Myth vs. Reality: Evaluating the Brazilian Response to HIV in 2016
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The Brazilian debacle and the AIDS epidemic

Once a model for the world in terms of public response to the AIDS epidemic, Brazil is today backpedaling and rapidly paving the way for a re-emerging public health crisis. Mired in the worst political-economic crisis of the past 30 years, the largest country of South America has lost its ability to construct a response to the epidemic using what was once its greatest triumph: the experience of the country’s social movements.

Brazil has decided to ignore expert opinions. It has shut down intersectoral dialogue, has disconnected health from human rights, and has unhooked attendance of patients from principles of universal care, justice and social participation. Because of these significant losses, we have prepared the following document: a thorough and critical analysis regarding the myths and realities surrounding the Brazilian response to AIDS.

The first issue we must address is the deep crisis that has shaken Brazil to the roots in 2016. This scenario is the backdrop for researcher Sonia Correa’s investigation presented in her article, *The Brazilian response to HIV and AIDS in troubled and uncertain times*. According to this author, the effects of the crisis are being felt on many levels, including in health policies. Correa provides an historical overview of the principal political events that paved the way for the current crisis that is rocking Brazil.

Researcher Alexandre Grangeiro also offers up a pertinent reflection on the times in his article, *From stabilization to reemergence: challenges for confronting the HIV/AIDS epidemic in its fourth decade in Brazil*. Grangeiro conducts a realistic evaluation of the different views related to the impact of prevention programs and universal access to anti-retroviral medicine. By looking at epidemiological indicators, he seeks to give us a window into the new tendencies of the epidemic in Brazil.

Over past 10 years, public policies in Brazil have increasingly been defined by a biomedical bias that has wasted the accumulated critical knowledge of key sectors of society that first responded to the epidemic. This situation is analyzed by researchers Fernando Seffner and Richard Parker in the article, *The neoliberalization of HIV prevention in Brazil*. It argues that recent
technological and technical approaches to HIV and AIDS emphasizing “test and treat” policies and “treatment as prevention” have a vested interest in hiding the severity of the epidemic and is thus not publically dealing with some of its more worrisome dimensions.

Seffner and Parker believe that because of the complexities and characteristics of the AIDS epidemic, the disease has become a potent social marker contextualizing social inequalities and vulnerabilities. Observing the changing shape of the HIV epidemic thus permits us to understand how the right to life is guaranteed (or not) throughout the Brazilian social fabric.

Specialists Maria Inês Baptistela Nemes and Mario Scheffer analyze The challenges of caring for persons with HIV and AIDS in Brazil. The authors point out that the main losses in continuous care for HIV patients occur after diagnosis, in relation to retention in programs and treatment. According to the authors, there is no prospect of improvement without the investment of additional resources in these areas. Rebuilding a vigorous care program is necessary for Brazil to move forward in combatting the epidemic.

The final article offers a critical reading, from a historical and political perspective, on policies regarding access to antiretroviral drugs, involving the attempts of important political actors’ (the pharmaceutical industry, government and civil society) to control the epidemic. Researchers and activists Veriano Terto Jr., Felipe Carvalho, Pedro Villardi and Marcela Vieira analyze this in their article, The fight goes on: advances and setbacks to access to antiretroviral drugs in Brazil. The authors offer up a scathing reflection regarding threats to the program that currently provides free access to medicine in Brazil, in the light of the current national political and economic situation and the equally problematic international context that undermines public health and human rights throughout the world.

This publication does more than denounce the serious Brazilian situation in order to draw international attention to it: it is also a warning that the world is today going through a very dangerous time in its dealings with the HIV epidemic. Brazil was, for many years, a worldwide model of a successful response to HIV and AIDS. Brazil’s experience, and the disintegration of the AIDS response in Brazil, may thus have important lessons for many countries, whether in Latin America and the Caribbean or in Eastern Europe, Asia and Africa.

What is happening in Brazil strengthens the argument that biomedical answers alone cannot replace social responses. The Brazilian situation calls our attention to the fact that biomedicalization – i.e., the emphasis on drugs as the primary and often only way to address the epidemic – can serve
as a smokescreen that hides a series of pitfalls. These setbacks, in many countries, are transforming the so-called “scale-up” aimed at containing the spread of HIV and AIDS into a de facto “scale-down”.

The biomedicalization of the response to the epidemic and the growing demobilization of civil society, globally, have caused great harm in addressing AIDS in many societies. We need to recreate spaces where the voices of affected communities can be heard, thus reintroducing community responses into the political agenda. Efforts must be made to achieve this by governments, aid agencies, scientists and activists on a global scale.

As for those who reside in Brazil – members of civil society, government civil servants, scientists and activists, managers, health professionals, service providers and people living with HIV and AIDS – we need to launch a challenge so that together we can rebuild an exemplary response to combat the epidemic. Inspired by the principles that move us – solidarity, human rights and social justice – we believe that it is possible to overcome these dark times.
The Brazilian response to HIV and AIDS in troubled and uncertain times

SONIA CORRÊA

The current state of the Brazilian response to HIV and AIDS in 2016 must be framed within the country’s broader political context. This is no simple task, however. In 2016, as Brazilians celebrate the 20th anniversary of Law 9.313 of October 13 1996, which guaranteed universal and free access to antiretroviral drugs (ARVs), Brazil is caught in a profound crisis, described by many analysts as the country’s most serious turbulence since Brazil returned to democratic rule in 1985. This report was produced as the country plunged into a brutal economic recession and formal impeachment proceedings against the president reelected in 2014 were begun. The crisis is profound and complex. The forces at stake and the distortions and risks involved in it

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have been analyzed and contested by institutional actors and Brazilian civil society, and interpreted by international observers. Developments in the short and medium term are difficult to predict.

In this unstable and uncertain scenario, many distortions have been exposed in the Brazilian political system, in addition to biases and weaknesses in the regulatory institutions constructed during the democratization process. The crisis has also had harmful effects on the Executive Branch’s capacity to govern and at different levels throughout the State. Health policy, in particular, has been affected, worsening the already poor performances of the last five years. Worse: this comes at a time when public health is faced with the challenge of responding to the intensification of epidemics transmitted by the *Aedes aegypti* mosquito, which have been particularly acute in the case of Zika virus, with its correlated effects upon prenatal health.

Although an in-depth analysis of this scenario’s complexity, instability, and uncertainty is beyond the scope of this report, it should be kept in mind by readers as the backdrop of this report, not the least because the history of the Brazilian response to HIV and AIDS – a direct result of the country’s democratization process – is now compromised by this context. This can be interpreted as the end of a “virtuous cycle”. In the 1980s, the emergence of the HIV epidemic coincided with the most vibrant moment of Brazil’s democratization movement, producing a virtuous convergence in the State’s reconstruction and the reformulation of Brazil’s social policies. At the same time, gender and sexuality issues took shape in public debates which maintained close ties to more general demands for citizenship and rights. This process, in turn, fostered the development of a response to HIV based on non-discrimination and human rights.

Simultaneous with this process, the reform of Brazil’s public health system (based on the premise of the right to health written into the 1988 Constitution) established an institutional framework for anchoring the healthcare system’s response to HIV, favoring the design and implementation of qualified actions in HIV prevention and care for people with AIDS, a policy exemplified by the passage of Law 9313 in 1996. This, in turn, facilitated measures designed to overcome barriers to ARV access that resulted from the prevailing system of intellectual property.

In the 1990s, national policy for HIV and AIDS received significant financial investments, including funds from a World Bank loan. These investments were framed in terms of substantial support for civil society organizations involved in education and prevention activities and in the creation of structures for social participation and control in dealing with the epidemic. It is no small matter that these policy definitions were made in a broader context in which the neoliberal logic regarding social policies (targeting, privatization, and basic care packages) was already dominant.

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By contrast (as we will analyze in detail in the following sections), the Brazilian response to HIV in 2016 shows striking deficits in terms of prevention and care and with regards to adherence to human rights. Intellectual property issues have once again become an obstacle in accessing quality treatment. Additionally, for several years now, civil society organizations (which have played a crucial role in public education and prevention programs) have faced difficulties in terms of their financial sustainability. Until recently, many of these organizations were subject to serious legal insecurity: new legislation potentially facilitating procedures for these organization’s access to and management of public funding was only passed in 2015.

Additionally, in recent years the incorporation of technological innovations regarding HIV have failed to occur at the desired pace, especially with regards to prevention. The redesigning of the Brazilian response (2013), which was intended to align our country’s policies with global test-and-treat guidelines and an expanded supply of pre- and post-exposure prophylaxis, has thus been jeopardized by the structural deficits currently faced by the Brazil’s public health system.

This problematic and worrisome situation is a perverse intersection between negative health policy trends in the broad sense, the weakening of State commitments to the human rights agenda, and the growing influence of moral conservatism in policymaking and lawmaking.

The disorganization of Brazil’s public health system

As mentioned above, the creation of the Unified Health System (SUS) in the 1980s inaugurated, a single, universal, free healthcare system with public financing, thus laying the basis for subsequent HIV and AIDS policies. Full implementation of the SUS was not an easy task, however, not the least because the system’s premises clashed with prevailing neoliberal policies. In 2006 (nearly 20 years after Brazil’s Constitutional reform), the SUS was still a work in progress facing numerous challenges, not least its daily operation as a gigantic apparatus providing services to millions of people in a diverse and unequal country. The system’s massive scale and heterogeneity in terms of its technical capability and human resources (but also in terms of its “ideologies”) means that excellent national policies have often been poorly translated at the local level.

Additionally, the mismatch between public and private health financing has never been resolved. Every new crisis in the SUS has opened more room for the private sector to expand its reach. Private financing currently accounts for more than 50% of national spending on health (approximately 9% of Brazil’s GDP). Only 28% of the population has private health coverage, but the private sector is supported by the public sector with tax write-offs, currently amounting to 20% of annual public health financing.

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Since 2006, the system’s fragmentation via decentralization has promoted the adoption of municipal legislation which allows the system to contract “social organizations” as health service providers – a policy that fails to guarantee public oversight, regulation, or accountability. Decentralization has also drastically jeopardized financing for civil society (which has a long tradition of involvement in HIV prevention), since the federal funds allocated for these activities at the local level lack rules to guarantee that resources reach organized civil society.

The weaknesses affecting the health system are also associated with distortions in the development model adopted by the Workers’ Party (PT) administrations. As analyzed clearly by Anderson, although these administrations were leftist, they opted for growth and the promotion of equality via the market and consumption, at the expense of strategies to expand public social protection systems:

.. private consumption was unleashed without restraint at the expense of public services, whose improvement would have been a more expensive way of stimulating the economy. Purchases of electronics, appliances and vehicles were encouraged (in the case of cars, through tax incitements), while the water supply, paved roads, efficient buses, acceptable sewage disposal and decent schools and hospitals were neglected. Collective services had neither ideological nor practical priority.

Although there are several “islands of excellence” in the SUS, the result has been that the problems and distortions described above have become insurmountable. They mainly affect the efficiency and quality of primary care, where early detection, prevention, and education occur. Prevention and primary care programs in HIV and AIDS have been the main victims of this disorganization, aggravated by the weakening of the AIDS movement’s capacity to demand policy accountability.

The human rights framework

In the 1990s, when the Brazilian response to HIV and AIDS was gaining momentum, the international and Brazilian human rights policy agenda was experiencing a virtuous cycle of legitimation and expansion. This cycle began with the International Conference on Human Rights (Vienna, 1993), affirming the indivisibility between civil and political rights and economic and social rights and leading up to the U.N. Conference on Population and Development (Cairo, 1994) and the 4th World Conference on Women (Beijing, 1995), whose action programs addressed the epidemic from the perspective of health and human rights. The creation of UNAIDS in 1996 and the Special Session of the U.N. General Assembly in 2001 were also premised upon equality, freedom and non-discrimination. Brazil was an important player in all these processes.
The scenario is radically different in 2016. Even though regional and international human rights agendas have been consolidated since the 1990s, global conditions are now determined by so-called competitive multi-polarity and a reactivation of the premises of national sovereignty. The instrumental and selective use of human rights is now increasingly frequent, and human rights principles have been abandoned by numerous State players, both north and south of the equator.¹¹

Negative trends are also felt in Brazil, where human rights have always had enemies. The National Human Rights Program, created in 1995 and transformed into the National Human Rights Secretariat in 2003, with ministerial status, was for many years an important source of support for the agenda demanding access to treatment and non-discrimination in the country’s AIDS policy. However, in 2010, during the third revision of its policy guidelines, this agenda was harshly attacked by conservative forces and its performance subsequently weakened. In the 2015 cabinet reforms, which took place in the midst of the current crisis, the Secretariat lost its ministerial status and was transformed into an internal division of a new ministry that also encompasses the Secretariat for Women’s Policy and the Secretariat for the Promotion of Racial Equality.

Even before 2010, however, there were already signs of dissociation between AIDS and human rights in the federal government’s policy guidelines. In 2008, the first report presented by Brazil to the Universal Periodic Review (UPR) of the Human Rights Council failed to even mention HIV/AIDS policy, a pattern that was repeated in the 2012 UPR. Today, a new debilitating factor needs to be considered: the current biomedical strategies being employed as the principal guidelines for Brazil’s national policy also

¹¹ The clearest example of this trend is the treatment of refugees by the European Union.

fail to favor the human rights and non-discrimination perspective that was formerly the strongest characteristic of the Brazilian response to HIV and AIDS.

The politics of sexual conservatism

Another characteristic of the Brazilian context in the 1980s, which was widely acknowledged as a facilitator for a response to the HIV epidemic that was exempt from moralism and based on human rights, was the peculiar place and meaning of sexuality in the social construction of Brazilian national identity. Over the last 30 years, however, there has been a transformation in Brazilian society and politics resulting in the continuous expansion of conservative and moralistic views towards gender, sexuality, and the family. Conservative view and actors were not absent from the scenarios in the 1980s and 1990s, however. For example, during the 1988 Constitutional reform, the small Evangelical caucus, already active in Congress and allied with other conservative forces, managed to block inclusion of any mention of sexual orientation in the final wording of the constitution. Later, on various occasions the Catholic Church’s hierarchy openly attacked the widespread free distribution of condoms by the Ministry of Health. Although such episodes were virulent, they do not compare to the systematic nature of the current backward trends in gender and sexuality policies in Brazil that have resulted from the accumulation of power by dogmatic religious forces in the country’s electoral politics.

As Brazil’s democracy has become consolidated, the contradictory nature of the pro-governability pact that served as the basis for democratization has become increasingly evident. Based on the rules of the Brazilian Presidential system, the Executive Branch is unable to govern without constantly negotiating with its own Congressional base. This dynamic becomes even more complicated due to the political system’s fragmentation. Today, there are more than 40 registered political parties in Brazil, 30 of which are represented in the House of Deputies. This creates extremely unstable conditions for negotiation, allowing Evangelical and other conservative legislators to leverage their influence, establishing a significant presence that crosses party lines and expands the areas open to negotiation with the Executive.

This dynamic has had a negative impact on public policies in many “morally sensitive” areas such as health and reproductive rights, HIV and AIDS, and sex education. In 2011, Brazil’s President suspended public school distribution of an educational kit with videos on sexual diversity. In early 2012, the Minister of Health censored the HIV prevention campaign for Carnaval (Mardi Gras), which was focused on young MSM. In June 2013, an HIV prevention campaign among prostitutes was censored, and the

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director of the Department of HIV, AIDS, and Viral Hepatitis resigned in response. In all of these cases, radical measures were taken to respond to heavy pressure by conservative legislators belonging to the government’s political constituency. These congressmen used these issues as currency for bargaining regarding issues that the Executive Branch understood to be more important. In 2015, with the inauguration of the most conservative legislature in Brazil since 1964 (the year of the military coup), a bill dating to 2001 proposing the criminalization of HIV transmission was resuscitated and channeled into fast-track review. Its passage was blocked by the mobilization of Brazilian civil society and by domestic and international institutional players committed to the HIV and human rights agenda. A final vote on this bill in the Lower House Committee is on hold, pending a break in the turbulence rocking Congress with the current impeachment proceedings.

Prospects are not exactly promising for blocking this and other backward bills in the near future. Under the current legislature, which lasts until 2019, the Evangelical caucus holds nearly 15% of the 586 Congressional seats. These belong mostly to the Assembly of God Church (25), the Universal Church of the Kingdom of God (12), and the Baptist Church (8), distributed across 23 different parties. There is also a strong presence of conservative Catholic and Spiritist deputies, both men and women. These groups are generally aligned with the Evangelical Congressman who was elected Speaker of the House in 2015 and who, as of this writing, leads the impeachment proceedings against President Dilma Rousseff, even though the Speaker himself faces solid and disturbing charges of corruption.

It is impossible to predict what will happen in the Brazilian political scenario in the short and medium term, but one thing is certain: the forces of moral conservatism that have been an important driving force in the current impeachment proceedings will continue to be present and active in both the country’s political institutions and in society itself. Any and all policy developments in response to HIV and AIDS need to take these forces into account with realism and creativity.

Postscript

This introduction, prepared in late March 2016, already underlined the difficulty in predicting the developments of Brazil’s profound political crisis. Two months later, Brazil’s institutional and political reality has changed substantially, but it is still difficult to predict what may happen in the middle and long term.

On April 17, the National Chamber of Deputies (Lower House) voted by an incontestable majority to allow impeachment proceedings against President Dilma Rousseff. The plenary session on the Chamber floor was
grotesque, with appeals to God and “family” and preposterous arguments by the Deputies. The worst moment was when Deputy Jair Bolsonaro – one of the most virulent voices in the attack on issues related to sexuality and rights – dedicated his vote to an infamous torturer from the military dictatorship, as he declared his support for the impeachment of a President who had been tortured herself. The scenes from the vote shocked both foreign observers and wide sectors of Brazilian society. An example was the article published by the habitually sober German magazine Der Spiegel, forebodingly entitled “An Insurrection of Hypocrites”.

On May 11, the Senate confirmed the Chamber’s decision, launching Rousseff’s temporary suspension, which will extend 180 days starting on that date, when the final vote on the impeachment will take place. According to formal legal analyses, the impeachment proceedings thus far have complied with due process as laid out in the legislation on the matter (dating to the 1950s). However, from the political point of view the two Congressional votes actually constituted a tour de force that some have called a political coup. For example, Ernesto Samper, former President of Colombia and current President of UNASUL, analyzing the institutional evolution of the crisis, stated correctly that by suspending an elected president on grounds of contested administrative acts, the Brazilian Congress established a dangerous precedent for the consolidation of democratic states in South America. Since then, protests against the impeachment proceedings have multiplied across the country and in high-profile international events like the Cannes Film Festival.

Despite these challenges and protests, the interim government headed by Vice President Michel Temer grasped power as if for good. Temer immediately proposed draconian cuts in public investments, eliminated various cabinet ministries (Culture, Human Rights, Racial Equality, and Women’s Policies), altered the operations of the public communication system without legal grounds, and subordinated the Ministry of Social Security to the Ministry of Finance, which can be interpreted as an extreme neoliberal act. The interim cabinet consists basically of conservative Members of Congress, with an Evangelical pastor heading the Minister of Industry as a prime example. Known for their political cronyism, several of these characters are under investigation for corruption.

But the biggest international repercussions came from the total absence of women in the interim Administration’s first echelon, in stark contrast to Brazil’s six years under a woman President. To correct this deficit, the interim President launched a search for women to occupy second-echelon posts. Not only was this effort largely fruitless – since several women turned down the invitation – but the effect was a chimera. On the one hand, a “modern” liberal female executive accepted the invitation to head the National Economic and Social Development Bank (DNDES), and a well-
known feminist took over the Human Rights Secretariat, now under the Ministry of Justice. On the other hand, the new Secretary for Women’s Policies is an Evangelical who has already come out publicly against abortion even in cases of rape.

From the point of view of health policy, in the broader and sense and specifically in the response to HIV and AIDS, it is extremely serious that in his first public declaration, the Minister of Health stated that the Unified National Health System (SUS) is financially unsustainable. Although the Minister later recanted, there is still a very real threat that the foundations of the public health system will be demolished.

In Congress, especially in the Chamber of Deputies, the current wide conservative majority could pass reforms to drastically curtail the rights written into the 1988 Constitution, including labor and social security rights, and even the right to health. As for relevant issues in the response to HIV, immediately following the Congressional go-ahead for impeachment proceedings, the Evangelical caucus proposed the suspension of an Executive Order signed by Dilma Rousseff in early May that ensured the right to change of name for transvestites and transgender people in all federal public institutions.

In other words, Brazil is witnessing a sweeping conservative restoration, but which should not be interpreted as an unexpected phenomenon. The origins can and should be found in the long cycles in the country’s social and political formation. As observed above, the symptoms of this restoration were already quite evident throughout the PT administrations, at least since the mid-2000s. This trait is illustrated by the fact that one-third of the current Administration’s cabinet members were also cabinet members during the Lula and Dilma Rousseff Administrations.

The extent and depth of structural corruption deserve emphasizing. Although the investigation into the corrupt practices that marked the PT Administration has been a major factor for social mobilization in favor of impeachment, in the last two weeks of May two cabinet members from the interim Administration have already been sacked due to evidence of obstructing the investigative procedures in Operation Carwash. One of the most unpredictable elements in the Brazilian scenario involves the spinoffs of this and other inquiries, with extensive ramifications across the political spectrum. Neither is it possible to predict the extent to which further challenges and protests may or may not gain momentum in the coming months. Not surprisingly, in the first week of June 2016 the Brazilian press announced that the initial forecast, i.e., that the Senate would second the Lower House and vote for impeachment, is no longer certain. In other words, only time will tell.
From stabilization to reemergence: challenges for confronting the HIV/AIDS epidemic in its fourth decade in Brazil

ALEXANDRE GRANGEIRO

The debate on trends in the HIV/AIDS epidemic in Brazil has sparked controversies and revealed different views of the impact of preventive measures and universal access to antiretroviral drugs. On one side, more optimistic views indicate improvement in various indicators such as stabilization of HIV incidence, maintenance of important rates of protective practices in sexual relations with substantial risk of infection, and an increase in the number of persons receiving antiretroviral therapy and a resulting decline in AIDS-related mortality rates.

On the other side are warnings from parts of the scientific community, activists, and public health policymakers that the magnitude of the HIV/AIDS epidemic in Brazil reached its highest levels in recent years. This has
been accompanied by a turnaround in the trend towards stabilization of the epidemic, especially in the younger generations; the existence of a relevant contingent of infected persons that are unaware of their serological status; HIV prevalence rates exceeding 5% in some specific populations and regions with a high degree of urbanization; and as much as a third or more of late diagnoses and/or loss to clinical follow-up in patients on antiretroviral therapy, reflecting high and persistent AIDS mortality.

A significant part of this controversy stems from different ways of analyzing the same data set, insufficient epidemiological surveillance research, and lack of information to allow more in-depth knowledge of the HIV dynamics in the country. According to recent official data, for the first time in the last seven years the AIDS incidence rates in Brazil dipped below 20 cases per 100 thousand inhabitants. From 2013 to 2014, the rate dropped by 5%. However, this news ignores an important issue: AIDS epidemiological surveillance in Brazil is relatively complex, reporting cases through four national information systems. This means that according to conservative estimates, more than 10% of the cases only appear in the statistics a year after diagnosis. A simple correction for this recording delay is sufficient to shift the AIDS incidence rates in 2013 and 2014 to among the highest since 1980 (Graph 1), slightly reducing the officially announced downward trend. In addition, three of the country’s five major geographic regions show sharper growth in the epidemic. The only region with a clear downward trend is the Southeast, with the best social development indices and the country’s largest cities, including São Paulo and Rio de Janeiro. Since the epidemic is older in the Southeast and concentrates slightly more than 50% of all the country’s cases, it influences the overall national results and masks the more critical realities in the other regions.

This possible reemergence of the HIV/AIDS epidemic in Brazil becomes even more evident when observing the epidemic’s behavior by generations. Circumscribing the analysis to AIDS cases diagnosed in the 15-to-23-year age bracket, namely those born in the 1990s and who initiated their sexual activity when the impact of antiretroviral therapy....

**Graph 1. AIDS INCIDENCE RATE (100 thousand inhabitants)**

Brazil, 1980-2013

Source: Boletim Epidemiológico de AIDS, Ministério da Saúde (2015), corrected for reporting delay in the years 2013 and 2014 (by 2.476% and 8.770%, respectively).

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3 The epidemiological surveillance system records AIDS cases by clinical and immunological criteria (CD4 < 350 mm³), case notification and searches in death certificates, information systems on CD4 and viral load tests, and dispensing of antiretroviral drugs.
was already heavily visible in society, showed AIDS incidence rates 3.2 times higher than among individuals born in the 1970s and who were possibly initiating their sexual activity at the time the epidemic emerged in the country. For homosexuals, this rate is 6 times higher (Graph 2). Importantly, the generations born in the 1960s and 70s account for half of the AIDS cases recorded in Brazil over the course of these 30 years. Likewise, homosexuals were the ones who most changed their sexual practices and engaged in the struggle against the Brazilian epidemic. Thus, if the upward trend in AIDS incidence is confirmed in the new generations and in young homosexuals, in the coming years we may observe a larger epidemic than has existed thus far. This may occur after the adoption of the public policy to supply antiretroviral therapy to all Brazilians infected with HIV, a policy that led to expectations of a significant reduction in the number of new cases of AIDS illness in the country.

The upward trend in AIDS cases has already appeared in the analyses of the number of new cases of HIV infection. An estimate based on CD4 count in individuals that were initiating clinical follow-up in Brazil showed 47 thousand new cases of infection in 2012, with an incidence rate of 21.7 per 100 thousand inhabitants (Graph 3).

Some factors may theoretically help explain this new trend in the Brazilian epidemic. The country may be experiencing a generation change in sexual behavior, marked by new arrangements for encounters and relationships among partners and lower adherence to HIV prevention practices, among other factors. Preliminary analyses suggest that the new generations are initiating sexual activity earlier, having more sex partners, and using condoms less frequently in relations with casual partners.

The increased susceptibility of new generations has been accompanied by a high proportion of individuals infected with HIV that are unaware of

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their serological status and/or present detectable or unknown viral load after diagnosis, which increases the community odds of HIV transmission in unprotected sexual relations. In 2015, this proportion was 54% (425 thousand) of the 781 thousand Brazilians infected with HIV.

Contradictory indicators are also seen when analyzing care for persons living with HIV. On the one hand, initiatives by the Ministry of Health to ensure universal HIV diagnosis and treat all infected persons have led to an important increase in the number of HIV tests performed in the public health system. In the 2010s, this increase was 19.3%. The same period witnessed a 59% increase in the number of persons that started antiretroviral therapy, representing a contingent of approximately 400 thousand Brazilians. Meanwhile, this undeniable success in test-and-treat strategies has overshadowed some weaknesses in the Brazilian response. Efforts at universal testing in the country are not reflected (to the same degree) in the number of persons that initiated clinical follow-up in public health services. This number remained stable between 42 and 46 thousand persons from the years 2008 to 2014. That is, during this period, the ratio between tests and persons that initiated treatment increased from 146.9 to 173.2. In other words, more people are tested, but there is not a corresponding increase in the identification of seropositive individuals. This fact further suggests that the number of persons that initiated antiretroviral therapy in the 2010s, already cited above, is associated more with recent changes in the criterion for initiating treatment than with an increase in diagnosis and greater inclusion of infected persons in health services.

Furthermore, an important share of the diagnoses and initiation of antiretroviral therapy have been performed late compared to clinical recommendations. From 2011 to 2014, some 20 to 22 thousand persons per year initiated antiretroviral therapy with CD4 counts below 350/mm³. It is also estimated that 12.5% of the persons that begin treatment late in Brazil take more than a year after diagnosis to reach the health service.
In addition, patient care strategies have proven weak in linking infected persons to health services. A prospective study\(^\text{11}\) that followed some 8 thousand patients on ARV therapy in four of Brazil’s major geographic regions from 2003 to 2013 found that 65% had a history of loss to follow-up at some moment in their treatment and that the probability of loss to follow-up 5 years after initiating therapy was 37.3%. According to the study, the consequence was a substantial loss in therapeutic effectiveness. Thus, the likelihood of having an undetectable viral load after 5 years was less than 50%, or far short of the United Nations’ goal that 90% of persons enrolled in health services after diagnosis should have an undetectable viral load.

This situation has been reflected in the persistently high AIDS mortality rates in Brazil, which have varied only slightly in the last 15 years, alternating up and down. In 2014, the standardized rate was 5.7 per 100 thousand in habitants. In absolute terms, however, the number of cases has increased slightly in recent years, which has also increased the social impact of AIDS. In 2013, the 12.5 thousand AIDS deaths meant 382 thousand potential life years lost\(^\text{12}\), considering the Brazilian life expectancy of 74.9 years.

In short, the information presented here indicates that Brazil may be experiencing a transition, with positive indicators in the country’s response permeated by indications that the epidemic is reemerging and has the potential to reach higher levels than those observed in the last 30 years. This is happening despite public policies that have guaranteed access to antiretroviral drugs for all those who need them, showing that the introduction per se of new drug technologies, as in the case of antiretroviral drugs, leads to exhaustion in the long term, requiring other actions in order for their effects to be lasting and as broad as possible. A good example is HIV vertical transmission: despite the availability of effective prophylaxis in the public health system for more than 15 years, leading to a drastic reduction in new cases in the initial years, there are still 400 new cases per year, with an AIDS incidence rate in children under 5 years equivalent to 3.6 per 100 thousand\(^\text{13}\).

The possible reemergence of AIDS becomes even more worrisome considering that Brazilian society has reduced its involvement in the response to the epidemic in recent years, marked by fewer news stories in the mass media, fewer preventive actions for populations more vulnerable to HIV, and less condom distribution in schools and workplaces and in activities by nongovernmental organizations, among others. This decreasing involvement by society marks a sharp break with one of the main pillars that had helped Brazil achieve various positive results in previous years.

In addition, a complex web of factors involved in the epidemic’s new trends in Brazil (like the increase in the susceptible young population) raises questions as to the possibility of greater control of the epidemic with the nearly exclusive use of test-and-treat strategies. These strategies may very well be insufficient if not accompanied by responses addressing the underlying structural determinants of the epidemic in Brazil, such as

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\(^{12}\) Calculated with data from the Linked Database on AIDS, Ministry of Health, 2014.

situations of prejudice and stigma, the health services structure – with staff shortages and insufficient strategies for embracing and retaining users – and violence and marginalization of the populations most at risk. In this sense, the epidemic in Brazil has disproportionally affected specific regions and populations, including\textsuperscript{14}: sex workers (prevalence 6.8%), men who have sex with men (prevalence 6.8%), drug users (prevalence 23.1%), and people who are homeless\textsuperscript{15} (prevalence 5.0%).

Public health indicators should be taken seriously whenever they point to a possible worsening scenario. Prompt action allows developing early measures to deal with the problem, avoiding the consolidation and expansion of negative impacts. In addition, negligence and lack of communication concerning these indicators prevent public awareness of the problem’s real severity and participation in lasting solutions. Anticipation and transparency in the response has helped Brazil guarantee positive results in the 30 years of struggle against the HIV/AIDS epidemic.


The neoliberalization of HIV prevention in Brazil

FERNANDO SEFFNER
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1. The Brazilian response to AIDS: contemporary dilemmas

AIDS is a disease with well-defined biological characteristics. Like any other health condition, however, it is also a highly complex social, political, cultural, and economic phenomenon. When designing responses to AIDS, it is thus important to not only include measures that deal with the biomedical characteristics of the disease (prescribing a certain drug for a given clinical condition, or employing one test or another to discover how the virus impacts a given individual’s system): equally important are responses to the political and social phenomena that not only “permeate” the disease, but actually constitute what we know as AIDS, particularly attitudes that promote stigma and discrimination.
Perceived as a highly complex political and cultural reality, AIDS acts as a social marker, highlighting groups, settings, contexts, and situations that illustrate the historical inequalities of social life. It also signifies a vulnerability that produces only a handful of viable lives alongside many more unviable, cheap lives that do not merit care or treatment since they have no future. To speak of a national AIDS situation necessarily means to speak of the country’s social structure; its hierarchies of inequality; the way it deals with the construction of public space and with social inclusion programs; how it builds political life and power-sharing between individuals and groups. Power-sharing between men and women, for example. Or between whites and blacks, between populations with greater or lesser degrees of formal schooling, between individuals of different faiths, between different regions of the country, between rich and poor, between youth, adults, and the elderly.

The path we have chosen for this paper is to attempt to understand the current situation with regards to the Brazilian response to AIDS. This is linked to certain strong characteristics of the country’s historical response to the disease (viewed here as relevant political experiences), as well as to neoliberal strategies that seek to design an end to AIDS, in a highly medicalized future, via the transformation of patients into homogeneous consumers of medicines while minimizing Brazil’s diverse cultural and political traits. In our view, the construction of the contemporary Brazilian response to AIDS combines elements from a glorious past (a Brazil whose response to AIDS was admired worldwide and in sync with human rights considerations) with actions involving the “promise” of a tranquil future (an end to the AIDS epidemic which is supposedly “just around the corner”) involving cures created via increasingly potent medicine. Completely in sync with this situation is the adoption of a strategy for responding to the epidemic that sees all individuals as identical and understands Brazil’s social situation as homogeneous, emphasizing the biomedical side of the disease to the detriment of the political, cultural, and economic elements that make Brazil an enormously unequal country.

2. The Brazilian response to AIDS: time, memory, history

The AIDS epidemic appeared in Brazil when the country was emerging from a prolonged military dictatorship (1964-1985) and was engaged in democratic reconstruction. From 1985 to 1991, the official response was bureaucratic and scarcely amenable to dialogue with civil society. Its campaigns reinforced stigma and prejudice, frightening rather than educating, with slogans that claimed “if you don’t watch out, AIDS will get you”. However, a prevailing atmosphere of political openness and grassroots participation combined with the force of the social movements in the struggle for freedom. This ended up “contaminating” Brazil’s response
to AIDS, whose second phase was based on bringing policymakers and NGOs together in cooperation, as well as on dialogues with the most affected social groups and the development of programs that promoted real inclusion for gender and sexual minorities in health care. This explains why the campaigns in the second phase were so pioneering, addressing gender and sexuality issues, sex education and harm reduction for injecting drug users. These programs combined biomedical actions with strategies for empowering diversity and the struggle against inequality.

The concept of vulnerability also began to orient the development of plans for confronting the epidemic, especially with the publication of the book *AIDS in the World*. This meant actions that increased the visibility of issues such as drug use, sexual orientation, gender differences, demands from youth cultures, regional diversity, and different family models. On a broader political level, the Brazilian response to AIDS engaged with the field of human rights, feminist struggles, and LGBT social movements. It aligned with the so-called “new social movements”, utilizing identity markers that were not necessarily linked to the world of work (e.g., trade unions), but instead to a plurality of subordinate social and cultural conditions (the landless movement, indigenous movements, movements against paying the foreign debt, anti-imperialist movements, coalitions against the rising cost of living, the homeless movement, women’s movements, movements of different sexual orientations, movements for school inclusion, etc.). In this process, the Brazilian response to AIDS – both that produced by health services and the campaigns in society – shifted from a behaviorist discourse based on the notion of an autonomous liberal subject to a discourse focused more on the social and political conditions that produce the existence of these individuals. Preventive campaigns specifically benefited from this view, which was consistent with the social determinants of health theory that had already been developed in Brazil and which oriented policies in the country’s Unified Health System (SUS), particularly in relation to class, race, ethnicity, gender, and sexual orientation.

The response to the epidemic thus began to operate with theoretical and political concepts that contemplated situations of inequality, stigma, discrimination, and exclusion, developing original strategies in which the struggle against the epidemic was combined with expansion of the country’s democratic institutions. In a unique way, these tools for struggling with and understanding AIDS were created in a hybrid space, where researchers, civil society activists, and government policymakers engaged in exchange and dialogue. This, in turn, fed the vigor and originality of Brazil’s responses to the epidemic and allowed interactions with other areas, both inside and outside the field of health (education, justice, social services, social security, etc.).

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7 For more information regarding the social factors impacting upon health in Brazil (in terms of history and the construction of parameters), see [http://www.determinantes.fiocruz.br/](http://www.determinantes.fiocruz.br/) (available in Portuguese and English).


solidarity, civil death, announced death, and a cure for AIDS. These became fundamental for understanding AIDS as a political and social phenomenon and for demanding responses, public policies, and actions to deal with the social and economic conditions that underlay the epidemic. The decisive inclusion of the Brazilian response to AIDS in the field of human rights helps explains a confrontation that occurred between the Brazilian Department of STDs, AIDS, and Viral Hepatitis and the U.S. government: Brazil turned down 40 million dollars in funds from the Bush Administration in 2005 for use in the fight against AIDS in Brazil. This money was linked to moral dictates that clashed with the underlying human rights principles in the Brazilian response, especially in the sensitive area of prostitution, which the U.S. government did not acknowledge as a way of life or profession, but which Brazil understood as a legal activity worthy of social protection. The foundation of a Human Rights Unit within Brazil’s Department of STDs, AIDS, and Viral Hepatitis dates to this same period, as do inter-sectoral and interdisciplinary working groups, participation in campaign design by persons living with HIV and AIDS, the explicit development of advertising campaigns promoting prevention and incorporating sexuality, race, and gender, and the funding of NGOs to conduct pilot projects and experiments.

Beginning in 2008, during the second term of President Lula (whose two terms ran from 2003-2006 and from 2007-2010), the policy began to suffer from the effects of this prolonged period during which civil society leaders joined government institutions (at the federal, state, and municipal levels), leading to a gradual loss of autonomy for NGOs. This process included both voluntary participation on the part of NGOs and deliberate cooptation of them by the government. Civil society thus increasingly came to be seen as the executor of actions defined by public policies, essentially supporting the government’s initiatives rather than helping generate them. As a result, NGOs lost financing for activities involving social control and for developing pilot demonstration projects. In general, civil society organizations that did not come under the wing of government programs experienced increasing difficulty in surviving, while those that more-or-less surrendered to government administration lost their autonomy and their ability to criticize. Furthermore, they saw their stance with regards to social control compromised.

This process has combined with conservative inroads into AIDS policies, which are often created based on moral objections. These have been led by strong social actors such as Brazil’s Neo-Pentecostal churches, which have established caucuses within Congress, drawing on their heavy media power and ability to recruit individuals. These conservative players are also courted by the federal executive branch which, following the logic of “coalitional presidentialism” that has marked Brazil’s republican life for some time now, can no longer count on a majority in Congress. The progressive agendas

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11 For repercussions of the case in the U.S. media, see [WSJ](http://www.wsj.com/articles/SB111498611657721646). It also sparked an editorial in The Lancet on May 14, 2005 [PDF](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(05)66522-1.pdf).

involved in the struggle against AIDS and in human rights advocacy for different sexual orientations and diverse genders, have become currency of exchange in political deals made in the name of “governability”. Since 2011, at the start of President Dilma Rousseff’s first term (2011-2014; 2015-?), Brazil has shown clear signs of backsliding in public policies on gender and sexuality. Three examples spring to mind: in 2011, the distribution of educational materials to schools through the Brazil Without Homophobia Program (referred to by the media as the “anti-homophobia kit” or “gay kit”) was suspended; in 2012, a prevention campaign during Carnival, targeting young gays, was suspended with much controversy; and in 2013 a campaign targeting sex workers, which combined prevention with self-esteem in prostitution, was vetoed. This last event also led to the summary dismissal of the coordinator of the Department of STDs, AIDS, and Viral Hepatitis.

Brazil also saw the gradual cooptation of certain social movements through the strategy of inclusion via consumption and the market. This has been the case of the LGBT movement, for example. The international economic market provided an argument that negatively affected the budgets of AIDS programs based on human rights. This was further aggravated by the political crisis involving the Federal Executive Branch following Dilma Rousseff’s reelection in 2014, which obviously undermined the government’s authority and triggered the Executive Branch’s pursuit of political support at any cost. Additionally, some international agencies and funders pulled out of Brazil— or stopped funding AIDS-related activities in Brazil. This intensified this trend towards the abandonment of the human rights agenda in HIV and AIDS policy. International funding dwindled for various reasons, including a prolonged decline in HIV-related mortality and broad access to ARVs. This helped to create an impression of “complete success” of the response to HIV in Brazil, which may have contributed to a feeling that AIDS in Brazil was a “solved problem”.

But this does not mean an effective change has taken place in the set of symbolic values the Brazilian population uses to deal with the epidemic, which currently favor a heavily pharmaceutical-centered model. While the huge strides in AIDS treatment should be greeted with enthusiasm, they have narrowed Brazil’s national response, which has been increasingly marked by a biomedical understanding of the disease, with an eventual cure understood as simply resulting from the proper application of pills and treatment. Such an understanding obviously wastes the experience gained in the struggle against AIDS in Brazil, particularly in the combination of responding to the epidemic and deepening the democratic process, guaranteeing the fight against discrimination, exclusion, stigma, and social violence.

The strategy of Treatment as Prevention (or TasP) that has been adopted in various modalities Brazil since late 2013 combines well with a certain liberal
reasoning, producing an agenda of individualizing ontology. This provides a cornerstone upon which individuals infected with HIV (and those who may be infected in the future) are constructed merely as individual consumers of medicine. In this individualizing paradigm, collective strategies and social responses to the complexity of AIDS are decisively weakened, and the epidemic’s nature as something that is far more than a simple biomedical condition is lost from sight. The most obvious result of all this for AIDS public policy is an emphasis on so-called “test-and-treat” programs that are linked to the TasP strategy. This, in turn, is closely linked to what might be called the neoliberalization of prevention in Brazil, where there is no funding for activities in health education or for the reduction of discrimination, but only for treatment, confusing the cure for AIDS with the elimination of the virus or the blocking of its replication. All this stands in sharp contrast with earlier times, when Brazil’s experience achieved worldwide recognition for its association with human rights, as discussed above. Importantly, the hegemonic dominance of the test-and-treat strategy clashes with Brazil’s chronic difficulties in referring recently infected people to the health system, initiating treatment, or even in keeping those who are already ill in the system. All this points to a structural weakening of the Unified Health System, with a loss of capacity for response, solidarity, and resolution. This is the result of the sector’s underfinancing, with budget cuts in health coming at all levels of government, along with shortages of local staff and lack of local policies. Despite the strides made by treatments with new drugs and the incorporation of Brazil’s programs by other developing countries, Brazil still basically implements a triple ARV regimen (EFV+3TC+TDF) that is considered obsolete for recently infected individuals, who need to initiate therapy early on. PrEP has still not been implemented, and although PEP has been regulated, it has not been properly presented to the population at large. In many Brazilian cities, this service is not offered.

One result of the conservative moral and political wave sweeping Brazil is the establishment of strategies by which government power, normalization technologies, and institutional and police violence converge. This has eroded the opportunities for dialogue between academia, social movements, and policymakers. The adoption of what we are calling a “single model strategy” points to test and treat, applied to everyone but without effective guarantees of social inclusion and support programs. The country is thus experiencing a two-sided movement: waste of the accumulated historical experience in the struggle against AIDS and a situation of “make live and let die” – that is, allowing to live via the massive supply of testing and treating, while letting die under the recrudescence of all manner of stigma, discrimination, and social violence.

The historical experience that has allowed Brazil to build original, daring, and socially inclusive responses in the struggle against AIDS thus only survives


as a crystallized and mythical construction, from which no lessons have been extracted in order to orient new policies for new times. Investing all the country’s energies in test-and-treat programs feeds the false hope for a peaceful future, represented by a cure for AIDS that is eternally promised as supposedly “just around the corner”. The hegemonic dominance of this view is attested to by analysis of interviews with authorities and media stories in Brazil. These repeatedly announce that the cure, the miracle drug that will finally eliminate HIV from people’s systems, is only a short distance away. But even if such a drug is applied quickly, it will not eliminate all the situations of social injustice that make some people more vulnerable to health problems than others, particularly in the case of sexually transmissible diseases. A major portion of the moral register of Brazilian society is anchored in sexuality and there is virtually no religious denomination that has not built its moral code around sex, far more than around other aspects of human life (such as honesty in business, to give just one example).

In short, the Brazilian response to AIDS now lives by feeding on its glorious past (although it is not equipped for a dialogue with present demands) and on the illusion of the early elimination of AIDS as a result of the test-and-treat strategy. It is understood that this strategy will lead to the reduction of society’s viral load to almost zero. Unfortunately, the strategy means treating everyone as identical, in a “one size fits all” manner, ignoring the markers of difference that we have discussed above, which continuously produce situations of inequality and their resulting health problems.

3. The Brazilian response to AIDS: principles to ensure high quality actions

Given the current and historical situation that we have briefly described above, we now wish to present some ideas which, in our view, would help to build a Brazilian response to AIDS that is truly engaged in dialogue with its past, while using foresight to prepare for the future, interacting positively with the construction of a more democratic society, with greater opportunities for social justice:

- Conceiving of the field of prevention as something that should be based on a pedagogy of prevention, or what might be described as prevention literacy: namely a personal and collective strategy that implies a willingness to reinvent what is today known as prevention. This would incorporate the newly available drugs, new knowledge regarding HIV transmission risks, time-tested principles involving dialogue with different cultures and actors, and the understanding that there are many ways of conceiving of risk management and of living one’s life to the fullest19.
• Connecting prevention literacy to a politics of emancipation. In other words, understanding that the end result of preventive strategies is not just someone who has avoided AIDS, but someone who has expanded their decision-making autonomy and who interacts with various information sources. Treatment literacy and prevention literacy must both be sensitive to different cultural realities, languages, subjects and desires. This means that treatment and prevention are pedagogical opportunities which are likewise sensitive to different cultures.

• Operating with a dialogue that allows one to offer groups and individuals the known range of preventive and therapeutic options, while respecting their own forms of decision-making.

• Conducting vigorous operations in the field of the symbolic cultural register, revaluing sexuality issues so they are not considered to be negative behaviors (that imply moral prejudice for many social groups). Keeping differences from becoming inequalities, which expand situations of vulnerability to include health problems.

• Linking the response to AIDS with the fight against stigma and discrimination of both individuals and populations, creating a courageous disposition in everyone.

• Developing plans to confront the epidemic that consider not only populations and social groups that are more or less vulnerable, but also specific contexts and situations that can increase the vulnerability of any or all individuals. This means creating prevention scripts that respect different life trajectories and which are in sync with knowledge about and availability of technologies and treatments. Acknowledging that each person and each group knows best about their respective lives and that this knowledge is essential for treatment as well as prevention.

• Anchoring responses to AIDS in mechanisms of solidarity that treat individuals as profoundly connected to the collectivity, and not in individual ontologies which exist at the whim of liberal strategies. This implies discussing what we mean by “the end of AIDS”.

• Ensuring wide availability of Treatment as Prevention modalities (PrEP, PEP) in terms of their existence and modes of access, but also combining this with a theoretical framework of vulnerability which does forget each individual’s connection to programs, inclusion processes, markers of difference, sets of historical inequalities, and the quality of the democratic system itself. In short, join, rather than separate, strengths in the struggle against AIDS.


21 For a comprehensive discussion on this topic, see http://abiaids.org.br/o-fim-da-aids-2/28751.
• Finally, build a response to AIDS that respects each social actor’s sphere of autonomy: nongovernmental organizations, researchers, policymakers, affected populations, public and private institutions, health units, schools, social movements, etc., investing in the creation of channels for dialogue and cooperation. Recognizing the public role of NGOs and social movements, considering their demands, characteristics, and potentialities and guaranteeing their access to public funds. Resisting the State’s temptation to practice cronyism with those NGOs employed to perform public tasks (that have been outsourced to the private sector), and which ends up compromising the role of social control that these organizations should exercise.
The challenges of caring for persons with HIV and AIDS in Brazil

MARIA INES BAPTISTELA NEMES
MÁRIO SCHEFFER

Brazil’s historical response to AIDS featured the decisive creation of government programs, allocation of public funding, and investment in professional staff and health services. This allowed for the construction of a daring policy of care and treatment, combined with expanded actions and innovative practices in prevention.

Researchers, universities, and persons living with HIV mobilized together with NGOs and networks in the struggle for the right to health. Accompanying the policy’s implementation, the movement alternated between a supporting role, the execution of projects, and the formulation of critiques and protests, helping shift AIDS from the exclusively biomedical realm onto the national public agenda.

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An eloquent example of policy decision combined with technical capacity-building and community mobilization was the passage of a specific law in 1996, requiring the federal government to supply antiretroviral drugs (ARVs) free of cost.

The main pillar in Brazil’s AIDS program is the Unified Health System (SUS), the founding of which coincided with the beginning of the epidemic. The fight against AIDS in Brazil was conceived within this national health system, incorporating the system’s principles of universal and equitable care.

The Unified Health System, created under the 1988 Federal Constitution and financed by taxes and social contributions, combines actions and services in the promotion, protection, and recovery of health, carried out by the federal, state, and municipal governments. Organized on a regionalized and hierarchical basis, the public system is complemented by the private sector in providing and managing services, and includes community participation through representative health councils and conferences (structures that were strategically occupied by health administrators, professionals, and activists in the fight against AIDS).

AIDS care and treatment in Brazil were thus designed in an exceptional context. This involved the disease itself, the health emergency it caused, its epidemiological severity, and the social, technical, and scientific mobilization in the response to AIDS, as was the case in many other countries. In Brazil, however, the existence of the Unified Health System definitely allowed this exceptional situation to influence the reactions of health services and health workers, leading to a health care policy that was unprecedented both in its breadth and in the nature of its responses. Unfortunately, Brazil’s response to AIDS now faces serious challenges.

According to Ministry of Health estimates (2015), 781 thousand people are living with HIV in Brazil. 649 thousand of these have been diagnosed and, of these, 623 thousand are connected to some health service, having done at least one viral load or CD4 test. Of these, 109 thousand (17%) have either not even initiated treatment or have dropped out of follow-up. Among the 514 thousand that remain in follow-up by health services, another 109 thousand (21%) are still not on ARV therapy, and among the 405 thousand in ARV treatment, 356 thousand (88%) have reached a viral load below 100 copies/ml.

**Retention and treatment**

The largest “losses” in the continuum of care after diagnosis have occurred in the retention and treatment “stages”, both of which are the main responsibility of the health care services.
Although there are places and states in Brazil where access to health services is still difficult, access to treatment and care in HIV and AIDS is not the country’s main problem. Guarantees of universal access to antiretroviral drugs and to the country’s extensive health care network – some 750 health services treat patients with HIV – have not been matched by the expected outcomes and impacts.

According to a nationwide survey of the network (Avaliação Qualiaids)\(^1\), the health teams that treat persons with HIV are installed in outpatient clinics as medical specialists, or in hospitals (51%) in specific outpatient clinics for sexually transmissible diseases (STDs) and HIV/AIDS (34%) and in primary care units (15%). Some 23% of these services see fewer than 50 patients, while 26% have more than 500 patients each.

This diversity of services is reflected in their organizational quality. The assessment survey was based on various structure- and process-of-care indicators, including activities for monitoring and supporting patients who miss their appointments or drop out of treatment. The survey classified services in decreasing order according to quality. At the two extremes, the highest quality included 33% of the services, while 11% were classified as being of the lowest quality.

In the services’ practices, activities aimed at patient retention depend heavily on the local administration’s performance. However, local technical management stood out as the area with the worst performance. It demonstrates few activities in supervision, evaluation, and monitoring of technical work, which in many cases even fails to take advantage of the national electronic database that gathers information on ARV dispensing and the results of viral load and CD4 tests.

The performance of the cascade of care that depends directly on the quality of health services (treatment and retention) will hopefully improve with the initiation of the clinical protocol for initiating treatment immediately after HIV diagnosis. Adopted in Brazil in late 2013, this protocol contributed to a 27% increase in new treatment between 2013 (56,557) and 2014 (71,936), further highlighting the need for actions focused on adherence to follow-up and drug treatment.

The health care network also needs to be adjusted to treat needs related to the prolonged use of ARV therapy, health problems that are common to the general population such as aging, alcohol abuse, and smoking, as well as cardiovascular diseases, diabetes, and cancer, which require more complex care and treatment and involve greater use of health services.

But there are major obstacles to all of this. Engulfed in Brazil’s serious political and economic crisis in 2016, the Unified Health System (on which the maintenance of AIDS care and treatment depends) faces cuts in public resources and investments, low management efficiency, deficiencies and fragmentation of the health care network, inadequate health workforce qualifications, and a specific shortage of medical specialists, who have moved away from the public health services, many of which are overcrowded and suffer from precarious employment relations, substandard working conditions, and low wage scales.

The health services that treat persons with HIV and AIDS are experiencing a paradox: good, homogeneous availability of antiretroviral drugs and specific tests, the supply of which is the responsibility of the federal government, but insufficient and heterogeneous availability of other essential resources such as physicians, whose provision depends on the local infrastructure of the Unified Health System. Insufficient local technical management further aggravates the deficient integration between the various levels of HIV care, ranging from primary to specialized outpatient and hospital care.

**What is the alternative?**

As an alternative for the expansion of AIDS care, the Brazilian Ministry of Health has recently recommended greater allocation of HIV care and treatment to primary services, which have an extensive and heterogeneous network in Brazil, including basic health units and family health teams.

Primary care units already handle 15% of the care for persons in antiretroviral treatment in Brazil. With a lower average number of patients, these units display variable quality, which is also common to other types of services.

Primary care in Brazil partly fills the role of first-level outpatient care (the user’s first contact with the health system) and adequately solves numerous health problems that affect communities, notably prenatal care, which was crucial in the drastic reduction in mother-to-child HIV transmission in Brazil.
However, in a large share of Brazil’s territory, primary care fails to fulfill its other role, namely as the starting point for organizing access to the health system’s other levels. The continuum of care is not always guaranteed in all its modalities in the services, hospitals, and other units in the respective region’s health care network.

Overall performance assessment of primary care in Brazil shows a shortage of physicians and multidisciplinary teams, besides various forms of outsourcing and precarious forms of workforce hiring, leading to high staff turnover, insufficient infrastructure, and a model of care centered on treatment of acute demands. With regards to sexually transmissible diseases (STDs) and AIDS, primary care displays important gaps in the control of vertical transmission of syphilis and in the expansion HIV diagnostic testing in more vulnerable groups.

Assigning the responsibility for HIV care and treatment to primary care services may be an alternative in specific local contexts, but for the time being it cannot be a guideline for the health system as a whole.

Primary care in Brazil has proven adequate in caring for conditions with high, homogeneous prevalence, such as uncomplicated arterial hypertension. AIDS is different, not only because of its relatively lower prevalence and highly heterogeneous demographic and geographic distribution, but also because of the social barriers caused by stigma and discrimination and the technical difficulties of clinical management, frequently characterized by complex and individual decisions based on therapeutic guidelines that are constantly updated, and on the patient’s health status and history. This requires physicians with training, continuous updating, and professional experience, acquired by treating a minimum number of patients.

According to the Qualiaids survey, 27% of the services treating HIV and AIDS in Brazil lacked a single infectious diseases physician. In a study in São Paulo State, one-third of the physicians treating HIV patients had no specialized training or practical experience in infectious diseases (with “experience” being defined as following 20 or more patients)⁴.

Although Brazil has 3,229 infectious diseases specialists, these are mostly concentrated in the country’s southeast and southern regions and in the state capitals. In addition to HIV, they work with other infections, internal medicine, epidemiology, immunology, hospital infections, and emerging and reemerging diseases like dengue, Zika virus, chikungunya, and H1N1⁵.

There is a high turnover of physicians, particularly specialists, in the HIV sector, and difficulties in hiring and replacing professionals – this is a common problem throughout the entire public health system. In 2013, Brazil passed the “More Doctors Act” (Mais Médicos), providing for an increased presence of foreign physicians, especially Cubans. But the policy has no direct impact on HIV and AIDS treatment, since the program allocates these physicians


only on a temporary and emergency basis in primary care within underserved areas, in small counties or peripheral urban areas\textsuperscript{6}.

A large share of public health care services in Brazil has come under the administration of private entities known as “Social Organizations” (Organizações Sociais) hired by state and municipal governments. Several difficulties, such as staff shortages and low integration with the various levels of care in the health system, have been attributed to this privatized manner of services management, which also displays little transparency in its accounting, as well as flaws in control and oversight in its use of resources\textsuperscript{7}.

Taken together, these characteristics indicate a need to guarantee access, maintenance, and strengthening of specialized services with broader scale and complexity, which are also integrated with primary care and other services used by persons with HIV.

There cannot be a significant and sustained improvement in the continuum of HIV care without additional resources that increase quality and network integration at all levels of health service. These must be configured in order to adequately absorb the increase in the number of patients fueled by the chronicity of AIDS and by the new treatment-as-prevention protocols that recommend expanding access to diagnosis and immediate initiation of antiretroviral therapy.

For Brazil to avoid new setbacks in the fight against AIDS (and given the cyclical and structural difficulties in overcoming contexts of individual and social vulnerability that impact upon the epidemic) it is essential that we reclaim a vigorous response in terms of care and treatment.


The fight goes on: advances and setbacks for access to antiretroviral drugs in Brazil

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The goal of this brief paper is to identify the triumphs and setbacks in the struggle for access to antiretroviral drugs to treat HIV over the last 26 years in Brazil. This issue has been the topic of many Brazilian and international studies, articles, and books, given that Brazil was the first country to successfully adopt universal access to ARVs (in 1996) for all those who needed these medicines. This pioneering and daring role was the result of a joint struggle by organized civil society, governments, and scientists. It established Brazil as an international reference for exemplary AIDS programs and best practices that were able to significantly reduce mortality rates, guarantee universal health care access, and reaffirm medicine as a human right.

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It is not our intent to exhaustively explore the issue because, as we have commented above, other more in-depth publications have already addressed it. However, Brazil’s current political and economic crises and the equally daunting international context for public health and human rights pose a series of threats to access to HIV medicines in our country. To understand these threats, we revisit Brazil’s recent history in order to reflect upon the present and future of AIDS treatment in the country.

This paper is organized around three historical phases: the 1990s, with its triumphs over a series of obstacles; the first decade of the 21st century, a time of conquests, but also of increasing difficulties; and the current decade, with its increasing setbacks and challenges.

The 1990s: Daring, dialogue, and human rights

In the late 1980s, the arrival of ARVs in Brazil coincided with the creation of the Brazilian response to HIV, characterized by the consolidation of a social movement around AIDS, which had been formed years earlier, and the organization of the National AIDS Program. Several NGOs founded during this period had already raised the issue of access to medicines as one of their main concerns, launching publications and debates to mobilize communities and democratize medical and scientific information so that it could reach a broader audience, including people living with HIV/AIDS.

NGOs began to take action in the early 1990s, including legal activities to pressure health insurance companies to pay for the treatment of their policyholders who had HIV and AIDS. These actions led to legal victories, with the inclusion of AIDS among the diseases covered by private health plans and insurance policies.
These NGOs also brought pressure to bear on the government, pushing to make treatment for HIV and AIDS available in the recently created public health system. Drawing on Brazil’s Federal Constitution of 1988, which (for the first time) made health care a right of citizenship and a duty of the state, legal action was taken to force federal, state, and municipal governments to supply ARVs and medicine for AIDS-related opportunistic infections. In many cases, these actions by civil society (with the complicity of some municipal and state administrators) resulted in the purchase and free distribution of antiretroviral drugs by the public health system.

Some local governments, such as the city of Santos in São Paulo State (and later São Paulo State itself), pioneered ARV purchases on their own initiative, independent of legal action, guaranteeing access for patients in their jurisdictions. These results boosted mobilization by civil society for access to treatment and helped strengthen the National AIDS Program.

Other measures, both legal actions and popular mobilizations, invoked the founding principles of the Unified National Health System (SUS): social justice, universality, social control, and comprehensiveness. This mobilization for rights guaranteed by the 1988 Constitution and the founding organizational principles of the national public health system demonstrated the importance of linking public health and human rights in the struggle against HIV and AIDS. It also highlighted the need to mobilize different stakeholders (jurists, activists, health professionals, policymakers, scientists, etc.) in order to achieve results.

The mid-1990s (and specifically 1996) were a milestone in the history of ARVs in Brazil. Federal Law 9.313/96 was passed in November of that year, providing for universal access to antiretroviral drugs nationwide. The law resulted from the activists’ struggle and action by some administrators and legislators as well as health professionals. Its enforcement marked the beginning of the program for universal ARV distribution, which quickly proved successful and made Brazil a pioneering country in this field – one of the global reference points for successful programs in response to AIDS.

However, that same year Brazil (already a signatory to the TRIPS Agreement of the World Trade Organization [WTO]), modified its patent law in conformity with the rules imposed by global trade agreements. In its national law, Brazil incorporated articles that mandated drug patenting as well as provisions that set limits on granting patents and possibilities for their use to meet the public and social interest. Beginning that year, the ARVs that were not yet marketed in Brazil came under the monopoly of the international pharmaceutical industry. A harsh battle began over the use of available measures for defending the public’s right to health.

Prior to 1996, when Brazil’s prevailing intellectual property legislation prohibited patents for medicine, antiretroviral drugs registered in Brazil

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5 An acronym for the Agreement on Trade-Related Aspects of Intellectual Property Rights, one of the documents signed during the creation of the World Trade Organization in 1994, which leveled intellectual property rules for all signatory countries, requiring them to grant patents in the area of pharmaceuticals.

6 A patent is a title granted by a country to a company, person, or university, allowing the holder to exploit his invention for 20 years as a monopoly. Various measures can be used to decrease the monopoly’s negative effects from the perspective of public and social interest. Reis, Renata, Vieira, Marcela & Chaves, Gabriela. (2011). Acesso a Medicamentos e Propriedade Intelectual no Brasil: A experiência da sociedade civil. In: Reis, Renata, Terto Jr., Veriano & Pimenta, Cristina (orgs.). (2012). Direitos de Propriedade Intelectual e Acesso aos Antirretrovirais: Resistência da Sociedade Civil no Sul Global. Rio de Janeiro, ABIA. Pp 12-58.
were not protected by this mechanism, which allowed the country to produce them as generic products. This applied to drugs like zidovudine (AZT), didanosine (DDI), nevirapine (NVP), lamivudine (3TC), and ritonavir (RTV), among others. The possibility of domestic production of generic drugs was essential for structuring the program for universal access to antiretroviral drugs, since Brazil could offer ARV combinations according to international treatment guidelines at a much lower cost than if it were forced to purchase brand name medicine. In the following years, the program’s success could be measured by a drop of approximately 40% in AIDS mortality and of more than 70% in the morbidity rate over the course of only 4 years.\(^7\)

The Brazilian response was still yielding good results in the late 1990s, with civil society mobilization, a committed national AIDS program, and the availability of ARVs. However, the high prices of new drugs, based on the patent-backed monopoly of the big international pharmaceutical companies, already foretold threats to the sustainability of the country’s ARV access program. To deal with the pressure of rising prices, Brazil used some measures provided under national patent legislation in accordance with the TRIPS Agreement, such as compulsory licensing, which allows for the production and/or importation of generic drugs, forcing competition and reducing prices. Brazil used these measures in the 1990s and early 2000s as a threat, leading to considerable reductions in the drugs’ prices, given the real possibility of production of generic copies by national public laboratories if the license were granted.\(^8\) This strategy eventually ran out of steam, however, as we shall see below.

The use of legal measures to protect health and the public interests has faced huge pressures from multinational pharmaceutical companies and the governments of their home countries, such as the United States and the countries of the European Union. In the late 1990s and early 2000s, complaints filed by the United States and other nations in the WTO against countries like Brazil and South Africa, which produced or marketed generics, required rapid and effective responses by organized civil society and the government sectors engaged in providing universal public health,\(^9\) giving rise to what we now call “the global movement for access to medicine”.

Despite these obstacles, Brazil continued to move forward with its program of ARV access, ushering in a decade in which the country was an international reference for dealing with HIV and AIDS. Brazil’s programs were described as being characterized by daring inter-sector dialogue and respect for human rights, forming the basis for an effective and integrated response to the AIDS crisis.

\(^7\) Idem, 2011.
\(^8\) Grangeiro, A. et al. (2006).
The 2000s: From high noon to twilight

In the wake of the mobilization and debates of the 1990s, expectations for the 2000s were that the debate on ARV access and pharmaceutical patents would progress and that human rights and the guarantee of the right to health and medicine as part of human rights would come face-to-face with trade issues in various arenas.

Following indications that the high prices of patented drugs covered were jeopardizing and even killing millions of persons, the terms of the debate changed substantially, even in the context of neoliberal hegemony. In the first year of the 2000s, it was already evident that such trends would be especially relevant for the policy agenda in Brazil and across the world.

In the international arena, the year 2001 witnessed negotiations regarding declarations on the issue of pharmaceutical patents and access to medicine. The WTO Ministerial Conference of 2001 passed the historical Doha Declaration on TRIPS and Public Health. Without hedging, the Doha Declaration affirms that the TRIPS Agreement does not and should not prevent members from taking necessary measures to protect public health. Among these measures, the Declaration specifically cites compulsory licensing, through which governments can allow other laboratories to produce a given patented medicine without permission from the patent holder.

Additionally, the Doha Declaration made it clear that trade rules had to adapt to human rights standards. Since access to medicine is a fundamental part of guaranteeing rights to health, intellectual property rights are thus not absolute.

This debate manifested itself in several ways in Brazil. After passing a law (under heavy pressure) that favored the interests of the multinational pharmaceutical companies and the governments of the Global North, especially the United States, Brazil took advantage of the issue’s international collateral effects, combining these with the gains achieved by the AIDS movement in the 1990s, as discussed above.

An amendment to the Brazilian patent law in 2001 included provisions that favored the defense of health and the public interests. Among these was the Bolar exemption (which allows the registration of a generic drug whose the patent is still in force) and prior approval by ANVISA (the National Health Surveillance Agency), establishing more rigorous examination of patent applications for pharmaceuticals. Prior approval means participation by ANVISA, (the health regulatory agency) in the examination of pharmaceutical patents, together with the INPI (the Brazilian Patent and Trademark Office, which deals with industry and trade). Prior approval and the Doha Declaration are manifestations of the same process of questioning and repositioning with regards to the right to health vis-à-vis trade rules that

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create barriers to access to medicine. For this same reason, prior approval is one of the measures that has come under the heaviest attack in Brazil.\textsuperscript{11}

From the perspective of mobilization and politicization of access to medicine by civil society and the Brazilian AIDS movement, the issue was still high on the government’s agenda during the first decade of the 21st century. During the National Meeting of AIDS NGOs (ENONG) in 2001 in Recife, there was a demonstration in front of the U.S. Consulate, demanding that the United States withdraw its grievance in the WTO against the articles in Brazilian legislation that safeguarded the country’s sovereignty. In 2003, groups from civil society formed the Working Group on Intellectual Property, of the Brazilian Network for the Integration of Peoples (GTPI/Rebrip), a collective of civil society organizations, social movements, trade unions, and activists, organized specifically to act around this issue.\textsuperscript{12}

A series of political factors (mobilization by civil society and the AIDS movement) and technological and industrial factors (domestic production of generic antiretroviral drugs) thus set the stage for the Brazilian government to deal with the challenges that arose in HIV/AIDS prevention in the 2000s.

As discussed above, domestic production of generic drugs allowed the Brazilian government to supply universal and free antiretroviral treatment to all who needed it. But new drugs were launched in the 2000s, offering less toxic and more effective treatments for people living with HIV and AIDS. Unlike previous ARVs, these arrived in Brazil under the new intellectual property law enacted in 1996. They were covered by patents and were monopolized.

The early 2000s posed a challenge for the Brazilian government: should it incorporate the new and more expensive drugs or to maintain treatment with the domestically produced low-cost options? The social movement had a clear answer to this question: the quality of life for people living with HIV cannot be subordinated to corporate profits or any other issues that might impede the distribution of these new medicines.

Thus, rather than hiding behind a false dichotomy (the incorporation of high-cost medicines versus the principles of the Unified National Health System (SUS), especially universality and comprehensiveness), the Brazilian government, pressured by civil society, took a different approach. As part of a social context that viewed patents as a barrier to the right to health, the Brazilian government took a serious stand against this barrier to channels, calling for participation by civil society on an equal footing and adopting different national and international strategies, leading the debate on patents and public health in different forums.

At the domestic level, price reduction negotiations with patent holders for new medicine continued to be the government’s most extensively used strategy. This was heavily based upon the proven capacity of Brazil’s public

\textsuperscript{11} Although applauded by patients’ groups, civil society organizations, and various experts and viewed as progress by different international bodies, prior approval by ANVISA in Brazil has been challenged in the Legislative and Judiciary branches, mainly by multinational pharmaceutical companies. Such attacks include a case involving Interfarma (the association that represents foreign pharmaceutical laboratories in Brazil), which filed a class action suit to prevent ANVISA from performing analyses in conformity with patentability requirements in the exercise of prior approval. If the suit prevails, it could mean the end of prior approval. The GTPI is currently conducting a campaign for Interfarma to drop the suit and honor Brazil’s sovereignty in adopting measures to protect the right to health. For more information on the campaign, see: http://deolhonaspatentes.org/item/interfarma-abandone-o-caso/.

\textsuperscript{12} For more information on GTPI/Rebrip, ver: www.deolhonaspatentes.org.
laboratories to produce generic ARVs, which allowed for an estimation of production costs, thus backing price negotiations. However, by the mid-2000s prices had stopped dropping, and universal access was effectively threatened by patents in Brazil.\(^\text{13}\)

From 1999 to 2005, Brazil incorporated eight drugs into HIV/AIDS treatment. Only six of these had previously been used. The new drugs featured abacavir, efavirenz, Kaletra (lopinavir/ritonavir), tenofovir, and atazanavir, all covered by patents and all with high price tags. Due to high prices, the Brazilian government officially declared in 2005 that there was a risk to the sustainability and feasibility of the program for universal access to HIV/AIDS medicine.\(^\text{14}\)

Government and civil society then began to focus efforts to keep the public policy alive, given that it was essential for guaranteeing the right to health of the people living with HIV/AIDS in Brazil. Two episodes stood out in this struggle, involving the drugs Kaletra and efavirenz and illustrating how effective participation by civil society is essential for a successful AIDS policy.

In 2005, Brazil paid more than US$ 3,200 per patient per year for Kaletra, which consumed US$91 million – 30% of the national budget for ARVs. The Brazilian government thus entered into hardball negotiations with Abbott an American pharmaceutical company that was selling the same drug for US$ 400 per patient per year in other countries. That same year, Farmanguinhos, a public laboratory affiliated with the Brazilian Ministry of Health, announced that it could produce a domestic version of Kaletra for less than half of Abbott’s price.

After the American company’s stubborn refusal to reduce its price, the Brazilian government declared that Kaletra was a case of public interest and granted Abbott a deadline to offer a lower price and thereby avoid compulsory licensing. While negotiations were under way ENONG, meeting in Curitiba in September of 2005, passed a motion to support the compulsory licensing of Kaletra. The National Health Council (CNS) also passed Resolution 352/05, ruling for immediate compulsory licensing not only of Kaletra, but also of other ARVs like efavirenz and tenofovir, which were also weighing heavily on the Unified Health System’s budget.\(^\text{15}\)

However, contrary to the social movement’s demands, the Brazilian government signed an absolutely abusive agreement with Abbot, allowing a price reduction but providing for a price freeze for six years after the patent’s expiration, as well as a clause prohibiting compulsory licensing. When the agreement became public, Brazilian civil society put huge pressure on the government to cancel it. ABIA/GTPI filed an unprecedented class action suit, denouncing the agreement and demanding compulsory licensing of Kaletra. The agreement was revoked, but the compulsory license was not

\(^{13}\) Idem, 2016.


issued. The following year saw a major price drop for Kaletra, now sold by Abbott for some US$ 1,500 per patient per year. This price cut also came in the wake of compulsory licensing of Kaletra in Thailand.\textsuperscript{16}

An important issue in all this is the way the Brazilian Judiciary deals with intellectual property cases. In this particular case, the rulings contended that the use of safeguards in favor of public health interests would violate international standards for the protection of intellectual property, leading to reprisals against Brazil. The courts explicitly cited unilateral (and illegitimate) pressure by the United States through the infamous Section 301. There was a clear reproduction of the international discourse adopted by the pharmaceutical companies and governments of the developed countries, with no critical analysis taking public interest or human rights into account.\textsuperscript{17}

Another relevant case from the same period involved efavirenz, another drug which consumed a significant share of the funds of Brazil’s universal access program. In 2007, efavirenz was sold to the Brazilian government for US$580 per patient/year and was being used by some 75,000 people. Beginning in late 2006, the Brazilian government sought to negotiate a price reduction with Merck, given that the price the company charged in other middle-income countries and the estimated production cost in the Brazilian public laboratory, Farmanguinhos.

The AIDS movement had already been pressuring the Brazilian government to declare compulsory licensing for efavirenz for some time. At the 2005 ENONG, there was a mass march with nearly 500 organizations demanding compulsory licensing, which by local standards showed a high degree of organized civil society mobilization in favor of sustaining the ARV access program.

Price negotiations continued throughout the first few months of 2007, always under the threat of compulsory licensing. After many unsatisfactory offers by Merck, the Brazilian government finally declared the expected compulsory license and began importing the generic version of efavirenz from India, later producing the same drug domestically. After five years, the compulsory license for efavirenz generated a savings of approximately US$ 103.5 million in public funds.\textsuperscript{18}

However, that was the last act by a daring administration, which in the final years of the 2000s and throughout the 2010s moved towards other approaches no longer based on confronting the patent issue or the interests of the transnational pharmaceutical industry and the private sector. The Brazilian government’s strategies abandoned their former daring and dialogue – fundamental trademarks in the Brazilian program’s success – and turned to the market and technical solutions to deal with the ARV issue. Meanwhile, the government moved steadily away from the more fearless ranks of the AIDS social movement, which had previously constituted a crucial political force for guaranteeing access to ARVs.


\textsuperscript{17} Idem, 2010.

The late 2000s and early 2010s: Flirting with the market – opacity, conservatism, and reliance on technical methods join forces.

In February of 2009, the Oswaldo Cruz Foundation (FIOCRUZ), Brazil’s largest health research institution, officially delivered the first batches of the Brazilian generic formulation of efavirenz. Some 46% of Brazilian patients on ARV therapy were taking efavirenz at the time and less than two years after the compulsory license had been decreed the drug had proven to be a milestone in the country’s public health policies.19

The head table at the official release featured the President of FIOCRUZ, the Minister of Health, and ABIA/GTPI, representing civil society. The screen behind the speakers displayed a huge portrait of sociologist Herbert de Souza, or “Betinho”20, a symbol of the fight against AIDS in Brazil. The production line for antiretroviral drugs at Farmanguinhos (the official FIOCRUZ laboratory), which at the time was producing eight of the 17 ARVs used in Brazil, was baptized “Betinho” during the ceremony.

The tribute to Betinho was highly symbolic. As a tireless human rights and citizens’ advocate, Betinho used to say that democracy cannot exist without a strong civil society. However, this political vision has unfortunately left center stage in Brazilian health policy since 2009. The efavirenz ceremony may have been the last big moment in which government and civil society had previously discussed, on equal footing, the domestic production of ARVs in Brazil.

In addition to breaking its commitment to engaging in dialogue with civil society, the Brazilian government’s discourse of “strengthening the health industrial complex” also signaled a political wager in favor of a lack of transparency. The year 2012 ushered in Brazil’s “Access to Information Act”, regulating Brazilian citizens’ constitutional right to access to public information, aimed at increasing transparency in public administration. Expecting the law to help resolve the government’s lack of dialogue with civil society, ABIA/GTPI issued 40 requests for information to the Ministry of Health and various public laboratories between 2012 and 2015, searching for data on prices and time frames in the numerous ARV manufacturing agreements that were being announced by the government with great fanfare. Of these requests, only seven received complete and satisfactory replies. In half of the requests, information was simply denied, classified as secret. Many cases received no reply at all, in blatant disregard of the law.22

20 Hebert de Souza, “Betinho” (1935-1997) is an emblematic figure in the history of the fight against AIDS in Brazil. He was the founder and president of ABIA, besides founding other organizations that are still highly active, like IBASE and Citizens’ Action Against Hunger. To this day he is an icon in the people’s struggles for social justice in Brazil. For more on Betinho’s importance to the AIDS movement, see Galvão, Jane. (2009). “Betinho: Celebration of a Life in Brazil,” in Daniel Perlman and Ananya Roy, eds., The Practice of International Health: A Case-Based Orientation. Oxford: Oxford University Press.
21 For example, the Executive Group of the Health Industrial Complex (GECIS) was created in 2008 as the decision-making body for discussing priorities, standards, and procedures concerning the production of medicine in Industrial Development Partnerships. Within the GECIS, the Permanent Forum for Linkage with Civil Society/Council on Competitiveness in the Health Complex was created, consisting almost exclusively of representatives from the business sector. See: http://portalsaude-saude.gov.br/index.php/o-ministerio/principal/leia-mais-o-ministerio/581-sctie-raiz/decis/12-decis/12076-grupo-executivo-do-complexo-industrial-da-saude-gecis.
22 GTPI/ABIA - Grupo de Trabalho sobre Propriedade Intelectual/Associação Brasileira Interdisciplinar de AIDS. (2013). Sigilofrenia na Saúde: Resultados do uso da Lei de acesso à informação pelo GTPI.
This disregard for transparency was aggravated by a disregard for prices, in stark contrast to the time in which prices were vigorously negotiated with transnational pharmaceutical companies. According to then-director of the Department of STDS, AIDS, and Viral Hepatitis, Dirceu Greco, "At the time, the government did not look at the product’s final price, but rather at the qualifications of the pharmaceutical company with regards to technology transfer."

All this meant a relevant change in the way government viewed the patent issue and related to pharmaceutical companies. Some consequences of these choices were: (1) a loss of the public laboratories’ strategic role; rather than regulating the market, these began to apply high profit margins to their work with no transparency regarding their production costs; (2) a loss of the Ministry of Health’s bargaining power, previously based on production cost transparency and linkages to civil society; and (3) a loss of the human rights perspective, to the extent that decisions began to be based on what was most advantageous for the companies involved in the Industrial Development Partnerships and for industrial policy, and not on what was best for patients and health policies.

These policy choices are illustrated by the case of atazanavir. In 2011, an Industrial Development Partnership was signed by the transnational company BMS and the Farmanguinhos public laboratory for production and technology transfer. GTPI/ABIA identified various problems in the contract, having obtained it through great difficulty and only after numerous requests for access to information had been denied. For example, the agreement explicitly prohibits Farmanguinhos from manufacturing the atazanavir/ritonavir combination, currently recommended by the World Health Organization (WHO). For BMS, this meant transferring to Brazil a technology that was on the verge of obsolescence. For patients it means lack of access to a superior treatment alternative.

The Industrial Development Partnership for atazanavir also illustrates the weaknesses created in the sustainability of ARV procurement. BMS holds the patent’s monopoly in Brazil until 2017, when the country should be capable of producing 100% of the demand for the drug via Farmanguinhos, if the contract sticks to the deadlines. However, since registration of the generic version (scheduled for 2012) only happened in 2014, the obligation to purchase the drug from BMS will extend until 2019, thereby stretching the monopoly, even with the patent no longer in force. Thus far, five years after signing the agreement, only the drug’s packaging is being produced in Brazil.

One of the few innovations in price negotiations occurred in 2015, with Arthur Chioro as Minister of Health, when Brazil led the creation of a joint price negotiation platform for MERCOSUL, the Southern Cone Common Market. The first round of negotiations included darunavir, for which Brazil pays 2.5 times more than the cheapest generic versions on the international

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24 For example, see the study by Eloan Pinheiro (in press) on the production costs for the generic version of tenofovir in Brazil, presented at the seminar “Access to ARVs: expanding gains and avoiding setbacks”, held by GTPI/ABIA in October 2015.


26 See the study by GTPI/ABIA (in press) on the Industrial Development Partnership for atazanavir presented at the seminar “Access to ARVs: expanding gains and avoiding setbacks” held by GTPI/ABIA in October 2015.
market. In late 2015, MERCOSUL announced significant price reductions, with purchases to be made in 2016 from a generics laboratory in India. However, Brazil is still paying the price charged before the joint negotiations. As ABIA/GTPI has argued in various memorandums sent to the Ministry of Health, no patent barrier exists to prevent Brazil from producing and/or purchasing generic versions of darunavir. However, the multinational company Janssen continues to exert pressure in favor of the exclusive purchase of its drug, arguing that there are patent applications pending examination in Brazil. This is a clear strategy of provoking insecurity by filing various patent applications for the same drug, even though the applications are low quality and fail to meet the legal requirements for granting a patent.

Also with regards to the issue of prices and patents, the last Director of the National AIDS Department, Fábio Mesquita, claimed that there was a lack of a sufficiently supportive political climate to take a firmer stance, and that the government was doing everything possible given current conditions.

Government response has been similar in the debate on the incorporation of innovations in treatment. Reacting to civil society’s demands concerning the inadequacy of the currently supplied initial treatment, the Ministry of Health claims that this is the best it can offer given the price of the new drugs. An example of this can be found in the ARV dolutegravir, which had originally been left out of the medicine program. After public consultation, including broad participation by civil society and health professionals, the drug was recommended exclusively as a third-line treatment, even while other countries have adopted it as a first line remedy. Even so, dolutegravir was only to be accepted into the Brazilian program pending a price reduction.

This position is diametrically opposed to that taken in the early 2000s,


when medicines were incorporated and universal and comprehensive care was pursued using various price reduction tools and strategies.\(^{30}\)

Despite Brazil’s growing domestic difficulties, the program for access to ARVs still functions continuously and treats a growing number of new infections. However, the current scenario is increasingly worrisome. Since late 2013, mirroring the international trend, Brazil has adopted a “test and treat” strategy, in which all individuals diagnosed with HIV initiate treatment immediately, regardless of CD4 count and plasma viral load.\(^{31}\) The combination of ARVs offered at the beginning of treatment has been “3 in 1” with lamivudine, efavirenz, and tenofovir. In other countries from the global “North” such as the United States, England, and Spain, this combination is already considered to be outdated, especially due to its middle and long-term side effects. In Brazil, however, it is still the preferred choice, imposed on thousands of people that are currently initiating treatment.

Resistance and hesitation by the Ministry of Health and some of its allies (including more conservative health professionals and administrators) in dealing with the incorporation of new drugs, especially as first-line treatment, has been a threat to the middle and long-term retention of persons living with HIV in treatment and in health services. Meanwhile, Brazil’s conservatism in this area may further deepen the growing inequality between the countries that access new and more beneficial ARV combinations and those who condemned to employing the older combinations and suffering the clinical, social, and economic ills produced by these older medicines’ side effects. After so many years of struggle, it is unacceptable to the entire international community dealing with HIV and AIDS that setbacks and inequalities between countries, in terms of access to ARVs, continue to threaten the quality of treatment and life for people with HIV.

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\(^{30}\) As examples, we quote former directors of the National AIDS Program: 2003 – Paulo Teixeira: “A trademark of the Brazilian program is to mobilize all mechanisms to make access to medicines feasible, including production, quality control, or breaking patents.” [source]. 2005 – Pedro Chequer: “The National Program clearly favors the use of compulsory licensing and has stated this position clearly.” [source]. 2008 – Mariangela Simão: “Industry’s policy is based on disease prevalence and mean income, but we defend fair price, which takes other factors into account, such as the fact that a country guarantees universal access.” [source].

\(^{31}\) For a critical view of the adoption of the “test and treat” policy in Brazil, see: “For the new AIDS policy to be sustainable: old and new challenges” [in Portuguese], GTPI, 2013.
Conclusion: should the struggle continue?

Brazil’s legacy teaches that the fight against AIDS can only be won if we pursue the impossible. When Brazil first tackled this challenge, it was considered impossible for a developing country to offer free and universal treatment consistent with international guidelines. It was also considered impossible that Brazil could withstand pressure by multinational companies against compulsory licensing. Above all, it was considered impossible to place human rights at the center of the struggle against the AIDS epidemic, which nevertheless resulted in the reinforcement of citizens’ rights and the democratization of knowledge. However, these triumphs were only possible through the convergence of various factors, including the role that Brazilian civil society has played during all these years, particularly in terms of inter-sector collaboration and equal footing relationships between government and civil society.

The ability to face such pressures with courage, an open dialogue, and a focus on human rights, made Brazil a global reference in the fight against AIDS. However, as we have seen, the daring of the 1990s and early 2000s lost ground to conservatism. The dialogue and participation that were the trademarks of Brazil’s response were replaced by lack of transparency and an exclusive dialogue with the private sector. Finally, the predominance of human rights in the formulation and execution of public policies gave way to packages of services based on an exclusively technical and biomedical discourse. This dangerous turnaround benefits companies that have always abused the intellectual property system, constantly jeopardizing universal access to medicine. Meanwhile patients lose. But the fight goes on. Organizing to guarantee that the Brazilian response will continue to ensure the rights of people living with HIV in Brazil and around the world continues.
MYTH VS. REALITY: EVALUATING THE BRAZILIAN RESPONSE TO HIV IN 2016

BRAZILIAN INTERDISCIPLINARY AIDS ASSOCIATION

Global AIDS Policy Watch