi: [https://doi.org/10.1016/S0140-6736\(16\)00273-7](https://doi.org/10.1016/S0140-6736(16)00273-7).
3. Ayres JRCM. Cuidado: trabalho e interação nas práticas de saúde. Rio de Janeiro: CEPESC, UERJ/IMS, ABRASCO; 2009. (Clássicos para integralidade em saúde).



4. Ayres JRJM. Cuidado: trabalho, interação e saber nas práticas de saúde. *Rev Baiana Enferm.* 2017; 31(1):e21847.
5. Hasue RH, Aizawa CYP, Genovesi FFA. Síndrome congênita do vírus Zika: importância da abordagem multiprofissional. *Fisioter Pesqui.* 2017; 24(1):1-1. Doi: <http://dx.doi.org/10.1590/1809-2950/00000024012017>.
6. Seixas CT, Baduy RS, Cruz KT, Bortoletto MSS, Slomp JH, Merhy EE. O vínculo como potência para a produção do cuidado em Saúde: o que usuários-guia nos ensinam. *Interface (Botucatu).* 2019; 23:e170627.
7. Secretaria do Estado da Saúde do Espírito Santo (SESA). Sesa divulga boletim de Zika e Microcefalia [Internet]. Espírito Santo: SESA; 2016 [citado 24 Jun 2020]. Disponível em: <http://saude.es.gov.br/Not%C3%ADcia/sesa-divulga-boletim-de-zika-e-microcefalia-26>
8. Bardin L. *Análise de conteúdo*. Lisboa: edições 70; 2009.
9. Diniz D. *Zika: from the Brazilian backlands to global threat*. London: Zed Books; 2017. p. 12-4.
10. Martins CP, Luzio CA. Política HumanizaSUS: ancorar um navio no espaço. *Interface (Botucatu).* 2017; 21(60):13-22.
11. Merhy EE. *Saúde: a cartografia do trabalho vivo*. 2a ed. São Paulo: Hucitec; 2005.
12. Ayres JRJM. Risco e imponderabilidade: superação ou radicalização da sociedade disciplinar? *Cad Saude Publica.* 2001; 17(6):1297-8.
13. Ceccim RB, Feuerwerker LCM. O quadrilátero da formação para a área da saúde: ensino, gestão, atenção e controle social. *Physis.* 2004; 14(1):41-65.
14. Carvalho MS, Merhy EE, Sousa MF. Repensando as políticas de saúde no Brasil: educação permanente em saúde centrada no encontro e no saber da experiência. *Interface (Botucatu).* 2019; 23:e190211.
15. Luisada V, Fiamengui-JR GA, Carvalho SG, Assis-Madeira EA, Blascovi-Assis SM. Experiências de médicos ao comunicarem o diagnóstico da deficiência de bebês aos pais. *Cienc Saude.* 2015; 8(3):121-8. Doi: <https://doi.org/10.15448/1983-652X.2015.3.21769>.
16. Nobre MIRS, Macedo TP, Moraes ACB, Montilha RCL. Grupo terapêutico: preparo familiar para inclusão. *J Res Spec Educ Needs.* 2016; 16(1):568-72.
17. Slomp Junior H, Feuerwerker LCM, Land MGP. Educação em saúde ou projeto terapêutico compartilhado? O cuidado extravasa a dimensão pedagógica. *Cienc Saude Colet.* 2015; 20(2):537-46
18. Santos MM, Boing E, Oliveira ZAC, Crepaldi MA. Diagnóstico pré-natal de malformação incompatível com a vida: implicações psicológicas e possibilidades de intervenção. *Rev Psicol Saude.* 2014; 6(1):64-73.
19. Dodou HD, Rodrigues DP, Oriá MOB. O cuidado à mulher no contexto da maternidade: caminhos e desafios para a humanização. *J Res Fundam Care Online.* 2017; 9(1):222-30.
20. Brasil. Ministério da Saúde. *Política Nacional de Humanização - HumanizaSUS*. Brasília: Ministério da Saúde; 2013.
21. Aguiar JM. *Violência institucional em maternidades públicas: hostilidade ao invés de acolhimento como uma questão de gênero [tese]*. São Paulo: Faculdade de Medicina, Universidade de São Paulo; 2010.



22. Collar JM, Almeida Neto JB, Ferla AA. Educação permanente e o cuidado em saúde: ensaio sobre o trabalho como produção inventiva. *Saude Redes*. 2015; 1(4):53-64.
23. Human Right Watch. Esquecidas e desprotegidas: o impacto do vírus Zika nas meninas e mulheres no nordeste do Brasil [Internet]. New York: Human Right Watch; 2017 [citado 24 Jun 2020]. Disponível em: <https://www.hrw.org/pt/report/2017/07/13/306163>
24. Missel A, Costa CC, Sanfelice GR. Humanização da saúde e inclusão social no atendimento de pessoas com deficiência física. *Trab Educ Saude*. 2017; 15(2):575-97.
25. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Diretrizes de estimulação precoce: crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor. Brasília: Ministério da Saúde; 2016.
26. Pitanguy J. Os direitos reprodutivos das mulheres e a epidemia do Zika vírus. *Cad Saude Publica*. 2016; 32(5):e00066016.
27. Daneluci RC. Instituições públicas de saúde e mulheres gestantes: (im)possibilidades de escolhas? [tese]. São Paulo: Instituto de Psicologia, Universidade de São Paulo; 2016.
28. Hamad GBNZ, Souza KV. Síndrome congênita do Zika Vírus: conhecimento e forma da comunicação do diagnóstico. *Texto Contexto Enferm*. 2020; 29:e20180517. Doi: <https://doi.org/10.1590/1980-265x-tce-2018-0517>.
29. Alves RLC, Dos Reis, Safatle YB. “Mães de micro”: perspectivas e desdobramentos sobre cuidado no contexto da síndrome congênita do zika vírus (SCZV) em Recife/PE. *Alterar Rev Antropol*. 2019;1(8):115-45. Doi: <https://doi.org/10.22478/ufpb.2447-9837.2019v1n8.42464>.
30. Falkenbach AP, Drexler G, Werler V. A relação mãe/criança com deficiência: sentimentos e experiências. *Cienc Saude Colet*. 2008;13 Suppl 2:2065-73.
31. Mongiovi VG, Anjos RCCBL, Soares SBH, Lago-Falcão TM. Reflexões conceituais sobre humanização da saúde: concepção de enfermeiros de Unidades de Terapia Intensiva. *Rev Bras Enferm*. 2014; 67(2)306-11.
32. Ceccim RB, Carvalho YM. Ensino da saúde como projeto da integralidade: a educação dos profissionais de saúde no SUS. In: Pinheiro R, Ceccim RB, Mattos RA. *Ensinar saúde: a integralidade e o SUS nos cursos de graduação na área de saúde*. Rio de Janeiro: Abrasco, CEPESQ; 2005.
33. Freire P. *Pedagogia da autonomia: saberes necessários à prática educativa*. 39a ed. São Paulo: Paz e Terra; 1996.
34. Merhy EE. O desafio da tutela e da autonomia: uma tensão permanente do ato cuidador [Internet]. Belo Horizonte: NESCON Biblioteca Virtual; 1998 [citado 12 Nov 2019]. Disponível em: <https://www.nescon.medicina.ufmg.br/biblioteca/imagem/0276.pdf>
35. Oliveira MC, Moreira RCR, Lima MM, Melo RO. Vivências de mães que tiveram filhos com microcefalia. *Rev Baiana Enferm*. 2018; 32:e26350. Doi: <https://dx.doi.org/10.18471/rbe.v32.26350>.
36. Ferreira LR, Artimann E. Discursos sobre humanização: profissionais e usuários em uma instituição complexa de saúde. *Cienc Saude Colet*. 2018; 23(5)1437-50.



A formação de vínculo entre famílias de crianças com Síndrome Congênita do Zika (SCZ) e profissionais de saúde é condição *sine qua non* para o desenvolvimento das crianças afetadas. O estudo objetiva compreender a perspectiva de mães de crianças com SCZ acerca da abordagem profissional e da formação de vínculos no processo de cuidado em saúde durante a epidemia de Zika vírus. Trata-se de uma pesquisa qualitativa, descritivo-exploratória que entrevistou 25 mães. Os resultados revelam que os profissionais de saúde tiveram práticas de desumanização da assistência e cometeram violência obstétrica. Contrapondo a desumanização, também houve casos esporádicos de práticas humanizadas com formação de vínculo. Os resultados deste estudo apontam a necessidade de estratégias e intervenções em prol de melhor atendimento à gestante com diagnóstico de malformação congênita e adequado manejo na abordagem de doenças emergentes e pandemias.

Palavras-chave: Zika vírus. Infecção por Zika vírus. Prática profissional. Humanização da assistência. Saúde da mulher.

La formación de vínculo entre familias de niños con Síndrome Congénito del Zika y profesionales de salud es condición *sine qua non* para el desarrollo de los niños afectados. El objetivo del estudio es comprender la perspectiva de madres de niños con SCZ sobre el abordaje profesional, formación de vínculos en el proceso de cuidado de la salud durante la epidemia de Zika Virus. Se trata de un estudio cualitativo, descriptivo-exploratorio, que entrevistó a 25 madres. Los resultados revelan que los profesionales de salud tuvieron prácticas de deshumanización de la asistencia y cometieron violencia obstétrica. Contraponiendo la deshumanización, también hubo casos esporádicos de prácticas humanizadas con formación de vínculo. Los resultados de este estudio señalan la necesidad de estrategias e intervenciones en pro de una mejor atención a la gestante con diagnóstico de malformación congénita y adecuado manejo en el abordaje de enfermedades emergentes y pandemias.

Palabras clave: Zika virus. Infección Zika virus. Práctica profesional. Humanización de la asistencia. Salud de la mujer.