



UnB



DAN

**FIELD REPORT
Brasília Team**

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1. Summary description of research

We had three funded research projects so far: a) FINATEC, the University of Brasília Research Foundation (2016-2017); b) Pro-IC, the University of Brasília's scientific initiation fund (2016-2019); and c) CNPq (2016-2019). The goals, activities and outcomes slightly changed and advanced.

a) FINATEC (2016-2017)

Project title: How do women of reproductive age perceive the zika virus, future vaccines, and participation in clinical trials?

Summary: In 2015, a zika virus, little known until then, aroused great attention and concern from Brazilian and international authorities. In this scenario, the phenomenon that most mobilized different audiences inside and outside Brazil, given its dramatic dimension from a humanitarian (but also scientific, clinical, welfare, social security) point of view, was the large number of births of children with congenital pathological syndrome, 70% of them very severely, and women's lack of protection in the face of decisions about how to avoid infection and how to deal with the risks of gestation and dilemmas as caregivers of these children. There is, however, a situation that deserves attention: the increased risks to women from contagion and their participation as pregnant women in experimental studies of preventive vaccines. We need to know the ways in which these women themselves hypothesize their contact with clinical trials in order to adapt the protocols of these studies.

b) CNPq (2016-2019)

Project title: Zika and microcephaly: An anthropological study on the impacts of the diagnosis and prognosis of fetal malformations in the daily life of women and their families in the state of Pernambuco

Summary: In 2015, a little-known virus aroused great attention and concern from Brazilian and international authorities. In this scenario, the phenomenon that most mobilized different audiences inside and outside Brazil had the largest number of births of children with congenital anomalies. The Brazilian government has focused efforts on the elimination of the mosquito and its breeding grounds. Although it is absolutely important to design preventive actions to reduce the future illness due to infection of the Brazilian population, it is important to focus attention on another picture that is already present. This research project intends to consider the repercussion of fetal malformation as a phenomenon that affects different actors, such as the child itself, the couple, the woman as the main (and sometimes sole) caregiver, the family and the other support networks, health services and municipal managers. This project aims to identify, meet and dialogue with women who between 2015 and 2016 were pregnant and delivered children with diagnoses of malformations that, in their explanatory narratives, have been associated with infection with the Zika virus.



Their recent experiences in caring for these children and in meeting with health services, justice, assistance in seeking care, care and information will also be investigated. The state of Pernambuco, that leads the cases of infection by the virus as well as of children being born with congenital anomalies, was chosen as a focus. Neighborhoods will be chosen to evaluate the difference in access to services and networks of support and care. The dilemmas and challenges regarding care today, but also during pregnancy and childbirth experienced by these women, will be known. Ethnographic data will be produced in the form of field diaries and texts (articles, chapters and dissertations) as well as a documentary, in the hope of being able to offer informative material and reflection on this reality that may be useful to these families, the feminist movement of Pernambuco, as well as the media and other actors.

c) Pro-IC (2016-2019)

Project title: Congenital Zika virus syndrome in Recife/PE: An anthropology of maternal, scientific and political impulses

Summary: In 2015, a little-known virus aroused great attention and concern from Brazilian and international authorities, the Zika virus, initially transmitted by the same mosquito that carries the Dengue or Chikungunya virus. In this scenario, the phenomenon that most mobilized different audiences inside and outside Brazil, given its dramatic dimension from a humanitarian point of view (but also scientific, clinical, welfare, social security) was the large number of births of children with congenital anomalies (Alves, 2016), such as microcephaly, visual and auditory complications, motor and cognitive impairment, joint and orthopedic diseases, difficulty in feeding and breathing, cerebral palsy, development of other syndromes such as refractory epilepsy, for example. The cases of microcephaly are being reported and associated with other malformations of greater or lesser severity, so many experts already discuss how the phenomenon as "congenital zika syndrome" (Mello, 02/02/2016). This project, which began in 2016, aims to continue to meet and dialogue with women from the Greater Recife/PE who, between 2015 and 2016, delivered children with SCVZ. The idea is to make an anthropology of the maternal, scientific and political impetus, strategies and paths, that is, of the practices of care and of interaction between these "micro mothers" (as they define themselves) and health services, professionals, researchers and scientists involved in thinking and responding to this congenital syndrome.



2. Objectives and Results

a) FINATEC

General goal: This project intends to understand three sets of representations and conceptions about the zika epidemic: i) the forms of contagion, symptoms and protection against the zika virus and the risks particularly experienced during pregnancy; ii) conceptions about vaccine (as substance) and vaccination (as public policy); and (iii) the risks and benefits of vaccine testing in groups of women of reproductive age, especially pregnant women.

Specific goals:

1. Contribute to understanding the broader context of the zika virus, microcephaly, and vaccine and vaccination conceptions.
 - a. This was our first project, the first seed money we were received that helped us jump into the field immediately. So this first goal was very important to us at the time, understand what was going on sociologically, get to Recife, feel the atmosphere.
 - b. Many causes for the SCVZ were at play. Vaccines appeared in two ways. On one side, “stale vaccines” were (and still are) considered by many women and their families for causing the syndrome. On the other side, vaccines are still considered as a possibility to protect the population from further contagions, including by the Zika virus. It is interesting that vaccines can hold, at the same time, two contradictory meanings.
2. Conduct focal groups with women in Brasília/DF and Recife/PE who have recently or not been infected by the Zika virus; who are/have been pregnant; who are taking care of children with the SCVZ. The idea is to know their opinions about the virus, the risks and benefits of vaccination campaigns and the possibility of vaccine trials occurring during pregnancy.
 - a. In total, 5 focal groups happened, 3 in Brasília and 2 in Recife. 27 women participated, some without infection, some without pregnancies, some with children with no syndrome. But many that had had Zika, had had babies with SCVZ.
 - b. It was very interesting to test the methodology of focal groups (instead of conversations and interviews that marked our other projects). When faced by a controversial issue – as vaccine trials during pregnancy – the discussion was intense. Many ideas appeared, many hypothetical scenarios were thought of. The format was very rich.
 - c. One of the main points was the use of a vaccine trial during pregnancy of a fetus already diagnosed with SCVZ, and the vaccine to be tried as a “medicine” to ameliorate the symptoms. Therefore, a therapeutical and retrospective (not prospective) vaccine.
3. Contribute to the partnership between departments and different areas within the university, as well as for the partnership between the university and the social movement and NGOs.
 - a. This project was coordinated by 2 anthropologists (Soraya Fleischer and Rosamaria Carneiro), from the Anthropology and Public Health department. Focal groups happened within the physical space of both departments. There was some visibility of the potential of interdisciplinary research. Both coordinators have been collectively writing up results since then. A lasting partnership has been established.
 - b. The 2 focal groups in Recife happened within the space generously offered by two different NGOs. This helped enhance Zika, reproductive rights and vaccination as discussion topics. It also helped consolidate partnerships between UnB and social movements, which have endured up to today.



4. Contribute to the professional training of post/graduate students.
 - a. 7 under/graduate participated in the project. One of them finished their dissertation on Zika (Lays Venâncio). Three developed Pro-IC projects (Thais Souza, Mariah Albuquerque and Yazmin Safatle). One of them was accepted in the UnB Master's Program and will start in March (Yazmin Safatle).
 - b. 1 PhD candidate (Rosana Castro) coordinated the project along with the professors, helped elaborate the final report, wrote an article on the results and is currently interested in vaccination as a research topic.
 - c. All the participants had the chance to cover and read the literature, be trained in the conduction of focal groups, produce and pretest the set of questions for the focal groups, organize and conduct the groups, record and transcribe the audio material, analyze and write up results. They were exposed to the entire cycle of researching.

5. To generate reflection and products that may be useful to women of reproductive age and who are facing the risks and dilemmas of the zika and microcephaly epidemic.
 - a. This research was designed in partnership with the Berman Bioethics Institute from the Johns Hopkins University. They conducted long-time research on ethics in pregnancy, especially interested in producing an ethical guideline for clinical trials during reproductive age.
 - b. The final report was produced and sent to the Berman Bioethics Institute, and helped produce the guideline *"Pregnant Women & the Zika Virus Vaccine Research Agenda: Ethics Guidance on Priorities, Inclusion, and Evidence Generation"* (2017).

b) CNPq

General goal: This project aims to identify, meet and dialogue with women from Pernambuco who between 2015 and 2016 were pregnant and delivered children with diagnoses of SCVZ.

Specific goals:

1. To know and understand the challenges related to the exercise of sexuality and reproduction that women faced in the zika virus epidemic.
 - a. Sexuality, especially due to sexual transmission, was a bit commented, but not extensively. Some women accused husbands of transmitting the virus, and this had repercussions on marital fidelity and also explanations of the cause of children disability. Depending on the marital situation, accusations could fly back and forth here. Did not become a major topic in our project.

2. To know the stories of women and men living with infants with severe congenital fetal anomalies, especially know the "moral etiologies" they have elaborated on the reasons for this phenomenon to happen within their family.
 - a. We did a huge effort to get to know the personal stories and biographies, where were couples born, how did they meet and marry, had they studied, did they work, previous offspring. This is a precious bulk of data to produce context, including historical density for these people.
 - b. Moral etiologies did appear and have been remodeling during time to explain why the child has the SCVZ, why are there disabilities, why this kid, these parents, this family and this moment. Different reasons are listed, from genetics, to behavior, to neighborhood, to city, climate, technologies, conspiracy theories, government and bad policies etc. Internal and external causes, individual and collective causes.



3. Know and understand the challenges to care for these children, in terms of survival, transportation, health services, rights, etc.
 - a. This is a main topic in the research. All these aspects and so many unsuspected ones have been presented and explained by the micro moms. Care is a major concern for them and we definitely followed this lead.
4. Promote discussion on disability, care, social protection and rights and stimulate dialogue between the university and social movements.
 - a. We started out in AMAR, from where many of our contacts flourished. Every time we visit Recife, we pay them visits and participate in their events. Our ties are with AMAR and this is where we have the chance to understand their priorities in terms of public policies. We respond to what they demand from us. But it has been a timid interaction so far. Could improve and has space and atmosphere to do so.
5. Produce small informative texts, periodically and parting from the research data, to subsidize the media and also feminist advocacy actions.
 - a. We have been actively producing the “microstories”, that is 2-page texts that reproduce and discuss intense stories that are shared with us in the field. Up to now, 20 stories were published. The first phase, they were put up on the blog and reproduced in our own social media. The second phase, they were published elsewhere, in wider public/conventional media and backed up in the blog.
6. Involve undergraduate and graduate students as assistant researchers, with the intention of academic socialization and professionalization.
 - a. Since the beginning, students have been involved in the project. During the 5 visits to Recife, under/graduates from Brasília, Recife and Natal have accompanied me. Fieldwork, field diary writing, collective work, planning meetings, research methodology – all have been offered in this research training opportunities.
 - b. Student writing and publishing has also been fostered.
7. Offer the view of Anthropology about a phenomenon that has received more attention from medical and biological areas as well as journalism and social media
 - a. Anthropology is still a minor area in the Zika problematic. But been in the field, staying longer than other areas, producing ties with the micro moms and fostering different kinds of publications, academic or not, have been strategies in putting Anthropology on the map.
8. Produce scientific articles (in open access journals), graduation dissertations, book chapters and a documentary from the ethnographic research data.
 - a. See Point 6.

c) Pro-IC

General goal: Continue to meet and dialogue with women from the Greater Recife/PE who, between 2015 and 2016, were pregnant and delivered children diagnosed with the SCVZ. The idea is to make an anthropology of the maternal, scientific and political impetus, strategies and paths, that is, of the practices of care and also of interaction between these "micro mothers" (as they define themselves) and health services, professionals and researchers and scientists involved in thinking and responding to this congenital syndrome.

Specific goals:



1. Know the stories of women and men who are living with babies with the SCVZ, especially to know the "moral etiologies" they have elaborated on the reasons for this phenomenon to have happened within their family.
 - a. This project has the main goal to continue the contacts started in the previous research project. So, this specific objective meant to deepen the understanding of how they explain and assimilate the child with disabilities and the origin for all this to happen in this family. These ideas have been coming up in wider conversations.
 - b. We have, more and more, access to the husbands, former or actual. Also siblings, parents, neighbors. This has helped to understand the wider spectrum of the moral etiologies of the SCVZ.
2. Know and understand the challenges that these families have faced to care for these children, in terms of survival, transportation, health services, rights, etc.
 - a. Same to CNPq (# 3 and 4).
3. Promote the discussion on disability, care, social protection and rights and stimulate dialogue between the university and social movements.
 - a. Same to CNPq (# 4).
 - b. But it has turned out to be a difficult task. The social movements (NGOs) have their own agenda, difficult to follow from afar.
 - c. We send the microstories, academic articles and interviews to them in the hope the material can serve and help in any way to promote social rights for these families.
4. Understand how science and scientists have come and enrolled these families in their research projects, conducted the projects, delivered results etc.
 - a. This is one of the new points in this second research project. Three new activities have been undertaken here. First, 16 interviews were held with Zika scientists. Second, past field diaries are being scrutinized for all the conversations and situations involving scientific matter. Third, pharmaceuticals have also become one of our interests.
5. Produce small informative texts, giving continuity to the blog "Microhistórias" (<https://microhistorias.wixsite.com/microhistorias>).
 - a. Same to CNPq (# 5).
 - b. We are now trying harder to get to bigger media. One idea is to bring a journalist to help.
6. Produce scientific articles, undergraduate and graduate dissertations, a media clipping and a short documentary (short) from the ethnographic data.
 - a. Academic production is on the way (Point 6, this report).
 - b. But we no longer have the intention to produce a media clipping nor short movies. This will be taken on, in a much more professional way, by the Recife team.



3. Most import findings

a) Time

- The fact of staying longer (than previous researchers) and coming back frequently presented us with the opportunity to see the child in different developmental stages.
- And also, to see this family in so many different situations, in terms of domestic finances, marital status, extended family support, work and study contexts.
- Also “time” became a very important category for the moms, families and professionals. Kill time, save time, rush time using all sorts of opportunities at hand to get the kid on a developmental path.
- So, the passage of time (diachrony) turned out to be not only a methodological choice, but a native priority.

b) Motherhood

- Many of these women were already mothers of previous children and were caretakers of nieces and nephews, younger brothers and sisters, older mothers, grandmothers. Care has been a reality for them. And also, the care of relatives with disabilities. Disability is not a novelty to them, so many people in the family and/or in the neighborhood were mentioned routinely. But, for many, it was the first experience-near, of a child, of very close kin. And an intense array of disabilities, not something already familiar as Down, physical disableness, disability by (car/shark) accident or aging. This intensity was new, hard, devastating at first.
- This kind of motherhood had to be learned, therefore. Quick and practical learning was demanded by these very young and with little schooling women. It was an express and hands-on maternity.
- Also, a much more public motherhood, exposing the child on streets, buses, hospitals every single day. Being watched, analyzed, criticized. A motherhood they had to be accountable for, explaining themselves, their children, their acts and decisions to strangers. They were demanded to be vocal mothers, as to explain and also as to defend and fight back prejudice, at times. So, it also became an advocate motherhood.
- We still want to write about native conceptions of disability in the context of Zika/SCVZ.

c) Science

- Especially in the beginning there was a bundle of researchers in Recife, from all kinds of scientific areas. The micro moms were engaging in every invitation they received, full of hope that this participation would have positive outcomes for their children. Results never came, were never delivered, by mouth, in paper or by mail. This produced a devastating effect on science’s reputation.
- So, our methodological approach of sticking to the same group of women since the beginning was correct. Our bet was to construct good and reciprocal relations with them. That and the fact that we return every semester has helped us stay in the field.
- So, there is a big (and problematic) repercussion about the presence of science and scientists in the Zika context. This is something we want to tackle/write about.
- At the same time, they were exposed and lectured on science as rarely a layman/woman can be. They had an intensified exposure to the scientific procedures, opening their eyes to the possibilities of schooling and education, and also to a more popular/home-based/artisanal science made at home. Observation of data, registration of patterns, communication of results became a trivial practice to these mothers on a daily basis at home and at the clinic. We see them as domestic scientists on the make, on the verge. But with no recognition of this scientific development, with no horizontal relationship with their lab counterparts.
- Pharmaceuticals have also become one of our interests. Not only the daily usage by the children (and the mothers), but also the relationship with this specific technology.

**d) State**

- The interaction with the State officials, paperwork and spaces is not a novelty to these women. But the intensity of this interaction increased immensely. They not only got in touch with completely new bureaucratic representatives but had to return many times to the same ones. Intensity, circulation, creativity in these contacts are a must.
- There is, in that sense, an unintentional specialization about the State. They became experts on details, strategies, formats of the State's operandi. They turn out as translators of the State to other members of the family and other micro moms, less experienced.
- But this interaction with the State is not all positive, not all learning and success. It is a daily routine of humiliation and frustration. They are caught in a "purgatory narrative" (The Moth), having to tell and retell their stories over and over again, with little success to achieve goals and have social rights guaranteed.
- The epidemic reveals – as a perverse contemporary photography – the decadent Brazilian welfare State, where minorities, diversity and social rights are being drastically destroyed. The epidemic appears exactly when Brazil is going through a political coup, a conservative backlash, an annihilation of vulnerable citizens.

4. Published works/in press**a) Published articles/chapters**

- FLEISCHER, Soraya e CARNEIRO, Rosamaria. "A alta terapêutica de crianças com a síndrome congênita do vírus Zika: O que esse fenômeno pode nos contar sobre o estado atual da epidemia?". *Gênero, sexualidade e saúde: diálogos latino-americanos*. Camilo Albuquerque de Braz; Carlos Eduardo Henning (Orgs.). Goiânia: Editora da Imprensa Universitária, p. 17-51, 2017.
- _____. "Eu não esperava por isso. Foi um susto. Conceber, gestar e parir em tempos de Zika à luz das mulheres de Recife". *Interface*, 22(66), 2018.
- FLEISCHER, Soraya. "Cenas de microcefalia, de cuidado, de antropologia (Recife, setembro de 2017)". *Revista Cadernos de campo (USP)*, 27(1), 2018.
- FLEISCHER, Soraya. "Segurar, caminhar e falar: notas etnográficas sobre a experiência de uma "mãe de micro" no Recife/PE". *Cadernos de Gênero e Diversidade*, 3(2), 2017.
- FLEISCHER, Soraya. Entrevista para Jornal do SINDSEP/Recife. [<http://www.sindsepe.com.br/newsletter/mensal/maio-2018.html>] Última página (acesso em maio 2018). Mai.2018. (entrevista).
- _____. Entrevista para Alexandre Yuri, jornalista do SINDSEP/PE. Site do Curumim. [<http://www.grupocurumim.org.br/>] (acesso em maio de 2018) Mar. 2018. Versão mais completa da entrevista. Site Rede Brasil Atual [<http://www.redebrasilatual.com.br/cidadania/2018/06/a-luta-das-maes-de-microcefalia-pela-vida-dos-filhos>], mai. 2018. (entrevista).
- _____. Entrevista para Paula Viana. [<https://www.facebook.com/GCurumim/videos/1573891732733042/>] (acesso em maio 2018). Mar. 2018. (entrevista).
- _____. Entrevista para Debora Brito, EBC, 25/11/2018. <http://agenciabrasil.ebc.com.br/saude/noticia/2018-11/maes-de-bebes-com-microcefalia-vivem-novos-desafios>. (entrevista).
- JUSTINO, André Filipe. "Fragmentos de (micro)Realidades Recifenses: deficiência como categoria mobilizadora de relações a partir de relatos da síndrome congênita do Zika Vírus". *Amazônica* 10, p. 160-180, 2018.
- FLEISCHER, Soraya; CARNEIRO, Rosamaria; CASTRO, Rosana. "Como mulheres em idade reprodutiva



percebem o vírus zika, futuras vacinas e a participação em testes clínicos?”. Berman Institute for Bioethics/JHU. (research report).

LUSTOSA, Raquel. Exposição fotográfica. Um dia com Josi: uma fotoenografia do cuidado e do cansaço”. Interface 22(66), 2018. (visual essay)

VALIM, Thais. “Elas”. (Resenha do filme “Elas”, de Stephane Ramos, 24 minutos, 2017). *Anuário Antropológico* 43(1), 2018. (film review)

b) In press

FLEISCHER, Soraya e LUSTOSA, Raquel. “O que adianta conhecer muita gente e no fim das contas estar sempre só? O desafio da maternidade em tempos de Síndrome Congênita do Zika Vírus”. *Anthropologicas*.

FLEISCHER, Soraya e CARNEIRO, Rosamaria. “Em Brasília, mas em Recife: atravessamentos tecno-metodológicos em saúde, gênero e maternidades numa pesquisa sobre as repercussões da epidemia do vírus Zika”. *Saúde e sociedade*.

FLEISCHER, Soraya e CASTRO, Rosana. “Risco, esperança e cuidado: ponderações éticas de mulheres de PE e do DF sobre pesquisas experimentais para desenvolvimento de uma vacina contra o zika”.

c) In writing

FLEISCHER, Soraya. “Zapzap no cenário da microcefalia: Oportunidades para pensarmos sobre cuidado, tecnologia e antropologia”.

_____. “Epidemia do zika, microcefalia e circulação de esperança no Recife/PE”.

_____. “Da criança guardadinha à criança em tudo que é lugar: Deficiência, circulação urbana e direitos ao transporte no contexto da SCVZ, Recife/PE”.

FLEISCHER, Soraya e KNIHS, Ana Claudia. “Minha filha é uma milionária”: Acesso aos medicamentos para crianças com a SCVZ.

d) Articles presented at the ProIC Congress

ALBUQUERQUE, Mariah. “Percepções do conceito de deficiência no contexto da microcefalia.”

GOSAVES, Lucivânia. “Terapias, terapeutas e famílias no contexto da Síndrome Congênita do Zika Vírus (Recife/PE)”.

LIMA, Beatriz. “Mães de Micro: Narrativas sobre maternidade e microcefalia no contexto recifense através da metodologia do desenho”

SIMAS, Aissa. “Conhecimento em movimento: notas sobre as relações entre pesquisas, pesquisadores e famílias no contexto da Síndrome Congênita do Zika Vírus (Recife/PE)”.

SOUZA, Thais. “Discurso religioso das mães de bebês com Síndrome Congênita do Vírus Zika, Recife/PE”

VENANCIO, Lays. “Dar um bale: ativismo materno na busca por serviços a bebês com síndrome congênita do vírus zika no Recife”.

e) ProIC articles in writing

CAMARGO, Ana Claudia. “Construção da maternidade, movimentos sociais e a solidão das mães de micro”.

FREITAS, Gabriela. “Um estado da arte nas ciências humanas sobre as pesquisas sobre a epidemia do vírus Zika”.

**UnB****DAN****f) Events**

“Seminário de apresentação de resultados: Três anos de epidemia: Uma antropologia do pós-Zika”. Universidade de Brasília, Auditório do Departamento de Antropologia. DAN/UnB, 7 de março de 2018. Soraya Fleischer, Amanda Antunes, Victor Vitor e Flavia Lima.

“Como cuidar de uma criança com uma doença rara”. 18ª Semana Universitária/UnB. DAN/UnB, 29 de setembro de 2018.

Painel fechado “Narratives of hope: ethnographies of moralities around suffering”. 18th IUAES World Congress/UFSC. 16 de julho de 2018.

g) Supervision

VALIM, Thais. “Ele sente tudo o que a gente sente”: Um estudo antropológico sobre a sociabilidade dos bebês nascidos com a síndrome congênita do Zika no Recife/PE. Monografia [Bacharelado em Antropologia]. Brasília: Universidade de Brasília, 2017.

VENANCIO, Lays. “Mães de micro: três redes de cuidado e apoio no contexto do surto de Síndrome Congênita do Zika Virus no Recife/PE” Monografia [Bacharelado em Antropologia]. Brasília: Universidade de Brasília, 2017.

CAMARGO, Ana Claudia. Epidemia do Zika e medicamentos. [Bacharelado em Antropologia]. Orientadora: Soraya Fleischer. Universidade de Brasília. Previsão de conclusão: primeiro semestre de 2019.

SIMAS, Aissa. Conhecimento em movimento: notas sobre as relações entre pesquisas, pesquisadores e famílias no contexto da Síndrome Congênita do Zika Vírus (Recife/PE). [Bacharelado em Antropologia]. Orientadora: Soraya Fleischer. Universidade de Brasília. Previsão de conclusão: segundo semestre de 2018.

LUSTOSA, Raquel. "Mães de micro": um olhar para os efeitos da epidemia zika vírus nas experiências e vivências de mulheres do Recife. [Mestre em Antropologia]. Co-orientadora: Soraya Fleischer. Universidade Federal de Pernambuco. Previsão de conclusão: primeiro semestre de 2019.

h) Links to blog

<https://microhistorias.wixsite.com/microhistorias>