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Sexual politics and HIV/AIDS activism: the experience of Loka de Efavirenz

Política sexual e ativismo de HIV/Aids: a experiência da Loka de Efavirenz

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ABSTRACT This article describes and analyzes, from an ethnographic perspective, how people participating in the Loka de Efavirenz Collective perceive, experience, and face the effects of AIDS in their daily lives, in order to contribute to the understanding of the new forms of HIV/AIDS activism that emerged in the 2010s in Brazil and their relationship as processes of subjectivation and construction of informal care networks. We show how the members of Loka articulate themselves as subjects crossed by the HIV/AIDS stigma, claiming the exercise of their sexualities and identities marked by gender, race, and class. In this way, they enter the dispute for rights through the production of knowledge and actions that acquire strength in the production of a network of care beyond health services. The analysis of the Collective's practices and elaborations highlights AIDS as a privileged lens to situate the challenges, struggles, discussions, and debates that cut across modes of regulating erotic-sexual practices and gender expressions, reflecting broader social tensions and changes.


RESUMO Este artigo descreve e analisa, de uma perspectiva etnográfica, como as pessoas participantes da Coletiva Loka de Efavirenz percebem, vivenciam e enfrentam os efeitos da Aids em seu cotidiano, com vistas a contribuir para o entendimento das novas formas de ativismo em HIV/Aids que emergiram na década de 2010 no Brasil e sua relação com processos de subjetivação e construção de redes informais de cuidado. Mostra-se como os membros da Loka se articulam como sujeitos atravessados pelo estigma de HIV/Aids, reivindicando o exercício de suas sexualidades e identidades marcadas por gênero, raça e classe. Desse modo, adentram a disputa por direitos por meio da produção de conhecimento e de ações que adquirem força na produção de uma rede de cuidado para além dos serviços de saúde. A análise das práticas e elaborações da Coletiva realça a Aids como lente privilegiada para situar desafios, lutas, discussões e debates que atravessam os modos de regulação das práticas erótico-sexuais e das expressões de gênero, refletindo tensões e transformações sociais mais amplas.

Introduction

Since its inception, the AIDS epidemic has triggered an epidemic of meanings in relation to the body and sexuality, redefining sexualized identities and tensioning processes of moral and sexual regulation. It gave rise to many forms of persecution, demoralization, and dehumanization of faggots, travestis, sex workers, drug users, black people, and immigrants; as well as to survival and struggle strategies of People Living with HIV/AIDS (PLWHA), which developed civic and political mobilization tools to understand and face the political economy of stigmatization and social exclusion.

The Brazilian AIDS social movement, composed of Non-Governmental Organizations (NGOs), networks, foundations, and collectives, has played a fundamental role in strengthening the social groups most affected by the epidemic since its early days. NGOs/AIDS were consolidated as spaces for political debates and the production of bioidentities, articulating with other social movements in a modality of service provision and peer prevention experience that puts Brazil as an international role model. Since the 2010s, the growth of the biomedical focus on Treatment as Prevention (TasP) strategies, supported by the advancement and increasing availability of Antiretroviral Therapies (ART), combined with changes in sources and forms of funding for community prevention actions, has shifted the centrality of NGOs/AIDS in the Brazilian response to the epidemic. In contrast, informal collectives, which gathers people with emphasis on the issue of living with HIV, gained space in the critical dialogue with the policies of Sexually Transmitted Infections (STIs/AIDS) in Brazil. In this scenario of diffusion of the idea of chronicity of AIDS, when the possibility of living with HIV with quality of life seemed to become the “definitive response in the field of prevention”, as long as it adhered to ART, activisms such as that of the Loka de Efavirenz Collective emerged as dissenting voices that tension the narrative that “the epidemic is controlled because there is medicine available”.

From an ethnographic perspective, this article aims to understand how the people participating in the Loka de Efavirenz Collective understand, experience, and face the impact of forms of AIDS management in their daily lives. We seek to show how Loka people articulate themselves as subjects marked by the stigma of HIV/AIDS, claiming the exercise of their sexualities and entering the dispute for sexual rights through the production of knowledge and actions that go beyond the individual scope and produce a network of care in addition to the health services. We consider that the practices of the Collective contribute to an intersectoral and intersectional critique of the epidemic, ranging from problems of access to health services by black, indigenous, trans, and travestis people to difficulties in adhering to treatment in contexts of structural and institutional violence.

The concept of sexual politics, which underlies the analysis, emphasizes the complex and heterogeneous nature of the ways of regulating sexuality, allowing different forms of public intervention to be approached together, including several types of activism and social movements. In addition to arguments and concepts of a technical and scientific nature, moral values, principles, and political positions involving confrontations and coalitions of different subjects and social forces are at stake. Since its outbreak, AIDS has repositioned and changed questions about personal behavior, morality, and social policy, dramatizing tensions and collective anxieties accumulated around erotic-sexual practices and gender expressions. The experience of the Loka de Efavirenz Collective helps to capture part of the recent dynamics of the ways of regulating the epidemic, highlighting AIDS as a privileged lens to situate the challenges, struggles, discussions and debates that cross sexual policies, reflecting tensions and wider social changes.
Methods

The ethnographic research that underlies this article is part of the master’s dissertation of Pisci Bruja Garcia de Oliveira, supervised by Júlio Assis Simões. This research explored the increasing stigmatization of PLWHA in association with the resumption of attempts to criminalize HIV transmission, in a scenario of increased records of HIV infection in young populations of trans and travestis people, gay people, and other men who have sex with men (MSM).

To address aspects of the knowledge production, articulation, and activism of the Loka de Efavirenz Collective (hereafter referred to only as Loka), we used data obtained from interviews and conversation circles with participants, as well as observation reports and social media records, in addition to field notes taken by Pisci Bruja while participating in the 22nd International AIDS Conference (AIDS 2018) in Amsterdam.

The interviews and the conversation circle are inspired by the methodological proposal of co-research, to highlight the shared, discussed, and jointly constructed character of Loka’s reading of AIDS, although its members are today in different places in the academia (anthropology, collective health, psychology, philosophy, geophysics, sociology, arts, languages), in institutional politics (one participant is a councilor in a joint mandate) and in the artistic and cultural scene, acting as performers, poets, and cultural producers, among others. The conversation circle is a form of debate and construction of shared knowledge that is part of the repertoire of several contemporary activisms. The conversation circle can pave the way to form, review, and change opinions with more depth and reflection, supported by the memory awakened by the dialogue, as a privileged and singular moment for sharing and exchanging experiences, speech, and listening, in which fraternization, venting, agreements, divergences, and ponderations can fit.

Pisci Bruja, the co-author of this article, also participates in the Loka, which gives the research a partially autoethnographic dimension. Although she mostly talks about her own experience with living with HIV/AIDS, the autoethnographer starts to analyze broader social and political issues, as she also refers to experiences shared and engaged with other PLWHA narratives and which, except for their intersectionalities, are similarly crossed by the power relations constituted by the different understandings of the epidemic. Thus, the exchanges generated from the conversation circles produce knowledge apprehended through the body itself that, in its movements and encounters with different environments, people, objects, experiences various emotions, thus enabling the re-elaboration of numerous processes around stigma and the formation of informal care networks.

What is Loka de Efavirenz?

Loka is a collective of young people (today between 20 and 35 years old) living with HIV/AIDS. The vast majority call themselves black, although the collective has some white people: Pisci Bruja, Ladyane Vieira, and Beatriz. Initially, Loka was composed of cisgender people, but this picture also changed when at least three members transitioned and became travestis. Most were born in São Paulo and live there. There are also members or collaborators from Maranhão and Bahia, as well as paulistas (those who were born in the state of São Paulo) who now reside in Rio Grande do Norte and Paraíba.

Loka emerged in 2016, from the course ‘Youth Participation, Activism, and Human Rights in HIV/AIDS in the State of São Paulo’, organized by Carolina Iara, Lili Nascimento, and Renan Moser. This course, promoted by the Rede de Jovens São Paulo Positivo, in partnership with the State Coordination of STD/AIDS of the State Secretariat of Health of São Paulo (SES-SP)
and supported by the United Nations Joint Program on HIV/AIDS (Unaids), brought together young people with the objective of building mobilizations in the face of the new challenges of the epidemic. It was in this space that most of the current members met and started to collectively build a network of affective support, material strengthening, and subjective reconstruction.

In the beginning, it was not only AIDS that affected them, but also poverty, hunger, the side effects of medications, among other vulnerabilities. Living ‘illegally’ in the Residential Complex of the University of São Paulo (Crusp), those who studied at the university shared their plate with those who had nothing to eat. Or, when this was not possible, they would go to the street market called Ceasa, seeking and collecting leftovers of fruits and vegetables to feed the group. Thus, the bonds were established through nourishment and sharing of the pains and joys of lives affected by violence. Their union was necessary for them to go through the most difficult moments and survive. The Lokas, in their own words, came together to survive.

During almost three years (between 2016 and 2019), Loka was building itself as a sharing and intervention group, creating a Facebook page with collective reflections. The discussions, mostly about AIDS, used to take hours and usually occurred during special moments while cooking, which would make them ‘put AIDS on the table and transform pain into joke’. Mockery, a characteristic that has always crossed Loka, is a way to ease the pain and help to ‘heal the wounds of life’. Several opportunities for actions began to emerge beyond Facebook: invitations to discuss AIDS and develop activities on safe sex, performances and other interventions in universities, national and international conferences, sex parties in São Paulo, as well as to writing and reflecting on various digital platforms. Loka started to compose other institutional spaces, such as the Rede de Jovens São Paulo Positivo, and to build political articulations and interventions in the Legislative Assembly (ALESP) and SES-SP. Some members returned to university, to finish their undergraduate studies or start a master’s degree. In addition, they even raised funds from public notices, such as VAI 2019, from the Municipal Secretariat of Culture of São Paulo, in which they developed the project called ‘Avivamento do Corpo PositHIVo’ (‘Revival of the PositHIVe Body’, throughout the first year of the Covid-19 pandemic.

Most Loka members named this process of collective construction and strengthening as ‘aquilombamento,’ an ancestral strategy of social organization and production of technologies that allowed black and indigenous people to survive the genocide. According to Beatriz Nascimento, the word ‘quilombo’, which means ‘union’, refers to an African social institution that allowed the incorporation of people through relationships of ‘initiation’ that transversally cut the structures of lineage. In the context of diaspora and slavery, the quilombo became a symbol of black resistance to oppression and the projection of an autonomous form of social organization. Thus, by translating bonds created through the ‘initiation’ of living with HIV/AIDS into an instrument of affirmation and resistance, many of the Lokas were able to get back on their feet, dream, and prospect for the future.

As in other experiences recorded in the literature on HIV/AIDS activism, the act of sharing memories and meanings opened up new horizons and perspectives for what seemed to be a single path. With the construction of safe spaces, exchange, maintenance of care and production of knowledge, Loka also moved from ‘HIV-prophecy’ to ‘HIV-territory,’ from curse to access to health care, reception and exchanges. Therefore, in general, Loka is understood as a space to produce knowledge, affection, and heal.
AIDS in question: crossings and perceptions of Loka

A conversation circle offered most of the issues discussed in this section. Marcelo Jardim, Lili Nascimento, Carolina Iara, Ramon Soares, Ya Mattos, Cadiva (Carlos Eduardo), José Daniel, and Pisci Bruja participated in the conversation. The triggering issue was raised by Pisci Bruja, who mentioned the main aspects of the criminalization of HIV transmission raised in her master’s dissertation. The construction of the categories ‘with AIDS’ and ‘risk group’, ‘AIDS policies’, the current LGBTQIA+ movement in Brazil and moral, political, and religious disputes motivated by accusations of alleged intentional HIV transmission were discussed.

Between 2010 and 2018, Latin America recorded an increase of 7% in the number of HIV infections, according to the 2019 UnAids report. Although between 2010 and 2013 there has been a decrease in the number of infections in Brazil, the number of cases increased on the continent in the remainder of the decade, with an individual growth of 21%. The epidemic has become more concentrated again, with an increase in the number of HIV infection, especially in the younger population, between 20 and 34 years old, mostly black and brown people. Regarding AIDS mortality, between 2010 and 2020, there was an increase of 10.4% in deaths among black people, with black cis women presenting 62.9% of deaths. Similarly, when looking at the population groups most vulnerable to HIV infection, an epidemic growth was identified among gay people and other MSM cis, with a detection rate of 18.4%. The population of transgender women and travestis was the most prevalent, with estimated rates above 30%, while there are no epidemiological data on HIV/AIDS for transgender men and trans masculine people.

In this scenario, it has been quite common to encounter discourses stating that HIV infections would be advancing in young people because they have lost the ‘fear’ of AIDS, or because, as there is treatment, there would be no more danger of dying. These statements are widely questioned in the social AIDS movement and also contradict the experiences of Loka members, who recalled, for example, the occasions on which they were tested, when there is always tension in the air. As Ramon commented: “I find this moment of the exam curious when everyone is waiting there. You feel the tension on your skin... there is tension in the air.”

Receiving the drugs at the antiretroviral dispensing stations is, likewise, a moment of distress and discomfort. As Cadiva reported:

_i always feel, and it may be that you realize otherwise, that even in the space, in the pharmacy, where you receive the medication, tension is in the eyes, i don’t know whether it is the fear of judgment... or sexual tension..._

The difficulties and emotions involved in the occasions of testing or picking up medication become a daily nuisance for people who experienced the haunting of having contracted HIV, such as an ‘HIV-prophecy’ (as Ramon mentioned: “In my mind, it is something... it is almost an equation: this is equal to this”); or, for the PLWHA, who pick up the medication or are simply in a specialized HIV/AIDS service these are embarrassments they wanted to avoid, as Pisci said:

_for more than a year, my mother was the one who would get my medications in Santo Amaro. I was really ashamed... for me, it was as if AIDS was written on my forehead._

Many PLWHA suffer numerous processes of mental illness and low self-esteem because they are ashamed and guilty of their condition. Therefore, it has also been common for this self-stigma – that is, this “limited capacity of a certain person to resist the symbolic apparatus that legitimizes inequalities of power” – to become decisive in restructuring social relations.
In addition, many labor relations are also impacted by the stigma of HIV/AIDS. According to the information released at an inter-ministerial meeting in 2016 between the Ministries of Health, Labor, and Social Security\(^3\), between 60% and 70% of PLWHA do not have formal jobs\(^3\). According to Carolina Iara’s report – for whom AIDS has become a ‘travestility assumption’ due to the way it was built and considering the degree of marginalization of trans and travestis people – there are other concerns at stake:

[...] I noticed it in the cinema, at Largo do Arouche. There is a hierarchy: the beautiful ones, the ugly ones, the xuxuzentas [who have beard or hair on the face] or not. AIDS also enters this hierarchy. Then one teases the other, saying ‘oh, that one is doce (sweet), that one there is doce, there is the tia (aunt) etc. [‘doce’ and ‘tia’ refer to HIV]. And this becomes a hierarchy, of those who charge more and those who charge less... And there is also the attempt to undervalue the others in front of the customers. This happens too!

According to the Stigma Index in relation to People Living with HIV/AIDS in Brazil, of the 1,492 research participants, about 379 (25.4%) claimed to have already avoided testing due to fear of the stigma of AIDS\(^3\). In this sense, the construction of an affective-political network, Loka, focuses on the transformation of this fear and guilt: “Loka’s work makes me understand that it is not my fault, I can have relations without being afraid of HIV,” said Cadiva.

When Cadiva mentions ‘having relations being afraid of HIV,’ she refers to everything that permeates the daily, sexual, and affective relationships and experiences of PLWHA. The issue of stigma and its consequent production of power asymmetries generates greater pressure around the responsibility for the prevention of the other, as well as organizes a new ‘risk management’ in PLWHA. This has developed in diverse ways: when ‘positives’ begin to relate only to other ‘positives’\(^3\); they transform their behaviors into a process of ‘personal self-modeling’\(^3\); they apply to their lives a kind of ‘preventive altruism’\(^3\); they manage the possibilities of care and co-responsibility through an ‘ethics of transmission’\(^3\), and they create strategies to expose or not their own serology to their partner\(^1\).

The issue of preventive liability is disproportionately charged to PLWHA, which is evident in the progress in the processes of criminalization of HIV transmission in Brazil. Between 2013 and early 2020, there was a proportional increase in the number of criminal cases for alleged intentional HIV transmissions three times greater than in the first 30 years of the epidemic\(^3\).

This process of advancing the judicialization of health, accompanied by the increasing constitutionalization of social rights, becomes a double-edged sword, because, while it allows rights to be assured, it also contributes to these rights being increasingly subjected to the scrutiny of legal institutions. Thus, if there is, on the one hand, a power in the sense of claiming rights to health, there may be, on the other hand, a series of challenges, contradictions, and even a ‘suffocation’ of participatory mechanisms\(^3\), depending on how the judiciary is operationalized.

In this sense, the criminalization of HIV transmission goes against the rights of PLWHA by requiring that only them have to reveal their serology to their partners if they want to have sexual intercourse without using condoms, ignoring the stigma and the ‘undetectability’ provided by the adherence to antiretrovirals – that is, when the viral load in the bloodstream is zeroed through the regular use of drugs and the AIDS situation and the transmission of the virus itself is avoided. These are processes that use the stigma to control the sexual and social conduct of PLWHA in the name of the ‘social order’\(^3\). The intersection between transphobia, AIDS-phobia and racism makes Carolina Iara’s social, sexual, and affective experiences permeated by these tensions:
after I transitioned, I think the fear of being criminalized increased. I lost sexual freedom. I used to do some things in the field of sexuality that I no longer do. And that was out of sheer fear of being raped, fear of a series of issues. Transphobia plays a role in this.

In criminal cases of HIV transmission tried in the court of appeals in four states (São Paulo, Rio de Janeiro, Minas Gerais, Rio Grande do Sul) and in the Federal District, which have been analyzed since the beginning of the epidemic until the end of 2019, there were no cases in which the use of biomedical discourse by the court system managed to advance and talk about prevention besides condoms and the false idea that AIDS no longer leads to death7. The undetectability and untransmissibility caused by the use of antiretrovirals were not considered to absolve any cases of supposed HIV transmission until that date7.

Still regarding the legal aspects and the understanding of the epidemic, Carolina Iara said that she went to court to obtain leave from work (in the hospital) during the Covid-19 pandemic and believes that this was only granted because of how the court system sees the experience of living with HIV/AIDS.

I think that in the court system, they still see some people as ‘people with AIDS.’ I see this because of what I am having to deal with the city hall. Usually, I am not treated as a person living with HIV, I am treated as a ‘person with AIDS.’ It is even this notion that keeps me away from work at this moment, because if there was an understanding of undetectability or viral suppression and living with HIV, I would probably have gone back to work.

Understanding that AIDS cannot be solved only with medication, but with policies of social reparation and combating stigma, Loka systematically criticized the biomedical approach of the epidemic present in the last decade, which fed the idea of the ‘end of AIDS’ as a possible strategy until 203040–42. The name of the Collective questions this direction and seeks to resume the interrupted debate around the side effects of drugs43, symbolized in Efavirenz, an antiretroviral widely used in Brazil in the form of a triple dose combined in a single pill. As a mockery, for a long time Loka has presented itself through her avatar photo on social networks with pills stuck in her nose and mouth, problematizing the routine medical advice that it is only necessary to ‘take a little pill.’

However, this does not mean that Loka does not recognize the immense importance that the use of antiretrovirals had in the reconstruction of their subjectivities and in the possibility of starting to think about a future again. Lili Nascimento, a person born with HIV, raised the issue of the differences she feels in relation to those who seroconverted at some point in life. She points out that “those who discover afterwards keep on saying ‘oh, I’m going to get the medication,’ ‘oh, AIDS…’; ‘oh, I can’t even talk about it...’”, and compares with what she feels as a person who has always lived with HIV:

I think the vertical transmission is coming in another pace... I think we can celebrate the revolutions, you know? I think that because we had AZT, we arrive at this moment now, it is much more concrete for us... living with HIV, this change from ‘AIDS’ to living with HIV. We felt it historically, we grew up with it, right?! I think that is the main difference from one group to another.

Initially, the term ‘AIDS’ was very present in public discourses, which produced a subjectivity shaped by risk, danger, guilt, shame, and fear of death, whose understanding is still updated in some instances and institutions. As a reaction to the punitive process of subjectivation as a bioidentity risk7, as an example of what should not be or do, there was a historical journey towards the humanization of PLWHA44, largely built by social movements.

Moreover, the evidence that undetectable is equally untransmittable has also emerged
as a revolutionary aspect in the sense of transforming ‘positive’ subjectivities. This recent bioidentity, made possible by the use and adherence to antiretrovirals, and brought by activists, researchers, and institutions through the ‘Undetectable = Untransmittable’ campaign (I=I), is beginning to grow in Brazil, and has acquired global status from the 22nd International AIDS Conference held in Amsterdam in 2018.

According to studies conducted by Kane Race on the sexual practices of PLWHA that do not use condoms, in Sydney, Australia, ‘undetectable’ has been a category mobilized among these groups, including in place of ‘posithive’, since 2015. Similarly, as observed in the field while participating in the AIDS 2018 and the 4th International Conference on Human Sciences and HIV, Pisci Bruja could note, when walking in spaces of gay sociability in Amsterdam, that the vast majority of cis gay men living with HIV/AIDS no longer identified themselves as ‘HIV positive’, ‘HIV seropositive’ or ‘people living with HIV’. They mostly referred to themselves as ‘undetectable’ people, which sounded almost like a new ontological status: ‘I am undetectable.’

Thus, this new bioidentity tries to re-signify the notions of risk and transmissibility of the virus, and connects with the current biomedical and state discourses (as in the Brazilian case) of TasP, an approach that, paradoxically, tends to minimize the structural dimension of vulnerability to HIV and the participation of PLWHA as autonomous producers of prevention and care practices. Evidence of undetectability and untransmittability is becoming increasingly familiar and appropriate in the daily lives of many PLWHA, in their sexual practices and affective relationships, as a new tool to cope with stigma. Risk is being recalibrated, which now seems to be moving towards the notion of ‘no risk,’ transforming the sociability of living with HIV/AIDS.

Conclusions

This article sought to contribute to the understanding of the new forms of HIV/AIDS activism that emerged in the 2010s in Brazil, focusing on the experience of the Loka de Efavirenz Collective. In this effort, we also made a brief journey through the social dynamics and policies associated with the experience with HIV/AIDS.

The presence of the ‘AIDS device’ in the fourth decade of the epidemic can be understood as an integral part of the new cultural and sexual wars that have recently intensified with the advance of various modalities of moral and religious conservatism in Brazil and worldwide. The current attacks of conservative and religious fundamentalist sectors, in their resumption of discourses of blame, mistakenly supported by the increase in HIV infections in a concentrated way, have disturbed the processes of ‘citizenship of sexual subjects’, aiming to dismantle the notions of human rights, especially in relation to sexual and reproductive rights. Parallel to the hegemony of biomedical discourse on AIDS, we live in Brazil in contradiction under constant disputes for the maintenance of the Unified Health System (SUS) and AIDS policies, seriously impairing treatment and prevention due to the lack of or the division of medication, lack of viral load tests and CD4.

In this scenario, a daily dimension of the criminalization of PLWHA persists, which transforms apparently simple situations into major problems, constraints, and afflictions, such as performing HIV tests, withdrawing medications, relating sexually and affectionately, going to school, working, attending toilets, sharing objects, and even talking about AIDS. The persistence of stigma in relation to PLWHA in social relations and institutional treatment, despite all biotechnological advances and the production of knowledge of the social AIDS movement is strongly allied to the production and cultivation of hatred against some groups and populations, marked
especially by their sexual and gender expressions, in the defense of a specific morality that does not hinder the advance of criminalization, but produces and feeds on it. The AIDS epidemic is not increasing because young people have lost their fear of AIDS, but because they are not recognized as subjects of their sexuality nor have their rights to integral health guaranteed.

It is in this scenario of moral and political disputes that Loka de Efavirenz emerged. From precarious lives, an affective-political network was formed, producing knowledge and elaborating strategies to face the multiple forms of segregation, demoralization, and dehumanization of experiences with HIV/AIDS. Since the middle of the last decade, Loka has been articulating and developing collective strengthening strategies, now considered a reference in youth activism in HIV/AIDS. By supporting themselves daily in multiple spheres, they have built a network of care based on the construction of safe relationships and sharing spaces aimed at forging new possibilities of life.

Collaborators

Oliveira PBG (0000-0001-6864-3422)* participated in the conception of the study, collection, analysis, and interpretation of the data, writing, critical review and approval of the final version of the manuscript. Simões JA (0000-0002-9000-3621)* participated in the study design, data analysis and interpretation, writing, critical review and approval of the final version of the manuscript.

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