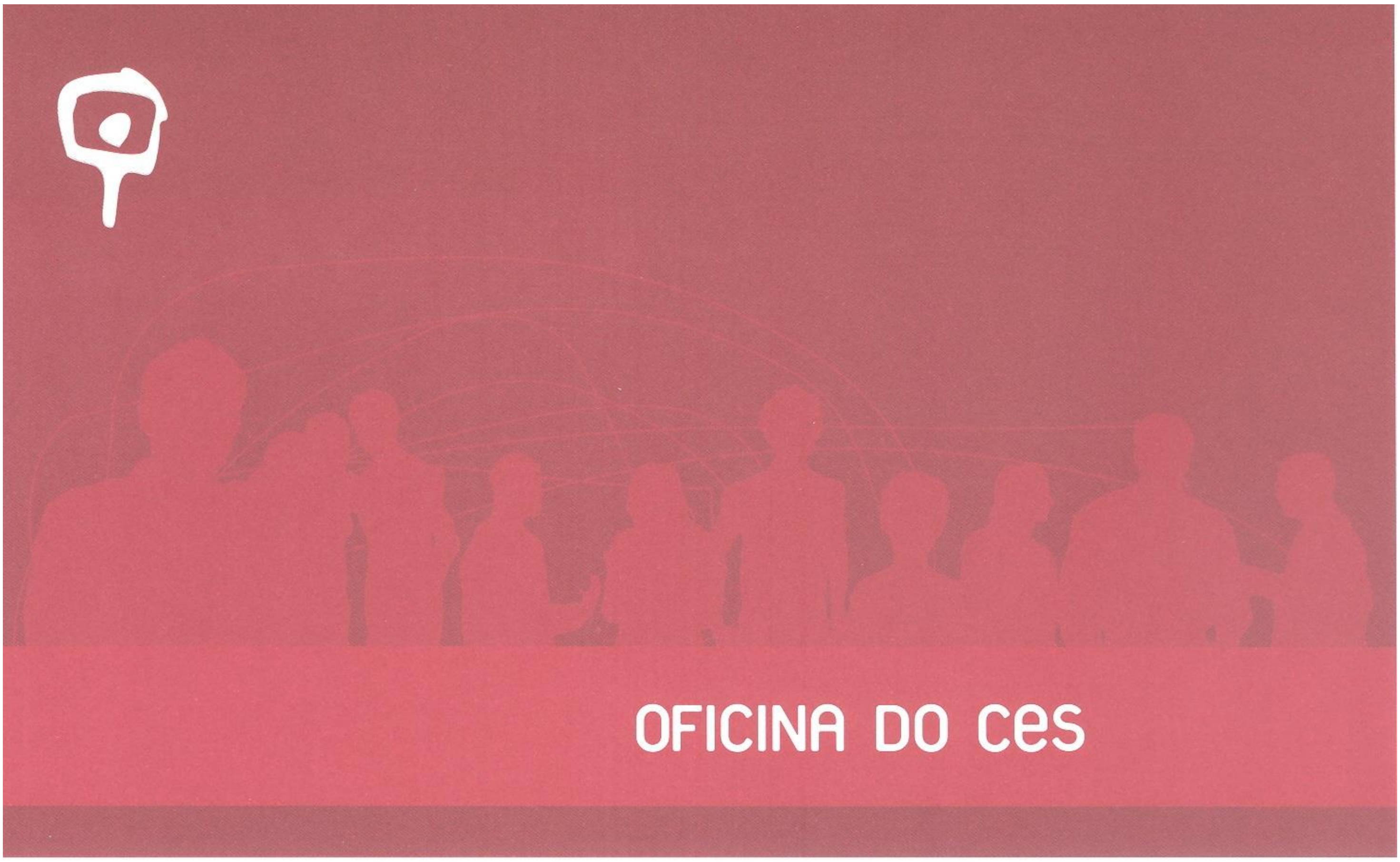

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Caring for Stories: Ontologies of Health Promotion, Infections and Structural Vulnerability in *Plataforma de Saberes*

Abstract: In this work I describe the multidisciplinary and collaborative efforts to develop the "health promotion appointment" as a space in which patients and community health promoters' stories enact their worlds and experiences, and diverse ways of living and responding to problematic situations, here represented as "matters of care". I propose rethinking the ways we listen to and tell stories at the intersections of the divergent worlds of global health we inhabit starting from the ontology of *Plataforma de Saberes*, a world composed by health promotion, infections, structural vulnerability, and "ecologies of perhaps".

Keywords: global health, *Plataforma de Saberes*, ontology, stories, matters of care.

One year ago, my colleagues and I wrote a brief text concerning "the complex social, ethical and political dimensions of the COVID-19 pandemic", and how they "interest us for the future lessons they offer towards the construction of a more critical, ecological and democratic epidemiology and global health"[1] (Ferreira *et al*., 2020). The emerging debates in medical anthropology and in the social studies of health and medicine that discuss the production of evidence, the design of interventions on health, disease and care, the ethics of research, and intervention in global health are, once again, in the "eye of the hurricane" when it comes to facing infectious diseases, epidemics and their social impacts (Adams and Biehl, 2016; Biehl, 2011, 2016; Bowleg, 2019; Farmer, 1999, 2020; Farmer *et al*., 2013; Messac *et al*., 2013; Nguyen, 2004; Nunes, 2020). Knowing the relations between new pathogens, animal factories, deforesting and so many others elements – not only with COVID-19, but with other infectious diseases such as Ebola, malaria, dengue, Zika and HIV – through their biology and epidemiology is not enough. We must also know the cultural and social spheres which infections inhabit (Benton *et al*., 2017; Biehl, 2011; Briggs and Mantini-Briggs, 2016; Singer, 2015), their unexpected consequences

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[1] All translations are by me.

and impacts both in the Global North and Global South (Farmer, 2020; Richardson, 2019), and to learn new and diverse forms of care in public and global health (Puig de la Bellacasa, 2017; Yates-Doerr, 2017a, 2020; Yates-Doerr and Carney, 2016).

Among the current challenges faced by global health, I suggest that it is urgent to build the capability to recognize the diversity of contexts where problems emerge, as well as the biological, social, political, cultural, historical and ecological processes that complexify and mark the need for plural and ethical practices. In my doctoral research I describe global health as a field of problems, divergent knowledge and practices, norms and subjectivities, encounters, and partial connections (Strathern, 1991) between worlds of experience and relations built in and outside the epidemiological, biomedical and clinic spheres that intersect research and treatment of infectious diseases. The relevance of my research, its practices and modes of knowledge production is entangled with a renewed pragmatic attention (Savransky, 2018, 2021) to the divergent encounters between biomedical, epidemiological and other kinds of knowledge and lived experiences in situated contexts where the “global” and the “local” intersect and entangle.

My questioning about global health knowledge and practices goes back to my previous work regarding knowledge networks in health cooperation projects in Angola and Mozambique dedicated to medical education in infectious diseases and maternal and child health (Ferreira, 2013). In these places, I encountered problems and heterogeneous situations that made me question the relevance and the consequences of my own practice as a communication specialist, namely on the definition of categories that shape what counts as knowledge about health, creating prescriptive implications and problematic consequences about “real conditions” (Savransky and Rosengarten, 2016). These projects also provided experiences and problems that were valuable to my doctoral research in the sense that I had to invent different ways of getting to know problematic situations in different contexts of global health.

This work acquires relevance in collaborative and multidisciplinary research and intervention in situated contexts guided by non-extractive methodologies and practices (de la Cadena, 2017). My empirical choices and concerns are guided by the purpose of intervening in the world, in which epistemic and cognitive values, interests and challenges are combined with an ethical practice that implies an exercise of reflexivity and a commitment to a “slow research” movement (Adams *et al*., 2014). Ethnography is central to my methodological approach, since it prepared me to observe, listen, take part in knowledge production, intervene and be attentive to its consequences in the definitions and forms of engagement with global health categories, crises and possibilities (Pigg, 2013; Viney *et al.*, 2015; Yates-Doerr, 2017b). The nature of my research is also configured by

> plural and ethical practices, situated in social, historic and political contexts that intersect the "global" and the "local", and that is based on the recognition of different ways of life, on dialogues and critical thinking, on the ethics of care, whether in the clinical encounter, in ethnographic work, or in spaces for social mobilisation. (Ferreira and Filipe, 2019)

In this text, it was my intention to provide the readers with an in-depth description of the stories that not only take part in the "monification" (Savransky, 2021: 5) version of global health, but also gather possibilities of composing pluralistic versions of it, one that is made up of stories of resilience and resistance (Horton, 2019), recovery (Petryna, 2013), and diverse ways of living together. Since 2016, this ethnographic and ethical effort became part of my affective and research engagement with the ontological trajectory of *Plataforma de Saberes* (which I will talk about below) coordinated by the Laboratory of Epidemiology Research and Social Determination of Health at the Evandro Chagas National Institute of Infectious Diseases (INI), Osvaldo Cruz Foundation (Fiocruz), in the northern area of Rio de Janeiro, Brazil. My connection with the trajectories of patients and community groups required me to learn how to think and write with care (Puig de la Bellacasa, 2017) about the stories of suffering, violence, social exclusion and complex entanglements between health, disease and the social processes that compose their ways of living with infections and structural vulnerability. This means caring for the experiences of neglected and systemic suffering that are narrated in the

> stories of people that suffer, [and] that through their testimonies and participation in the collaborative production of knowledge built from their experience uncover what the lens centred on epidemiology and knowledge legitimised by science (including the social sciences) fails to recognise, and which therefore ignores or disqualifies. (Nunes, 2020)

My work in *Plataforma de Saberes* became writing "newly visible stories of the significance of the present moment in terms of globalisation" (Blaser, 2010: 8) and its consequences by focusing on singular stories that are partially connected with the global scientific narrative. They also compose other narratives of rupture that are complementary and entangled with the first, but do not only replicate its knowledge system (Harman, 2020).

During my fieldwork, I dedicated careful attention to the knowledge practices and caring relationships that sustain *Plataforma de Saberes* and to the challenges they pose to monocultural conceptions of knowledge regarding health and disease, care and cure (Nunes and Louvison, 2020). The encounters between the "diversity of knowledge, practices and experiences" and "struggles for social and cognitive justice and the multiple and diverse struggles for health and access to medical care" (*ibidem*) in *Plataforma de Saberes* configure it as a space of visibility for the neglected experiences that are not part of the dominant global health narratives. It enables one to look for "the best possible life, as part of a complex and interdependent web, weaving the relationships that sustain life and existence" (*ibidem*).

What Is *Plataforma de Saberes* Capable of?

Plataforma de Saberes is part of a long-running action-research trajectory (since 2005) focused on collaborative knowledge production and the creation of innovative practices in health promotion in the context of clinical, epidemiological and social research on infectious diseases (HIV, Chagas disease, tuberculosis, among others). The multidisciplinary alliance that sustains *Plataforma de Saberes* develops initiatives focused on the "social determinants of health" and "health promotion". These actions take place in the context of clinical, epidemiological and social research at INI/Fiocruz and aim to produce knowledge related to health problems, conditions and determinants, and innovative technologies that meet the challenges of healthcare in infectology and the promotion of well-being and quality of life of the population (Souza *et al.*, 2019). *Plataforma de Saberes* is also a space for encounters and engagements between researchers, health professionals, patients, and members of community groups ("community health promoters") with the practices and knowledge related to diseases, health care and health promotion. The health promotion initiatives became the space for *encountering health* and sharing problematic situations that are not visible in clinical spaces, and cannot be faced by individual responses – situations of neglected suffering, stigma in clinical encounters or social exclusion in their communities as HIV patients, among others (Ferreira *et al.*, 2020; Souza *et al.*, 2020). *Plataforma de Saberes* is under construction within a technoscience infrastructure, where new meanings and new ways of dealing with problems emerge, opening up the possibility for patients/citizens to become more than what is expected in the normative guidelines of global health – the patient/citizen compliant with positive living movements (Sangaramoorthy, 2018). Beyond the biomedicalisation of subjects, living spaces and the processes through which healthy lifestyles and sanitary citizens are co-produced through clinical research (Nunes *et al*., 2014), studies from medical anthropology on HIV infection and its co-morbidities reveal the importance of accompaniment (Palazuelos *et al*., 2018), care and sociability in health promotion initiatives for HIV seropositive patients (Niehaus, 2014, 2015; Prince, 2014; Sangaramoorthy, 2014, 2018). These studies allow us to understand how people interact and participate in access to treatments and how this is related to other dimensions of their lives.

In *Plataforma de Saberes*, structural vulnerability and the social and cultural aspects are part of a situated approach to health that goes beyond the nosological entities recognised by the dominant biomedical paradigm or in the guidelines of global health. Concerns over care, support and treatment for patients with infectious and chronic diseases become progressively visible and are a significant part of the individual and collective actions towards those who are affected by health problems and structural vulnerability and demand diverse forms of care. This approach requires the capacity to critically engage scientific knowledge and health standards with local knowledge and contexts in collaborative settings. My fieldwork in *Plataforma de Saberes* became focused on the ontology of the complex and entangled worlds composed by health, infection, structural vulnerability and suffering, as I said above, but also in making visible the possibilities that arise at the intersections, tensions and temporalities that co-exist in this platform. The health promotion initiatives became the space for *encountering health* and sharing problematic situations that are not visible in clinical spaces, and are impossible to transcend alone.

Marisol de la Cadena and Mario Blaser (2018) describe in their work the heterogeneous alliances that support the possibility of negotiated futures, based on the different struggles and heterogeneous worlds. The collective actions of “community health promoters” address neglected things (Puig de la Bellacasa, 2011) that are not visible if we look at a problematic situation as a clinical case, or even as part of a cartography of the intersections between clinical research and social epidemiology based on a normative vision of public health interventions. The situated production of knowledge, closer to the lives connected to places and stories, and the ability to act in solidarity with others is “grounded on a conception of care as an ontological requirement of relational worlds” that is part of “vital ethico-affective everyday practical doings that engage with the inescapable troubles of interdependent existences” (Puig de la Bellacasa 2012: 199). In *Plataforma de Saberes*, health promotion practices are sustained by our relational and ontological care with the knowledge and experiences of patients and community groups.

The *Health Promotion Appointment* as a Space for Caring for Stories

In 2019, the *health promotion appointment* was imagined as a space to engage with the narratives and trajectories of patients and community groups and produce alternative accounts of the complex entanglements between health, disease and the social processes that configure structural vulnerability. These aspects are relevant in public health and clinical research, and in intervention in situated contexts. But the *health promotion appointment* also revealed itself as a space for “making time for care time” (Puig de la Bellacasa, 2015: 691).

The protocol definition and implementation were developed by the *Plataforma de Saberes* team, including its coordinator, an epidemiologist, and me, a social researcher, as a space for informing and solving individual and collective problems and concerns. These are shared by patients and groups actively engaged as “community health promoters”, with increased agency in addressing situated health problems together with researchers and health professionals. The protocol is inspired by the work of Philippe Bourgois *et al*. (2017) and by our long-term collaboration in action research in *Plataforma de Saberes*. In addition to the categories of the original protocol – access to food, financial support for attending clinic appointments, sanitation and water, racial issues, stigma in the clinical appointments – we adapted the protocol to also focus on the solidarity actions and care given by “community health promoters” in their families, in their communities and in diverse health institutions. My collaboration as a social scientist focused on developing theoretical contributions from the encounters and stories shared in this space, and responding to the new and complex methodological challenges this intervention generated in *Plataforma de Saberes* and in INI/Fiocruz.

The *health promotion appointment* pilot phase was implemented in April 2019 and was held by a specialist in public health and epidemiology once a week at the INI/ Fiocruz Hospital. The appointment was organised in the following stages: reception, welcoming, listening, solvability, and a final group dynamic, such as art workshops. In this pilot phase, we invited INI patients, their friends and families, and members of local community groups and associations to participate in this appointment. The sessions were audio recorded (approved by the INI ethics committee and with informed consent from participants), transcribed and analysed by the epidemiologist and myself. After each appointment, the epidemiologist shared a written clinical description of the case with the team. For each session, three documents were prepared: a description of the self-perceptions of the health professional; the appointment transcription, organised according to the predefined categories of the structural vulnerability protocol assessment; and a visual diagram illustrating the sequential steps and the actors involved in the solvability of the situation were presented, detailing the steps and people engaged in the resolution of the problematic situation brought to each appointment. The accounts reveal the importance of looking at this space as a representation of "matters of care" (Puig de la Bellacasa, 2017), challenging us to think and care about what might be possible if we commit ourselves to think about the care that is produced in this space. It implies an ethical practice based on care in fragile contexts, where neglected things and programmatic tensions of health models guided by biomedical evidence and clinic co-exist.

From the stories brought to us by those who relate to them, who are affected by them and seek to care for and affect others, the *health promotion appointment* challenged us to design it as a space of thinking with care and taking responsibility.

The Story of K.[2]

This is the self-perception registered by the epidemiologist in the INI/Fiocruz hospital information system. It resumes the story shared by K. during the *health promotion appointment*.

> On July 16 2019, V., a community health promoter and active participant in *Plataforma de Saberes* for more than 10 years, referred patient K., HIV-infected by mother-to-child transmission, for a health promotion appointment. K., female, 35 years old, told her story from childhood to the present day. She lost her mother and her 9-year-old sister when she was 12 years old due to opportunistic infections related to HIV. She was raised by her aunt (mother's sister), who was killed in a

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[2] To ensure anonymity, the names of the people in question are presented this way.

> bank robbery when she was 15 years old. She is currently married, her partner knows her serological status (this is a serodiscordant couple) and she has a 3-year-old, HIV-negative daughter. Her viral load has been undetectable for several years, which proves her adherence to treatment. During the appointment the patient reported that she attended the university and graduated as social worker. In the end, she said that having shared her story motivated her to return to study and work in this area, a way to help others who had similar problems.

V., one of the founders of the Association Fighting to Live – Friends of INI and a very active community health promoter – invited K. to participate in the *health promotion appointment* and engage with the actions of *Plataforma de Saberes*. K. met V. during her hospitalisation in the INI hospital when she was 17 years old. V. became like a father to her since he accompanied K. during her hospitalisation at INI. Their friendship and bond last until today, and are of great value to K.

Her mother died of tuberculosis when she was 12 months old. K. was infected with HIV through vertical transmission, but only learned that she was HIV-positive at the age of 17. Vertical transmission was also responsible for the infection of K.'s sister, who died at the age of nine, after several episodes of infections. K. was then 12 years old, but the memories of suffering are still vivid in her words about her sister's illness and death. She recalls one day when her sister was throwing away the AZT medicine bottle and their aunt found out:

> she faced my aunt saying she already knew she was going to die! She was nine years old… and she already knew that this disease she had was going to kill her! It seemed she already understood what she had, poor thing… The doctors discharged her from the hospital, she was very weak and at the time there was nothing else they could do… She went bald and very, very skinny... When she passed away, I didn't even feel I was mourning or sad... Because she was suffering a lot! She was really suffering… She couldn't take it anymore… she was wearing a diaper… I still feel very sad today when I remember the night she died at home with my aunt and calling for me.

When K. was 14, her aunt was murdered during a bank robbery. After that, K. found shelter at her uncle's house. He had younger children and feared that K. would transmit the disease to them. At the age of 14, K. did not know yet that she was HIV-positive, although the whole family was aware of that. She suffered from family discrimination, based on their lack of knowledge about the transmission of the disease. Until the age of 15, K. believed that she regularly suffered from pneumonia, just like her sister did, until a social worker finally informed her of it at the hospital she had attended since she was a child. K. was living alone, but refused to live in shelters. She was temporarily housed by friends and struggled financially. Between her escapes from the hospital, non-compliance with HIV treatments and her rebelliousness (as she calls it), she went through numerous relapses and hospitals during her adolescence.

At the age of 17, K. had already lived through the death of her parents, her sister, her aunt with whom she had a strong affective bond and who raised her, and a boyfriend. K.'s words describe a life permanently at risk, amid efforts to recover her health and live a "normal life" that was never accessible to her. Her story intersects with the story of the virus that has always lived with her, disease, poverty, violence, loss and trauma:

> I started dating a thug, and I saw a lot of people die, then I suffered a trauma… I got panic syndrome, until today I'm afraid of seeing a body in a plastic bag like that on the street, I can't sleep at night… Then I went to live my life away from these places, from all these things… I began to live just for work and kept saving money. I had a big teddy bear, and I kept the money inside it because I didn't have a bank account. Then I would collect money inside it... If someone took the bear, they would take all my money...

Due to her extreme physical weakness and severe infections, as well as the inability to comply with the treatment that "gave her hallucinations", she became seriously ill and was admitted to the INI hospital for several months. Her socioeconomic situation began to improve when she was 22 years old and finally got her disability benefit. She was already married and with the amount she received from retroactive payments and her savings, she managed to buy a house with her partner. The situations of stigma and discrimination that she had experienced during her life led K. to only tell her partner she was HIV-positive when she was no longer able to explain her regular visits to INI/Fiocruz. K.'s story is also focused on becoming a mother. This time, she returned to the hospital because she couldn't get pregnant, even though her viral load was undetectable. At that time, she became aware that she could not become pregnant unless she underwent medical treatment that was only funded by a private health insurance. Her partner included K. in his health plan (which he had access to through his job) and she was able to carry out the treatments to solve the clinical problem that prevented her from becoming pregnant, later advancing with in vitro fertilisation (IVF). In this period, the discrimination she suffered from a private doctor led her to give up antiretroviral treatment for HIV again, and become depressed:

> I went to the hospital in the city centre to do the treatment and the doctor there was rude to me; he asked how could I want to put a child in the world knowing what I had, and that it was easier for me to adopt a child… I left the hospital even more depressed, then I wanted to quit the treatment… I didn’t want to do it anymore. I said that if I was supposed to be alone, I wanted to die…

When her partner was fired from his job, he received financial compensation and they decided to go ahead with IVF, despite it being very expensive. This time, K. managed to comply to the HIV antiretroviral treatment and get pregnant. But then she had to deal with other problems. In the private hospital the doctors told her she needed a C-section, but in the public hospital where she also had medical accompaniment, the doctors promoted a normal birth even in HIV-positive women, leaving K. with more decisions to make:

> I was like “But which is best for my daughter?” and, at the same time, I wanted to have a normal pregnancy like any other woman, right? I wanted her to be born normally…

K. says that the lack of information on breastfeeding for mothers with infectious diseases is a form of discrimination:

> I knew I wouldn’t be able to breastfeed, but I thought that it wouldn’t move me so much… In the hospital they don’t separate women with HIV to give lectures to pregnant women, it’s everyone together… So, they teach everyone how to breastfeed; I’m there and I know I won’t be able to breastfeed…

This situation is experienced as a source of concern that lasts for the first six months of her daughter's life:

> I didn't breastfeed... but she cried a lot because she took this formula milk and had cramps… In my head I knew I was not going to be able to breastfeed, but I [thought I] was going to be able to take her to a milk bank, and I couldn't ... The milk bank is only for children who are hospitalised or children in very serious situations, malnourished… And it wasn't her case, so my daughter never had contact with breast milk… And they didn't inform me, you know? When she was born I was like my God, how am I going to do it now? Then they gave me medicine to dry up the breast milk, at the maternity hospital… but even so, I still had milk and she cried a lot… it seems that a child has the instinct... you take her and she goes straight to your breast and stays there… that made me more and more depressed… I couldn't feed her, and she was crying with hunger… I dreamed that she was hospitalised because she was hungry… I was in a horrible state because I thought she was just crying because of me, until those six months passed…

Despite all the struggles to stay alive and with "undetectable" viral load, K. was now faced with the impossibility of her daughter not being breastfed, and this concern grew with the fear that her partner's family would discover her HIV status:

> during the first month I didn't go to their house so they didn't know I couldn't breastfeed… When she was two months old I had chikungunya, and it was the excuse I used to say that my milk dried up…

The epidemiologist asked if her daughter "took the medicine" (antiretroviral) and K. stated that she did, that she followed the medical guidelines and that her daughter is "negative" to this day. But K. wanted to talk more about breastfeeding. She felt she had taken something from her daughter that would be good for her – the breast milk – for the fear of vertical transmission, but she felt a lack of guidance regarding the baby being breastfed by other women:

> At that time, I would go to my mother-in-law's house, and my mother-in-law would say "let her breastfeed", because I have a sister-in-law who had a recent child, "let

> her breastfeed", and I would say "No! She cannot…!" What if she has a disease… does she not know that even if she thinks she is healthy, it may be that she acquired a disease yesterday, not only HIV! Other diseases! […] Then I kept thinking "People are crazy" … but no, sometimes people don't have this information.

K. wishes she had been informed about the use of silicone prostheses to have an experience similar to breastfeeding, and to have been better able to lessen the negative impacts she thinks she had on her daughter and on her social role as a mother. She regrets that she didn't breastfeed, and even if she could not breastfeed, she would like to have access to feel what breastfeeding is like to help to create a bond with her daughter. She suggested that we hold a collective activity, such as a lecture on this subject in *Plataforma de Saberes*, which she believes is important for women who have infectious diseases that prevent them from breastfeeding. As K. says, "I don't even have those traditional photos that mothers have with their child breastfeeding". This would be her way of helping women who have infectious diseases that prevent them from breastfeeding, just like her.

In the *health promotion appointment*, K. told her life story in a way that she never shared before in clinical encounters, describing the obstacles and risks of recurring negative health outcomes, both in relation to her health and that of her daughter. Her story and her previously neglected and devalued memories in health care spaces were heard and represented as issues that deserve care. As researchers, we assumed an ethical commitment to think about these care issues based on their potential to generate more care through the creation of meaningful interventions within *Plataforma de Saberes*. K.'s *health promotion appointmen*t pointed out the importance of this topic not only for women, but to all the "community health promoters" engaged in *Plataforma de Saberes*. The promotion of access to knowledge concerning breastfeeding, not only for HIV patients, but also for friends, family members and their communities, became the focus of a new intervention in *Plataforma de Saberes* that began with K.'s story.

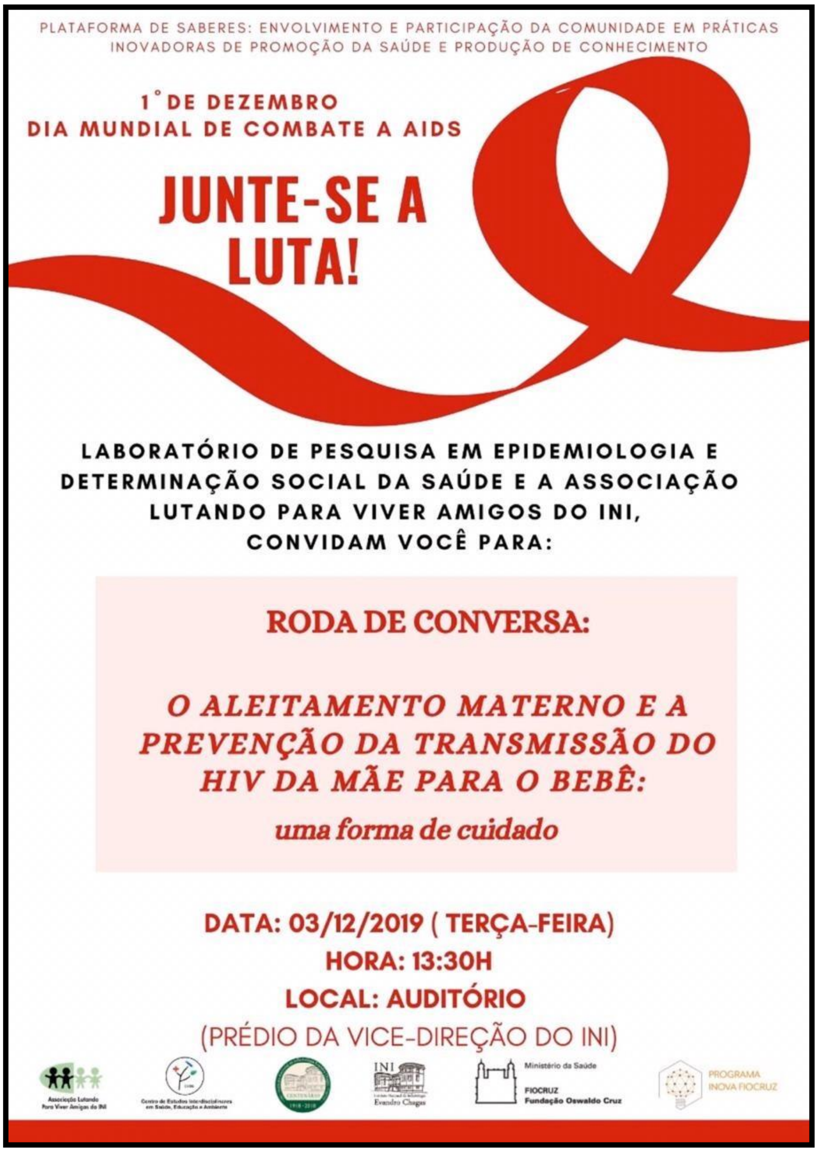
During her appointment, K. also shared with the epidemiologist that she has a background in social work. Once again, her story is linked to V. and the INI patient association, since K. worked temporarily in this association during her training and internship. She no longer works as a social worker; now she sells baby clothes. Nevertheless, we wanted to value her experiences and problems she shared with us, by responding to her demand: organising a lecture with her participation, as part of the contextual health promotion practices and ethics of care that sustains the infrastructure of *Plataforma de Sabere*s.

Roda de conversa: Between Facts and Concerns about Breastfeeding and HIV

In themes such as that which emerged from K.'s story, it is not only important to understand the knowledge (or lack of) problem in the face of disinformation that affected her experience as a mother. Despite being a "good patient" during pregnancy and having managed to prevent mother-to-child HIV transmission, the literacy she reveals about the topic was not enough to overcome what she experienced at that time. K. wanted to help other women that going through the same situation, but not as an HIV patient or a mother. She didn't want to share it publicly, and wanted to present herself as a social worker. She wanted to re-signify her experience in a space where it is valued together with scientific knowledge on the topic.

Her story reveals the importance of looking at the *health promotion appointmen*t as a representation of "matters of care" (Puig de la Bellacasa, 2017), challenging us to think about these encounters from the standpoint of the care they produce. This interest and health concern were shared by the community health promoters, the epidemiologist and the team of *Plataforma de Saberes* with the organisation of a group conversation (*roda de conversa*) on breastfeeding and vertical transmission of HIV to the community health promoters. The *roda de conversa* constituted a space for collaborative knowledge production that is close to people's experiences. Despite of the centrality of scientific knowledge, this event was open to diverse forms of expression of situated definitions of problems by all the participants.

The *roda de conversa* took place on December 3, 2019, in commemoration of World AIDS day (Figure 1). The event was promoted by the *Plataforma de Saberes* team by phone, in the community groups chats and by spreading the word. 27 participants attended the event at INI/Fiocruz. We invited two INI infectious disease specialists in HIV vertical transmission (both of them had already participated in previous activities of the *Plataforma de Saberes*), one paediatrician from a public hospital/maternity in Rio de Janeiro, and a social worker (K.).



PLATAFORMA DE SABERES: ENVOLVIMENTO E PARTICIPAÇÃO DA COMUNIDADE EM PRÁTICAS INOVADORAS DE PROMOÇÃO DA SAÚDE E PRODUÇÃO DE CONHECIMENTO

1° DE DEZEMBRO
DIA MUNDIAL DE COMBATE A AIDS

JUNTE-SE A LUTA!

LABORATÓRIO DE PESQUISA EM EPIDEMIOLOGIA E DETERMINAÇÃO SOCIAL DA SAÚDE E A ASSOCIAÇÃO LUTANDO PARA VIVER AMIGOS DO INI, CONVIDAM VOCÊ PARA:

RODA DE CONVERSA:

O ALEITAMENTO MATERNO E A PREVENÇÃO DA TRANSMISSÃO DO HIV DA MÃE PARA O BEBÊ:
uma forma de cuidado

DATA: 03/12/2019 (TERÇA-FEIRA)
HORA: 13:30H
LOCAL: AUDITÓRIO
(PRÉDIO DA VICE-DIREÇÃO DO INI)

Figure 1 – Poster "Breastfeeding and the transmission of HIV from mother to baby: a form of care"

The infectious disease physicians presented the WHO data on the number of cases of HIV infection in the world, and the need to develop different perspectives on retroviral therapies for babies, children and pregnant women living with HIV in Brazil. They shared the alarming numbers of infected pregnant women in Brazil, detailing that between 2000 and 2018 the number of notifications exceeded 116,000 cases, and more than 7,000 new cases were registered in 2017 alone. They presented the Brazilian policies on this matter, as well all the procedures that are required by the Ministry of Health for the notification of new cases in the diagnostic units, which are then sent to the Secretary of Health. The government supplies the medications free of charge, namely the ones used during pregnancy. They highlight the importance of early diagnosis, combination of antiretroviral therapy and undetectable viral load as “the three most important things during the pregnancy of woman with HIV”. The message shared by the infectious disease doctors is that “access to therapies during pregnancy becomes the best way to have a healthy child”. Their knowledge of the Brazilian reality revealed the complexity associated with HIV treatment compliance, and that it is common to find women in the eighth month of pregnancy, sometimes even at the time of giving birth, without having undergone treatment. To reinforce the importance of keeping the medication, they describe the specific aspects of the treatment that need to be done in the puerperium, which will allow the mother to have an undetectable viral load and avoid other infections. Regarding breastfeeding, the Brazilian Ministry of Health states that women cannot breastfeed, and the obstetrician will inform the mother of the need to stop the lactation process and encourage her to follow the treatment adherence:

> to keep the virus quiet and controlled in the body. That is why the Ministry of Health’s recommendation says that women should not breastfeed. Even if the viral load is undetectable, the mother can pass the HIV virus while breastfeeding, and this risk can increase with herpes in the breast, mastitis… if the viral load of the mother’s blood is high, it is likely that the viral load in the milk is also high…

The coordinator of *Plataforma de Saberes* describes how community health promoters can help pregnant women so they may know to comply with these guidelines:

> the group can work and guide people from the community or families to attend the pregnant health appointments. This is very important, and it is our role to act in prevention by disseminating this information and promoting contact with the health multidisciplinary team (nurses, psychologists, obstetricians…).

By promoting the dissemination of knowledge and guidance to the health system, this form of agency taken by the community health promoters becomes a relevant strategy to approach pregnant women, their families and communities that do not know how to access the health system, or how to have regular follow-ups with the multidisciplinary health teams. These women are, therefore, at greater risk of not complying with treatment adherence and, consequently, at greater risk of vertical transmission. The role of community health promoters is thus linked to prevention, guidance actions and to the resolution of problems associated with the maintenance of pregnant women in the health system, as an infectious diseases doctor states:

> you, as knowledge multipliers, carry extremely important information. A very important message today is that every pregnant woman has the right to an HIV test. One thing is the national guideline, another is what is working. So, you as multipliers... if you know a pregnant woman, or a cousin, a friend, a neighbour, remember that healthcare for pregnant women is universal. Health services, not only infectious diseases but also general practitioners, take care of pregnant women with HIV in specific care centres for mothers and babies in Rio de Janeiro. If women have this information, we already helped…

To avoid the transmission of diseases by breast milk, the paediatrician adds that, in Brazil, mothers whose breast milk dries up receive powdered milk every month until the child's sixth month of life, but there are weeks when there is not enough powdered milk in the public hospitals to provide for this need. K. intervenes at this moment to talk about her experience as a social worker, and shares another view on the guidance given by doctors to women that struggle with breastfeeding:

> Some hospitals don't give the milk, and mothers leave the hospital without powered milk to feed the baby. If she doesn't have it, what is she going to do? It is a social problem… is she going to buy the milk that costs 12 to 15 [Brazilian] reais? No, she is going to breastfeed, which is the natural thing to do, and in a way some mothers think it won't do as badly as running out of milk. In the place where I worked many mothers reported this… During prenatal care, they had all the support, but after the child was born, these mothers felt abandoned with milk that is not natural, provokes cramps in the baby, and the financial hardness… they will eventually breastfeed and stop attending the health system. They are afraid of being criticised by [both] the health professionals because they are HIV-positive and breastfeed, and by society. Also, the medicine that is used to dry up the breastmilk… when she leaves the hospital, she needs to buy it, and it is not cheap, and she also feels judged because of this too! It is very important to care for this

> mother, she is breastfeeding but she does not want to say what disease she has, and sometimes she has no money… We should have another outlook on this!

The questions of the participants are, at first, centred on scientific facts. For instance, one participant asked if all pregnant women are tested for HIV. Another participant wanted to know the probability of the child being born with the virus of an HIV mother with an undetectable viral load:

> What if the child is born with the virus? I read that the child who is born with a positive diagnosis for HIV after some time is not actually HIV-positive, can you talk about this?

Other concerns about care and support given to HIV mothers arose, as we realised from these questions:

> When vertical transmission happens in homeless people, is there anything we can do? We see that HIV risk is higher in unsanitary areas… Let's try to do something about this! Sometimes she doesn't come to the medical appointment because she didn't have money for a ticket, or the family doesn't know she has a problem… can you visit them in their homes?
>
> In the place where I live, in Nova Iguaçu, there are some health clinics but it would be good if you would go there to talk to people… Unfortunately, our neighbours are people who barely know how to sign their name, they go to these clinics and nobody there is prepared to talk to them… they give up the treatment because they weren't well informed… sometimes they go to churches to get information.

One of the infectious diseases doctors reinforces the need for women to have someone close that knows about their chronic situation, and that supports them by listening and caring, because "taking medicine requires a daily discipline that the person who takes the medication has to internalise. It is difficult to comply!". K. adds that "family is very needed, because the mother ends up quitting her treatment to take care of the child". She describes her experience as if it was another woman's experience:

> She didn't want to breastfeed, but her body and society said she had to… Society excludes the mother and forgets that she is a human being who needs psychological support...

The *Plataforma de Saberes* coordinator closes the *roda de conversa* by recalling the role of all of us as community health promoters:

> Where can you look for information that can strengthen you in such a delicate moment? You stop taking care of yourself to take care of your child... listening is fundamental, [as well as is being] welcoming and taking care of the other…

"We Live and Die by the Stories We Tell"

In this text, I share a partial account of the story of *Plataforma de Saberes* as an ethnographic exercise and commitment to an ethical practice and ecological engagement with its ontological trajectory and relational complexity. How I dealt with difference, heterogeneity and the "stories-within-stories" (Savransky, 2021) that emerged during fieldwork is also part of my own encounter and engagement with the existence of a multiple health promotion (Mol, 2002) in an "unfinished composition of forms of divergence, togetherness, and experiment" (*ibidem*: 9). Inspired by ethnographic and collaborative methods (Fortun, 2009; Marcus, 1995; Messac *et al.*, 2013; Pérez-Bustos *et al.*, 2018), I learned to recognise the knowledge and experiences that constitute stories that persist because they are anchored in the lives and struggles of patients and community groups that face exclusion, violence, suffering and oppression.

The creation of the health promotion appointment as a place for caring for stories describes our engagement with persistent forms of exclusion, power and domination in science, starting from the care and attention devoted to those who are vulnerable, whose lives, experiences, knowledge, interests and care needs that are devalued by scientific knowledge. The experience of this collaboration and the commitment with the futures of those who will be most affected by infectious diseases and epidemics is guided by a concern with those who also care for others. It also indicates the need for a renewed attention to the complexity of situations and problems in different parts of the world, as well as to the divergent encounters between biomedical and epidemiological knowledge and knowledge that arise from experience (Savransky, 2012).

Global health is made of complex problems in different parts of the world and ethical dilemmas we must navigate. In the future, I hope to continue to investigate and write stories composed of science, activisms and "ecologies of perhaps" (Savransky, 2020) by caring for knowledge, integrating science and pragmatic solidarity with ethics centred in achieving a dignified life (Povinelli, 2011; Puig de la Bellacasa, 2015). As Martin Savransky says in his recent work (2021: 13), "Stories do things, they infect our lives and practices, they weave and tear worlds, they shape how they might come to be inhabited […]. We live and die by the stories we tell".

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