

Interface - Comunicação, Saúde, Educação

ISSN: 1414-3283 ISSN: 1807-5762

UNESP

Williamson, K. Eliza
Cuidado nos tempos de Zika: notas da pós-epidemia em Salvador (Bahia), Brasil
Interface - Comunicação, Saúde, Educação, vol.
22, núm. 66, Julho-Setembro, 2018, pp. 685-696
UNESP

DOI: 10.1590/1807-57622017.0856

Disponível em: http://www.redalyc.org/articulo.oa?id=180156829003



Número completo

Mais artigos

Home da revista no Redalyc



Sistema de Informação Científica Redalyc

Rede de Revistas Científicas da América Latina e do Caribe, Espanha e Portugal

Sem fins lucrativos acadêmica projeto, desenvolvido no âmbito da iniciativa acesso aberto

DOI: 10.1590/1807-57622017.0856

dossier

Zika virus: an epidemic in/and its social world

Care in the time of Zika: notes on the 'afterlife' of the epidemic in Salvador (Bahia), Brazil

K. Eliza Williamson^(a)

(a) Departamento de Antropologia, Rice University. Sewell Hall, P.O. Box 1892, 6100 Main St. Houston, Texas. EUA. 77005. eliza.williamson@rice.edu

This article presents a reflection on the "afterlife" of the Zika virus epidemic, drawing on the narratives of mothers of children born with neurological malformations associated with the virus in Bahia. Based on eleven semi-structured interviews with mothers and fathers whose children are attended in a state rehabilitation center, and in dialogue with contemporary theorizations of time and disability in cultural anthropology, it proposes an approach to the temporality of Zika and its effects. Three narratives are highlighted, showing how their children's unpredictable condition, together with the precarities they already experience, make the future almost impossible to imagine. In the face of so much uncertainty, mothers create alternative forms of thinking about, interacting with, and appreciating the child in her or his own terms. This article suggests that hope may include, paradoxically, "expecting nothing".

Keywords: Zika. Time. Deficiency. Maternity. Anthropology.

Introduction

The declaration of the "end" of the public health emergency, nationally and internationally, appears to have put a period on the story of the Zika virus epidemic. But appearances can be deceiving. Although Brazil has seen a significant decrease in the number of new cases, children are still being born with with Congenital Syndrome Associated with Zika Virus Infection (*Síndrome Congênita Associada à Infecção pelo Zika Vírus*, or SCAIZV). Zika's reproductive consequences guarantee that its story will continue for long years to come. The *Aedes aegypti* mosquito still plagues the country, particularly the lower economic strata; new infections and new cases of SCAIZV continue to appear; and many of the mysteries of the virus still have not been untangled. The women who gave birth to children with SCAIZV now find themselves in a





long-term struggle to care for children with multiple disabilities¹. According to the latest data reported to the Pan-American Health Organization, Brazil had registered almost three thousand confirmed cases of SCAIZV.² The state of Bahia had 1,682 suspected cases as of the last Epidemiological Bulletin from the Bahia State Secretary of Health³. The affected children, still in early childhood, are now living with multiple disabilities resulting from congenital Zika virus infection. Besides microcephaly - the most visible manifestation of the syndrome - they may have, among others: brain calcifications, epilepsy, auditory and visual impairments, delays in psychomotor development, dysphagia, hypertonia, ventriculomegaly and hydrocephaly. Although no one can say exactly how they will develop, many of these children will likely need specialized care for the rest of their lives.

This article is a reflection on the "afterlife" of Zika, focusing on narratives of Bahian women who are mothers of children with SCAIZV. I dwell specifically on the ways in which they perceive and experience time, showing how their children's unpredictable condition, together with the precarity that already characterizes these women's lives, make the future almost impossible to imagine. I highlight that, in the face of so much uncertainty, they formulate alternative ways to think about, interact with, and appreciate the child on her or his own terms. They learn to live "one day at a time" and to embrace what comes—and let go of what might not come. Through their narratives, I also show some temporal aspects of "resignification", suggesting that hope may involve a conscious effort to "expect nothing". Rather than generalize the experiences of these women, I aim to point out some possible ways to think about the temporalities of Zika via the experiences of those with the most intimate understanding of its afterlife.

Methodology

Here I present partial narratives of three mothers I have interviewed since May of 2017, as part of a series of semi-structured interviews I have conducted with mothers and fathers of children with SCAIZV in Bahia. Their children were or are patients in early intervention therapy (*estimulação precoce*) at the State Center for the Prevention and Rehabilitation of People with Disabilities (*Centro Estadual de Prevenção e Reabilitação da Pessoa com Deficiência*, or Cepred), in Salvador-BA. Considered a center of excellence, Cepred is 100% public (SUS) and attends people from all over the state of Bahia. After the Zika outbreak, Cepred became one of the primary centers of evaluation and early intervention for children with SCAIZV, as well as a provider of orthotics and other equipment for those who need it. Cepred opened their doors to my research project and provided me with an unused consultation room to conduct several of the interviews. No Cepred staff, however, participated in participant recruitment, or in data collection and analysis.

All of the children of the mothers and fathers interviewed are or were receiving care at Cepred, whether evaluation or early intervention therapies. The interview questions addressed

experiences of pregnancy, the diagnosis of neurological malformation, birth and the months after birth until the time of the interview. These conversations were transcribed in full, the themes that emerged were categorized and the narratives analyzed using a Grounded Theory approach⁴.

This research project was approved by the Research Ethics Committee (CEP) of the Collective Health Institute (ISC) of the Federal University of Bahia (UFBA) (CAAE 60894816.0.0000.5030), as well as the Rice University Internal Review Board (No. 702001-2) and the Cepred Research Ethics Nucleus (NEP) (Decision issued 20/09/16).

Disability, motherhood and time in anthropology

Although still under-theorized in anthropology, disability offers us the opportunity to think difference and the diverse forms in which difference is approached in historical and contemporary societies. People with disabilities are embodied subjects who perceive the world in other ways, who acutely experience stigmas and social inequities, who in being cared for and caring for themselves point to other possibilities of relating to oneself and to others^{5, 6}. The humanities and social sciences offer us ways to think disability as not merely a social construction defined in contrast to a supposed "normal", but as embodied difference that nevertheless demands equal rights^{5, 7-9}. Disability also highlights relations of dependence and care that complicate liberal notions of individuality and invite us to reconsider the various ways in which we all depend and care.

Many anthropologists have highlighted how reproductive technologies modify experiences of pregnancy, the ways of thinking about the fetus and the decisions made in the face of the alterations detected. 10-12 Several scholars show how the specter of disability haunts future imaginaries for the child, the family and even the nation 13-14. The few who focus on the intersection of motherhood and child disability underscore a rich diversity of experiences that emerge from daily care of children with disabilities. Rayna Rapp and Faye Ginsburg show how, confronted with the challenge of raising children with Down syndrome, mothers reconfigure the terms of kinship and become activists for disability rights 5, 15-16. Gail Landsman highlights, among other themes, the social construction of the "perfect baby" and its pitfalls as well as the diverse ways of knowing among mothers and health professionals 17. These and various other social scientists point out that those who shoulder the burden of care for people with disabilities—both children and adults—are, in the majority, women 18-21.

In her ethnography of black mothers and grandmothers caring for children with disabilities and chronic illnesses in the United States, Cheryl Mattingly suggests that hope is a practice that

⁽b) Data collection for this project was funded by the U.S. Department of State (Fulbright-Hays P022A150055-002) and Rice University (graduate stipend). Earlier stages of my wider dissertation research on maternal and infant health policy were funded by the Wenner-Gren Foundation, the Brazilian Studies Association, and small grants from Rice University.

must be maintained in the face of the uncertain future of affected children^{22, 23}. She also shows how these women come to see their children, and themselves, in new ways as they cultivate care. Being a caregiver of a child with "special" needs—particularly when one belongs to an historically marginalized population - is, among other things, a temporal experience. Between long and anxious waits in hospitals and clinicals, in the reconstruction of experiences through narratives and in the struggle to maintain hope despite grim prognoses, time becomes other.

Time, like the diverse concepts of disability, is a cultural, social and historical artifact²⁴. Living in time is a fundamental aspect of human experience, albeit banalized. Cultural anthropologists have increasingly examined the ways in which people think about and experience time in different places in the world, particularly in the current moment heavily marked by the rhythms of capitalism and neoliberalism²⁵. In times of crisis and precarity, they show, the future becomes difficult to envision,²⁶ life is marked by comings and goings to and from the formal labor market²⁷ and people experiment with forms of caring for one another²⁸⁻³⁰. In these precarious times, disability brings novel instabilities and reorientations to the future.

"Crip time" and care time

In an essay on her own experience of disability, Ellen Samuels writes that "crip time is time travel" (c). She continues:

Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings. [...] [W]e who occupy the bodies of crip time know that we are never linear...³¹ [2017: 5th paragraph]

Bodies that demand specialized care and follow different rhythms do not conform to an idealized progressive march of time. In this way, crip time also complicates the idea of linear progress embedded in clinical rehabilitation and in child development¹⁹. Zoë Wool describes lived time in spaces of rehabilitation as a "Möbius strip" (p. 26), where the body remains in a kind of temporal loop in which treatment itself can delay or complicate the process of cure³². Here, "[t]he simple *telos* of a healing body [gives] way to the material facts of precarious bodies" (p. 26)³². This

@interface comunicação, saúde e educação

⁽c) The neologism "crip", in English, is an abbreviation of the word "cripple", which is a pejorative way to refer to a person with disabilities. Activists and scholars working at the intersections of disability, feminist, and queer studies have reappropriated the term, transforming it into an identity and a robust area of social theory.

circular and constantly interrupted time is characteristic of what Wool and Livingston call "collateral afterworlds" - "sites of disaffection and stasis in the shadow of large-scale political and economic forces" (p. 3) that are "marked especially by the temporality of a difficult present where life is unhinged from the pervasive hope for a better tomorrow" (p. 2)³³.

Time, for people with disabilities and chronic illnesses, is also governed by schedules for appointments, medical exams and medications. Santos et al. show, for example, how people with renal failure come to live their lives around hemodialysis sessions, which in themselves can last hours, multiple times a week, taking away precious time while simultaneously prolonging life³⁴. In these sessions, time passes slowly, generating anxiety, agitation and resignation (pp. 135-136). The present often becomes almost unbearable. On the other hand, "renals" cultivate an appreciation of the present, since due to their condition, they do not know how much longer they will have.

The "difficult present", however, is felt not only by people with disabilities, but also by those who care for them. In a way, for Barbosa et al., "although only one member of the family is disabled [deficiente], all the rest are affected and, up to a certain point, incapacitated by it [the disability]" (p. 47; my translation)³⁵. But no one experiences this indirect "incapacitation" more than women, and more specifically mothers, who bear the great majority of caregiving labors^{5, 17, 20-} ²³. In a certain sense, in their close, often near-constant contact with the child, mothers also experience crip time. They see how the "progress" of their children goes in circles, repeats itself, even seems to stop. Their daily lives are rearranged to accommodate their children's full clinical and pharmaceutical schedules. This non-linear, "Möbius strip" time, encourages mothers to adopt a different orientation to a future that is difficult to envision. As one mother of a child with mental disabilities said, in Bastos and Deslandes' study: "Ah! Look, I (...) I'm not thinking about his future" (p. 2146)¹⁸.

For caregivers too, time becomes other. Cheryl Mattingly writes that for people "in the crisis of life", such as mothers of children with disabilities and potentially fatal illnesses, "time has changed its speed; it has become concentrated, portentous. It may be too fast or too slow, but it is never luxurious" (p. 2).²² Caregivers also live their lives between eternal waits and sudden crises, between hope and lack of it. "Hope lives in an uncertain place," says Mattingly, "in a kind of temporal lobby. It points us toward a future we can only imagine" (p. 15)²². Hope, although present, is suspended, waiting for the future to unfold.

We will see in the mothers' stories below that time is experienced as a matter of profound uncertainty. It is a precarious time in which one does not know what to expect, or even if to expect or hope. It is also a paradoxical time that seems to pass simultaneously too quickly and too slowly, a present full of "starts and stops", of loops that interrupt and complicate a supposed linear developmental progression, a "difficult present" that obscures the future.

Precarious bodies, precarious lives

Caring for a child with SCAIZV means a lot of running around (*correria*). Mothers traverse the city, "up and down" (*pra cima e pra baixo*), "going after" (*correndo atrás*) clinical appointments, diagnostic exams and medications for their children. The rhythm of life is, in this sense, frenetic. From birth until three years of age, the Brazilian Ministry of Health recommends that children born with disabilities be placed in early intervention programs (*estimulação precoce* in Portuguese), "seeking the best possible development" (p. 5; my translation)³⁶. The first three years of life make up "the phase in which the brain develops the fastest, constituting a window of opportunities for the establishment of the functions that will lead to good health and optimal productivity in the future" (pp. 9-10; my translation)³⁶. For many of the children with SCAIZV in Salvador, there is less than a year left until this limit. In this sense, the mothers and their children are racing against time, trying to get the maximum benefit from therapies before the child's third birthday.

Despite their attempts to guarantee linear progress, however, it is not only a matter of will. The bodies of their children rebel, fall ill, have seizures, do not conform to the therapeutic plans drawn out. Other aspects of everyday life also interrupt linear progress, bringing with them things unexpected (*imprevistos*) and setbacks (*contratempos*) that trouble rehabilitation. Some *imprevistos* are positive, such as when a child gives a coveted smile or is able to lift and keep her head up by herself. Many others, however, generate crises that destabilize the child's development and the mother's life.

Míriam, a 33-year-old black woman^(d) who raises her son, Bruno, by herself in a working class neighborhood in Salvador, told me: "Everything is very uncertain. You never have a guarantee that he's going to be ok the whole week, without presenting something new. There's no such thing. There is always something new, good or bad. [...] Everything comes up very, for the parents, very suddenly". She continued:

The children, I think, it's still very unknown [incógnita]. We don't know... [...] I don't know if it's because for us everything is new, or if it's because of this condition of theirs that everything is very new, something is always coming up [toda hora aparece uma coisa]... He's fine, he's not convulsing, in a little while he starts convulsing. He's not taking medication, [then] in a little while he starts taking it, and in a little

⁽d) When I refer to my interlocutors' race here, I do so on the basis of their own self-declaration. This is standard practice in census-taking in Brazil, where skin color classification is notoriously complex. To my question, "How do you identify in terms of race/color?" (*Como você se identifica em termos de raça/cor?*) Both Míriam and Amanda said they identified as black (*negra*). Jéssica said she identified as brown/mixed (*parda*).

while he does that, the boy is ok, then in a little while [you] put in a gastro [feeding tube], you put in a tráqueio [breathing tube]. It's insanity, insanity!

Although her son does not have microcephaly, the results of the ultrasounds and, later, the CT scan, showed that he had numerous brain calcifications as well as ventriculomegaly (dilation of the lateral brain ventricles). He was born premature with an open arterial canal, which was corrected later via surgery. Some five months after he was born, Bruno had his first seizures. The anti-seizure medication (phenobarbital) he started taking worked, perhaps even too well: he stopped not only having seizures, but, according to Míriam: "he stopped completely. Everything he did, held his head up, he looked, he fixed [his gaze], he laughed - everything that he had been doing he stopped doing." Míriam is certain that this "reversal" in Bruno's development was due to the medication, because "it was very instantaneous, like, he just stopped doing everything. He stopped crying too. Stopped everything, stopped everything." The solution to one problem ended up causing others, making Bruno go around in circles, or even stop, in time.

In a parallel way, as Bruno's principal and only caregiver, Míriam's life also goes in circles. A few weeks before our interview, Míriam had left the job she took after Bruno's first birthday. In order to return to work in commercial sales, where she was before being obligated to leave during pregnancy due to a threat of a premature delivery, she had put Bruno in a municipal daycare center close to home. However, during the few months her son was in daycare, he had to be hospitalized twice for pneumonia. Míriam suspected that it was because of the daycare workers' lack of knowledge of how to feed a child with dysphagia (difficulty swallowing). Sometimes she would find food inside the little one's nose when she picked him up, which made her think that he had choked while eating. Food trapped in his nasal passages could have led to the respiratory infection. Once again, a solution caused other problems. She removed Bruno from daycare and left her job, to depend solely on her son's government benefit(e). Bruno's time is, as Samuels describes, 31 a time of stops and (re)starts, a precarious time, even almost circular. It is not linear, a series of successive steps, but rather a series of "spasmodic stops and starts", a "Möbius strip" time^{31,32}. New things are always appearing without forewarning. Very much because of the imprevistos that come up in relation to her son, Míriam also lives in precarious time. She tried but failed to reinsert herself into the labor market - something that, for many working-class mothers, would be the normative progression. She stayed with Bruno during his hospitalizations and returned to

(e) The Continuing Cash Benefit (Benefício de Prestação Continuada, or BPC), established by Brazilian Law 8.742/1993, is a form of social assistance provided by the country's National Social Security Institute (Instituto Nacional do Seguro Social, or INSS), in the form of a monthly cash transfer of one minimum montly wage (salário mínimo), to the elderly and people with disabilities who are not able to sustain themselves financially otherwise. In the case of families affected by the Zika virus, the

principal caregiver of the minor (most commonly the mother) receives this benefit.

dedicating herself exclusively to his care. She doesn't know when she will be able to work again, the way things are going.

If the arrival of a child with multiple disabilities was a destablizing factor in these women's lives, it was just one more in a life already replete with uncertainties. In their narratives there emerged a sensation of living in an eternal present, dealing with what came up, trying not to think much about what was to come, even though they spent much of their time caring for the future. The mothers' worries, however, reveal a series of precarities already present in their lives, even before the birth of the child with SCAIZV.

Caring for shadow futures

Despite their attempts to banish it, the future haunted the mothers' thoughts, surfacing in fragile moments. Two of them, when I asked what they thought their children's futures might be like, spoke of the possibility of their own deaths and the unmet need this would leave for the children. They spoke of "not having time" to help their children become self-sufficient, and of not having anyone with whom to leave their children in their absence.

One of these women was Amanda, a 35-year-old black woman, resident of a working-class neighborhood in Salvador's metropolitan area. She lives with her partner (*marido*)^(f) and the couple's daughter, Melissa, who was a year and seven months old at the time of our interview. When I asked Amanda about the future, she said:

I say, if Melissa doesn't walk, then I want her to become independent, I want her to be able to call me, to be able to go to the refrigerator and get a water by herself. Even if I have to adapt the house for that, I want her to be able to do everything herself, so that... [Her voice trails off and she stops.] Imagine, she only has me. She only has me, quote-unquote [entre aspas]. I'm 35. I'm not a person who's in good health. And what if I'm not there for her? What will become of her? That's my big worry.

A few days before our interview, Amanda said, the doctor she went to see for a routine checkup told her she would need surgery to remove a benign tumor from her throat. Despite the doctor's insistence, Amanda knew she couldn't go through with the operation because of the time it would cost her and Melissa: "I'm not going to do the surgery", she told the doctor, "Who's

@interface comunicação, saúde e educação

⁽f) Here I use the English term "partner" to indicate that Amanda and Melissa's father co-habitate and are in a long-term relationship, although they are not legally married. *Marido* (husband) is the term most of my interlocutors use to refer to their partners, whether legally married or not.

going to watch [ficar com] my daughter?" When she found out that the recuperation period would prohibit her from talking and carrying weight, she was even more convinced that it was impossible: "I'm not going to be able to carry weight [pegar peso]? I have to take my daughter to therapy. Who's going to converse with my daughter in this period that I'm... [recuperating]? I can't do it." Days later, the abnormal results of a routine pap smear left Amanda in tears. When she got home, her mother noticed her agitated state and asked her what was wrong. Amanda told her, "Imagine if I'm not able to get [deixar] my daughter independent in time. What will become of her?" Her biggest fear, she told me, was "not having enough time to see her bigger and independent."

Amanda worries about seeing her daughter "independent", but she fears the possibility of "not having enough time" to get there with her. She races against the clock to give Melissa the best chances of being able to care for herself in the future, able to, for example, "go to the refrigerator and get a water by herself", because she foresees the difficulty of someone caring for the girl in Amanda's absence. She must do everything possible now to prepare Melissa for an uncertain future. A surgery that could prevent bigger health problems for Amanda becomes an impossibility, given the caregiving responsibilities that she must assume not being able to count on anyone else to assume them—take her to therapy sessions, talk to her, "stay with her" (ficar com ela) in general. In this way, Amanda finds herself in a great dilemma: she cannot care for her own health because she must care for her daughter, but if her health problems worsen, they may take her life, leaving her daughter alone in the world.

Between the lines of Amanda's preoccupation is the tacit assumption that her partner, Melissa's father, would not take care of the girl. Although they had been together for fourteen years, he was, Amanda told me, "a person of phases", who "one instant is here, the next he packs his bag and leaves. [...] Who can guarantee me that he won't leave?" she asked rhetorically. She lives in a constant state of uncertainty in relation to her partner. The "person of phases" by her side is unpredictable, not allowing her to trust in his presence tomorrow, let alone long-term. Amanda spoke of this inconsistency with a certain naturalness, almost resignation. For her, such instability was a banal, expected aspect of life. Paradoxically, unpredictability is expected.

The child's health appears as a factor that destabilizes time, for both child and mother. This destabilization is a question of care: Amanda sacrifices care for her own health in order to care for Melissa. Míriam left her job and the source of income in order to dedicate herself full-time to Bruno. Caregiving, although oriented toward the future, helps to obscure this very future. In the next section, we will also see how uncertainty regarding the future engenders reorientations to the time of the present.

Resignifying the child's time

"Live one day at a time" has become a personal motto for Jéssica, one of the few middle-class women interviewed. A 35-year-old "brown" (*parda*) woman, resident of an upper-middle class neighborhood in Salvador, shares the care of her daughter, Giovanni, with her husband and a nanny. Giovanni, like Melissa, has microcephaly and various other neurological alterations. Jéssica told me about the recursive process of "resignification" that she has undertaken since the diagnosis during pregnancy:

When she was born I got a lot of instructions to resignify: 'Look, now you have to resignify what it is to have a child that is like such-and-such, create another way.' And I, like, deconstructed everything that I had constructed and surrendered. Live one day at a time, and... and that's been my motto: live one day at a time... and deconstruct everything. So like, I deconstructed everything, and each new thing that comes is a novelty, a good thing, unexpected. So I started to expect nothing. So whatever comes, receive it with... *né*, with gratefulness.

Jéssica explained that she had to "deconstruct the child that [...] I dreamed of when I got pregnant", which she "didn't imagine, nor wanted" to have "various limitations". If, before she knew about her daughter's malformations, she imagined a normative future for Giovanni - a future in which she would play with her older sister and go to preschool, for example - after the diagnosis she had to "deconstruct all of that and stop myself, and train myself [me exercitar] to not have any expectations". This is an "exercise that I'm already doing", she said, "not expecting anything in return".

There were various milestones, conventional expectations in relation to growth and development that Jéssica consciously stopped regarding as appropriate measures for her daughter, conventional expectations in relation to growth and development. In Giovanni's first pediatric neurology consultations, the doctor advised her to "forget" the typical child development monitoring chart (*mapa de acompanhamento*):

The [growth] curve, she's not even on it, *né*. Because we have the first vaccination card—the card that the Ministry of Health gives, for tracking—growth, weight, height, whatever. There isn't anything for her. So I began preparing myself... Forget that, forget it. Because it does no good to keep looking and frustrating myself, because she won't have the size—[the curve] doesn't even have the head size she had when she was born. It's not [...] on the chart.

According to the "Children's Booklet" (*Caderneta da Criança*), (g) parents should carefully monitor their children's development (p. 36)³⁷. Its pages contain a checklist of abilities that the child should acquire in more or less linear time, one step after the other, like a ladder: "Observes a face", "Reacts to sound", "Elevates head", "Social smile when stimulated" (p. 44) - these are some of the expected developments in the first months and years of life of a so-called "typical" child³⁷. Since Giovanni had no way of following this progression, documents like the Booklet and the vaccination card became artifacts of failure.

Jéssica found it upsetting to compare her daughter's development to that expected for children without neurological alterations. Seen in these terms, her daughter would always "fail", falling behind and outside of conventional curves. Rather than continuing to subject herself to the emotional torment of comparison, she and the pediatric neurologist created a curve just for Giovanni. They record the little girl's accomplishments in "real time", as they happen - moving her hand, lifting her head, a "social smile" in reaction to tickling on her neck - and not in the time that they "should" happen. This way, they create, with Giovanni, a time that is uniquely hers, learning to understand and appreciate the little girl on her own terms.

Resignification, a process common among mothers and fathers of children with disabilities, is also a resignification of the child's time. "Forgetting" child development norms and "deconstructing" previously held notions about how the child would be are ways of actively reorienting oneself to the child the way she or he came. This process involves a conscious effort not only to reformulate expectations, but, in Jéssica's case, to rid oneself of them completely. Paradoxically, perhaps, the hope that leads these mothers to keep struggling, keep "going after" what their children need, may involve "expecting nothing". Hope is not absent, but "unhinged from the pervasive hope for a better tomorrow" (p. 2)³³.

Discussion: Hope, or the practice of expecting nothing

In caring for their children with SCAIZV, mothers live in a "difficult present" ³³ that occludes future possibilities. This present is conditioned by the precarities with which many alread live—among others, ephemeral and poorly remunerated employment, unstable relationships—but it is strongly impacted by caring for children who, with their precarious bodies and their non-linear time, bring yet another layer of uncertainty. Given the difficulties and uncertainties, the mothers learn to live for the moment, attending to what must be done to care for their children's futures, without dwelling much on those futures. They consciously strive, even, to "expect nothing".

⁽g) The Caderneta da Criança is a booklet issued by the federal Ministry of Health that provides information relating to children's health. It also contains charts for tracking children's growth and development, recording medical visits, exams and vaccines.

If Amanda's worries about her own untimely death surprise us, we should remember that many of these mothers belong to sectors of the Brazilian population that have always experienced infinite uncertainties, including in relation to their very lives³⁸. Being in their majority black women³⁹, they have a lower life expectancy than do white women^{40,41}, a product of the structural racism that leads to less access to health services and higher rates of community violence including state violence40, 42-45. Being black women from the lowest-earning social classes, economic and labor precarities—which particularly after the parliamentary coup have only increased daily are never far⁴⁶. And being women, they confront the machismo^(h) embedded in Brazilian society which relegates child care and all other "domestic" tasks solely to women⁴⁷⁻⁵⁰. The two interviewees who expressed strong doubts about the possibility of their children's fathers assuming caregiving responsibilities in their absence, were (and are, as of this writing) in long-term relationships. Even so, they imagined futures in which their partners would not care for their children, or would not care appropriately. In this set of intersectional precarities, the question "Who's going to watch my daughter?" makes a lot of sense. This question is gender-, class-, and race-specific.

Paradoxically, hope is expressed precisely through expecting nothing - a facet of the "practice of hope" that Mattingly proposes²². Hope is in constant dialogue with uncertainty, molding an orientation to the future that discards any guarantee, yet still persists. So, hope is something lived not in the potentiality of the future, but in the present, in "whatever comes". In the process of resignifying the child and her or his non-linear time, child development charts and curves are thrown out in favor of constructing temporal trajectories that conform to the child, and not the other way around. The child, with the help of her parents and healthcare professionals, creates her own time.

As with other anthropogenic disasters of our time, the Zika virus casts a long shadow over the lives of those affected, whether directly or indirectly. Although the end of the epidemic has officially been declared, its aftereffects persist, requiring the permanent attention of public policies and from those of us in the social sciences who seek to advance knowledge of the "social" side of the virus. The lived temporalities in the aftermath of Zika invite us to critically engage the ways in which the epidemic carries on into the present and future.

(h) Machismo here refers broadly to the cultural valorization of hegemonic masculinity that structures patriarchal societies and whose flip-side is the active de-valuing of women and "feminine" work.

Ointerface comunicação, saúde e educação 2018; 22(66):685-96

Acknowledgments

I am indebted, first and foremost, to the women and men who have shared their stories with me, and who continue to teach me about disability and care. Additionally, I owe a great deal of gratitude to the Cepred staff, who welcomed this research project. I also want to thank Rosamaria Carneiro and Soraya Fleischer for inviting me to participate in this series, and Soraya and Lynn Morgan for reading and commenting on earlier versions of this manuscript. I would also like to thank the Wenner-Gren Foundation, the Fulbright-Hays Program, the Brazilian Studies Association, the Association for Feminist Anthropology, and Rice University for funding this project at various stages of research and writing.

References

- 1. Diniz D. Zika em Alagoas: a urgência dos direitos. Brasília: Letras Livres; 2017.
- 2. Organização Panamericana de Saúde. Organização Mundial de Saúde. Zika cumulative cases [citado 14 Dez 2017]. Disponível em: http://www.paho.org/hq/index. php?option=com content&view=article&id=12390<emid=42090&lang=en.
- 3. Secretaria Estadual de Saúde da Bahia. Boletim Epidemiológico de Microcefalia e outras alterações congênitas relacionadas à infecção pelo Zika vírus e outras etiologias infecciosas. Salvador: Secretaria Estadual de Saúde da Bahia; 2017 [citado 14 Dez 2017]. Disponível em: http://www.saude.ba.gov.br/wp-content/uploads/2017/11/BOLETIM-21- NOVEMBRO-2017 final.pdf.
- 4. Bryant A, Charmaz K. The SAGE Handbook of Grounded Theory. Thousand Oaks: SAGE Publications; 2010.
- 5. Rapp R, Ginsburg F. Disability worlds. Annu Rev Anthropol. 2013; 42(1):53-68.
- 6. Staples J, Mehrotra N. Disability studies: developments in anthropology. In: Grech S, Soldatic K, editores. Disability in the global south: the critical handbook. Nova Iorque: Springer; 2016. p. 35-49.
- 7. Diniz D. O que é deficiência. Brasília: Brasiliense; 2007.
- 8. Garland-Thompson R. Feminist disability studies. Signs. 2005; 30(2):1557-87.
- 9. Shakespeare T. The social model of disability. In: Davis L, editor. The disability studies reader. 2a ed. Nova lorque: Routledge; 1998. p. 197-204.
- 10. Morgan L. Imagining the unborn in the ecuadoran Andes. Fem Stud. 1997; 23(2):322-50.
- 11. Rapp R. Testing women, testing the fetus: the social impact of amniocentesis in America. New York: Routledge; 1999.
- 12. Georges E, Mitchell LM. Cross-cultural cyborgs: Greek and Canadian women's discourses on fetal ultrasound. Fem Stud. 1997; 23(2):373-401.
- 13. Gammeltoft TM. Haunting images: a cultural account of selective reproduction in Vietnam. Berkeley, CA: University of California Press; 2014.
- 14. Roberts EFS. God's laboratory: assisted reproduction in the Andes. Berkeley, CA: University of California Press; 2012.
- 15. Rapp R, Ginsburg F. Reverberations: disability and the new kinship imaginary. Anthropol Q. 2011; 84(2):379-410.
- 16. Rapp R. Enabling disability: rewriting kinship, reimagining citizenship. Public Cult. 2001; 13(3):533-56.
- 17. Landsman G. Reconstructing motherhood and disability in the age of "perfect" babies. New York: Routledge; 2008.

- 18. Bastos OM, Deslandes SF. A experiência de ter um filho com deficiência mental: narrativas de mães. Cad Saude Publica. 2008; 24(9):2141-50.
- 19. Fisher P, Goodley D. The linear medical model of disability: mothers of disabled babies resist with counternarratives. Sociol Health Illn. 2007; 29(1):66-81.
- 20. Read J. Disability, the family, and society: listening to mothers. Berkshire: Open University Press; 2000.
- 21. Traustadottir R. Mothers who care: gender, disability, and family life. J Fam Issues. 1991; 12(2):211-28.
- 22. Mattingly C. The paradox of hope: journeys through a clinical borderland. Berkeley, CA: University of California Press; 2010.
- 23. Mattingly C. Moral laboratories: family peril and the struggle for a good life. Berkeley, CA: University of California Press; 2014.
- 24. Munn ND. The cultural anthropology of time: a critical essay. Annu Rev Anthropol. 1992; 21:93-123.
- 25. Bear L. Time as technique. Annu Rev Anthropol. 2016; 45:487-502.
- 26. Bryant R. On critical times: return, repetition, and the uncanny present. Hist Anthropol. 2016;
- 27(1):19-31. 27. Millar K. The precarious present: wageless labor and disrupted life in Rio de Janeiro, Brazil. Cult Anthropol. 2014; 29(1):32-53.
- 28. Brodwin P. Everyday ethics: voices from the front line of community psychiatry. Berkeley, CA: University of California Press; 2013.
- 29. Davis E. Bad souls: madness and responsibility in modern Greece. Durham, NC: Duke University Press; 2012.
- 30. Han C. Life in debt: care and violence in neoliberal Chile. Berkeley, CA: University of California Press; 2012.
- 31. Samuels E. Six ways of looking at crip time. Disabil Stud Q [Internet]. 2017 [citado 20 Out 2017]; 37(3). Disponível em: http://dsq-sds.org/article/view/5824/4684
- 32. Wool ZH. After war: the weight of life at walter reed. Durham, NC: Duke University Press; 2015.
- 33. Wool ZH, Livingston J. Collateral afterworlds: an introduction. Social Text. 2017; 35(1):1-15. 34. Santos VFC, Santos ASF, Reis FP. Deficiência, gênero e tempo: renais crônicos em Sergipe. Rev Fórum Identidades. 2017; 23:127-39.
- 35. Barbosa MAM, Chaud MN, Gomes MMF. Vivências de mães com um filho deficiente: um estudo fenomenológico. Acta Paul Enferm. 2008; 21(1):46-52.
- 36. Ministério da Saúde (BR). Diretrizes de Estimulação Precoce: crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor decorrente da microcefalia. Brasília: Ministério da Saúde; 2016.
- 37. Ministério da Saúde (BR). Caderneta da criança menina. Brasília: Ministério da Saúde; 2017.
- 38. Diniz D. Vírus Zika e mulheres. Cad Saude Publica. 2016; 32(5):1-4.
- 39. Carvalho LP. Vírus Zika e direitos reprodutivos: entre as políticas transnacionais, as nacionais e as ações locais. Cad Gênero Divers. 2017; 3(2):134-57.
- 40. Marcondes MM, Pinheiro L, Queiroz C, Querino AC, Valverde D, organizadores. Dossiê mulheres negras: retrato das condições de vida das mulheres negras no Brasil. Brasília: IPEA; 2013.
- 41. Pinheiro L, Fontoura NO, Querino AC, Bonetti A, Rosa W. Retrato das desigualdades de gênero e raça. 3a ed. Brasília: IPEA; 2009.
- 42. Cerqueira D, Lima RS, Bueno S, Valencia LI, Hanashiro O, Machado PHG, et al. Atlas da violência 2017. Brasília: IPEA; 2017.
- 43. Martins AL. Mortalidade materna de mulheres negras no Brasil. Cad Saude Publica. 2006; 22(11):2473-9.

- 44. Perpétuo IHO. Raça e acesso às ações prioritárias na agenda da saúde reprodutiva. In: Anais do 12º Encontro Nacional de Estudos Populacionais; 2000; Caxambu-MG. Caxambu-MG; 2000 [citado 02 Nov 2017]. Disponível em: http://www.abep.org.br/ publicacoes/index.php/anais/article/view/1051/1016. 45. Smith C. Afro-paradise: blackness, violence, and performance in Brazil. Chicago: University of Illinois Press; 2016.
- 46. Millar K. The precarious present: wageless labor and disrupted life in Rio de Janeiro, Brazil. Cult Anthropol. 2014; 29(1):32-53.
- 47. Hirata HS. O desenvolvimento das políticas de cuidados em uma perspectiva comparada: França, Brasil e Japão. Rev Polit Publicas. 2012; 16:283-90.
- 48. Silva EM. Cuidadoras de pessoas com deficiências: uma análise à luz da categoria gênero. In: Anais Eletrônicos do 3º Seminário Nacional de Educação, Diversidade Sexual e Direitos Humanos; 2014; Votória. Vitória; 2014.
- 49. Falkenbach AP, Drexsler G, Werler V. A relação mãe/criança com deficiência: sentimentos e experiências. Cienc Saude Colet. 2008; 13 Sup 2:2065-73.
- 50. Scott RP, Quadros MT, Rodrigues AC, Lira LC, Matos SS, Meira F, et al. A epidemia de Zika e as articulações das mães num campo tensionado entre feminismo, deficiência e cuidados. Cad Genero Divers. 2017; 3(2):73-92.

Translated by K. Eliza Williamson

Submitted in 23/11/17. Approved in 27/11/17.