

“Early stimulation” in the scenario of Congenital Zika Virus Syndrome: Challenges in three temporalities in the Metropolitan Recife Area, State of Pernambuco

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Abstract

In 2015, the Zika virus epidemic was declared in Brazil. More than 4,000 children were infected and developed what is known as the Congenital Zika Virus Syndrome. Incurable and only palliated with drugs, for the syndrome, “early stimulation” was presented as the only therapeutic possibility. In 2020, a pandemic, Covid-19, arrives in the country, severely disrupting the lives and care of these children and their families in the Recife, State of Pernambuco region. In this article, three times pervaded by these two health emergencies will be described. At the beginning of the Zika epidemic (2016), rehabilitation therapies were being organized, known and demanded by families. In 2019, with the virus cooled down, vacancies for therapy began to dwindle and families were more discerning and critical about them. In the third period (2020), clinics are closed in the name of social isolation and rehabilitation presents new dilemmas for these families. Rehabilitation routines have allowed for an expansion of the public sphere and spaces for dialogue and questioning of the State and its policies aimed at children and both epidemics. Withdrawal from these routines has far wider consequences for the children, their family and the wider community.

Keywords: Early stimulation. Zika virus. Medical Anthropology. Recife. Brazil.

“Estimulação precoce” no cenário da Síndrome Congênita do Vírus Zika: Desafios em três tempos na Grande Recife/PE

Resumo

Em 2015, a epidemia do vírus Zika (ZIKV) foi decretada no Brasil. Mais de 4.000 crianças foram contaminadas e desenvolveram o que se convencionou de Síndrome Congênita do Vírus Zika. Incurável e apenas paliada com remédios, para a síndrome, a “estimulação precoce” foi apresentada como a única possibilidade terapêutica. Em 2020, chega ao país uma pandemia, o Covid-19, desorganizando severamente a vida e o cuidado dessas crianças e de suas famílias na região do Recife/PE. Neste artigo, serão descritos três tempos perpassados por essas duas emergências sanitárias. No início da epidemia do Zika (2016), as terapias de reabilitação estavam sendo organizadas, conhecidas e demandadas pelas famílias. Em 2019, com o vírus arrefecido, as vagas de terapia começaram a escassear e as famílias estavam mais criteriosas e críticas a seu respeito. No terceiro tempo (2020), as clínicas são fechadas em nome do isolamento social e a reabilitação apresenta novos dilemas para essas famílias. As rotinas de reabilitação têm permitido uma ampliação da esfera pública e dos espaços de interlocução e de interpelação do Estado e suas políticas voltadas para a infância e a epidemia do ZIKV. O retraimento dessas rotinas tem consequências muito mais amplas para a criança, sua família e comunidade de modo geral.

Palavras-chave: Estimulação precoce. Zika Vírus. Antropologia da saúde. Recife.

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Introduction

In June of 2019, in the Metropolitan Recife Area (MRA)¹, we visited the home of one of our research interlocutors. A small team of three anthropologists there to know where Maria Claudia, her husband, her teenage daughter and her youngest daughter lived. Bela, born in 2015, had received the diagnosis of Congenital Zika Virus Syndrome (CZVS, henceforth)². We arrived at an apartment from the *Minha Casa Minha Vida*, a public housing program, located in a peripheral neighborhood also considered as quite dangerous. A two-bedroom dwelling, fully furnished and decorated in various shades of green, chromatic strategy to stimulate the child’s meager eyesight. In the center of the room, leaning against one of the walls, was a small, squared rubber tatami, where toys and instruments used in rehabilitation therapies rested. Above the tatami, hanging on the wall, were a flat-screen TV and a shelf with trinkets and picture frames. On the shelf, one of the ornaments that caught our attention was a small doll, made out of air-dry clay, sitting in a wheelchair. Looking closer, we saw that it was Bela, Maria Claudia’s little daughter, easily identified by her curly black hair, pink glasses and the “farda”, as was called the uniform of the clinic where she attended therapy since she was a baby. Noticing our interest, Maria Claudia quickly explained that it wasn’t just any ornament, but the one she had used on her daughter’s three-year birthday cake earlier that year. And she already had plans for the following year: on the next cake, the adornment would represent Bela smiling and affixed to her parapodium, an orthopedic equipment that encourages the standing posture and an upright position³.

1 We prefer to use this term, MRA, instead of simply Recife because we also circulated in Olinda, Paulista, Jaboatão dos Guararapes and São Lourenço da Mata, which form a large and continuous urban area of 12 municipalities.

2 At the time, Soraya Fleischer was accompanied by researchers Ana Claudia Knihs and Raquel Lustosa. This article was written with Júlia Garcia. We are all part of the same research team, share our empirical materials, and generally write as co-authors. We take this opportunity to thank the whole team, interlocutors, funding institutions and the two anonymous reviewers who helped improve this article. We also are indebted to David Fleischer, who reviewed the translation from Portuguese to English.

3 We have met women like Maria Claudia since 2016, when this research project began. Until 2019, we returned to the MRA seven times, once every semester, to visit and continue conversations with the same dozen women (and two other dozens we met more sporadically). We accepted invitations to accompany them in consultations, exams, public hearings, pharmacies, meetings at NGOs and, above all, daily therapy. We also went to their homes, neighborhoods, churches, and parties. We produced notes, field diaries, recordings and photographs. With the arrival of the Covid-19 pandemic and unable to return to the MRA, we chose to keep in touch with these women via WhatsApp, a digital messaging tool very well-known and intensely used in Brazil. In addition, as a result of social distancing and in order to keep their support network amidst the pandemic, they increased the use of social media networks, online events as Instagram and YouTube lives. Watching these events, open to the general public, was also a way of understanding the new routines of these mothers and children, as well as keeping closely to our interlocutors, even if separated by a geographical distance.

Less than a year after this visit to Recife, a new epidemic began to circulate in the media. The new virus soon arrived in Brazil and on March 11, 2020, the World Health Organization (WHO) declared the Covid-19 pandemic, suggesting strict measures such as the closure of commercial activities, schools, basic services and borders; new hygiene protocols; and social distancing and isolation. Although Brazil did not adhere to all effective recommendations in managing and controlling the virus (REUTERS, 2020), therapies, consultations and rehabilitation procedures for children as Bela were abruptly interrupted, interfering in the life and development of countless other families and children with CZVS.

The most common medical specialties that treat these children are: Neurology, Pediatrics and Endocrinology. Consultations must happen, at the most, every three months. Exams had been very intense in the beginning, but, over time, they were carried out only when new symptoms appeared. State pharmacy and the Instituto Nacional do Seguro Social (Social Security System) counter were approached respectively until medications and the Benefício de Prestação Continuada (Cash Benefit to Disabled People) had been guaranteed, often through court decision⁴. All these spaces were visited sporadically by mothers and “micro children”⁵, unlike the other space where they were at on a daily basis – rehabilitation therapy.

Given the syndromic condition of the CZVS⁶, incurable through surgeries or transplants and only palliated with drugs, the “early stimulation”, “based on physical, visual, hearing and speech stimulation” (Souza, 2017: 26; Brasil, 2015), was presented as the only possibility to be systematically offered to these children through such as physiotherapy, occupational therapy, speech therapy, visual stimulation, music therapy, hydrotherapy, hippotherapy, etc. “Early stimulation” was designed as an intensive rehabilitation therapy to be undertaken during the first three years of age. Along this period, as we often heard in Recife, there is a “window in the brain”, with greater opening for learning and training. This specific capacity at the beginning of life is called, by Physiotherapy studies, “neural plasticity” (Oliveira et al., 2019). “Plasticity”, “stimulation”, “precocity” were the main categories mobilized by the State officials and rehabilitation professionals, mainstream biomedicine and public policies.

To take advantage of this “neural window”, families should be available and committed to take their children to rehabilitation services on a daily basis. The expectation was that “early stimulation” could offer “development” to the child and gradual independence from external care. Walking, eating, and, above all, talking by themselves were desired activities, even if at a different pace and style. The “conquest” of each development stage has been called by health professionals as a “victory” (Duarte et al., 2019: 252), although these “advances”, another widely used term, are not as linear or definitive as the mothers reminded us. Children such as Bela, who at the time were over three years old, the age limit for “early stimulation”, had not yet developed as expected by biomedicine, requiring continuous treatment and therapy in different clinics and hospitals around the city. As described by Williamson (2018: 689), for children with CZVS, not only advances escape an imagined linearity, but the development time of these boys and girls can be experienced and permeated by uncertainties, by a series of “stops and [re]starts”.

4 Benefício de Prestação Continuada, as known as BPC, “is a social assistance benefit consisting in an unconditional and monthly transfer of a minimum wage to people with low-income and/or disability and elders with more than 65 years” (Santos, 2011: 1).

5 “Micro” became a synthetic version of “microcephaly”, a political identity widely used to identify children, their families and all sorts of services and spaces allocated for them (Fleischer, 2020b).

6 Among children with the CSZV, there are “changes in structure, body functions and deficits in skills, 52% have changes in visual function, such as difficulties in visual fixation and tracking, visual exploration of the environment and the hand; 12% in tactile function, with skin hypersensitivity; 40% of infants have congenital and muscle function malformations; 72% have changes in muscle tone, predominantly hypertonia in the upper and lower limbs, especially in the hands; 28% have an exacerbation of primitive motor reflexes such as moro reflex, RTCA; 68% had difficulties in the manual function, such as searching and reaching the midline, and also difficulties in performing postural changes; 92% had delays in the motor development milestones for the age” (Cruz et al., 2017: 3). Although referring to the context of Maceió, a city in the State of Alagoas, this study offers a general picture of the type, predominance and degree of deficiencies from this syndrome.

In general, therapies helped children to socialize, live together and overcome their disabilities, but they also supported mothers and families by expanding possibilities of imagining the future. In daily encounters within the institutions, these women learned about the syndrome and the medical, justice and education services available around the city. They also met other mothers, organized themselves politically, found clients for their crafts or snacks, navigated through other neighborhoods and social classes. Altogether, these women and their children went through an intense process of citizenship (Quadros et al., 2019). In other words, based on their daughter or son's disability, they learned about and demanded rights, space, and technologies. They expanded their idea of the public sphere and of the spaces suited for dialogue and for questioning of the State and its policies for children and the ZIKV epidemic.

First, we will present how the rehab services were organized for the micro children and, in a second moment, we will discuss how their mothers understood these services before and during the beginning of the Covid-19 pandemic. This general framework will allow us to reflect on further dilemmas. From the beginning, the mothers, as immediate caregivers, accepted "early stimulation" as the main therapeutic proposal for their sons and daughters and, since then, they have been attending, on a daily basis, tatamis, swimming pools, exercise rooms around the MRA. But since the children were over three years old, and with the interruption of activities due to the Covid-19 pandemic, they did not know what would be offered to them, they did not know if they would manage to continue the stimuli on their own and they were fearful for the future health and development of their children. On that one visit, Maria Claudia showed us the exercise mat, the therapy gadgets, the wheelchair and even imagined the mini parapodium on top of Bela's next birthday cake. But, given the closing of services in early 2020, this mother was no longer so sure if the stimulation strategies would continue beyond the living room of her house. Therefore, we chose to dialogue especially with the recent production of rehabilitation sciences, in order to know how they have understood the broader context of the Zika epidemic, and the more specific therapeutic care offered to these children.

In the next sections, three temporalities will be described. At the beginning of the Zika virus epidemic (ZIKV), when we first went to the MRA, between 2016 and 2018, rehabilitation therapies were being organized by medical authorities, and demanded by the families. Toward the end of our field research, in 2019, ZIKV had not stopped infecting fetuses, but no longer was characterized as an epidemic. At that moment, therapy slots began to dwindle, and families grew more critical, prioritizing quality over quantity of sessions per week. In the third temporality, starting in 2020, another virus arrives, Covid-19, also on a pandemic scale. Clinics were closed in the name of social isolation and rehabilitation presented new dilemmas to the care of children with CZVS. If, in the beginning of ZIKV, the official biomedical orientation was to focus on "early stimulation" through rehabilitation, more recently, and also because of Covid-19, this orientation was losing centrality in policies aimed at these children. In this relationship with the State, care moved from the public to the private sphere, from the clinic to the home, increasingly overloading these mothers. This article intends to contribute to the interface between State, public sphere, disability and motherhood.

Supply and demand of rehabilitation services – at the beginning of the Zika Virus epidemic (2016-2018)

Since the first year of the Zika virus epidemic (Diniz, 2016), we noticed a myriad of different rehabilitation services being offered in the MRA. As public facilities, managed by the municipality, there are the Specialized Rehabilitation Centers (SRC), "an outpatient care point specialized in rehabilitation, which performs diagnosis, treatment, concession, adaptation and maintenance of assistive technology"⁷. Managed by the State of

⁷ <http://saude.gov.br/saude-de-a-z/saude-da-pessoa-com-deficiencia>

Pernambuco or the Federal government, there are larger hospitals that dedicate a space and part of the staff to a rehabilitation ward. In the private sector, there were foundations with mixed resources (public-private), charitable entities, colleges and universities, societies of medical professionals (Vasconcelos et al., 2017), small neighborhood clinics and renovated rooms within non-governmental organizations. All these services were offered free of charge, but those, located in affluent neighborhoods, awarded vacancies or “scholarships” to low-income patients. A mother told us that her son went to “a clinic for the rich, where everyone is nice, and I was the only one who didn’t pay”. In all these spaces, there were specialized professionals, often assisted by students, interns, or residents. The only exception were the NGOs, that offered transportation and a meal and, therefore, were only able to attract physiotherapy or speech therapy graduate students or interns. Small or big, private or public, professional or not, all these places formed a local version of the SUS (Sistema Único de Saúde/ Brazilian Unified Health System) rehabilitation network.

All the children we know were in (or had been in) therapy. There was a clear hierarchy among therapies, professionals and spaces, a classification fueled by the experience of all these mothers. At each field visit, a new rehabilitative technology was sought after by the mothers. Orthotics, parapodium, orthopedic surgeries, specific therapeutic methods were examples with increasing costs. But we never met a child who had worn, for example, a Therasuit⁸ and paid the annual R\$120,000 for its maintenance. Mothers seemed to crave a constant technological update, expecting that different stimuli through the “window in the brain” would benefit the child (Fleischer, 2020a). They tried public or family *crowdfunding* and, when these initiatives failed, they tried to sue the health insurance companies and the municipal health department to get specific therapies only available in private clinics.

The more prestigious the service, the longer the waiting line. Therefore, vacancies were conditioned to attendance (Silva, Y. et al., 2019: 450). Right at the front desk, usually sat an attendance list to be signed by the mother when arriving that day. With more than two unexcused absences, the vacancy was lost. Illness of the child or of the mother, hospitalizations due to surgery or complications of the syndrome were among the few accepted absences excuses, that always had to be documented on paper and hold signatures and stamps from the respective medical authorities. Formal justification for non-attendance generated a lot of tension among mothers (Fleischer and Carneiro, 2018). On the other hand, absences created a turnover of slots, especially in less prestigious clinics. So, there would always be some therapy available, even if it wasn’t the most desired one. Families often accepted untrained therapists, outdated equipment or even distant clinics just to offer some kind of therapy to their child and, at the same time, demonstrate their interest and commitment to “early stimulation” while waiting for a place at a more renowned or convenient clinic. Perhaps this is why we never knew of judicialization of rehabilitative therapy. Meanwhile, daycare, transportation, medication, and surgery, also seen by our interlocutors as complementary to the development of their sons and daughters, were often taken to court.

Thus, these conditions generated, on the one hand, an ethical issue, since missing a session was not taking advantage of the service, while other people were waiting for the opportunity. On the other hand, it was also a moral issue. Not going to rehab was understood, by the group of managers, therapists and mothers, as depriving that child of therapy. As rehabilitation was the most valued technology to face the CZVS, slower child development could therefore indicate maternal irresponsibility. Mothers, however, resented this surveillance coming from all sides, “I am the one who lives my life”, as one of our interlocutors put it. Tension involving therapy, attendance and motherhood revealed a broader facet – an entire arrangement necessary to arrive and remain in the services.

⁸ Therasuit is an intensive care method, not provided by SUS, and aimed at people with neuromuscular disorders. Therasuit is supposed to aid postural alignment, sense of balance and position and is presented as a garment with dynamic orthoses interconnected by elastics that work to stimulate and reproduce the role of the muscles that need to be activated.

To arrive, to stay and to return

Rehabilitation usually took place once, twice or three times a week and in sessions of 20 to 40 minutes at most. The main purpose was repetition and routinization, not necessarily equal to the duration or intensity of the therapy. Exposing the child to stimulation several times was a way of getting him or her used to the exercise, to the manipulation of his or her body, and also to the presence of therapists and other children. But frequency required mothers to leave their home and move around town several times a week. This urban circulation requires fine coordination between time, space, technologies and different actors, as many scholars have noted (Fleischer, 2017; Scott, 2020; Williamson, 2018).

The MRA is known for its narrow and uneven streets, subject to flooding during the rainy season, lengthy traffic jams and an outdated and unreliable transportation system (Lustosa and Fleischer, 2019). At the beginning of the Zika epidemic, these families used buses, where they faced discrimination against their sons and daughters and the unwillingness of drivers and other passengers to accept free passes, baby carriages, wheelchairs, extra escorts etc. Then, as a second alternative, came vans and ambulances offered by the municipality, but with little punctuality. Mother and child risked arriving late, missing the session and, in a chain reaction, missing the next activities of the day. The vans did not allow these mothers to take their other children along, even if they had no one else to care of them at home. Mothers found out about their mobility rights, as free passes within the city, *Tratamento Fora de Domicílio* (Out-of-Home Care)⁹ between municipalities, donation of wheelchairs, mandatory car seats in taxis, etc. Rapidness, reliability, safety and air conditioning were increasingly prioritized by the families and, as a result, family cars and also app cars were sought after over time. The city, transportation systems and drivers can definitely affect therapy attendance.

It is worth adding that, on the part of therapists and health services, challenges of urban circulation were associated with the supposed poverty of micro families, in an understanding that punctuality and attendance were due solely to individual responsibility and are not influenced by urban management, for example. A study in the Pernambuco hinterland reported: “The main difficulties raised by professionals are the socioeconomic issues of families who face difficulties in the cost of transportation and food for the children” (Souza, 2017: 24).

Still other aspects should be considered so mother and child could arrive at the sessions. All means of transportation required that the family routine begin at dawn, given the peripheral location of homes, as is also the case in other metropolitan areas affected by the epidemic (Silva, M. et al., 2019). Families living in other municipalities would travel hundreds of kilometers to arrive in Recife every day. They would wake up at 3, 4 or 5 in the morning to shower, prepare breakfast, pack a bag to spend the day, prepare the older children to go to school and also leave lunch ready for those who stayed at home.

Mornings are also difficult because it is hard to settle down the night before. Since birth, these children take medicine that helps them swallow, avoid irritability and seizures, and finally fall asleep (Knihs, 2020). We saw Keppra’s or Sabril’s¹⁰ colorful syringes appear in the late afternoon, when mother and child had returned home. The medicine time was calculated so that the children could follow the family’s night rest, and also be awake for the daytime activity. Although it was necessary to calm the child during the night, these mothers did not want a “dead”, “still”, “soft” child at physiotherapy the next day. They had been striving to find a balance between “agitated”, considered as an excessive condition, and “active”, considered as the ideal condition of protagonism during therapy. Also, medications were essential to treat spasms, the main cause for infantile suffering and also for unlearning what was being taught day after day in therapy.

⁹ The “Out of Home Care” is the legal tool which aims to make treatments possible, through transportation or the cost of tickets and daily rates, for the citizens who bear highly, non-treatable diseases or conditions but do not count with the necessary service in their original cities.

¹⁰ Keppra (levetiracetam) and Sabril (vigabatrin) are drugs used in the treatment of epilepsy and resistant seizures.

Although tranquilizers and antispasmodics were given in the late afternoon or early evening, some were slow in effect, especially when the child had already developed some type of drug saturation. Many kids had consumed the same brand and dose for years, and their moms reported how hard it was to schedule an appointment with the neurologist or pediatrician to, among other things, update these prescriptions. So, faced with inefficient medicines, many of these children and families could only fall asleep at dawn and had a few hours of sleep until they had to get up and start organizing for the day again. So, mornings were tough. Added to this, many mothers claimed the routine between one therapy and another, between different clinics and hospitals, was exhausting. Children, sleepy and tired, became stressed out and had a hard time absorbing whatever was taught in the sessions.

Besides sorting out medication, food had to be planned. The night before, these women, in order to reduce costs during their urban wanderings, prepared lunch boxes for themselves and for their children. Food should be offered before therapy so the child would have energy, but in a certain amount so as not cause discomfort or sleepiness. Or be offered later, especially after hydrotherapy, when the appetite had been awakened. Food was a sensitive issue in the case of these children who, from an early age, had many eating challenges (Lima and Fleischer, 2020). And, as so many studies in Brazil have shown, child weight has been treated proportionately to maternity quality (Nascimento and Lima, 2018). These mothers used the facilities of the clinics, but also the interior of vans, buses and cars to offer the meals. Delays in therapy and in transportation impacted this entire sleep-medicine-food routine, with deleterious consequences, such as hunger, irritability, seizures and suffering for children and caregivers.

In order to be able to commit and to attend rehab sessions, these mothers depended on a backup structure. The BPC and the free bus passes guaranteed them some income and transportation; unpaid medication relieved the household budget; orthotics and wheelchairs were made available or donated; a percentage of the *Minha Casa Minha Vida* apartments had been reserved for these micro families. An equation seemed to be progressively in progress: citizenship enabled therapies, which generated child development, which positively moralized motherhood and encouraged the production of hope for this family (Fleischer, 2020a).

Thus, several temporalities needed to be synchronized: the biological clock, the alarm clock, the clock on the wrist of drivers and on the clinic walls, the clock ticking of public policy. The organization of family routine, sleep, medication, food, rehab sessions and urban transportation was not an uncomplicated task. Each of these elements, as we just showed, involved a set of other scenarios and actors. Arriving, staying and returning to therapy sessions, day after day, was laborious and did not depend solely on the personal effort of these micro mothers and their children.

Therapy formats

Therapy took place as a routine¹¹. In general, it began with the reception for those who were arriving, each woman took her child out of the wheelchair or baby carriage, unattached her/his orthotics from arms and/or feet and placed the child between her legs on the mat. Mothers, children and therapists could sit in a circle, play a game, sing a song or simply let the conversation happen more freely. Then came stretching the muscles and limbs, followed by one or two specific exercises. And, finally, the closing occurred, when everyone gathered again in a circle and evaluated the session, planning the next meeting, week or stage, anticipating holidays and festivities. In this group format, all children went through these three moments.

¹¹ Rehabilitation science scholars have noted that, although recommended as the main therapy for children with CZVS, the way to actually perform this “early stimulation” has not been described in publications in the area (Rodrigues et al., 2017). For an exception, see a detailed presentation of these activities by a MRA team (Borba et al., 2019: 544-546).

Occasionally, a therapist would perform a different activity on a single child. Perhaps a specific reinforcement was needed for a skill to be developed, perhaps it was an experimental technology to be demonstrated by the therapist and learned by all the caretakers. The mothers continued the exercises on their children, but paid attention to the new activity.

There was also the artisanal making of instruments to be used at the clinic and/or at home. Accessible and low-cost materials were used. One example was the roll, made with 15cm of foam and another 15cm of velcro, planned to be a lighter and cooler alternative to the official thermoplastic hand orthosis. The goal was to keep the child's little palms open, preventing them from closing over time in a claw position. Another example were the blue jeans stuffed with an acrylic filling and commonly used to lean the children on to relax. Or even the rattles made of plastic yogurt containers filled with grains of sugar, rice or beans, for different degrees of sound stimulation.

Services were organized in various ways. We knew places where mothers left the child with the therapist and remained in the waiting area. Inside, there was one therapist working with each child and several children were attended to simultaneously. This format was common in hydrotherapy. On the one hand, this format would reduce the chance of the mother getting to know about the exercises and rehabilitative challenges faced by her child thus, with less possibility of learning about the syndrome and reproducing this work at home. But, on the other hand, they would get a few minutes of rest, either in solitude and silence, or in a lively chat with other micro colleagues. Some told us that, especially in the beginning, the children had a hard time in the company of new people and, if they stayed inside the room with their sons and daughters, it would be a distraction and would make it difficult for the child to adapt to the therapist. When we stayed with the mothers outside, we heard their impressions, more or less critical, about therapists and clinics they attended on other days of the week. When we chose to stay inside the rooms, we knew the therapists' opinions about the child's progress, as well as the comparison among them.

We also visited clinics where mothers performed on their children's bodies what was instructed by the therapist. This arrangement could happen collectively, with several pairs of mothers and children around the room (music therapy, physiotherapy, occupational therapy), or individually, in a smaller and cozier room, with one pair only being guided by the therapist (speech and hearing therapy or visual stimulation). Each movement had its purpose explained and corrected by the professional and replicated by the mother. Because they need to sit on the floor and accompany the child, mothers planned ahead to wear comfortable clothes. This format, on the one hand, allowed women to learn in a hands-on approach about the therapeutic movements and goals and, in our view, it raised them to another level of autonomy and protagonism with the syndrome. On the other hand, some mothers thought that their child was receiving a lower quality therapy, as it was not carried out directly by the health professional. It was interpreted, at the same time, as an apprenticeship to be applied at home, and as an outsourced and unpaid job done by the mothers, a service offered wholesale and with amateurism. They thought it was important for therapists to touch and feel the child's body so that they could also identify the specific resistances and difficulties to be developed. Our interlocutors valued, above all, individualized and customized therapies for each child.

In other places, patients were stimulated directly by the professional, but the mothers could stay nearby, also sitting on the mat or in chairs close to the walls of the room. Therapy, therefore, was observed from a distance and could be discussed by the mother and/or the therapist. We noted, however, that even though it was not mandatory, some mothers followed the therapy closely because they did not fully trust the clinic, the equipment or the therapist, especially if they were new interns, residents or too young in age. For example, we were told of a physiotherapist who broke a child's arm while forcing too much a maneuver; of one who accidentally pulled the tube from the child's belly, not noticing that it was trapped in the chair where she was sitting; another who put a bandage on the child's face that caused allergies and skin rashes.

In all of these therapeutic formats, the child's crying was closely considered. In private clinics, especially, where therapists took over the exercises, we saw them interrupt their work and return the sobbing child to the mother. They wanted to avoid that the child relate therapy and therapist to suffering and pain, creating resistance or trauma. Mothers were uncomfortable with this protocol because they knew that tears could indicate sleepiness, side effects of a new medication, typical irritability of the syndrome, etc. When the child was promptly dismissed, they felt it was a waste of time and effort to go all the way to the clinic and the service not happen or be interrupted. In other clinics, usually public ones, the child's body was manipulated, even if he/she was crying. For these therapists, tears indicated some discomfort, but was not a sufficient reason to interrupt the work. Mothers and therapists tolerated a little drowsiness in the child, even as a way to avoid crying and irritation. But on the other hand, too much torpor could prevent the therapy from being carried out in an active way, with learning and retention taking place on the part of the child. The mother, at times, was touched by her son's crying or sleepiness, but she was also learning about the different meanings of these manifestations. They knew that crying could be of pain, signaling an iatrogenic intervention by the professional; or it could be used by the mother to rush appointments that were running too late or too long. In these cases, the child would be helping the mother coordinate the service. Tears and tiresome would not always be a problem, but were considered, more and more, as a way of communication.

In all these scenarios, there was a lot of conversation. The topic could be spontaneously brought up by the mother, the therapist or even the child, based on something they had recently experienced; related to CZVS or not; or to the clinical scene or not. Regardless of the inspiration, the topic ended up being widely discussed by everyone, with words, laughs, emotions. Sometimes, a confidence, and other women listened carefully and offered support; sometimes, it was a comment with self-irony and generated general laughter and joy. We heard complaints about late drivers, unresponsive authorities, abusive husbands, harassing loan sharks. We witnessed anguish with the child's condition, the limitations imposed by his/her disability, the struggle of glimpsing into his/her future. We also saw plans being imagined together for a birthday party, a baby shower or a Christmas party there at the clinic. The therapy environment was used in many ways.

And among the more outgoing mothers or those who had been attending the service for a longer time, there was an active approach to the therapy. The mother could, for example, count aloud the number of repetitions of the exercise or monitor the time devoted to each step of the routine, with the clear intention of making the session more focused, dynamic and efficient. Another one could correct a colleague, cheer up a gloomy one, think of strategies to bring back whoever was missing and risking losing the slot. Rarely, though, a mother would openly question the therapist. This might happen in a humorous way. But, in general, it was outside the room or already inside transportation that we were told about any problems with that session. Even free conversation could be criticized, if it distracted the therapist, slowing down the pace of the exercises, consuming the short duration of therapy.

In addition to the exercises and rehabilitative techniques, we learned from these women that good therapy was followed by affection. The therapist should address the child by the name, ask about his/her day and week, imitate, in a kind of a ventriloquism, what they supposed the child might be wanting, thinking, or talking about. Above all, kissing, hugging and scenting the child, with close physical proximity, were all attitudes highly valued by family members. Whatever was going on at the moment was used to address the child. Researchers who experienced rehabilitation during Carnival in Recife, for example, reinforced this point:

It is up to this professional to use elements of everyday life as therapeutic resources, to reframe stories and experiences in the rehabilitation process. (...) The availability of families to participate in the activity and bring their children in costumes, as is valued by the people of Pernambuco, made possible the belonging and engagement of children in real life. This, for us, reinforced one of the competences of the occupational therapist, which is to promote the social and cultural insertion of their patients and family (Silva, Y. et al., 2019: 449-451).

All this could demonstrate that the therapist was not lazy, impatient, fussy, or repulsive of that child, but that she considered him/her as a whole person, with a story and a personality, with specific limitations and capabilities. Mothers valued a personalized treatment that respected the “way of being” and the “time” of the child.

Supply and demand for rehabilitation services – at the end of the Zika Virus epidemic (2019)

In our fourth and last year of in-person research (2019), we noticed two new phenomena: the closing of vacancies in the clinics and the lack of interest by the families. The general retraction in vacancies was noticed and criticized by caretakers (Fleischer and Carneiro, 2018). To be included, some services required the child to have advanced skills. These clinics considered that physical disability was easier to be treated than intellectual disability, which was the case of children with microcephaly. Some professionals claimed that children recently born with disabilities, not just with the CZVS, also needed to be tended to. Thus, each clinic created its own priority: residents of a specific municipality; children born in a certain hospital; justifications for absences delivered only on paper; unavailability of graduate students to take on internships and residencies in university outpatient clinics; reports proving the direct relationship between ZIKV and CZVS etc. Or, simply, clinics started giving out what they called “therapeutic discharge” which, in our view, was nothing more than a euphemistic expedient for closing specific vacancies to the CZVS. It seems that the syndrome lost its centrality in the rehabilitation care network, in stark contrast to the first years of the Zika epidemic (Matos et al., 2019). The only novelty was the opening of some therapy slots in NGOs. Offering this service was now a strategy to have mothers come to activities and help amplify the work of these organizations.

We also noticed, from 2019 onwards, a lack of interest on the part of caregivers to attend therapies. Stimulation therapies during the day; medicine to fall asleep at night. Urban circulation stressed out the children; at home, they found a little quiet and intimacy. Mothers perceived this oscillation and, at times, prioritized the rest of the whole family. So, they would not attend the morning sessions of rehabilitation even if the absence would risk losing the vacancy. Everyone commented on tiresome, on managing so many aspects to offer therapy to the children (Lustosa, 2020). They resented having to sacrifice the whole family on behalf of only one of its members.

It was mainly in rehabilitation clinics and NGOs that mothers also had access to diapers, medicines and powdered milk. With the decrease of the epidemic, donations also disappeared, and these spaces lost their attractiveness. Mothers had to look for other sources of income, many women returned to the paid labor market, occupying the time they previously dedicated to therapy.

After so many years, many husbands were still not used to the intense schedule outside the home and continued to accuse their wives of adultery, vagrancy, leisure. But husbands were not willing to replace their wives in therapy either. We remember very few fathers at rehab clinics. Many men were unable to accompany their sons and daughters in therapy because they were at work or, at least, looking for ways to earn some income. Besides, they were not interested in the routine of waking up so early, moving around the city and attending sessions, but, at the same time, they demanded the re-domestication of these women. At the time of birth, many fathers had left the CZVS scene. If they had stayed, some of them directed distrust, accusations and domestic violence to their partners. And, in recent years, we learned of many divorces and remarriages. Women had to face violence and separation from previous spouses, and also, when in a new union, had to consider the care of another baby that eventually arrived. Caretaking was a lonely load to carry.

We also realized that, in addition to the situations experienced within the family and around the city, these mothers had been criticizing not only the quantity, but the quality of rehab services: that sessions were too short or quick, that professionals were not caring or that there was a dizzying turnover in the staff. Some interlocutors

noticed that the children's gain in mobility, dexterity and autonomy were minimal in some treatments. Focusing eyes, controlling drool, keeping the head up, raising hands, swallowing food, interacting with others illustrate some of the goals set for these children. When achieved, it made sense to continue assiduously in therapy. When not, discouragement could take place, motivate absences and even withdrawal. When the child, for some reason, did not learn or did unlearn something that had already been extensively worked on, mothers suffered and became fragile. But none of this devalued stimulation as a therapeutic practice. Some women began to demand more from therapists, report to the hospital director or ombudsman, and denounce problems to the media. Others chose to dedicate themselves to repeating exercises at home. Many cherished autonomy and expertise not only to do what Mattingly et al. (2011) called "homework" (the therapeutic tasks that were taught by health professionals and replicated by caregivers at home), but also to analyze which procedures produced more or less results in terms of child development. Little by little, they stopped demanding a huge range of therapies to select a smaller set that they thought was more appropriate and efficient.

One of our interlocutors felt that therapy was aimed more at mothers than at children, as it was in this space that they were convinced of the importance of rehabilitation technology and learned how to stimulate their children. For these mothers, stimulation took a secondary role, and the meetings became a pedagogical and emotional moment for them. At home, stimulation could be performed calmly, with more time and attention, directed from mother to child. According to Maria Claudia, for example, "At the clinic, it is just the beginning, but at home we have to reinforce it, we have to continue, we can't expect everything from the therapist". Similar opinions were heard from health professionals who also saw time in the clinic as insufficient and valued the stimulation performed by mothers at home. Therefore, there was a common understanding that attending therapy was important, but, once the technique was learned, independence at home was encouraged.

In fact, many studies show that replication of therapy at home is a central part of the concept of "early stimulation". Borba and colleagues represent this idea, "the family is the main source of support for child development, and this takes place through stimulation and participatory activities" (2019: 541). In a study at São Lourenço da Mata, also located in the MRA, "with regard to stimulation and games, all caregivers reported performing them in their daily routine, recognizing their importance in the child's development" (Duarte et al., 2019: 253). These interviewees even "cited the role of the physiotherapist in this process, because, in addition to this stimulation being carried out at the clinics, the professionals guided and taught games for the caregivers to perform in their homes" (*ibid*). In Maceió, in the State of Alagoas, the same was found, since "88% of mothers follow the instructions of the physiotherapist to be done at home" (Barbosa et al., 2017: 194). More than anything, therapeutic success was directly linked to the performance of the families: "It is noteworthy that the possible evolution in treatment happens when the family engages in the process, as they spend more time with the child at home than in therapies, which have very restricted time" (Silva, Y. et al., 2019: 451). Anthropologist Cheryl Mattingly suggests that the moralization of motherhood also involves "homework", the rehabilitation that is carried out and continued at home. Women were observed not only on the official mats:

A good mother, according to the moral norms governing appropriate clinic behavior, is certainly not one who sits on the sidelines. The structure of rehabilitation depends upon the delivery of massive amounts of "chronic homework" to patients and family caregivers who are expected to carry out home programs under the guidance of health experts (Mattingly, Grøn, and Meinert, 2011). When clients (including family members) do not do their parts, they are labeled noncompliant (2014: 71).

After all, "since parents and children are given a great deal of the responsibility for making clinical progress, all parties are potentially culpable. Lack of progress encourages suspicion" (Mattingly, 2010: 94-95). If families were critical of the rehabilitation professionals, these, on the same grounds, evaluated the therapeutic replication family members carried out at home. Suspicion was mutual.

Supply and demand for rehabilitation services – at the start of the Covid-19 pandemic (2020)

With the arrival of the Covid-19 pandemic in early 2020, the CZVS's capacity to mobilize public solidarity was notoriously diminished (Williamson, 2020). The staff became insufficient to meet the demands of people with disabilities, since, according to our interlocutors, many professionals were dismissed from their positions or relocated to help the growing number of people infected by Covid-19. Therapies were still vital services for these children, but were not considered essential by the Brazilian State, thus, discontinuing the rehabilitation process for many boys and girls. Routine medical follow-up appointments, as well as the renovation of prescriptions for controlled pharmaceuticals were interrupted by mobility restrictions imposed by the pandemic and little was said about the impact of the interruption of necessary services for people with disabilities during this period (Maboloc, 2020). Many mothers started to demand the inclusion of their children as a risk group, since these children have respiratory comorbidities and needed priority care. These women began to see their children lose what had been learned, restarting frequent spasmodic crises, as in the beginning of the Zika virus epidemic, back in 2015 and 2016. They also saw a shortage of medicines and donations, so generous and frequent in the first years of the previous epidemic.

CZVS children who were entering school also had to interrupt their activities. And their mothers, who had just recently started finding some time to dedicate themselves to other activities (such as their other children, study and work), had to postpone their plans to offer stimulation to their children at home and often without the help of a health professional. Some women told us that therapeutic telecare was infrequent, occurring at most twice a month, and that the physical distancing imposed by Covid-19 between patient and therapist hindered any effect on the child's development. Some institutions, to mitigate the effects of the lack of services, offered "stimulation kits", with toys and equipment to facilitate activities to be carried out by the family at home. Although these women had, over the years, gained autonomy to choose and learn some maneuvers and exercises, not all of them could be performed without the help of a professional or of a specific equipment. This is the case, for example, with respiratory physiotherapy. Without adequate help, again children began to have more respiratory problems and, consequently, were more exposed to bronchoaspiration, pneumonia and, above all, the new coronavirus. We heard from some women that even though they did their best to perform all the procedures at home, their children seemed to be returning to "ground zero", as other studies also indicate (Williamson, 2018). Seizures, crying, choking, irritability and loss of abilities, so common at the beginning of the diagnosis of CZVS, were reported by many of these women, now faced by Covid-19.

On the one hand, from the perspective of many mothers, doing some therapy at home saved time and effort previously dedicated to getting around the city, spending hours in buses, city vans or app cars. Some children acquired new skills in these pandemic times, such as drinking liquids from a glass and holding objects. Other mothers observed that simply playing and socializing with siblings could also have an effect on the child similar to what he or she had previously found at the clinics. Cruz et al. (2019), for example, had already noticed, in a pre-pandemic moment, that the activity that most involved fathers in caring for their children was playing and going for a walk, activities recognized by them as central to a child's development. Mothers tried to involve the extended family and the neighborhood in the child's stimulation, something that had already been recommended by therapists for a long time (Cruz et al., 2019).

Staying indoors, sleep routine could be replanned, the child could be less stressed out with traffic and moving among so many institutional environments, and he or she could be more open to learning. In addition, their mothers began to save on transportation and babysitting for the older children who needed to stay at home. They would have the chance to be with these children who had felt left out by the attention focused on their disabled sibling. Finally, not leaving the house would also meet the expectations that their husbands and sometimes their Christian churches had of a married woman.

However, if before the arrival of Covid-19 it was already clear to these women that children still needed therapy, with the general interruption of these services, its importance became even more evident. While the therapy routine did not stabilize again, they improvised. Maria Claudia had to manage on her own when Covid-19 hit. She placed the leg orthotics – which had become small due to Bela’s growth – on her arm, in an attempt to avoid the atrophy of the child’s limbs. The daughter was not only without therapy, but without consultations, exams and measurements necessary to acquire new equipment suitable for her size.

In mid-2020, some rehabilitation centers started operating again on an emergency basis, with a very reduced offering of activities and time schedules. If before the pandemic, they happened twice or three times a week, they were now offered once every fifteen days and received fewer children at a time. Not even all modalities were offered. But many mothers confessed facing a “Sofia’s choice” between one virus and the other, let’s say, between staying at home, protecting themselves from Covid-19, but facing the effects of Zika; or leaving the house, investing in the stimulation of children, but facing the effects of the coronavirus. They claimed, for example, to be afraid of crowded public transportation, risking contamination and infecting themselves, their children and bringing the new coronavirus to those who stayed home.

Before Covid-19 arrived, in that year of 2019, we noticed that, given the frustration with therapies and the difficulty of reaching them, there seemed to be a greater tendency to abandon than to plead for more vacancies or better services. But now, with the challenges presented by the new epidemic that had arrived in Recife, these women seemed to be even more involved in reflecting on rehabilitation than in criticizing it.

Final considerations: the crossing of epidemiological times

Discussing rehabilitation and CZVS is, necessarily, discussing children and their efforts, but it is also discussing mothers and how the world of female work is permeated by constraints of gender, race, generation, education and urbanity. A study showed what we have found in the MRA, when considering therapeutic exercises at home, “unanimously, they [mothers] are also the ones who perform these actions at home and not other family members” (Barbosa et al., 2017: 194). Other colleagues from the Rehabilitation Sciences have also noticed that “the limitations covered in the care process” (Souza, 2017: 29) are many and of various orders. But the solution these authors found to carry out the ideal stimulation is tricky: they are not pressuring for more public policies but are assuming that this work is naturally complemented at home (*ibid*). They seemed to expect mothers to simply do the work the State should be doing. As Mattingly sums it up well, “homework is the need to provide care or to carry out health programs at home” (2010: 26). This solution, in 2020, is more than misleading, it becomes morally perplexing in the face of the Covid-19 pandemic, especially because the reference to rehabilitation, taught and corrected by health professionals, were not available, as before, when weekly visits took place in clinics and hospitals. Mothers had to count on general guidelines, such as audio or video messages eventually sent by their children’s therapists, with the memory they kept from the past sessions, with eventual help from other mothers. But the children, in the meantime, grew up, presented new developmental challenges, outdated the knowledge accumulated until then.

Maria Claudia went further and, by the end of 2019, had already clearly realized that not only were the vacancies diminishing, but they had already been initially designed to have an expiration date, long before the new pandemic. In the closing of vacancies, she noticed what was behind the great campaign for “early stimulation” designed at the beginning of the ZIKV epidemic. It had been a therapeutic proposal directed only at the child’s first three years of life. And she proposed, critical and ironic at the same time, “How is my daughter after the third year? No stimulation? So, we just remove the word ‘early’ and leave only ‘stimulation’.

No problem”. It was a criticism directed at the “brain window” protocol, at the discourse that the biomedical State had decided to adopt for the CZVS. Now, in 2020, she could add another question, “How should my daughter be after a new epidemic?”.

It is not fortuitous, therefore, that we started this article describing the rehabilitation services and now we end it bringing tensions from two distinct but intertwined phenomena: the redomestication and re-internalization of these women as well as children and their disabilities. But there are different tensions in 2019 and 2020. First, there will not be a decentralization of rehabilitation services, as some scholars in the area had optimistically expected (Souza, 2017: 30) because, in fact, there is no investment in the creation of new services in the smaller cities, for example, but just a closure of those in the capital area of Recife, where services are concentrated in the state of Pernambuco. This picture insinuated itself in 2019 and seems to have intensified in 2020. We do not see the expansion of services for the CZVS, but a simple and perverse minimization of the welfare state. Thus, including and valuing home rehabilitation is also a way of circumventing or compensating for the progressive closing of places for these micro children in clinics and outpatient clinics.

Second, as exhausting as their street routines were, these women were gaining a public world beyond their neighborhoods, with several positive consequences. Giving up on these therapy vacancies would contribute to a convenient neo-domestication in the sense that staying at home might mean succumbing to the complex set of forces these women had initially faced so intensely on behalf of their children, such as transportation, bureaucracy, justice system, husbands, the Church, and the State. And, in addition to women, staying at home would contribute to a reprivatization and subsequent invisibility of the disability of children with the CZVS, as tends to be the most common scenario pointed out by the comparative literature from the Disability Studies (Grinker, 2010).

One research shows the failure of medical professionals to communicate details and referrals of the diagnosis of CZVS (Oliveira et al., 2019) and, in the same sense, our study shows that many doubts were solved by rehabilitation therapists, characters that families encountered daily. We agree: “The health professionals most cited as support in the care [of these] children were physical therapists and speech therapists” (Duarte et al., 2019: 253). Some studies indicate that accessing the rehab network was easier and faster than consulting with medical specialists, as Santos Bosaipo showed in the region of the city of São Luís, State of Maranhão (2018: 25). Accessing this network of services was essential, including having the help of professionals other than the health sector, such as the social workers, shown by Alencar and colleagues in another city in the region, Teresina in the State of Piauí (2019). This professional was even part of the “interdisciplinary team” of a rehabilitation program. Proximity, intimacy and trust were important to create bonds with these professionals in a much more stable and continuous way than with medical doctors. Doubts, clarifications and insights were widely shared during the therapies, as the therapists were more available than their medical colleagues or state bureaucrats.

It was during urban circulation and while waiting or undertaking therapies that many mothers heard about free passes, BPC, the judicialization of the Keppra medicine, the housing quotas, etc. An intense and daily circulation of information took place. In addition, many items were sold and bought (cosmetics, clothes, crafts, homemade orthotics, etc.), pleasant and relaxed conversations took place while waiting for the session to start or having a snack in the vicinity of the clinic, sympathies and friendships were deepened. Attending the same therapeutic service every week and for so many years meant meeting and getting to know the same group of women and children. This atmosphere was fundamental for mutual support and political organization. Two main organizations that support this micro community, according to their founding narratives, started in the waiting rooms of rehab clinics (Scott et al., 2017).

Going to therapy, on a day when the child does not seem to indicate any improvement, can be important to find a shoulder and a heart in other mothers, in therapists or sometimes in people who come along the way, a neighbor, a taxi driver, the canteen lady who sold coffee. A word, a closer look, or even a piece of cake made by a therapy partner can infuse some affection and clear a stunned mind. We noticed how many of these women, until the birth of their children, were not very used to circulating outside their neighborhoods. As much as they talked about being tired of the weekly routine of transportation and clinics, going to other institutions and neighborhoods and meeting with so many different people could also mean expanding their own world. It could be a way of learning, walking, networking, and airing out. A mother told us, “Now I understand my rights, now I know how to speak, I leave the house, I go here and there, I even stayed at a hotel for the first time, thanks to a raffle I won at a clinic. I never imagined I would stay in a hotel as a guest”.

It was also in the rehabilitation services, as well as in medical offices and outpatient clinics, that research on ZIKV and CZVS took place. The researchers went there, with their consent forms and their coolers to collect material. And it was there that journalists found sources to witness and record the epidemic. Interviews, books, photographs, and documentaries were produced in rehab rooms, State offices and waiting spaces of hospitals around the city. These research subjects and media sources, on the other hand, were offered food baskets, spa and massage coupons, gifts, trips and leisure. Thus, these women found in these spaces much more than therapeutic sessions, but learning opportunities, sociability, science and politicization.

“Early stimulation” was the main technology aimed at micro children, but, as one interlocutor reminded us, “mothers also need to be stimulated”¹². This technology, therefore, surpassed its initial goals, from the child to the whole family, from one syndrome to a whole lot of citizenship. Spending so much time on clinic mats, they experienced this intense literacy about the child’s condition, about the rights of a person with a disability. During this interaction, the therapists had a chance to know that child more closely, notice his or her progress and communicate all this to the mothers. These were ingredients to instill some hope, to build some future for the child, for that family. Hope was one of the great incentives that made these women return day after day to the mats and to the pools (Fleischer, 2020a).

Therefore, therapies aided these women to situate themselves in the ZIKV epidemic, to make sense of a motherhood in the scenario of disability, to discern the types of professionals and colleagues around them. During the Covid-19 pandemic, this sociability lost its face-to-face character and moved, with adaptations and limitations, to the virtual space of text and audio messages, *emojis* and videos, phone calls, lives and online events. Many mothers already had the therapists’ WhatsApp contact and communicated with them whenever they deemed necessary. The relationship was also prolonged remotely, with exchanges of photographs, when doubts, compliments and advances were noticed by the mothers and sent to the therapists. Certainly, these health professionals were very useful during the social isolation of 2020, but they had to divide their time among all the families who wrote or called them. Attention became more fragmented, synthetic and infrequent.

We realized that many of the services that, as early as 2019, were closing their doors to micro children had the understanding that they had fulfilled the goal of offering therapy during the first three years of their lives, as advocated by the policy of “early stimulation”. They argued that they had to treat other children who had been born more recently, with other syndromes even. Talking to a team of physical therapists back then, we asked them how they imagined the micro children would be in a few years. One of the professionals explained that it would all depend on the stimulation carried out at home and on the network of services that that family could guarantee around the city. At no point did she mention the State’s role in organizing this network. For her, the family should be held responsible for the child’s development alone, by reproducing on the rug at home what had been learned on the official mat, or by continuing to pressure for the creation of new vacancies.

¹² What kind of “stimulus” do mothers want or need? What does the idea of “stimulus” consist of, more broadly in the context of the CZVS, anyway? As well suggested by a reviewer of this article, the point deserves further elaboration and remains as a suggestion for future studies.

As the central argument of this article, in the relationship among maternity, care, clinic and the State, the common understanding was that the main role should be played out by the families. These mothers would have to seek the opportunities offered to people with disabilities in general. They were losing more and more the priority that the adjective “micro” had managed to mobilize in the beginning (Matos et al., 2019). If “early stimulation” was configured as the main therapeutic solution for these children and, therefore, marked the beginning of the Zika epidemic so intensely, interestingly, now that the two epidemics met and intensified each other, the withdrawal of the “early stimulation” illustrates the most generalized withdrawal of public policies for this micro community.

In this article, we try to move forward from our last discussion on therapies, when the beginning of the shrinkage of slots enunciated itself (Fleischer and Carneiro, 2018). The closing of rehabilitation continued, with new arguments, new justifications. 2019 was an unplanned harbinger for 2020 because the pandemic has only intensified that pullback, causing some doors and spaces to close temporarily and then definitively. Here, we present some of the aspects, over the years, of opening, maintaining and withdrawing therapeutic efforts for children with CZVS. These aspects do not run loose, but are articulated, creating new difficulties at each fold. The decisions taken by mothers are directly influenced by urbanity, biomedicine, State infrastructure, in addition to gender relations, kinship, parenting and conjugality. This maternity is and continues to be taking place within a very difficult sociocultural, economic, political and epidemiological context.

Finally, we are seized by two consternations. On the one hand, we think about the consequences of the long-term deceleration of therapies on children’s development (Gaverio and Lourenção, 2020). Will the destigmatization of disability within the family and the presence of these children back at school eventually help offer inclusion and stimulation? On the other hand, will these women lose a space for coexistence, learning and citizenship that perhaps they had not yet experienced in their life trajectories? We fear the increase in loneliness, overload and its consequences on the self-esteem, self-confidence and mental health of mothers and other caregivers. The two consternations also have broader implications, since the presence of mothers and children with microcephaly in the public space is a way of maintaining disability politicized and directly questioning the State and its representatives. And the arrival of a new virus, by limiting the construction of this public space, only reinforces the immense and varied values this space holds for these mothers, their children, their families and communities.

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