

An essay on the chronicity of living with HIV/AIDS in childhood, adolescence, and youth

Um ensaio sobre a cronicidade do viver com HIV/Aids na infância, adolescência e juventude

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ABSTRACT This essay works on the intertwining of time using the notions of experience, memory and disturbance from a socio-anthropological perspective to discuss the chronicity of living with HIV/Aids in childhood, adolescence and youth. Following the essay definitions, we propose a conceptual craftwork that offers another way of looking at stigma, precariousness, vulnerability, and chronicity. We invested in a perspective that faces the barriers of living produced by stigma, discussing to what extent chronicity can accentuate the precariousness that constitutes humans, although for many, due to their social location, it can mean greater precariousness and vulnerability; considering that, when one is a child, adolescent, and youth, this precariousness can lead to an impossibility in the flow of affections, in the fundamental daily exchanges within groups, and to a constant feeling of inadequacy.

KEYWORDS Chronic disease. Acquired Immunodeficiency Syndrome. Adolescent. History.

RESUMO *O presente ensaio trabalha nas dobras do tempo, acionando as noções de experiência, memória e perturbação, a partir da perspectiva socioantropológica, para discorrer acerca da cronicidade do viver com HIV/Aids na infância, adolescência e juventude. Seguindo as definições de ensaio, propôs-se um artesanato conceitual que ofereça outro arranjo de olhar sobre estigma, precariedade, vulnerabilidade e cronicidade. Apostou-se em um olhar que enfrente as barreiras do viver produzidas pelo estigma, discutindo em que medida a cronicidade pode acentuar a precariedade que constitui os humanos, mas que, para muitos, em virtude de sua localização social, pode significar maior precarização e vulnerabilização; considerando que, quando se é criança, adolescente e jovem, essa precarização pode levar a uma impossibilidade na circulação dos afetos, nas trocas cotidianas fundamentais dentro dos grupos, e a uma sensação constante de inadequação.*

PALAVRAS-CHAVE *Doença crônica. Síndrome de Imunodeficiência Adquirida. Adolescente. História.*

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Introduction

In this triple-authored essay written by researchers who have worked together for more than 20 years, we observe that in the transition from the 1990s to the 2000s, especially in the last decade, we have witnessed a transformation of clinical and technological basis, as well as of theoretical and methodological conceptions, which has displaced AIDS from its fatalistic aspect, of the almost immediate end of life, to a place of chronicity and daily management of HIV infection^{1,2}.

This essay arises from this joint observation. The notions of experience and memory sustain the reflections. According to Meneghetti³, the essay is based on questions that generate deep considerations; or yet, as suggested by Bondia⁴, it appears as a hybrid genre supported by a clearly subjective time and space. The author defends the essay as a thought in the present and for the present, a place of the authorship of thought in the first person, based on critical distance and conditioned in its existence to the writing process.

As a theoretical essay, it is not absent from evoking the research records we have carried out in which certain extracts of narratives tell us about a certain thread of history in the health of children, adolescents and youngsters living with HIV/AIDS – ‘characters’ built upon the ‘fight’ against the disease and in the set of political and social responses to it⁵. This construction enables us to trigger personal and collective memories and archives questioning them from a present time of our concerns in dialogue with other moments in the ‘history of AIDS’, observing transformations and continuities over more than 20 years of study in this field.

At the same time, following the essay definitions, we need a conceptual craftwork that, when (re)visited offers us another way of looking at stigma, precariousness, vulnerability, and chronicity. In other words, we look at HIV/AIDS in the interface with chronicity searching for other interpretative keys,

putting it under the perspective of a web of relationships whether those established in the course of our research or those produced by the interdisciplinary interweaving of different theoretical frameworks.

Our argument in this text is based on the idea that the affirmation of life in the experience of chronicity takes place in a complex map of at least two moments of the epidemic: ‘before’ and ‘now’. In these moments, there remains as a common thread a ‘disturbance’ in the condition of living with HIV/AIDS, instigating us to revisit this field questioning it as experience and dramaticity in the context of care and research with children, adolescents and young people living with HIV/AIDS.

The construction of young people living in this expression that suppresses ‘with HIV/AIDS’, is forged in a moment of positivization of those who were once ‘condemned to death’. These subjects who ‘to exist’ need to get rid of some embarrassments in a field that: starts to defend sexuality as a right and health; hides sickness and death; omits reproduction and ‘prevents sexuality’; expresses itself in a context of scarcity and material and symbolic precariousness, paradoxically concealed as responsibilities and expressions of individual life⁵.

Such a dimension, therefore, is analyzed in its folds, in what is not immediately perceptible seeking to capture the vibrant dimension⁶ of experiences, memories, and encounters with this group – which, marked by partial responsibility and reduced autonomy due to their age, are interpreted as ‘uncontrolled’ in the exercise of sexuality, ‘carriers of’ a virus linked to deviation and lethality, and earn the attribute of promise for the future⁵. From this point on, we ask ourselves: what, despite all the social and technological advances, does living with HIV/AIDS still refer to the ‘drama of the human condition running through one’s own veins’⁷? What is placed as proper of childhood, adolescence and youth in this stigmatized arid terrain of many doubts and uncertainties? What would be characterized as a giving up on

life or as the ‘potency of life’ – which allows us to make our own deterritorialization a subjective territory?⁸.

The experience of chronicity with HIV/AIDS happens through this complex map of experiences dictated by living with the ‘disease’ and the various stages of the epidemic. In this picture of multiple subjectivities under construction marked by biopolitical dimensions and technologies of the self⁹, we observe resistance and lines of escape related to: the bodies that remain (re)acting to/in the world in spite of the infection and the therapeutic possibilities; the management of the secrecy of the diagnosis and the stigma; the support provided by associative actions, non-governmental organizations, activist networks, and social movements; the new drug and prevention technologies; the improvement in the therapeutic program with the reduction in the number of pills and side effects.

All these experiences sometimes contradictory, oscillating between the rhetoric of success, hope and failure come together in the ‘various AIDS’; in what we call ‘AIDS before’ and ‘AIDS now’, and their different times of ‘living with’ and of the social and political responses developed in that field⁵.

We understand that at the base of chronicity lies the temporality of care as interdependence and recognition of human precariousness which is accentuated in the handling of illness. For this definition, we have turned to Kittay¹⁰, Butler¹¹, and Honneth¹². Since the experience of illness refers to extended care relations, it is necessary to radically resume interdependencies and precariousness as something that refers to the human condition¹¹. These intersects with the struggle for recognition that begins in childhood. This structure depends on a safe environment and the conviction that one is recognized in an intersubjective movement and in interaction. Moreover, to be recognized and motivated in having positive experiences is to trust oneself and feel valued, respected, and welcomed. Kittay¹⁰ attains a critique of the idea of independence through a

feminist perspective on disability. To this end, she reaffirms dependence as a value that humanizes us and which refers to the relational environment of care. Being interdependent is part of the human condition. In this essay, in which we bring chronicity into dialogue with a temporality for HIV/AIDS, it is important to highlight that disability even if it is not dealt with here in its specificity – which is triggered on the basis of the formulation of an Ethics of Care by Kittay¹⁰ – may become a constant presence due to the emergencies generated by epidemics and pandemics, in which the HIV/AIDS epidemic is placed¹³.

In this definition, we shall provoke the field of care practices and their practitioners on how we interpret children, adolescents and young people in this typology of the ‘times of AIDS’. This action justifies this essay in its provisory nature as a trigger to reflect on care, whose interdependencies are in tension with the mediation of stigma¹⁴.

Thus, the questions that permeate this work are: to what extent the experience of chronicity, and no longer the lethality of living with HIV/AIDS, is effectively incorporated (in the sense of producing bodies and new subjectivities) to the point of diluting the stigma that historically constitutes this field? What are the metamorphoses that the senses of ‘danger’ and ‘risk’ go through since the existence and availability of prevention technologies for pre- and post-exposure to HIV? How can the recognition of care as constitutive of an affirmative politics of our precariousness help to confront the stigmas attached to the experience of chronicity?

We are interested in analyzing the place of creation of possible existences in the midst of the chronicity of the disease, taking as an analytical scenario two historical times of the HIV/AIDS epidemic which have as an insertion the emergence of the High-Potency Antiretroviral Therapy (HAART), the cocktail, as it is known. It makes a radical difference between dying and living. Such change not only allows a radical turn in the experiences in

the ways of living life, but also starts to dictate the policies and care practices in the field of childhood, adolescence and youth living with HIV/AIDS built upon the memories and embodied experiences of our interlocutors and of ourselves, health professionals, and researchers among many successes, failures and constraints.

AIDS configurations in childhood, adolescence and youth: 'AIDS before' and 'AIDS now'

The idea of 'two AIDS', before and now, was born in another study context⁵, being now resumed from new elements. As emic categories, transformed into analytical categories, they intend to question changes brought about in the course of the epidemic, especially after the introduction of ART, allowing to move from an AIDS in which one died to another in which one lives. Such categories, related to the different temporalities of the epidemic, bring together a set of material and symbolic changes that allowed building in the 'history of AIDS' an 'AIDS before', as a 'catastrophic narrative' that compiles failures, frustration and suffering, and an 'AIDS now' as representative of a 'heroic history' of the knowledge achievements that have been accumulating and allowing increasing levels of intervention on the clinical and epidemiological reality¹⁵⁽²¹⁾.

Thus, we propose a new layer to the 'AIDS now'. When we resume these typologies, we realize that the 'AIDS before' is marked by the idea of 'absences' of answers, of medicines, and the possibility of the continuity of life. On the other hand, 'AIDS today' makes a turn in the sense of re-signifying an entire experience with the disease, which started to be guided by the possibility of life, and with quality, bringing as emblems the 'future' and the 'potential' of a generation until then seen as unviable and marked by death and invisibility.

The new layer of the 'AIDS now' refers to the recent transformations in treatment and prevention guidelines and policies forging even more the biomedicalization of bodies within the epidemic and, in a way, seen as 'universal', that is, supposedly disentangled from their social groups and marks of gender, class, color/race, and generation. Paradoxically, in some cases they emerge apparently attached to certain social markers of difference, with a visible predominance of the notion of epidemiological risk in this understanding and in the redirection of responses to the epidemic. This is embodied in the expression 'key population' - some population segments considered as 'more vulnerable to HIV/AIDS' since they would present 'higher prevalence than the national average': transvestites, transsexuals, gays, men who have sex with men, people who use alcohol and other drugs; people deprived of freedom, and sex workers.

To build our stories and memories and incorporate the two 'AIDS' contexts, we will construct them as 'movie scene cuttings' (cutting in film and audiovisuals is the passage from one shot/scene to another), composed from transition field that we consider exemplary in the sense that they contain thematic and emotional densities in the scope of interactions capable of elucidating the core of the issues at stake, and bring the necessary intensity to the point of representing many other observations made within the scope of the research. In the scenes, we value the 'cutting' that ends one to start the next. We follow, therefore, the leads of Deleuze and Guattari¹⁶⁽²⁷⁾ - "It is a whole because it totalizes its components, but a fragmentary whole" - to affirm that the concept refers to the question of articulation, cutting, and superposition.

First scene: 'AIDS before'

Our first research experience dates back to the year 1999, when we started a work of psychological assistance and study with the then-called 'children and adolescents living

with HIV/AIDS', and their families, during hospitalization in a reference hospital for the treatment of severe chronic and infectious diseases. The investigation gathered a qualitative record with observations and interviews with health professionals and with hospitalized patients and their companions, often mothers and grandmothers¹⁷.

The health situation of children and adolescents was almost always very serious. The discovery of the HIV infection was frequent after a serious and painful illness resulting from the disease manifestation. Most of the children and adolescents were in advanced stages of AIDS due to problems of 'adherence' to treatment because of late diagnosis and poor evolution of the disease.

Not rarely, we heard complaints from patients and family members about the strong side effects of the medications such as diarrhea, vomiting, skin rashes and dizziness, among others, which made them stop the medication, besides aspects such as having to deal with difficulties in administering the 'bad-tasting' medications and with situations of prejudice and discrimination arising from the stigma of the disease.

Our contact with these children and adolescents was always in very delicate and emotionally stressful situations. Many of them had lost parents and siblings and orphanhood and death were looming over them. Many times, we found them quiet, unappealing, weary, and tired of the medical interventions and of living with illness, complaining about the invasive effect that the technical procedures had on their bodies.

A scene that portrays well this situation was performed by Tim, a 6-year-old boy, in the context of an intervention using game playing as a therapeutic tool¹⁷. Our encounter with him took place during one of the many hospitalizations that marked his early life history. On that day, Tim was unaccompanied, his helplessness was visible and his arms were purplish from so many vein hits. At his suggestion, we went to the corridor leading to the wards to walk

with a doll in a toy stroller. We kept walking from one end to the other playing with closed and open signals. On this walk, the boy suggested that we take the doll out of the stroller so that she would stand on a dividing line on the floor as if she were crossing a street. In his second proposition, Tim came racing and with all his force and ran over the doll with the cart and then exclaimed: "*she's all broken up!*". After the successive runs over, the boy would go into the infirmary and with the nursing materials make the bandages. This game was repeated several times, and later, the roles were inverted; he would hold the doll to be run over by the therapist and both would do the bandages.

Tim's case was part of our discussion about the function of the role of playing in the hospitalization context, but this is not our focus now. What we would like to emphasize here is how physically and emotionally 'broken' these children were and that in the face-to-face with them – as health professionals and researchers – we were not far from the images of 'AIDS contagion',

one of the strongest images of the other as a source of threat and danger, raising a generic fear in which contact is perceived as a possibility of aggression¹⁸⁽⁹⁸⁾.

It was hard for us, despite being fully aware of the ways of HIV transmission, to recognize ourselves as being afraid or fearful of skin-to-skin contact and with secretions such as saliva, sweat and tears of these children and adolescents. This was a field where, arduously, we 'researched the pain' of childhoods and adolescents that seemed to live under an inverted sign of life: pain and suffering prevailed more than the vigor of life in the common representations of childhood.

In this context, the moments of 'diagnosis revelation' were part of the 'war metaphors': stories about the bad soldiers (the virus) and the good soldiers (the antibodies). However, we were aware that "war is not an innocent

and casual metaphor”¹⁵⁽¹⁷⁾ since it creates representations and dictates the very course of the understanding of the disease and the social and political responses to it.

In this context, when health professionals were ‘fighting the disease’, there was a strong optimism, despite the strong side effects of the medications. The cocktail was at its peak. Its universal and free availability in public health services was recent. The memory of ineffective therapies that were difficult to access for the general population was still very vivid. Very little was enough to save more and more lives; and the main criterion was ‘adherence’ to treatment, which depended essentially on how patients would face this situation.

However, AIDS did not stop being seen and felt as a serious and fatal disease. Its lethality was still very much emphasized by health professionals. Thus, death was on the horizon and the disease still killed, and very much so.

On the part of mothers and grandmothers who take care of their children and grandchildren, the adherence to treatment took on different contours from those perceived by the health team permeated by stigmas and negative representations of AIDS. There was also an overwhelming feeling of guilt on the part of mothers due to vertical transmission (from mother to baby) and shame on the part of grandmothers in having to manage a disease linked to sex and promiscuity. Thus, to adhere or not to treatment seemed to be less a ‘choice’ for these people than the result of a struggle of the most diverse forces in the face of shame, fear, discrimination, poverty, and family and religious beliefs provoked and challenged by the disease.

In this context, the case of adolescents was particularly emblematic. As they were considered by professionals as essentially ‘problematic’ due to the phase of life they were in, ‘full of hormones, doubts and uncertainties’, and for having some ‘level of awareness’ of their seropositivity and the stigma that weighed on them, they were seen as ‘rebels and rebellious’, making a satisfactory treatment unfeasible¹⁹.

The relationship between the ‘disclosure of diagnoses and ‘adherence’ was close. The knowledge of serology was the condition and the assumption of not ‘exposing others’, that is, not transmitting the virus through sexual means. However, it is interesting that, even though strongly considered, this possibility was not exactly conceived as a ‘reality’ at that moment, but rather projected as a ‘near future’ even though it already demanded reflections and preparations.

The ‘problems of adherence to treatment, disclosure of the diagnosis, and prevention’ appeared interconnected in the field and constructed the moral subjects themselves⁵. On one hand, the disclosure of the diagnosis had as a goal an ‘awareness’ of the adolescents as to their understanding of the extensive and intense experience of treatment and hospitalization – an aspect almost always neglected for the child for the cause: AIDS, configuring the secret kept by families and by the health team. On the other hand, taken as a presupposition for future prevention, it gains other contours of adolescence and the sexualization of life as if it had not been before that.

End of scene.

Second scene: ‘the AIDS now’

“You are the future!”. An activist enthusiastically exclaimed to the Young People Living with HIV/AIDS (JVHA) during the Positive Prevention Seminar: state of the art, held by the Brazilian Interdisciplinary AIDS Association (ABIA) in the end of October 2007, in Rio de Janeiro. It was from this first impression in our return to the field of HIV/AIDS studies, that we were able to deduce that part of the construction of the emic category of young people living was a result of a movement of positivation of these young people⁵.

‘Health’ appeared as a value to be cultivated and preserved with the emergence of a certain ‘obligation to be a happy (sero)positive person’, thus the expression we coined ‘happy AIDS and an educated level of pain’. Being healthy

was a kind of duty, an ethic and an aesthetic that would make the appearance of ugliness, pain, sickness and death impossible⁵.

It was in this sense that young people living with HIV/AIDS was made possible as new character in the epidemic. A subject that at the same time must be responsible, autonomous, self-determined and conscious, needs to be and show himself (con)formed, which presupposes the deepest and most intimate belief that he represents a 'danger' to society. It is as a 'danger', in the sense of being able to spread the virus through sexuality seen as 'exacerbated' and 'uncontrolled' by age that they are supposed to build excellence in 'self-control'⁵.

All this construction in the first decade of the 21st century took place in a context in which the subversive mark of the epidemic disappeared; the political model as to the treatment being a universal right was not translated into an 'assistance model'; the consequences of the prolonged use of the cocktail became serious; the discussion on 'the rights' and 'social insertion' of the people living with HIV/AIDS took over the agenda of activism; the number of young people sexually infected increased; children infected by vertical transmission grew and gave birth to other children; and assisted reproduction emerged amidst strong recrimination of 'HIV-positive pregnancy', especially in 'adolescence' and in 'poverty'⁵.

Thus, in this period what we perceive is a demand for the development of a self-management capacity on the part of the JVHA with an emphasis on sexuality and condom use. There is a demand on these individuals to build an exemplarity in the presentation of themselves²⁰; and in the wake of activism or engaged actions in the transformation of their stories and experiences of pain and suffering in pedagogical activities or products of a utilitarian nature in a daily policy of displaying exemplarity⁵.

Paradoxically, in this context of strong control, it was vehemently expected that the

JVHA would be creative and autonomous enough to renew AIDS activism overcoming its problems and difficulties. The intention of the old activists to pass the torch to the new activists in the AIDS movement was fully established²¹.

It is noteworthy, in this first moment of the 'AIDS now', a call for the visibility of the JVHA with a constant call to reveal themselves, show their faces and openly say that they live with HIV/AIDS - an aspect tensioned with the stigma of the disease. At this moment, 'showing oneself' was the assumption for 'existing' and 'positively', composing a list of social and rhetorical expectations around the JVHA, the affirmation of life, the search for the joy of living, the intensity of experiences of the juvenile phase in spite of HIV/AIDS, the affective and sexual satisfaction⁵.

It is interesting to note that the protagonism of the JVHA, or of the emerging JVHA Movement created by the actions of NGOs-AIDS of historical importance such as the Life Incentive Group of São Paulo (Grupo de Incentivo à Vida - GIV), was from the very beginning strongly and parallelly invested in by the government. The then-called National DST/AIDS Program (PN-DST/AIDS/MS) took over this management, especially of bodies that did not die and started to have sex and to reproduce, the young of vertical transmission⁵.

Already in the second decade of the 21st century, the JVHA Movement reflected the ideas of the Joint United Nations Programme on HIV/AIDS (UNAIDS) and its 90/90/90 goals (90% of all people living with HIV/AIDS know they have the virus; 90% of people diagnosed with HIV receive antiretroviral therapy, and 90% of people receiving treatment have undetectable viral load and can no longer transmit the virus), and the principles in this same direction that since the end of 2013 had been dictating the actions of the Brazilian government (early testing and treatment and the use of antiretroviral treatment as prevention). In this way, juvenile and infected bodies no longer seemed to need

to show exemplarity in prevention with discourses around condom use. The exemplarity evoked the ‘young protagonist’ who complies with his treatment, then the prevention, keeps the viral load undetectable (number of copies of the virus circulating in the blood) and still brings new young people to the testing and treatment centers²¹.

It was in this context that JVHA began to constitute themselves as ‘detectable’ and ‘undetectable’. The transformations in life-sustaining technologies structured in the new anti-AIDS drugs whose centrality began to guide testing, diagnosis, and prevention – such as Treatment as Prevention; Pre-Exposure Prophylaxis (PrEP), which is the use of Antiretrovirals (ART) by a seronegative person to reduce the risk of becoming infected with HIV and Post-Exposure Prophylaxis (PEP), which prevents HIV infection by taking ARTs after probable exposure to the virus – in addition to the Undetectable equation = Untransmissible (I=I), cases in which the person living with HIV/AIDS has had an undetectable viral load for at least six months have come to refer to the subjects and subjectivities they generate the newest and most recent layer of the ‘AIDS now’.

However, JVHAs still face the stigma of the disease, which often causes the need to handle a secret in the social groups to which they belong, added to the difficulties of using ARTs, implying a readjustment of routine, study and/or work, changes in eating and sleeping habits, care of the body and sexuality, among others. These factors are aggravated in the social experiences of JVHAs by the synergy of the HIV status with certain social marks of difference, impacting treatment adherence and promoting psychological illness: abandonment of treatment with anxiety and depression, associated with family and/or sexual rejection due to serodifferent partners. This leads to the search for support in social networks, especially virtual ones, and psychological and/or psychiatric treatment²².

Currently, it is observed that the JVHAs move between ‘two worlds of AIDS’: one

technological which contemplates the existence of groups and virtual support networks, support and meetings in social networks with wide dissemination of communication, prevention and treatment technologies of biomedical nature able to mediate health care, the exercise of sexuality, reproduction and forge identities and collectives; and another one that, despite the existence of these new technologies, remains immersed in basic issues related to diagnosis, treatment and prevention as a result of deep social inequalities, with undesirable outcomes such as illness and even premature death²².

Final cutting.

From the relation us and them, to the relation us with them: chronicity as disturbance and the place of experience in the theoretical essay

Here, we understand experience as something that is not to be confused with perception, much less with living. In experience, there is the mark of what is reflexivity about what happens to us in relation to what happens to many like what is going on with us, what happens to us, and what connects us and crosses us²³. Experience is the event embodied in the memory of an intersubjectively shared construction. The author reaffirms the need to understand the experience as something that ‘co-move’ us and, therefore, comes to constitute us.

This is a thread of argument for rescuing the experiences and memories of policies and care practices for children, adolescents and young people living with HIV/AIDS after 23 years of studies in this field. In this line of revisited history, ours with them, it justifies after so many years, the argument that ‘if you didn’t live before, you live today’. Therefore, how to think about these practices in a certain

historicization for children, adolescents and young people of what was ‘positive to die’ and today is ‘undetectable to live’?

The definition of experience that we evoke enables us to understand the relationship of HIV/AIDS in childhood and youth as an event that enables us to think that the disease does not have its own internal functioning that defines it in itself. By revisiting Foucault and Canguilhem, Saflate²⁴⁽¹²⁾ tells us that the expression of a disease “depends on the way we organize what is to be seen and heard”. Therefore, looking at the history of HIV/AIDS today and its presence in the field of children and adolescents involves asking how we have placed as caregivers, health professionals, and researchers involved in this struggle. How do we talk about these subjects without reifying images produced by the epidemic?

Pierret²⁵ points out that the disease is unique for each individual and that it has meaning due to its own history interpreted in reference to essentially social values and norms. For this reason it is worth asking: in what way do the situations arising from HIV/AIDS and its representations call into question the considerations of time and space? The author underlines that illness is an experience that deals with duration since it leads to thinking about the past and the future. Moreover, due to its development and its different phases, it incessantly provokes a series of adjustments in the different places of social life which, in turn, calls into question the problems of identity and self-reconstruction. There is an understanding of the temporal dimension as an individual dimension that, however, is part of a collective experience. We also add - in dialogue with the chronicity category - that it makes us return to the need to look at the interdependence and precariousness that constitute us.

O’Brien et al.²⁶ show that with ART in developed countries, HIV/AIDS is assumed to be a long-term experience. The authors illuminate the interfaces between inclusive policies in meeting HIV/AIDS and disabilities. According to them²⁶⁽³⁾:

[i]n both fields, biomedical models overlap and reinforce the ‘pathological’ dimensions of personal experiences, rely on drug interventions, and leave aside the social, political, environmental and cultural factors that determine the experience of people living with disabilities and with HIV and AIDS.

The production of abject bodies was a hallmark of AIDS history. At the beginning of the epidemic what was most stigmatizing in each of the initially most affected groups, the so-called ‘risk groups’, was highlighted.

[the] injecting drug users were already perceived as urban outcasts, as deserving of their disease as well as the ‘perverts’ of homosexuals; ‘Haitians’ were the lowest rung of poverty; ‘hemophiliacs’ already had the lifelong stigma of their disease¹⁵⁽⁴³⁾.

Prostitutes carried the (historical) burden of transmitting sexually transmitted infections. Moral judgments were frequent in various communication spaces, with consequences in the constant search for distinguishing ‘innocent’ and ‘guilty’ in new configurations of the epidemic and the ‘risk categories’, produced throughout the history of the disease.

This movement of classifying victims and perpetrators in the course of the epidemic – and of exposing marks to the bodies already triggered by the stigma of the infection and its physical consequences – accompanied the shift from care for children and adolescents living with HIV/AIDS to ‘youth’, emerging in the mid-2000s⁵. The type of transmission (sexual versus vertical transmission) triggered different moralities since the young people infected through sexual transmission would be considered ‘guilty’ as if they had wanted the infection, and the young people infected through vertical transmission, ‘victims’ of the circumstances⁹. This type of social classification process has biopolitical effects²⁷ of control over individual bodies and the collective⁵ and organizes, in the model keys of the passage

from the 'AIDS before' to the 'AIDS now', the turning point of the condition of those who did not die and started living.

As already mentioned, the transformations of the technologies aimed at life structured in the new anti-AIDS drugs, whose centrality started to guide the testing, diagnosis and prevention, start to orient the activist movements and the perception of self of the JVHA members, with a transition already clearly defined from childhood and adolescence formerly condemned to death¹⁹ to one that experiences a bio-identity and bio-sociability²⁸ on behalf of a 'healthy' life, with quality based on living with an 'undetectable' virus'.

In this path, the transformations in the way of naming and recognizing what it is to live with HIV/AIDS go through the establishment of other individual and collective identities in the case of assuming themselves undetectable as a symbolic currency to live life within a 'normality' giving it other meanings. However, it is still worth asking: what remains as dramatic between the logic of the disease and those living with HIV/AIDS and its effects in the field of interpersonal relationships and health care today?

This issue is fundamental when reconfiguring not only in relation to HIV, but also to a series of chronic and complex health conditions from which today 'one no longer dies, but lives in the adversity of struggles and with stigmas²⁹. That is: what to do when there is a real possibility that life prevails? For the 'obviousness' of death that was imposed there was mourning, despair, and suffering; but what about life that emerges and settles in hope? We can extrapolate the AIDS field and converge with what is built around other rare, chronic, and complex health conditions. What is it to be a young/adult living with these health conditions? This is a question that has crossed many individuals in the history of HIV/AIDS, many of those who have followed the death of parents, friends, family members and companions, but who stayed alive due to other conditions started to wonder how to go

on from there having other challenges ahead. By invoking Canguilhem³⁰, we affirm that if life knows no reversibility, it makes possible states of innovations and reparations fundamental when we think of chronicity as interdependence, recognition, and precariousness.

Within these frameworks, talking about chronicity means asking about the logic of health, politics, ethics, technology, and the events in the lives of people who live managing their interdependencies and precariousness. For in this field, some will go through active processes of life precarization – which as Butler¹¹ reminds us, it is not to be confused with precariousness – but dehumanizes, elects which humans deserve to be 'more human' and attention. The structures of patriarchy, racism, sexism, ageism, and ableism produce active precariousness and do not operate for something fundamental which is recognition.

Therefore, we summon 'AIDS before' and 'AIDS now' to think about chronicity in the framework of precariousness as a human condition producing recognition for these political subjects and the possibility to (re)invent life.

Final considerations

In this essay, we attempted to show displacements and transformations in the course of AIDS, both in its technological aspects and in the way we have been summoned to face and live these changes, particularly in the population of children, adolescents and youth. This whole changing scenario does not only point to the transitions that have occurred in the way we deal with HIV/AIDS and its clinical confrontation. It also, and mainly, tells us about a change in the subjective position since we have left the positivity/negativity game and entered the detectable/indetectable panorama with regard to the viral load and its changes in the ways of 'contagion', in the sense of the dramas it carries.

All of this, which seems to be only a change in the 'bios' of the disease, reveals a much more

complex condition of change, since it launches us into the question of thinking about the very status of life. If before these groups we brought here and died in a quickly and fatalistically way, today what is observed is the possibility of establishing prolongation bonds with life, its unfolding and re-significations. Thus, the essay by committing itself to talk about an AIDS 'from Before' and another one from 'Now' indicates that issues related to prevention, diagnosis, and treatment still remain while we need to embrace other categories related to chronicity – interdependence, precariousness, and recognition - in order to think about this scenario, we are now dealing with. We then speak of access, social inequalities, and integral care related to a specific chronicity that HIV/AIDS demand from us in its confrontation. In other words, if children and young people remain alive today, not abruptly ending the cycle of life it is important to affirm another form of struggle and understanding of this new condition of living and establishing relations with the world.

Based on this understanding, this essay brought the field of scenarios and memories to show that, if it was important to have built a technological way to face HIV/AIDS, we still need to produce other permanent bonds with this public by affirming 'projects of happiness'³¹, but also opening space for the experience of pain and suffering that are legitimate and necessary. In other words, our confrontations with HIV/AIDS must be situated in the very logic of contemporary and daily changes for this will always potentialize our attention to establish and think about an ethics of care that is affirmative for children, young people, and adolescents.

Collaborators

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