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Zika virus in Northeast Brazil:

retrospective for research

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Abstract: This article deals with the shared impressions of researchers and their experience in fieldwork in Northeast Brazil, within the project's scope: Health promotion in the context of the Zika epidemic: actors and scenarios in decision-making processes (FIOCRUZ/ZIKAlliance). Here, we seek to share field impressions of research on the Zika Virus in two municipalities located in different locations in the Northeast. We highlight the importance of the field notebook in qualitative research and reflect on the results of interviews conducted with women of reproductive age, pregnant women, health professionals, mothers and fathers of children affected by microcephaly, and self-employed workers. From the testimonies, it was possible to observe similarities, identifications, and estrangements between the research subjects and the researchers, constituting a vital thermometer for our perception of the field and the possibilities of producing scientific knowledge about the Zika epidemic in Northeastern Brazil.

➤ Keywords: Zika Virus disease. Qualitative research. Health care. Northeast of Brazil.

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This article takes on the challenge of sharing field impressions about research into the Zika virus epidemic in Northeast Brazil. In this work, we highlight the importance of the field notebook in qualitative research, a generator of reflexivity for memories of experiences.

Experience, as Larrosa (2002) inspires us, takes the form of an actively reflected encounter process with what happens to us and affects us. This process potentially generates knowledge through the active reflexivity of those willing to take it on. According to Ferreira and Brandão (2023), reflexivity, although often uncomfortable, is the guiding thread of doubts that must accompany the entire research process. Bourdieu (2012) points out that it is through reflexivity that the individual learns to act strategically to modify and be modified to participate, belong, and be recognized. Thus, the interlocutions of the experiences analyzed here are imperative.

The questions shared here are developments of reflections and experiences regarding the results of interviews carried out with women of reproductive age, pregnant, health professionals, mothers and fathers of children affected by microcephaly, and self-employed workers, carried out as part of the research fieldwork "Health promotion in the context of the Zika epidemic: actors and scenarios in decision-making processes".1

The text is structured in three parts. Firstly, we sought to contextualize the Zika epidemic, and the challenges experienced by Brazilian society in confronting it, between 2015 and 2017. Next, we dealt with the methodological experience, which made it possible to gather important content from the field notebook and the necessary dialogue with the research subjects. Finally, we deal with the experience of the relationship between the institutions involved, the researchers, and the research subjects themselves.

Introduction

In November 2015, Brazil was faced with the Zika epidemic, assumed in 2016 as a health emergency by the Ministry of Health (MS) and the World Health Organization (WHO). This process created – as Diniz reminds us – a humanitarian emergency, which remains with us today in the lives of children who reach six years of age. The mobilization at the time related the surprises and unknowns that linked pregnancy / Zika virus contagion/birth of babies with cephalic changes previously unknown in these research associations in the field.

There was great coverage in the national and international media due to the unexpected situation of initially unknown origin: the involvement of thousands of babies with a set of impairments in their neuromotor development, later establishing its association with the Zika virus, transmitted by *Aedes aegypti*. This fact generated great concern among the Brazilian population, especially among pregnant women and other women of childbearing age.

Less than a year after its introduction, Zika spread throughout all regions of Brazil, although with uneven distribution between them, with the number of cases being higher in the Northeast and Southeast regions (Peiter *et al.*, 2020).

In April 2017, the Ministry of Health announced that, in total, 10,232 suspected cases of newborns and children with changes in growth and development related to Zika infection had been reported, of which 2,829 remained under investigation in February 2017 (Brazil /MS, 2017). The disease began to exhibit continued transmission in a large part of the Brazilian territory. Its evolution highlighted difficulties in vector control, deficiencies in actions aimed at family planning, failures in maternal and childcare and failures in health information and communication.

This combination of adversities, along with the striking social inequalities that characterize the country, contributed to the Zika epidemic and its most devastating consequence, microcephaly in babies, becoming an endemic illness, especially in the gestational trajectory of women, most of whom are black and brown, with low education and living in the most impoverished regions of the country (Moreira; Mendes; Nascimento, 2018). The outbreak ended in 2017, but its consequences extend into the long term, as the damage caused by Zika infection persists in affected children and their families (Kely *et al.*, 2020; Pepe *et al.*, 2020).

Recovering these antecedents almost becomes a memory of the present. We are not even a decade away from this experience and the risk of another Zika epidemic is already announced. This is in addition to the still existing cases, and the recent Covid-19 pandemic and its repercussions also marked by inequalities. As a public testimony (Boltansky, 2015), this article presents reflections that serve researchers who, in their work, need to understand how the field is not exempt from commitments and responsibilities. In other words, this article illuminates the place of knowledge production not based on the analysis of the collection – reserved for other production. However, critical reflexivity is used (Alvarez, 2020) to rescue the procedural character of the knowledge that doing the field instigates. In other

words, where, how, and through what lenses we recover this experience of doing research, its experiences, estrangements, encounters, and disagreements with lived experiences and their challenges.

Share some scenes and situations that shaped the interactions experienced by us, researchers who have social markers in common: black people from the Northeast region and specialists in the field of health, one being a man with a degree in Social Work and the other a woman, with a degree in Nursing.

Contact with women of reproductive age, mothers of children with microcephaly, and pregnant and health professionals was, at the same time, an approach to their dramas, fears, doubts, and uncertainties about the possible consequences of Zika. As well, also a moment searching for information; after all, one of the field researchers was a nursing professional who knew how to welcome, listen, and patiently explain doubts about the association of microcephaly cases with Zika infection in pregnant women. The women in the focus group, research participants, felt comfortable collaborating in research and at the same time also being assisted in providing guidance on health care related to Zika.

The focus group as a research technique that values interaction and exchange between participants, brings together the unexpected aspects of current meetings. In other words, the fact that the researchers are in the group, introducing themselves, composes the research scenes with their apprehensions, and at the same time allows the participants to position themselves with expectations and evoke memories. In this case, the memories may refer to experiences with other groups that are very common in health services, carried out by nurses, where the informative nature occupies the center. In the case of research, there was an understanding that this way of interpreting also formed the research scene.

As warned by Cruz Neto (2003, p. 56), research activity is not restricted to the mere technical dimension of collection instruments for data acquisition. It meets the need for understanding the dynamic meaning of what occurs, and we seek to capture in the field. In this process, although we did not have the opportunity for prior face-to-face contact with the focus groups – as it was a field in different cities and far from the ones we lived in – correspondence contacts enabled some communication to prepare the field before our arrival. Even so, the surprise elements during face-to-face contact with the focus groups were of unquestionable relevance to understanding the meanings of the dynamics of the places that welcomed us –

Natal and Feira de Santana – and the complexity of the relationships established between researchers and research subjects, with identifications and estrangements.

It is interesting to state that this research experience enabled a delicate and successful care relationship. Invitations to participate in the research, interview guides, as well as data collection were presented. However, the exchange of knowledge between us and the research participants was what was new in these meetings, especially due to the thought-provoking, interesting, intense conversations between the pregnant women and the nurse who was part of the research team. This same researcher in this article assumes herself as one of those responsible for sharing mind-operated reflective memories here.

If a nurse as a researcher instigated meetings, in a circuit of reciprocity and exchange, it is worth situating the other researcher on the team as a male social worker. Common to both are their location as black woman and man. The researcher, whose training was in social work, was perhaps close to detaching himself from naturalized views, finding the daily routine of conducting interviews strange, making the unexpected and what seemed simpler and more commonplace analytical fields of reflection and knowledge. This reflection follows Minayo (2012) in warning about the risk of our imprisonment in the speeches of research subjects as one of the greatest weaknesses of those who work with qualitative analysis. In his words, this imprisonment means that researchers were unable to overcome the descriptive level of their empirical material (Minayo, 2012, p. 624). Here, we continue to seek to do things differently.

In this sense, we would like this essay to represent a translation exercise on the symbolic mediations between researchers, participants, and research scenarios, with a view to increasing the reflexivity of the research process on Zika in the lives of women, children, and health professionals in the Northeast of Brazil, which during the Zika pandemic faced health care with a level of difficulty that had not yet been experienced.

The methodological experience: paths and challenges

We assume this writing as an essay, in the light of Meneghetti (2011), recognizing the permanent gaze between the subject and object, a becoming constituted by the interaction of subjectivity with the objectivity of those involved. And it was from

this perspective that the field produced experiences, which we share reflectively and critically in this essay.

The fieldwork, which supports the reflections of this essay, was carried out in March and August 2018 in two municipalities in Northeast Brazil. The municipalities were selected because they are in the Brazilian region most affected by the epidemic and have a significant number of cases in the analyzed period (2015 to 2017).

The immersion in the field was preceded by a series of telephone contacts and emails to plan travel dates, in addition to choosing who would be our "local coordinator". This is because carrying out research in places where we are not residents and have no relations requires qualified mediators and privileged informants like Doc in "Sociedade de Esquina". Therefore, a common action for both fields of research was the choice of someone to welcome us, as there was a movement of researchers to these regions. Furthermore, since the researcher was a resident and worked in one of the municipalities, this mediation was necessary, considering that she would be occupying a different position from that in which she was seen and recognized. Not the nurse, but the researcher who would be asking, interacting, and understanding relationships that were initially unknown. Entry into the field took place only after signing the agreement from each Municipal Health Department (SMS), which contained the necessary information, such as research objectives, ethical issues, etc.

The choice of participants in the fields followed a more formal pattern, with the invitation and presentation of the research made by the local coordinator. The interview script consisted of semi-structured and open questions focusing on the group's perceptions about the health situation in the city where they live, about Zika and its consequences, knowledge about Zika and sources of information and health needs and access to services, answers to social aspects to combat the epidemic, relations between services and the community in combating Zika and service challenges in dealing with Zika and its consequences.

The behind-the-scenes aspects of conducting the interviews and all fieldwork notes were recorded in research diaries, with data and analyses carried out from the researchers' perspective. To understand the possibilities of this approach, it is necessary to keep in mind that the field diary helps in the analysis of the researched collection since it is a legitimate source of information, events, verified relationships, the researcher's personal experiences, reflections, and comments (Fakembach, 1987).

The study fully met the ethical requirements of Resolution No. 466/CNS/12, approved by CAAE number 67311617.8.0000.5240, which establishes the guidelines and regulatory standards for research involving human beings, including ensuring the rights and duties that concern research participants, the scientific community, and the State (Brasil, 2012). Respect for these guidelines guided the relationship with the research subjects and the institutions involved from the first contacts.

The research that supports the reflections in this article is called "Health promotion in the context of the Zika epidemic: actors and scenarios in decision-making processes", supported by the Zikalliance Consortium (CEP/ENSP n. 67311617.8.0000.5240).

The experience of contact: research subjects and institutions

When we began the investigation, the previously scheduled contacts with professionals were unmet. After all, the interviews took place during opening hours at the health units, which, in March and August 2018, faced an outbreak of dengue, zika, and chikungunya. It is worth emphasizing here that priority and respect for daily life with rules and routines led to all invitations for potential participants to accept or not participate in the research.

In interviews with professionals, it was common for interviewees to look for the researcher's professional category to explain the answers presented to them. This can be illustrated by the fact that they frequently approached the researcher with a degree in Nursing to answer the questions in the interview guide, manifesting two types of occurrence: on the one hand, they responded abruptly, that "as a nurse, you know very well what it is like" the routine of health practices in caring for families in the face of the Zika epidemic"; on the other, comments appeared such as: "interesting, important to have a nurse researching these issues." Or even: "I'm happy to know that such an important institution is concerned with the health care of families in the Northeast affected by the Zika pandemic." This situation revealed a negotiation between a nurse – known, recognized, and close to the health field – and a researcher in a Fiocruz group. These two statuses under negotiation refer to an important analysis of who the researcher is and their relationships of greater or lesser proximity and lack of knowledge with their field.

According to Velho, however, this similarity between the researcher and the researched does not impede the researcher's work, as what "we see and find may be

familiar, but is not necessarily known, and what we do not see and find may be exotic, but even certain. known point" (Velho, 1978, p. 39). In this sense, the researcher's meeting with the subjects destabilized what was being understood as familiar and known, making research and problematization of what was being trained possible.

As they did not understand the researcher, as they found her strange, the researcher, who was also in the scene, was automatically disconnected from this game of interaction, approximation, and strangeness. In the field, the researcher was silenced a few times, not only in his questions but as if he were not authorized to speak in this space of communication and meeting.

Therefore, during some individual interviews and focus groups, the researcher discovered that, for methodological and ethical reasons, it was necessary to distance himself and operate more as a support for the activity, to activate the relationship and make the interviewees comfortable by establishing a relationship of trust, tranquility, and security (Gaskell, 2002). In fact, it was not an easy task, as it was necessary not only to mediate the approach and reduce the difference that the interviewees created in relation to the researcher – a man, who was not a nurse, had not treated children with Zika wanting to know about the practices of health care. Even considering these elements of gender representation and specific professional experience, it is worth considering that training in Social Work may have been an important limitation of rapprochement and encouragement of estrangement.

It should be noted, as Costa (2013) observes, that in health services, the insertion of social workers in serving the population is mediated by the social recognition of the profession and by a set of needs that are defined and redefined based on the historical conditions under the which public health developed in Brazil. The lack of this recognition among the assisted community can generate discomfort in relation to a researcher in the field of Social Work investigating health issues. Perhaps this also explains the strangeness of this group with the member of the research team.

In this context, the social markers that located the researcher – a woman, black, resident of Feira de Santana, a nurse, and experiencing pregnancy – operated as facilitators for familiarity, recognition, and proximity. In a focus group carried out with pregnant and mostly black women, such proximity to the researcher operated as a symbolic set for welcoming and dialogue. The women wanted to share with a black, pregnant woman and health professional their expectations, fears, and doubts about what it was like to have a child at the time of the Zika epidemic, or about what

the risks were in the third trimester of pregnancy, finding out that her child could be born with some sequelae because of Zika.

This moment was mediated by tension, as during this activity the unit's health professional – who was responsible for the group, refused to leave the room – and tried to enter the scene, several times, informing that these doubts had already been clarified in other meetings, but the women were emphatic reporting that: "[...] I don't remember that moment. He is sure? I want her to keep explaining." "I think it's important for her to continue." The professional's discomfort with this group behavior was visible, which she called: "collective forgetfulness".

The situation also suggests considering the issue of local power, in which the SMS representative may have understood that certain statements from the women interviewed could expose the municipality's management. This implies the idea of control, as the municipal management may have instructed the employee to insist on remaining at the meeting to "inspect" what the deponents reported, which, in some way, could compromise the municipal management since the research team recorded any and all complications in a field notebook.

In this scene, what was observed was perhaps not a lack of information about the epidemic. However, the way in which this information was prepared, with the researcher and her locations, generated interest. This acted as motivation for another circuit of knowledge production about Zika, related to a collective interest, directed not only at the theoretical and technical knowledge of the nurse – who for 40 minutes dominated the interaction with the group – but also the black woman, nursing professional and pregnant woman, it is worth highlighting that the researcher was attentive to the guidelines provided in the CEP regarding ethical care as well as preventive care guided by health surveillance in the context of the epidemic for the condition of pregnant women. In other words, this identification with traits converging with the action's target audience may have been the element of novelty and motivating interest in the dialogue about Zika, prevention, and pregnancy.

According to Schelles (2008), communication is an essential tool in all types of relationships, which only happens satisfactorily when the message is received with the same meaning with which it was transmitted and can be done in various ways, through verbal or non-verbal language, as long as it is a complete and coherent process. Communicating is considered a light technology in health, that is, within the scope of relational and dialogic practices that act as fundamental mediators in the

relationship established between health professionals and users and family members, whose role is fundamental in building the care process in health. Therefore, in addition to the status of a scholar of health and Zika issues – which the researcher assumes –, this experience suggests the need to deepen and expand the discussion on communication/welcome in health actions.

Another aspect to be highlighted concerns the focus group carried out with men and women of reproductive age, which included the participation of a sweet's seller, a woman and two men who work at the photocopy stall – located at the SMS entrance. When we invited them to participate in the research, the group said: "Wow! We are just workers. Will we be able to contribute to your study?".

The expression "we are just workers" says something about the way in which relationships between bearers of different knowledge/trades were experienced in the field. We also risk stating that this seems to be a reality that affects other regions of Brazil, not just the Northeast, as workers who offer alternative support services in the external area of the units are not considered due to their autonomous status in relation to the structure of the services offered by SMS. However, we understand the importance of the testimony of these professionals in the research.

In this context, it was necessary to activate symbols of trust that included (a) valuing the stories and knowledge of the participants and (b) inform that we were not there to make a moral judgment on their knowledge but rather to hear their experiences with dengue, zika and chikungunya. With this, we made it possible for them to feel close to discussing sexual and reproductive health and Zika.

It should be noted that the team was called to clarify the habits, knowledge, and beliefs of these participants. One of them believed, according to his testimony, that children were born with "nail heads" [an expression used to refer to microcephaly] because they had been bitten by a "black spider", to which the nurse duly clarified the real transmitters that resolved these and other doubts. The group members generally knew little about dengue, zika, and chikungunya. It is important to say that at the end of the interview, we were surprised by the importance of the meeting, manifested, once again, by statements that summarized the desires of each of the workers invited to give their testimonies: "Damn, it was great to have talked to you. Now I have managed to clear up my doubts about this disease [zika]. We have worked here at the secretariat for years and have never been guided like this... thank you!"

In this dimension of information processes, we resort to the ideas of Paulo Freire (1992). For him, education is communication, dialogue, insofar as it is not a transfer of knowledge, but a meeting of interlocutor subjects who seek the meaning of meanings. This line of thought converges towards dialogue with Health Promotion, as it represents the political process that understands social demands and proposes actions aimed at developing and strengthening individual and collective capabilities and skills. When understood as a collective strategy of shared action, which operates and articulates the knowledge and skills of the actors and the different technical and public sectors involved, it can enable sustainable social changes in a given context (Brazil, 2002).

In this regard, it is even necessary to point out the differentiation between prevention and Health Promotion. According to Czeresnia (2009), prevention means anticipating, influencing, and avoiding something that requires early action. Preventive actions are specific and are based on modern epidemiological knowledge that aims to control the transmission of infectious diseases and reduce the risk of degenerative diseases or other specific problems. Health promotion deals with broad measures; it means favoring, promoting, and generating. The strategies emphasize the transformation of living and working conditions through the political articulation of different sectors; that is, they have an intersectoral basis since the determinants of the health-disease process are external to the health sector.

In this art of encounter, not only the interviewees were affected by the research (Favret-Saada, 2005). And perhaps the most interesting thing is highlighting that researchers do, too. One of the moments of greatest involvement occurred with the group of women who were mothers of children with microcephaly because of Zika.

On the day scheduled for the activity, it was raining a lot in the city, and we were worried whether the participants would attend, as we knew that these families lived far away. To our surprise, five women appeared accompanied by their children, bags, and umbrellas. This meeting revealed the imposition of an exhaustive care routine, generating social isolation, exhaustion, and overload for these women, and the difficulty of accessing public policies. Among the resources for coping with these adversities, coordination with other women who were going through the same experience stood out, appearing as the main means of information and guidance in relation to access and treatment (Campos *et al.*, 2019).

In addition to the material conditions of the weather, instability, and rain, other reflections are in order. The exhaustion of participating in research, as well as the feeling that this participation would result in an additional burden, and in no concrete return to the urgencies of life, must also be considered. Other researchers have already highlighted this process that occurred in studies related to the emergence of Zika, such as the works of Fleischer (2022) and Moreira *et al.* (2022).

Carneiro and Fleischer (2018), when analyzing the Recife experience, point out the lack of support and reception for women in the context of communicating the diagnosis, which led to seeking the meaning of what would become Zika on the internet, at home, and in support networks. In this sense, the authors suggest that although the subject was little known by health professionals, nothing seemed to "justify the way in which women were communicated and, after the diagnosis, received so poorly".

Just as in Recife, mentioned above, in the field experimented here, it was also possible to demonstrate that women were "so poorly received" regarding information about Zika and to identify other situations that require attention from public authorities and institutions. care, as pointed out at different moments in this narrative. But it also demands research, telling the scientific community that much of what happens behind the scenes of care needs to be highlighted and guided by health policies.

Final notes

The field experience shared here allowed us to go beyond the mere description of the material collected with the tools used in the research, namely, semi-structured interviews and separate notes in a field notebook. The reports problematized here made it possible to understand beyond the oral statements, guided by the questions contained in the semi-structured interview. It revealed important behind-the-scenes elements of the contact between researchers and research subjects. It was possible to identify a set of elements that directly or indirectly interfere with the results of the investigation, such as power/knowledge relations, as the perspective of qualitative research, by its own epistemological nature, makes it possible to reach realities between the lines of the speeches recorded by the collection instruments. Furthermore, it enabled a greater approximation of the social universe of the research

subjects, their experiences, and perceptions about Zika, but also and mainly with the relationships established with other subjects and institutions within the scope of assistance and reception.

The field allowed us to diagnose the negligence of the local system in combating Zika. It brought to light the lack of greater public intervention, both at the municipal and state levels, regarding prevention and health promotion. In the reports of mothers and fathers of children affected by Zika, for example, complaints appear that the State could have provided greater support, and they were fully aware of their rights to certain information and guidance about the disease and its consequences, which was not satisfactorily attended to.

The Zika epidemic, as well as other health events with lasting consequences on the lives of affected people, leaves us with lessons on how to build research where participants can dialogue more horizontally with their processes. The fact that this research involves one of the researchers living in a northeastern region, with professional insertions there, was something that the team designed as a facilitator. And we can reflect that the way in which the focus groups were also managed as a space for learning and exchanges, was an analyzer of this appropriation by the local community. However, funding agencies and financiers, as well as the main researchers of large teams, need other, more permanent strategies to create exchange links and lasting learning. A certain hegemonic model of doing research deserves to be reviewed and transformed.

Therefore, the field built a school here, teaching us about the researcher/research subject relationship in a way that no scientific literature could do in such a short time. Approaches, identifications, and estrangements were fundamental thermometers for our perception of the field and the possibilities of producing scientific knowledge about the Zika epidemic in Northeast Brazil.²

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Notes

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² M. C. N. Moreira: thematic organization of the collection, conception, writing and final review of the article. E. H. S. de A. Oliveira and D. de S. Campos: data collection, writing and final review of the article. M. A. F. do Nascimento and P. C. Peiter: writing and final review of the article.

Resumo

Zika vírus no Nordeste do Brasil: retrospectiva para uma pesquisa

O artigo trata das impressões compartilhadas de pesquisadores e sua experiência no trabalho de campo no Nordeste do Brasil, no âmbito do projeto Promoção da saúde no contexto da epidemia de zika: atores e cenários nos processos de tomada de decisão (FIOCRUZ/ZIKAlliance). Aqui procuramos compartilhar impressões de campo sobre uma pesquisa acerca da epidemia de Zika vírus, em dois municípios situados em diferentes localidades do Nordeste. Evidenciamos a importância do caderno de campo na pesquisa qualitativa e tecemos reflexões acerca dos resultados das entrevistas realizadas com mulheres em idade reprodutiva, gestantes, profissionais de saúde, mães e pais de crianças acometidas por microcefalia e trabalhadores autônomos. A partir dos depoimentos, foi possível observar aproximações, identificações e estranhamentos dos sujeitos de pesquisa com os pesquisadores, constituindo importante termômetro para nossa percepção do campo e das possibilidades de produção de conhecimento científico sobre a epidemia do Zika no Nordeste do Brasil.

> Palavras-chave: Doença por Zika vírus. Pesquisa qualitativa. Atenção à saúde. Nordeste do Brasil.

