

The waste of experience and precariousness of life: contemporary political moment of the Brazilian response to aids

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Brazil was once a country known worldwide for the quality of its response to AIDS. Today Brazil experiences a clear setback, especially in the area of prevention. The text intends to analyze this situation, with the help of two concepts: the waste of experience, inspired by Boaventura Santos, and the precariousness of life, a category that builds on the ideas of Judith Butler. In line with these two categories, the text takes up the concept of solidarity, an important political organizer that gave force to the initial Brazilian response to AIDS. Brazilian public health policy deal with the AIDS epidemic today in a permanent tension between making live (expanding the supply of tests for knowledge of HIV status and universal provision of antiretroviral medication) and letting die (reinforcing the situations of stigma and discrimination in relation to vulnerable populations).

Keywords: Acquired Immunodeficiency Syndrome. Brazil. Solidarity. Precariousness. Vulnerability

Advances, setbacks, stagnation – will we make it?

Ever since its creation, the direction of Brazil's response to AIDS has been the center of debate between managers, activists, researchers and people living with HIV/AIDS. There have been moments of agreement and praise; for example the recognition of the success of providing free access to antiretroviral therapy through the public health system. This policy was not successful only from a technical perspective, but also represented the consolidation of a response based on human rights principles, reaffirming that all life has equal value (see

for example: Berkman et al.¹, Galvão², Teixeira et al.³, Okie⁴, Greco et al.⁵, Mesquita et al.⁶). The Brazilian response was also a confirmed success from the epidemiological perspective⁷. However, the cancellation of a prevention campaign targeting young gays during the 2012 carnival and scrapping of a prevention campaign aimed at sex workers in 2013 generated a great deal of controversy.

The current moment ^(c) is characterized by conflicting opinions over the AIDS response. Many are optimistic about a “definite solution” to prevention and treatment in the form of a single medication that will dispense with the need for other methods. This drug-based response relegates political thinking about AIDS, which recognizes the inextricable link between HIV/AIDS prevention and human rights and tackling gender inequalities, to the sidelines. Other voices alongside this boastful optimism about an “around the corner” solution to the “AIDS problem” signal a decline in the capacity of policies to reduce homophobia, to provide adequate care to people living with HIV/AIDS, to educate young people about sexuality, gender and sexually transmitted diseases, and to avoid the criminalization of HIV transmission, resulting in an increase in mortality. According to Grangeiro et al.⁸:

... the resurgence of the disease in Brazil is most evident in the trends in mortality. After consecutive years of reductions, the number of deaths and the mortality rate have begun to rise again. In 2013, there were 12,700 cases of death caused by the disease, a figure similar to that of 15 years ago, when the policy enabling access to antiretroviral drugs was implemented. Over the last seven years, the national mortality rate increased by a little over 5%, from 5.9 per 100,000 population in 2006, to 6.2% per 100,000 population in 2013. (p. 7, authors’ translation).

We propose that these setbacks are the result of a long process of waste of experience, rather than the deliberate act of this or that particular manager. The Brazilian response is provided by society as a whole, in which agents of public policy are one of the, but not the only, protagonists. This text examines policies (or their proposals therein) addressing the issue in question and the reactions of society. Our assessment draws on the perception that Brazil’s health policies deal with the current AIDS epidemic in a state of

^c By current moment we refer to the period 2012 to the first semester of 2015.

constant tension between ‘*make*’ *live* (widening the provision of AIDS serological testing and universal provision of antiretroviral medication) and ‘*let*’ *die* (reinforcing stigmas and discrimination of vulnerable groups)^(d).

New and old concepts and possibilities for understanding and action

The emergence of AIDS in Brazil was marked by a new way of thinking about the connection between disease, health and society, fruit of the expansion of democracy after the military regime. Addressing the disease involved talking about homosexuality, human rights, the fight against prejudice and discrimination, questioning medical procedures, criticizing medicalization, confronting the major pharmaceutical companies about the price of medication and patent laws, defending the unified health system, and accepting prostitution as a socially recognized activity.

This widening of the web of meaning about the disease was anchored in concepts and political strategies. Here we take up the notion of solidarity, central to understanding this initial period, and then go on to discuss Judith Butler’s concept of the precariousness of life. Our intention is also to avoid wasting the experience of so many years of struggle and, at the same time, bring the national response in line with the political language that has emerged over recent years. The concept of solidarity with the context of national political language was introduced by Herbert de Souza, otherwise known as Betinho, and cited here by Parker⁹: “Brazil, through representative segments and their characteristics and potential, can be said to be an example of mobilization, diffusing another vision of the epidemic that restores cure as a prospect and solidarity as the principle of all prevention work”.

The notion of solidarity employed in the fight against AIDS was connected to Paulo Freire’s pedagogical ideas, which explicitly refer to the concept¹⁰. It is worth remembering that solidarity was proposed at a time of struggle against AIDS, and represented the political battle flag of the urgent call for mobilization. The way the term is employed and the concrete experiences of solidarity reveal its essential features. Once again, we emphasize that the

(d) Here we freely use the expression. “make live and let die” coined by Michel Foucault “In Defense of Society” (São Paulo, Martins Fontes, 1999) without drawing on his theoretical framework as basis of analysis.

political construction of solidarity occurred during the struggle against AIDS, in response to urgency and emergency, and not within a theoretical investigation, which explains why it is more easily defined by acts rather than theory. According to Rorty¹¹: “Solidarity is not discovered by reflecting, but rather created. It is created by increasing our sensitivity to the particular details of the pain and humiliation of unfamiliar persons. This increased sensitivity makes it more difficult to marginalize people by thinking that people are different to ourselves” (p. 20).

This way of looking at solidarity resonates with the idea of “societies in movement” (Sitrin¹²); a product of the actions of social movements that intensely politicize the issues that concern them and offer models of wide-scale social organization that goes beyond the struggle in which they are engaged. This has clearly been the trajectory of a large number of social actors involved in the struggle against AIDS, who transit between individualist educational strategies to community approaches, which, according to Parker, reveal the following¹³:

[...] shift in understanding of how the struggle to respond effectively to HIV and AIDS is in fact part of a much broader and more long-term struggle but with more far-reaching social change aimed, of necessity, at addressing the underlying issues of inequality and injustice that have created the conditions for the spread of HIV infection and AIDS. (p. 101)

By tracking actions, meeting proposals and managers’ manifestations, we have developed the following overview of solidarity in the context of AIDS: 1) the guarantee of rights for people living with HIV/AIDs in accordance with the Declaration of Fundamental Rights of People living with HIV, approved in 1989 in Porto Alegre¹⁴; 2) attempts to improve civil society’s response to AIDS in Brazil by using the name of Brazilian Solidarity Network¹⁴, deviating from a purely biomedical understanding of the disease; 3) establishment of mutual support groups to help people living with HIV/AIDS to share life experiences¹⁵, seen as the active practice of solidarity and strong appeal to volunteers through NGOs that emerged in response to AIDS; 4) combat against abandonment, loneliness, discrimination, prejudice, marginality and guilt through an appeal for solidarity¹⁵, combined with disseminating

accurate scientific information about HIV; 5) a strong notion that the learning experiences that lead to the development of the Brazilian response to AIDS are linked to the possibility of establishing dialogue between different individuals and communities in tune with the ideas of Paulo Freire: “Nobody educates anybody else, nobody educates himself; people educate among themselves mediated by the world”¹⁶ (p. 39). The notion of solidarity rejects the possibility of someone or some group detaining complete knowledge about and ways of understanding the epidemic, and establishes an absolute need for dialogue and respect for different types of knowledge in developing the national response; 6) solidarity is linked to a simple and politically powerful statement: the cure for death, suffering and discrimination is life¹⁷; 7) solidarity actions interest everybody, since AIDS is all around, we all live in a world with HIV, and maintaining life in this world is not only up to us all, it also benefits all of us. This idea reveals humanity’s political project, which counts not on individual autonomy inherent in freethinking, but on life continually produced through social relations with other actors; 8) the notion of solidarity clearly points to something that is immediate, which does not need to wait for the discovery of a drug that is going to eliminate HIV from the organism. Solidarity is about an AIDS that is more closely connected to what we could call “the ideological virus of prejudice and intolerance”, which kills more people than the biological virus because, apart from killing, it shortens the life expectancy of individuals, based on the concepts of civil death and pronounced death. In this way, solidarity is a strategic action that occurs simultaneously with the search for a pharmaceutical cure, a provably effective vaccine against what has recently become known as the “third AIDS epidemic”^{18,19}, an epidemic of discrimination against people living with HIV/AIDS. Solidarity places AIDS decidedly in the political field, enabling the involvement of all types of people in the struggle, not just health professionals. The use of the notion of solidarity also incorporates the thinking of Paulo Freire¹⁰:

I would like to add solidarity as another desirable quality. Solidarity goes side by side with a critical mind. I cannot imagine the world getting any better if we really don't adopt the feeling and immediately

become a great mass of solidarity, if we don't struggle for solidarity.
(Chapter 3 Pedagogy of Solidarity: a Dialogue, p. 522 ^(e))

These attributes resonate with Judith Butler's notion of the precariousness of life, mourning and violence²⁰. Butler analyzes two politically complex themes: the attack on the twin towers on September 11 2001 and Israel's invasive attitude in Palestine. She highlights the notion that human life is fundamentally precarious, which decisively implies the vulnerability – or fragility – of the life of the other and others with whom we interact. The book breathes an air of ethics into human relationships that allows us to contemplate the dependence and vulnerability of the autonomous other who depends on us and on whom we depend. It fiercely combats the notion of existential autonomy or unrestricted sovereignty, which establishes a division between *our* world and the world of *others*. Failure to recognize the notion of precariousness as one of life's fundamental truths opens the way to violence and revenge, represented in the book by the revenge dealt out by the US on groups, peoples and countries defined as terrorists and guilty of the attack on the twin towers.

As mentioned above, the response to AIDS is characterized by permanent tension between 'make' live (widening the provision of AIDS serological testing and universal provision of antiretroviral medication) and 'let' die (reinforcing stigmas and discrimination of vulnerable groups). Extraordinary HIV drug and treatment advances have made making live possible by improving life expectancy, enabling patients to live with AIDS as a chronic disease that is not cured, but which does not restrict daily life.

We would now like to concentrate on "let die" by drawing on other ideas set out by Judith Butler²⁰ in the same book. One of the most evident symptoms of the ease of letting die is the absence of mourning produced by the death of others. The deaths referred to by Butler are the Muslims killed in the US-led bombing campaigns and the Palestinians killed during Israeli incursions, presented in the news as mere numbers, without regard for names, and not acknowledged as viable lives or worthy of being lived. These deaths are therefore not mourned. The mourning analyzed by Butler²⁰ is political mourning, not an individual action (p. 49). It is a type of mourning that reveals the real extent of our bond with others, a less emotional form of mourning. Without wanting to discredit individual mourning, what is

^(e) This reference is based on the ebook.

relevant here is mourning that produces collective change, when mourning becomes a strategy against mass deaths, political mourning^(f). It is, after all, mourning where sadness does not drown the possibility of becoming mindful of the social phenomenon involved in the production of such deaths, and much less a medicalized conception of mourning as we have frequently witnessed.

The book mentions the political mourning of the United States, the loss of arrogance, the desire for revenge and the notion that it is a self-sufficient country²⁰. The pain, mourning, violence and vulnerability to which we are all exposed are dimensions of life in the public space. Based on the absolute recognition of these attributes, Butler seeks conditions to build another type of political community. Her proposal is based on the notion of precariousness of life, on the radical idea that that we are all social beings deeply connected to others by human bonds, and goes on to include the ethics of nonviolence, which is connected to human rights²⁰. The ethics of nonviolence implies acknowledging each life as a viable life, and that mourning only exists for viable lives. If we look at the other and recognize nonviable life, not worthy of being lived, we lose the capacity to mourn. The loss of life produces political mourning insofar as it permits clearly assumed concerns: what did we do as a society to make this life worthwhile? Did this loss bring us together as one “us”? We have the sensation that something was lost, expressed by the questions “what am I without you? What have I lost?”²⁰ (p. 46).

Here we have brought vulnerability and precariousness closer together. Provided we safeguard their origin, these concepts are a step in the right direction in the way we think about the human being. They involve paying attention to ordinary life, viewed as precarious or intrinsically vulnerable. There are actions that increase the precariousness of life, and actions that contribute to reduce or even eliminate it. In the same society, at the same moment in history, action games compound the precariousness of life or make life less precarious. Actions that jeopardize life are liable to cause indignation, shame, exploitation of the body as a nonviable life, steal people’s futures, and lead to a constant separation between us and them.

^(f) The initial stages of the struggle against AIDS was clearly marked by the memories of the names of people who died, viewed as viable lives that deserved recognition, and not mere numbers. This struggle strategy is registered in the Names Project: <<http://www.aidsquilt.org/>> and represents a form of political mourning.

It can be generally confirmed that breaking the norms implies increasing individual vulnerability. An example of this are homosexuals, affected by the epidemic on account of their “decision” to live a life that goes against the norm. On the other hand, the AIDS statistics show that faithful married women, who live up to the norms, are also vulnerable to infection. The vulnerability that we are talking about here is a relationship, not the essence of a person or group. We are all subject to vulnerability and, as Judith Butler says, we all have precarious lives. Invulnerability does not exist, and vulnerability cannot be eradicated; it can only be well managed or considerably reduced. The struggle to reduce vulnerability may be thought of as exercising solidarity, and this struggle is influenced by the resources at our disposal for this struggle. Vulnerability has more to do with institutional and social arrangements than personal characteristics and these arrangements can shift. Vulnerability will always be present; therefore, what we need is solidarity. Solidarity is a horizon of obligations, derived from the recognition that vulnerability is common to all people. Vulnerability is not restricted to the bodies of women, young black people, gays, transvestites, transsexuals, transgender people, or drug users; it is in the social relationships that build these lives as lives that do not matter ²¹.

If you can see, look. If you can look, observe⁽⁹⁾

An examination of the current situation of the AIDS response provides some clues to help us understand the possibilities of the present moment. Our goal is to avoid wasting experience²². In his work, Boaventura Santos suggests that the present moment is a time of shifting paradigms: between modernity, heavily criticized but still extremely prevalent; and an emerging paradigm that is still blurred around the edges and has various names. He draws particular attention to experiences in societies at local level, and especially those that provide elements that feed emancipation. He criticizes the idea that we will achieve a “total alternative” to the society which we live in developed from a single principle of transformation, preferring to rely on a watchful eye on the many social struggles. This eye

⁽⁹⁾ Epigraph of the book *An Essay on Blindness* (José Saramago, Companhia das Letras, São Paulo, 1995).

values political experiences according to certain criteria, which can build what he calls “prudent knowledge for a decent life”, as Almeida shows²³:

For the author, the emerging paradigm is built upon a triple transformation: the transformation of power into shared authority, the transformation of despotic might into democratic rights; the transformation of regulatory knowledge into emancipatory knowledge. (p. 292)

The following is an analysis of two episodes in this political vein based on the aforementioned concepts and history of AIDS giving substance to our assessment in which we insist that the Brazilian response to AIDS is today marked by a permanent tension between ‘make’ live and ‘let’ die.

The first episode happened in June 2013, when the Department of STD, AIDS and Viral Hepatitis launched a campaign with the slogan “I am happy being a prostitute”, including publicity material with the phrase “2 June the International Day of Prostitutes” and “shameless girl”, and guidance on using a condom. The campaign was designed during a workshop involving representatives from nongovernmental organizations, associations and social movements that work with sex workers across the country. The campaign generated both favorable and negative reactions. Those against objected to the proposal “be a prostitute and be happy”. After two days, the Ministry of Health dropped the campaign and dismissed the campaign coordinator. Soon after, the campaign was, in the words of the ministry, “relaunched”, while according to the prostitutes associations “another campaign was launched”. The new campaign was called “Prostitutes Who Take Care of Themselves always Use Condoms”, and the phrases “I am happy being a prostitute” and “2 June the International Day of Prostitutes” were withdrawn from the material, adding phrases directly related to the use of condoms such as “a kiss for those who use a condom and protect themselves”. Needless to say, the repercussions of the campaign were enormous both in Brazil and abroad. The main justification given by the Health Ministry for scrapping the campaign was that “health should publicize messages restricted to guidance on AIDS prevention”.

The general consensus between the scientific community, international bodies and leading figures in the struggle against AIDS is that actions directed at combatting the disease should be intersectoral and that fighting stigma and promoting human rights are essential to reducing the vulnerability of the most affected groups^(h). Prostitution has been recognized as a profession in a number of countries for some time and in Brazil it has never been considered a crime under the country's legislation. It may have been subject to moral judgment, but Brazilian history shows the notable life led by many women that dedicated themselves to this activity. These days, prostitutes are organized into associations across all Brazil's states, maintain dialogue with the police, collaborate as activists in AIDS prevention campaigns, promote debates, and go back to school to complete studies that are often interrupted due to the stigma they face in the school yard. They are celebrated characters of literature, movies and soap operas.

Based on the conceptual framework adopted above we can affirm: 1) the new campaign reinforced the vision of *us* and the *other*, given that something that is common heritage of mankind and brings us all together in one us, the desire to be happy, was withdrawn, and replaced by practical recommendations on how to use a condom in the exercise of the profession; 2) solidarity was eliminated, given that in the new campaign it was not possible to put oneself in the other's place, the common goal of humanity, to be happy, disappeared, and with it went the possibility of realizing that everyone, us, and the prostitutes, have precarious lives and are in search of happiness; 3) Boaventura de Sousa Santos' three prerequisites for the creation of a new paradigm mentioned above were bulldozed in the process: power was once again concentrated at the bureaucratic level, not shared; despotic might was shown, rather than democratic rights, and translated into censorship; the scientifically available and socially validated knowledge of the design of prevention campaigns was not transformed into emancipatory knowledge, but rather remained as regulatory knowledge; 4) while the campaign is committed to 'make' live by recommending the use of condoms, it also upholds 'let' die, belittling the life of prostitutes,

^(h) Most of the arguments used here are based on the manifesto "Sad Hookers! Or sad Minister?", by Ronaldo Hallal and Fernando Seffner.

eliminating the possibility of publicly proclaiming that they can be happy, and thus increasing the precariousness of their lives.

The second episode is the controversial decision to ban homosexuals from giving blood because of HIV. A resolution enacted by Brazil's National Health Surveillance Agency (ANVISA) in 2004²⁴ and supported by the ministerial order N° 1353 of 2011 of the Ministry of Health²⁵ provides that "men who have had sexual relations with other men or with the sexual partners of these men will be disqualified as blood donors for one year". However, the ministerial order also confirms in article 5 that "sexual orientation (heterosexual, bisexual, homosexual) should not be used as a criterion for selecting blood donors since it does not present a risk in itself", which is contradictory and subject to different interpretations. We selected the following article found in the newspaper *Jornal Opção* related to this context, ²⁶.

"You can't trust it" says Bolsonaro about blood donated by homosexuals. Jair Bolsonaro talks about the controversy surrounding the separation of blood donated by homosexuals and heterosexuals in blood banks. The congressman Jair Bolsonaro (PP-RJ) announced that he is going to deliver a bill that aims to enable people who need a blood transfusion to choose whether they want to receive only blood donated by heterosexuals. He justifies the bill by saying that homosexuals run a greater risk of contracting sexually transmitted diseases. He also says that the blood donated is 'all mixed', and that the recipient should be aware of whether he/she is receiving blood from a heterosexual or not. Recently, the Ministry of Health relaxed the rules relating to blood donation by homosexuals, who had up until then been prohibited from donating blood. Gays and lesbians have been able to donate blood since June of last year, provided they have a permanent partner or have not had sexual relations in the last 12 months.

This manifestation by the congressman reaffirms how the association between homosexuals and AIDS promotes the separation between us and others. Highly symbolic, blood has historically been used to distinguish the upper class from working class, and the expression *blue blood*, still in vogue, is a vestige of the concrete inequalities between nobles and commoners. By establishing the need to separate blood, the congressman also triggers a mix of moral judgment and fear, not only of contamination with HIV, but also the symbolic transformation of a heterosexual into a homosexual. It is worth remembering that a similar fear was frequently expressed by whites receiving blood donated by blacks. By placing homosexuals in a space of abjection, this proposal leaves them open to abuse. Establishing

that certain subjects are to live indefinitely “on the margin” places them in a situation that compounds the precariousness of their lives, in what Butler calls “precarity”, as opposed to “precariousness”, a term that defines the vulnerability that is inherent to all human existence.

The bill is in line with strategies that transform individuals into dangerous beings due to their race, class, gender, sexuality, religion, place of birth, or illness. The possibility of solidarity disappears and is replaced by exclusion. Disciplinary power legitimizes world views that authorize the acknowledgement of certain lives as viable and others as unviable and that should be shunned, on the margin, or eliminated. Fighting against this condition is to exercise solidarity, taken up here in the sense of avoiding pronounced death, which is announced while the subject is alive, but belittles the possibilities of life. Exercising solidarity, in its full political sense, is to denounce the political order that places some as more precarious than other, allowing us to bring the two concepts together²⁷:

For when bodies gather as they do to express their indignation and to enact their plural existence in public space, they are also making broader demands. They are demanding to be recognized and valued; they are exercising the right to appear and to exercise freedom; they are calling for a liveable life. These values are presupposed by particular demands, but they also demand a more fundamental restructuring of our socio-economic and political order. (p.2)

‘Make’ live by providing medication, treatment and examinations is not sufficient in face of the precariousness of life. Caring for life goes beyond health care, taking place on decidedly political terrain; and AIDS is an intensely political issue. Medicalization will not resolve these issues. It is necessary to invest in other means of responding to the disease, understood here as essentially political, without forgoing advances in medicine (see, for example, Paiva et al.²⁸).

The continuation of treatment strategies without addressing the political dimensions of AIDS is taking action on two fronts which seek different goals. Two monologues do not make a dialogue: one makes live, while the other lets die. One talks of testing and treating, while the other denies the political dimensions of AIDS. Clearly, we must associate the self-esteem of groups and individuals with the possibility of HIV prevention. This implies

designing futures that are possible for these lives, since after all more livable and viable lives include happiness. Prevention campaigns must revive the erotic, promote access to human rights, build a world of equal opportunities. Campaigns should not merely address the healthcare dimension of AIDS, because of the simple fact that AIDS, like any other disease, is above all an indicator of the precariousness of life and, therefore, a political problem that can only be resolved through solidarity, as suggested here.

Campaigns that only suggest that one group or another should take precautions to prevent HIV infection operate within an essentialist concept of vulnerability, reinforcing the separation between us and others. It is not only about recognizing that the other exists; actions must be linked to society's political project in which I let myself be contaminated by this other. A large number of actions that address AIDS have lost this notion of political project, and we could say that this is one of the effects of treatment, which individualizes approaches and has no need or desire to deal with the collective or social movements. Medicalization and individualization exist well together; with an isolated individual who is always the *other*.

The game of 'make' live and 'let' die expresses itself in a number of ways. The epidemic is exploding among adolescents; we provide examinations and treatment, but we are restricted when it comes to generating debates about sexuality and youth culture. Treatment means people can live with HIV and have an undetectable viral load, but transmission is criminalized. We provide tests and treatment to injectable drug users, but we refuse harm reduction programs and manage to go against our neighboring countries when it comes to criminalization of drug use. Medicalization brings with it liberal individualistic ontology, while the beginning of the Brazilian response to AIDS, with its strong connection to human rights and emphasis on solidarity, pointed to a social ontology, which emphasizes the interdependence of human beings, the importance of communities and public space as place of respect for diversity and negotiation of differences. The Brazilian response to AIDS assumed that life is precarious, and precarious for all of us. If people are living with HIV, we are all living with HIV. We live in a world with AIDS. This political perspective is different to perceiving a world with some people with HIV. We have to invest in a shift in the ontology of the response, from the individual to collective level. If vulnerability is collective we have to

have a collective response. Moreover, we have to be critical of managers who let themselves be taken in by a medicalizing strategy that promotes waste of experience. It does not have to be this way but, between us, clearly desirable medical advances are making us waste political experiences and lose the memories of struggle and the connection with human rights and solidarity. In hope that we can be proud once again of the Brazilian response to AIDS, we leave you with Betinho's inspirational words: "Solidarity, friends, is not something you say thank you for, it's something you celebrate."⁽ⁱ⁾

Collaborators

The authors worked together in all the stages of the production of the manuscript.

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