

## FAMILY SPACES AND THE PLACE OF CHILDREN DIAGNOSED WITH MICROCEPHALY <sup>1</sup>

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<sup>1</sup> The present study is an excerpt from the Matrix Project entitled “Microcephaly: qualitative study of chronic condition experience”, duly registered under the number: PROPEq-UFMT 408/2016.

**Abstract:** It is proposed to present impressions and reflections on the space and place of children with microcephaly in the context of housing and family, based on fieldwork carried out for a doctoral thesis. The data produced came from observation and in-depth interview techniques, one complementary to the other. In total, 9 families participated in the research, 11 children were diagnosed with microcephaly due to Zika Virus, allowing us to explore some situations from years of coexistence and daily care reported by the parents. The results demonstrate the inside of the homes of family members of children with microcephaly, their interactions and family care context. Such aspects mark the stories, experiences and trajectory of research participants, produced in face-to-face situations (subjects and researcher).

**Keywords:** Family spaces, microcephaly, Zika virus.

## INTRODUCTION

When entering the research field, its interactions, scenarios and impressions, the researchers' intention is to get as close as possible to the reality studied in order to grasp, analyze and understand the object of the study. In this sense, observations and impressions reveal a glimpse of the scenes and interactions that emerge, from what Schutz (2012) calls the disinterested attitude or technical detachment of the observer, for a better elucidation of the phenomenon.

In addition to a methodological and technical procedure, field activity places the researcher in relationship with those who the anthropological perspective calls "natives" (MALINOWSKI, 1978). According to Killinger (2017), spaces for dialogue open up in the countryside that intensify this relationship, where natives show their points of view and their realities, in which views, interactions and dialogues make up this

dynamic of exchange and sharing.

In the private sphere, the home is the most intimate space that you can enter within the limits of the "other", symbolically, in addition to your own body, it is what offers you basic protection, your environment, in addition to your skin. Considered as a symbol of the self, the house that is shown from the "inside" side is intimate, that is, it is only revealed to those who are invited there (COOPER, 1971).

The house can, then, be understood as a family identity, as a space destined not only to fulfill its basic survival requirements (shelter, protection, housing) but a fruitful place for the construction of relationships, bonds, affections and memories, which they are quickly evoked, signified and re-signified (MUSSI; CÔRTE, 2010).

For Rybczynski (2002), domestic space is a fundamental human need, deeply rooted in the self, which needs to be satisfied, allowing social identification, the feeling of intimacy, privacy, and domesticity, which generates an environment marked by the traces of its experience. So, what is perceived, every detail, every scenario, every organization, can reveal the "family portraits" (MUSSI; CÔRTE, 2010).

In the case of families of children with microcephaly, we find in this space an intertwining of the experience of chronic illness and the configuration of housing and environmental contexts. Thus, as there are subjective characteristics that permeate the experience of these families, there is also a set of physical characteristics in the housing context, acting as therapeutic spaces, a "special" place intended for the care of these children.

In these scenarios, in homes, individual and collective experiences are mobilized, where complex experiences are expressed, especially when it involves chronic conditions and physical disabilities, situations in which there is no possibility of cure and which

require extensive efforts for management. continuous.

Given this perspective, it is believed that the experience of a chronic condition contains full meanings and, especially when in childhood, because it is also experienced by those around them: parents and family members (the children's main caregivers), making the experience familiar and lived (also) at home. Therefore, it is believed that its effects, challenges and learnings are reflected in the family. Experience, in the form of knowledge and knowledge that is recognized in practice, is capable of penetrating all spaces of everyday life, being mediated by sociocultural elements.

Based on the above, this discussion proposes to present impressions and reflections on the space and place of children with microcephaly in the context of housing and family, based on fieldwork carried out on visiting days and meetings. Being where the families live was the way researchers found to get closer to the family experience and thus better understand their points of view.

This article is one of the fieldwork products of a qualitative study in health, which forms the body of analysis of a doctoral thesis in Nursing, whose aim was to analyze how families experience, interpret and act in the face of the Zika Virus and microcephaly in their daily lives (CRUZ, 2019).

To carry out this study, the bioethical principles set out in Resolution Number: 466 of the National Health Council (CNS), referring to research involving human beings, were followed, approved by the HUJM Ethics Committee (CEP/HUJM) through opinion, number: 1,842. 018, CAAE, number: 59553716.9.0000.5541.

Therefore, it is reiterated that to guarantee the anonymity of research participants, all names mentioned (both adults and children) are fictitious.

## **FIELD WORK: PREPARING FOR MEETINGS**

Fieldwork in research is carried out in several stages, including: planning, scheduling and meeting with families, an opportune moment to carry out individual and collective interviews. The meetings with the 9 families participating in the research took place between the months of February/2017 and April/2019 (with a total of 19 incursions, 16 interviews), and, for some families, more than one meeting was necessary.

Notably, scheduling visits to the homes of family members of children with ZIKV microcephaly was a procedure that required many adjustments to the family routine, due to the difficulty of finding a time when the mother (most of the interviewees) was not accompanying the children undergoing rehabilitation therapies, consultations and hospital admissions.

During this process, it was possible to perceive the intense routine of mothers in treating their children. When contacted, via cell phone application, mothers reported having difficulty booking a date for the interview, due to having a weekly schedule full of daily appointments and various health services. On some occasions, mothers needed to rearrange their schedules so that they could be interviewed in their homes.

Regarding hospitalization, some mothers reported that their children had been hospitalized for a long period of time, requesting that the researcher get in touch later or claiming that, at that moment, they were indisposed to give an interview - when it was suggested that the meeting at the hospital.

However, the main intention was to be present in the space where the daily care given to the child takes place and to have a moment of interaction with the participants long enough to produce research data, without rushing, without too many inconveniences, so that the

family can feel comfortable. felt comfortable talking and sharing their experiences.

The data produced in the present study came from observation and in-depth interview techniques, one complementary to the other. This methodological combination allowed the researcher to develop certain possibilities of approaches, as it provides a broader perspective and obtains more information about contexts and realities (FLICK, 2009).

In this sense, for fruitful fieldwork and conducting in-depth interviews, it is essential to avoid impersonal formalism during meetings, so that spaces are opened for interactions, dialogues and exchanges, seeking to transcend the problem under investigation to give way to the flow of reciprocity of knowledge (FERREIRA, 2014).

For Kaufman (2013, p. 80), the interviewee (research participant) “is not vaguely questioned about his opinion, but for what he possesses, a precious knowledge that the interviewer does not have”, valuing his subjectivity, his knowledge, your way of looking at and living life.

In turn, the field observation technique for data production promoted proximity to the field and interaction with the people involved there, serving for an attentive description of the scenario and real situations (MINAYO, 2011). It is widely used in social research that seeks to understand people’s lives and everyday reality.

For its operationalization, a field diary was created, consisting of observation notes and the researcher’s impressions about the scenarios, behaviors and social interactions (WEBER, 2009), from the journey to the house, upon entering the field, upon approaching families until they return from the research field.

The construction of this tool took place after each visit and each meeting, recording the most striking visual aspects, non-verbal data (gestures and body expressions) and the

nuances of the participants’ speeches during the interview meetings, enabling the breadth of understanding of the phenomenon. The data produced during the collection was standardized and compiled into a single field diary using field notes.

## **GETTING TO KNOW FAMILIES: ACCESSED SPACES AND FIRST IMPRESSIONS**

Of these 9 families that participated in the research, 11 children were diagnosed with microcephaly due to Zika Virus, aged between 3 months and 3 years (during the period of each meeting), allowing the researcher to approximate the recent situation of the pregnancy and birth of a baby, as well as exploring some situations of years of living with microcephaly/SCZV reported by the parents.

Among the families interviewed, only one lived in the interior of the State, this one chose to hold the meetings in a private room in a health service, as she did not feel comfortable inviting the researcher to go to the family member’s house where she was staying.

At Laura’s request, the interview was carried out in a classroom in the Hospital’s teaching block, very close to the Outpatient Clinic. It was suggested to the participant that, if she thought it more comfortable, the interview must be carried out at the home of her family member who lives in Cuiabá, but Laura seemed uncomfortable, claiming that she felt insecure about making an appointment for the interview at the residence of another person. **Field note, 13/02/2017**

This was the only meeting held outside the home environment. It was also the shortest duration of the interview. The mother shared the attention given to the researcher with her daughter Clara (a 3-month-old baby), who cried a lot, even on the lap of her sister Yasmin (16 years old, Laura’s first daughter) who always accompanied her to appointments.

Through this interaction experience, the researcher realized the importance of the ambiance at the time of the interview. There was something missing in that meeting environment, in that space for dialogue, the child's place.

The beginning of the conversation was peaceful, however, after a few minutes Clara began to cry intensely, requiring Yasmin to take her out of the room for a moment. Laura continued talking to us, but had to be interrupted to breastfeed Clara, in an attempt to calm her down. [...] The classroom didn't offer much comfort and there were no toys for Clara to play and have fun. Even so, Laura was very willing to tell the story of her daily life and her family. **Field note, 13/02/2017**

To better utilize the research, adjustments were made to the selection criteria for participating families, so that the other families interviewed lived in Cuiabá and Várzea Grande. Of these families, only one lived in the central region of Cuiabá, a location chosen on purpose by the family due to their move from the interior of the State to the Capital, in order to attend to the child's routine rehabilitation therapies. The other families lived in neighborhoods further away from the central region.

In the context studied, most of the health services accessed by families were concentrated in the central region of Cuiabá; In the case of Roberta's family, it took around 20 km to travel each way to get to therapy, requiring a car and fuel expenses on a daily basis.

Regarding the long distances to reach homes, this was already expected as part of the process, considering the participation of some families from the neighboring city, Várzea Grande. However, so much effort on the journey was rewarded by the possibility of observing and getting to know the living conditions of these families, their surroundings, their neighborhood, their

domestic organization, their particularities, their family territory, which made it possible to draw closer to their daily lives and their contexts of life.

It is challenging to organize data produced from so many different realities, taking care not to focus only on the description of facts and scenarios. The observation sought to cover face-to-face interactions and understand expressive actions, since the "world of my everyday life is not my private world, but is an intersubjective world, shared with my peers, experienced and interpreted by others" (SCHUTZ, 2012, p. 179).

During the researcher's journey to the family's address, an exercise was carried out to imagine the distances traveled by families every day morning and afternoon from their homes to the clinics and offices to carry out rehabilitation therapy sessions (for example: motor physiotherapy, occupational therapy, hydrotherapy, equine therapy, speech therapy, etc.), which are generally located in the most central neighborhoods of the Capital.

There were examples of the long distance traveled to reach health care, such as that of a family, with whom we maintained contact for the interview, living in a neighboring municipality, called Poconé, 110 km away from the Capital. The mother brought her son three times a week for physiotherapy and speech therapy sessions at the rehabilitation reference service in Cuiabá (CER), due to the lack of specialized health services in her city of residence. She, along with her 2-year-old son, came on a city hall bus, along with other patients from her city, to undergo health monitoring in the Capital. Due to the child's treatment routine and several (re)scheduling with the researcher, it was not possible to interview the child.

Regarding the housing situation, 04 families live in their own house, 03 in a rented house and 02 in a rented house. Some houses

needed renovations and painting, especially those in more remote neighborhoods. A family lived in an urban occupation situation, with no minimum income:

The house was very small, without walls, without glass in the windows. Inside the house there wasn't much furniture, just two chairs and a small table. Roberta soon explained that she had been living there for a short time, about a month, that the house was provided by an acquaintance and that she moved in with very few things that she had received. There was no sink or refrigerator. Just a small stove in place of the kitchen. The bathroom and bedrooms had no doors. **Field note, 12/7/2018**

In families with higher family income, a basic housing structure was noted:

Sônia's residence is in a neighborhood far from the capital, in a housing complex with a paved street, public lighting, walled and, apparently, very safe. Sônia welcomed me at the gate with Máisa on her lap and immediately asked me to enter the large house, with good finishing, simple, well organized and clean. [...] We sat on the sofa in the living room to talk. **Field note: 18/12/2018**

## **THE INSIDE OF THE HOUSES OF FAMILY CHILDREN WITH MICROCEPHALY: INTERACTIONS AND CARE CONTEXT**

Upon finding the family's address, the first contact with the mothers was welcoming immediately providing a comfortable place to sit, a calm environment to talk; Sometimes, there was a certain distrust and a lot of curiosity about the researcher's interest.

Some mothers believed that the interview would be for some media outlet, thinking it was a newspaper or television report, as most of them reported that they were being sought out for this reason and that they had already given interviews for this purpose.

Having overcome their doubts, all participants felt a desire to talk about their life, their trajectory, their daily lives, as if they were already prepared to share, as if the speeches were already organized in their minds. The question "tell me about yourself" was followed by long answers, generally emphasizing the diagnosis and care for the children, in an attempt to say everything at once. This reveals that, with (co)living with the chronic condition, people start to have stories to tell, these are not separated from the process of living, but converge with the way of seeing the world and living in it (PINHEIRO, 2018).

Generally, the living room was the place chosen by the participants for the conversation, their children were always nearby on their lap, or on the sofa next to them. With the children in home care, known as home care, the place chosen was the bedroom.

Occasionally, the mother would need to comfort the crying child and/or carry out some other activity during the conversation, changing diapers, giving a bottle, putting them to sleep. There were times when it was necessary to interrupt the recording to meet certain needs: loss of a nasogastric tube, preparation of a special diet, choking, visits from professionals who carried out therapies at home (home care). In everything, the researcher did her best to make the participants feel comfortable, revisiting, when necessary, some important points for the research.

Looking at housing conditions, in general, most houses were simple (few rooms and a basic structure), but welcoming. There was something observed in common in the homes visited: the notable presence of various health equipment (with greater visibility in home care homes) and the place reserved to accommodate the child's belongings (wheelchair, sensory toys, medications, etc.). In other words, the physical space of the

house revealed the routines and needs of family members, with emphasis on children's care needs.

An example of this is Flávia's family apartment, where in the living room, the sofa for the family's accommodation gave way to a colorful rug. There are many colorful sensory toys and rehabilitation materials (ball, glove, etc.) that serve to stimulate Matheus's sensorimotor skills. It is also a place where the family plays and interacts with the children, especially their older sister, Gabriela.



Image 1: Matheus' place in the family home

Source: Provided by participant Flávia

*The decoration here at home is very beautiful, right? [he said this showing the room full of toys]" Flávia, mother of Matheus, 2 years old*

It is evident, in this example, that the organization of the space in these families' homes, by denoting the family social environment, is shaped by the care needs of the children - as one of the elements that make up the experience, as well as This was demonstrated by the intense daily routine of rehabilitation therapies when constantly accessing health services.

In the case of organizing the space in these families' homes, it is necessary to carry out a theoretical elaboration of the term space, since there is a certain polysemy and several

multidisciplinary studies on the topic. Among theorists, Tuan (1983, p. 06) states that "space is more abstract than place.

What begins as an undifferentiated space becomes a place as we get to know it better and endow it with value." From this perspective, it is understood that space, the house and its physical structure is a condition of survival and protection for families which, when organized and (re)signified, becomes a place. According to the author, this meaning depends on several factors, including culture and social memory.

Therefore, in the space of the houses visited, the place reserved for the care and interaction of these children revealed the way in which the memory and social identity of these families undergo changes depending on the moment in which they are being expressed (POLLAK, 1992), in this case, as a result of experience with the chronic condition. In this sense, the concerns of the moment constitute an element of its structuring (POLLAK, 1992), reflected by its practical and interpretative actions, which are revealed in everyday life, in spaces, in places, and which shape the experience.

It was possible to observe in family scenarios that there is a centrality in the action of the mother, who accompanies the children's daily therapeutic sessions and who designs, builds and organizes each place, according to the family's economic conditions, but which expresses their care potential, being called by themselves a "special corner". Special, according to the mothers, referring to the place occupied by a child with special needs (disabilities), or as they call them special children.

Evidently, the care required by children takes place in several other spaces in the house, but it is in this special place that the activities intended to stimulate their abilities are concentrated, resulting from the mothers' constant contact with professionals and health

services that develop learning and potential for family care as a response to the chronic condition (BARSAGLINI, 2015; LIRA; NATIONS; CATRIB, 2004), making them experts in the treatment of their children (PEREIRA, 2015).

*[...] through the corner we will work on all possible potential in the child [...] it is the reflection of what we learn in therapies, so, we try to reproduce at home what we learn in therapies, on the internet....and then we do it as if it were therapy too, but at home, you know? Samara, mother of Eloá and Camila, 3 years old*



Image 2: Eloá and Camila's place in the family home

Source: Provided by participant Samara

Thus, in the family space, it is possible to grasp the mobilization of knowledge and the family's capacity for transformations for care, which are marked in the mothers' experience, expressed both in the subjective dimensions and in the more objective and structured dimensions. A certain degree of appropriation and internalization of knowledge is also perceived, which is generally concentrated in the matrices of biomedical knowledge (LIRA; NATIONS; CATRIB, 2004; PEREIRA, 2015) and becomes part of their social memory, which, in part, is inherited (POLLAK, 1992).

Regarding interactions between family members who were present at the time of the interview, it was observed that, most of the

time, the older siblings of the affected children were present. They observed the interview situation as if they were part of the dialogue and, at times, were questioned by the mothers as a way of reaffirming what had been said by them. They were also active in caring for their siblings, listening to their parents' eyes, playing and comforting them when asked. The parents (men), when they were on scene, shared the interview's attention with taking care of their children, placing them on their lap or preparing a bottle, for example, when taking turns with their wife during the interview; however, there was little to talk about.

Another presence, in some interview scenarios, specifically in homes where there was home care, was that of health professionals who made up the routine and daily life of the family, whether by carrying out daily therapy sessions or by the constant care of a nursing professional. With the arrival of visiting professionals for home care therapies, mothers preferred to pause the interview until the home session was carried out, resuming previously reported topics. They felt more comfortable with the nursing professionals, however, the parents asked for a certain distance from them when giving the interviews.

In the reports, some health professionals were frequently mentioned by parents. It was noted that some health professionals had a strong presence in the trajectory of several families (an ultrasound doctor, a nurse and a physiotherapist), considering two aspects, first: because they are the reference specialists for the diagnosis, referral and treatment of microcephaly/ SCZV in the Capital; second: for participating in such a remarkable moment in the lives of those families (discovering and dealing with the chronic condition involving disability).



## SOME FINAL CONSIDERATIONS

Visiting the families' homes for the interviews was a very important moment, not only for data collection, but above all, for getting closer and interacting with the

families, which allowed the researcher to broaden her perspective on the contexts that mark the stories, the experiences and the daily lives of the participants in this research, produced in face-to-face situations.

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