

# Biosocial Activism, Identities and Citizenship: Making up ‘people living with HIV and AIDS’ in Brazil

*Carlos Guilherme do Valle*

Federal University of Rio Grande do Norte

## **Abstract**

This article discusses how Brazilian AIDS activism has emerged and been reconfigured over the last 25 years. I analyze how societal forms were created and particular problems emerged in a specific context affected by the AIDS epidemic. Based on ethnographic research in concrete contexts in Brazil, I follow the ways by which people have united around various ideas and practices related to life, health and illness, morality and politics. People affected by the epidemic were engaged in sociality, identity formation and the definition of a wide range of health, political and judicial demands, which take a particular biosocial activism as their main form of collective mobilization. My main aim is to reflect, therefore, on the formation of particular biosocial worlds, socialities, collectivities and identities related to specific modes of subjectification surrounding life and death, biomedicine and biotechnologies, politics and citizenship.

**Keywords:** AIDS, Biosocial Activism, Identity, Sociality, Biomedicine.

## **Resumo**

Este artigo discute como o ativismo brasileiro de AIDS emergiu e foi sendo reconfigurado nos últimos 25 anos. Analiso como formas societárias têm sido criadas e problemas particulares emergiram em um contexto específico afetado pela epidemia da AIDS. Apoiado em pesquisa etnográfica em

contextos concretos do Brasil, investiguei os modos através dos quais pessoas se reuniram em termos de várias ideias e práticas relacionadas à vida, saúde e doença, moralidade e política. As pessoas afetadas pela epidemia engajaram-se em socialidade, formação identitária e na definição de amplas demandas judiciais, políticas e de saúde, que tiveram um ativismo biossocial particular como sua principal forma de mobilização coletiva. Meu principal objetivo é refletir, portanto, sobre a formação de mundos biossociais particulares, socialidades, coletividades e identidades relacionadas a modos de subjetivação específicos envolvendo vida e morte, biomedicina e biotecnologias, política e cidadania.

**Palavras-chave:** AIDS, Ativismo Biossocial, Identidade, Socialidade, Biomedicina.

# Biosocial Activism, Identities and Citizenship: Making up ‘people living with HIV and AIDS’ in Brazil

*Carlos Guilherme do Valle*

Since the early 1980s, AIDS<sup>1</sup> has spread to every country in the world, becoming one of the most destructive global epidemics. Epidemiological estimates calculate that 35 million people were living with HIV and AIDS in 2013 (UNAIDS/WHO 2013). In the last three decades, massive economic investments have been channeled towards biomedical research and clinical practice to control HIV and AIDS. Governmental responses and humanitarian interventions have also been implemented in accordance with international guidelines established by the World Health Organization. Partially related to the difficulties of medical practice and research in responding effectively to AIDS, societal mistrust and apprehensions in relation to science have coexisted with high expectations and promises of new developments in biomedicine, biotechnology and genetic research. The latter became increasingly relevant in the 1980s and 1990s (Rabinow 1996a; Rose 2007; Lock and Nguyen 2010). This complex ambivalence towards biomedicine was reintensified in the face of by the huge escalation in AIDS-related deaths. At this time, the ‘new genetics’ also seemed to promise huge advances. A powerful cultural imagination concerning science coexisted with societal fears and moral panic as the AIDS epidemic began to spread widely. At the same time, biotechnology and biomedicine showed unexpected advances in many different areas, such as reproductive technologies. It is no coincidence that the rise of the new genetics and the scientific conundrums caused by AIDS were compared to one another by Paul Rabinow. He clearly emphasized that the logic of risk prevention can be found in relation to AIDS as well as genetic diseases (1996a, 1996b, 1999).

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<sup>1</sup> Acquired Immune Deficiency Syndrome is caused by HIV (Human Immunodeficiency Virus).

Paul Rabinow termed biosociality as a heuristic category (1996a, 1999, 2008) that could uncover the social and cultural impacts caused by genetics, molecular biology and biotechnologies on the ‘practices of life’ related to biopolitics in the contemporary era, which evince novel modes of conceptualizing and destabilizing the ideological contrast between ‘nature’ and ‘culture’. Consequently, social forms and collectivities have been created in response to specific events and processes. These also produce specific socialities and identities marked by biological conditions and recreated by genetics and molecular biology, although they normally entangle with culturally and/or morally shared meanings and practices of gender, sexuality, race, ethnicity, and so on. Patient groups and health advocacy organizations have been set up, therefore, to mobilize, engage and empower people with genetic diseases, their families, friends and their significant others to claim particular rights and social benefits, but also demanding investment in scientific research and accessible treatments. Their interactions with experts, scientists and health professionals have been crucial to understanding new mediation practices in the measures against illness. These actors have become committed to intervening in, managing and deciding on social practices associated with people’s lives, trajectories and futures, aiming to achieve new parameters for a ‘healthier’ and more predictable life, regulated by the constant presence of biomedical technologies and knowledge in everyday life. In sum, novel assemblages bring together a variety of people, networks, organizations, knowledge, policies and technologies which relate to each other in articulated and conflictive ways, depending on the contexts involved, to create biosociality and bioidentities around practices of life (Rabinow 1996a: 99-103; Rabinow & Rose 2006).<sup>2</sup>

Paul Rabinow’s theoretical concerns have influenced researchers who have taken up his ideas and developed them in new directions, applying his preliminary theoretical and methodological assumptions to different cases and contexts not confined to genetics (Gibbon & Novas 2008; Rabinow 2008). New categories have also been tested and used to interrogate other questions related to biosociality and the “politics of life itself,” in the words of Nikolas Rose (2007), including biogitimacy (Fassin 2009) and therapeutic

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<sup>2</sup> According to Rabinow, biosociality cannot be defined as a ‘natural’ principle of relatedness. He stresses the heuristic function of this category, which is considered in relation to specific societal contexts (Rabinow 2008; Gibbon & Novas 2008).

citizenship (Nguyen 2010), all of them focusing on different aspects of new forms of biosocial configuration (Gibbon & Novas 2008).

Although AIDS is not caused by a genetic factor, many societal aspects can be cited here to explain why I identify some similarity between the questions approached by genomics and those concerning the biosocial impact of HIV/AIDS. One of these is the development of biomedical research on HIV and AIDS treatment which proved instrumental to the evolution of the epidemic from the mid-1980s. Nikolas Rose, for example, has called attention to the way in which the human body has been screened by biomedical knowledge and technologies at a molecular level (Rabinow & Rose 2006; Rose 2007). This molecular apprehension of the human body has been directed towards different biological conditions, such as those related to genetics and 'race' (Santos & Maio 2004; Fullwiley 2007), but also those concerned with the molecular dynamics of HIV/AIDS, so important to developments in immunology (Patton 1990; Martin 1994). PCR,<sup>3</sup> a diagnostic test whose biotechnological creation was studied by Rabinow (1996b), has shown a real effectiveness in AIDS treatment since the early 1990s. In addition, biomedical knowledge and the technologies of life have also affected the ways in which identity formation is derived from a biological condition, both for genetic diseases (Rabinow 1999; Gibbon 2007) and HIV/AIDS as well. In fact, HIV testing convincingly demonstrates how biomedical technology can play a key role in identity formation, related to personal experiences of risk and illness, but also operating through the biopolitical effects of governmentality by which a population becomes focused on the regulation of 'life' (Foucault 1979).<sup>4</sup>

Another important question is the sociopolitical mobilization related to health and illness (e.g. Epstein 2007; Rabinow 1999; Rabeharisoa 2006; Gibbon 2007). These forms of mobilization show particular historical trajectories, which sometimes influence one another. AIDS activism needs to be considered in this context and, in fact, Paul Rabinow indeed recognized this aspect (1996a, 1996b). Forms of health activism have maintained

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3 PCR stand for polymerase chain reaction.

4 Since the eighteenth century, 'life' has been understood by scientific and technical knowledge (biological, medical, etc.) as a universal reality defined by 'nature.' 'Life' became a crucial (bio)political theme to be prioritized by the Nation-States, justifying diverse forms of governmental regulation and political intervention through which biopolitics was constituted and promoted.

complex relations with governmental and global agencies. At the same time, we have seen a rich debate on the effects caused by these forms of biosocial mobilization and activism, including access to scientific production and the politics of treatment (Epstein 1996, 2007), though attention has been mostly directed towards the changes in judicial and political-administrative practices with a real impact on the meanings of citizenship. A biopolitical problematic arises, therefore, from the practices of contestation, conflict and negotiation conducted by a variety of agents, including biosocial activists, regarding questions and decisions surrounding life, health/illness and death.

Although I engage here in a theoretical dialogue with recent studies of biosocial groups and identities, the article draws extensively from social research on AIDS and its examination of the emergence of new kinds of social activism and identity formation. AIDS has been the subject of a large scientific and academic literature that approached the same problems concerning the creation of societal forms, groups and identities based on biological and therapeutic conditions. Connected from the outset with 'cutting edge' scientific research, AIDS drugs and biomedical treatments were soon available to HIV infected people. In addition, different forms of AIDS activism were created and gained legitimacy through their cogent demands for the recognition of particular rights and benefits for people with HIV in specific national contexts (Pollak 1988; Patton 1990; Kayal 1993; Altman 1994; Epstein 1996; Weeks et al. 1996; Ariss 1997; Gatter 1999; Fillieule & Broqua 2000; Fassin 2007; Sívori 2007; Nguyen 2010; Gregoric 2013; Smith 2013), including Brazil (Vallinoto 1991; Parker 1990, 1994; Bastos 1999; Silva 1999; Galvão 1997, 2000; Valle 2000, 2002; Pelúcio Silva 2002; Ferreira 2006; Biehl 2007; Lima & Jeolás 2008; Cunha 2011)<sup>5</sup>. Law making and political struggles for citizenship have thus been a central issue in relation to the epidemic in Brazil.

Drawing from my earlier research on Brazilian HIV/AIDS activism (Valle 2000, 2002, 2008, 2013), this article discusses how societal forms were created and particular problems emerged in a specific context affected by the epidemic. Based on ethnographic research in concrete contexts, I enlarged the scope of this earlier research material with recent fieldwork that I carried out

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5 The main goal of this article is not to review the large academic and scientific literature on Aids in Brazil.

during the 2000s and early 2010s<sup>6</sup>. Mainly I follow the ways through which people have come together around certain ideas and practices related to life, health and illness, morality and politics. Since the late 1980s, people affected by the epidemic were engaged in sociality, identity formation and the definition of a wide range of health, political and legal demands, which take a particular kind of biosocial activism as their main form of collective mobilization. Over the last three decades, we have seen the emergence of truths and the creation of modes of subjectification (Foucault 1982) informed by events, settings, groups, agencies, ideas and practices historically constituted around a particular health problem. In fact, many significant changes happened since the 1980s as a result of governmental and social “responses” to the AIDS epidemic in specific national contexts. They were associated to new HIV treatments, such as “combination therapy” (ART)<sup>7</sup>, community organization and the guarantee of specific rights to people with HIV and AIDS. However, I am convinced that many aspects show strong continuity with this early past, including questions of subjectification and identity formation. Therefore, I begin by describing some of the aspects that allowed the socio-genesis of Brazilian AIDS activism. However the main purpose of this article is to explore the formation of particular biosocial worlds, socialities, collectivities and identities related to specific modes of subjectification around life and death, biomedicine and biotechnologies, politics and citizenship.<sup>8</sup>

## **A Brazilian AIDS? Scapegoats, groups, numbers and identities**

In the late 1970s, democracy began to return in Brazil after fifteen years of military dictatorship. During this period, social mobilization forced the

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6 Since 1994, I have been researching the formation of biosocial worlds and forms of activism connected to HIV/AIDS in Brazil. In particular, I conducted fieldwork in Rio de Janeiro, where I visited organizations, groups and networks related to HIV/AIDS. This ethnography was carried out primarily with the *Grupo Pela Vidda*, a leading AIDS organization. I also attended public events, such as the World AIDS day, political demonstrations and Brazilian activist meetings, including the *National Meetings of People Living with HIV and AIDS* (Rio de Janeiro: 1994, 1997, 2012, 2014), the biennial *National Meeting of Brazilian AIDS NGOs* (Salvador, 1994) and the *I Northeast Brazil Meeting of People Living with HIV and AIDS* (Recife, 2012). Some health services and public hospitals were also researched in Rio de Janeiro: a public HIV testing Clinic and a Hospital Day Care Center. Multi-sited ethnography was carried out (*World Aids Conferences*: Vancouver, 1996, and Geneva, 1998) in order to understand the regional and transnational connections between Brazilian AIDS activism, government agencies and international agencies.

7 ART stand for “antiretroviral therapy”.

8 I would like to thank Peter Fry, the periodical’s editor, and two anonymous reviewers for their constructive comments, which helped me to improve this article.

reinstatement of civil rights and 'traditional' political actors were joined by the emergence of new social movements, such as feminism and 'homosexual' politics. Improvements in the political climate were not matched by the same in the economy, however. This sharply affected the public health system, which occupied a crucial position in determining how Brazilians perceived their social, economic and moral plight. *Crisis* seems to be the defining category of the 1980s. The AIDS epidemic started to affect Brazil and would become inserted within a larger framework of other crises that erupted in the 1980s. Brazil had quickly become one of the four countries with the highest prevalence of AIDS cases in the world and the highest in Latin America. In 2014, there were 757,042 reported cases (1980-2014): 491,747 men (65%) and 265,251 women (35%) (Brazil 2014). One of the particularities of the Brazilian profile in the evolution of the AIDS epidemic is the social diversity of HIV infection in the country (Brazil 2014; Parker 1990, 1993), characterized mostly by homosexual and heterosexual HIV transmission. Cultural values and disputes related to sexuality, gender, class, race, ethnicity and life-style should be kept in mind when we consider AIDS in Brazil.<sup>9</sup>

AIDS first became a well-known health problem in Brazil following mass media coverage (Galvão 2000; Valle 2000). Since 1984, the Brazilian news media has reported on the epidemic with regularity. Normally the media plays a powerful pedagogic role in the incorporation of 'a cultural arbitrary' (Bourdieu & Passeron 1977), re-elaborated from other sources, such as scientific and epidemiological reports. Supported by a range of dominant cultural discourses, the Brazilian media outlets produce their own discursive practices popularizing ideas about AIDS. They constitute a comprehensive ideological framework through which Brazilians have created their understandings of the epidemic.

As in other countries (Sontag 1989; Patton 1990; Watney 1994; Weeks et al. 1996), AIDS was initially linked to male homosexuality by the Brazilian media and the general public. While gay men were considered responsible for the spread of the epidemic, they had been characterized as the most affected 'risk group' due to their sexual life. In the 1980s, this epidemiological conception became crucial to defining the gradual understanding of the

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<sup>9</sup> In 1984, the male/female ratio of HIV infection was 44.5/1, but had reduced to 1.8/1 by 2013: 18 men for every 10 women infected (Brazil 2014). On AIDS, gender and women in Brazil, see Guimarães (2001) and Knauth (1998).

AIDS epidemic in Brazil. The idea of a 'risk group' with causal associations to sexual promiscuity made gay men the social signifiers of AIDS (see also Pollak 1988; Patton 1990). The epidemic gave fresh impetus to the negative representations of homosexuality sustained by various bodies of knowledge, especially those linked to Christian religions, law and medicine. While the media highlighted AIDS as a 'gay disease,' this reporting had a conversely negative influence on many gay men, who refused to believe that they were at any risk of being infected. For many Brazilians, AIDS was a 'distant' health problem for most of the 1980s.

Until the early 1990s, the news media repeated the assertion that AIDS was a '100% fatal disease,' while the 'AIDS carrier' was represented as someone 'doomed to die.' Ideas such as 'general risk' also exposed a groundswell of fear and mistrust. Impelled by the discursive rhetoric of fear and panic surrounding a 'general risk,' the heterosexual mode of HIV infection began to be culturally depicted in the Brazilian media, which reported that AIDS was "becoming a worrying issue for the whole of society." These threats alluded to the expanding range of the epidemic. Metaphors strongly informed the cultural discourses propagated in the press, whether referring to the body of a particular individual, or broader phenomena, related to the social body as a whole (Sontag 1989; Patton 1990; Watney 1994).

Here it is worth stressing the important connection between these media reports and the epidemiological data produced by the Brazilian Ministry of Health. The number of HIV cases, AIDS deaths and cases among 'risk groups,' along with general statistical and epidemiological data, were used by the Brazilian press to describe the evolution of the epidemic in the country. It seemed that the drama of the epidemic was told through epidemiological data, numbers, rates and statistics, all of which had a significant cultural effect in terms of identifying AIDS with one or more "risk groups."

Various identity categories have been used to refer to people with HIV/AIDS. From 1983 to 1987, terms such as AIDS 'carrier,' 'victim' or 'patient' were the most widely used by the news media, such as happened in the United Kingdom (Watney 1994: 27). These categories emphasized the unavoidable physical deterioration experienced by HIV+ people. Soon a new term became the most frequent social category used by the media to identify someone living with HIV and AIDS: the *aidético*. Brazilian journals were one of the main sources for the discourses popularizing this new identity. This marked

a substantial shift in people's understandings both of the epidemic and of those individuals who could be infected. To be an *aidético* came to suggest a broader identity that categorized and united people with different social trajectories, no longer confined to a particular sexual identity or homosexuality. The cultural meanings of the *aidético* were crucial to defining the social identity of an HIV-positive person. It was essentially generic and could refer to anyone infected by HIV. *Aidético* thus became a mainstream Brazilian cultural category, implying ideas of illness and death, related to bodily wasting and an undesired finitude. Similar categories were also found in countries, such as *sidétique* in France (Pollak 1988) or *sidótico/sidoso* in Argentina and Spanish speaking countries (Sívori 2007). The question of stigma is central to any analysis of the *aidético* as a category (Goffman 1990; Seffner 1995). According to one informant: "I prefer to call someone *seropositive* or HIV+. Although I think they're all just the same thing. Just the same, but the word *aidético* sounds hideous to me [...]. I always read it in the newspapers."<sup>10</sup>

Cazuza, a famous Brazilian pop/rock singer, embodied the cultural representation of disease, bodily decay and death. From 1989 to 1990 when he died, the weekly magazines reported on his plight in highly stigmatizing ways. For example, cover story of one popular news magazine read: "Cazuza: an AIDS victim agonizes in public" (Veja 1989: see image below). Represented as the "face of AIDS," Cazuza became the best known embodied cultural image of an 'AIDS victim' and an *aidético*. We can compare Cazuza with Rock Hudson and Freddie Mercury, who became important figures in the cultural imagination of the AIDS epidemic in the United States and Great Britain.

Although illness and death were the basic conditions attributed to anyone infected by HIV, the *aidético* identity emerged just when AIDS began to be managed by more efficient forms of clinical intervention. Certainly, the news media was capable of generating a number of paradoxes: how would 'clinically healthy' HIV+ people live if they are "marked by a death sentence"? (Veja 1989). Seen from this viewpoint, I was surprised by the categories used in the first articles on the clinical efficacy of an AIDS drug, AZT. The category *assintomático* ('an asymptomatic carrier') was also present in the news media

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10 Interview with Júlio; HIV+ gay man; 32 year old; middle class; higher education degree; North Rio; no link to AIDS/NGO (20/03/1998).

around 1987, enriching the terrain of identity categories mostly originating from medical contexts. *Seropositive* was another identity category, undoubtedly appropriated from the international news media as an intellectual and cultural source. Their meanings were primarily clinical in origin, therefore universalistic, and forged a medicalized identity (Heaphy 1996; Valle 2002), which partly explains their widespread acceptance in AIDS NGOs, health services and public clinics.



To what extent did these different forms of identity categorization by the Brazilian news media have any real impact on social process of identity formation? It is difficult to provide a straightforward answer. However, we may assume that this impact diverged in meaning and practice. Although categories like 'AIDS patient,' 'AIDS carrier' and *aidético* circulated through the news media, they did not originate from journalism. Some of these terms had clinical origins, while others had been popularized from AIDS research sources. Even their specific social uses might be differentiated, such as the category 'seropositive,' which became used largely among Brazilian AIDS activists. It should be emphasized, however, that the people who composed these new social worlds presented more complex and subtle understandings of the images and meanings of being 'seropositive' and *aidético* than those circulated in the mainstream press.

What I have also attempted to show thus far is that a cultural history of the formation of new 'objects of perception' (Bourdieu 1990) became configured over the course of 1980s and 1990s. 'Risk groups' need to be seen as cultural 'objects' that have been used to classify and differentiate social experiences. 'Risk groups' might therefore be perceived as part of a symbolic process of objectification linked to the concurrent formation of the *aidético* as a stigmatized identity. Statistical and epidemiological data provided the news media with objectified public health parameters, legitimizing these 'objects of perception.' As a new social identity, the *aidético* was created in association with 'risk groups' and sexual identities. Risk groups are not just 'objects,' however, since they relate to people who were 'made up' (Hacking 2002) around life and death, health and illness. Moral and political aspects must

be highlighted if we are to understand the historical and biosocial processes behind the AIDS epidemic in Brazil.

## **The emergence of Brazilian AIDS activism**

Up to now, I have employed a particular textual strategy to contextualize the emergence of singular social worlds, organizations, groups and networks, as part of a biosocial mobilization and generation of new socialities around HIV/AIDS since the 1980s. The media was just one of the important agents in creating these new realities of life and death in Brazil. Following Didier Fassin, I agree that HIV/AIDS has to be seen from “diverse local vantage points, encompassing the tensions and contradictions of local experiences” (2007: xiv), including illness, gender and sexuality, among others. Hence we have to examine the formation of organizations, collectivities and identities within a historical context of promising biomedical advances, the main focus of this article.

Around 1983, the earliest civil mobilizations in response to the epidemic emerged among gay organizations in Brazil’s major cities, such as São Paulo. Although the Brazilian ‘homosexual movement’ was unorganized at the time, the few existing gay groups distributed HIV information materials to the local population and predated responses from the government, though their impact was limited by a lack of resources and volunteers. It was only in 1985 that the Ministry of Health held a meeting to discuss the epidemic, and the National Division of STD and AIDS was set up.<sup>11</sup> In fact, public health decisions were taken only after extreme delays and without any rigorous epidemiological control policy. As Fassin reported in relation to South Africa, political anesthesia was current in Brazil, “causing suffering and ignoring suffering” (2007: xii). As a result, the increase in the number of AIDS cases had a significant social impact.

To understand the emergence of Brazilian AIDS activism, especially NGOs, we first need to examine its links to so-called ‘homosexual militancy’ (MacRae 1990; Valle 2000; Simões & Facchini 2008). In fact, what we

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<sup>11</sup> Established by the Brazilian Ministry of Health on May 2nd 1985, this Division was renamed several times over the years.

know today as ‘AIDS activism’ overlay and contrasted with the meanings of ‘homosexual militancy’. This militancy was framed by a historical context in which an anti-authoritarian ideology was prominent. However it suffered from a lack of political strength in the wider social field of struggles for citizenship in Brazil. With the rise of AIDS activism, different perspectives and practices were created. Although criticism of the Brazilian government endured after the new civilian regime came to power, activists were not fighting for ‘democracy’ but rather for citizenship and the guarantee of human rights. AIDS activism was related to a particular social field and specific health-defined issues, intersected by ideas of citizenship. Initially, the fear of ‘AIDS ghettoization’ was also a discernible factor. Many former ‘homosexual militants’ realized the need to divert attention around AIDS away from homosexuality (Terto 1996). For them, AIDS had to be considered a health problem affecting all Brazilians. A number of political ideas were highlighted to justify and reinforce this standpoint. Many gay men thus started or joined AIDS organizations informed by values of universal affiliation. They sought to establish activist groups that privileged collective demands and promoted citizenship in general. They pointed to the possibilities of collective action without being limited to sexual orientation or any other singularity. Therefore citizenship turned out to be the central political criteria to understand AIDS activism in a country such as Brazil. This shows a subtle contrast to the United Kingdom, for instance, where a similar shift for the “de-gayng of AIDS” was questioned in the early 1990s, especially by GMFA (*Gay Men Fighting AIDS*), a voluntary agency based on sexual identity (Weeks et al 1996). In France, “where AIDS organizations had avoided a gay image, the reverse trend took place” (Pollak et alli 1992: 45; Fillieule & Broqua 2000)<sup>12</sup>.

In 1985, the first Brazilian and Latin American AIDS non-governmental organization (NGO) was created in São Paulo: the *Grupo de Apoio à Prevenção à AIDS (GAPA-SP)*. The first AIDS NGOs adopted a highly critical stance in relation to the state of structural decay, scarcity of resources, stigmatization and bigotry shown against HIV+ people, issuing political statements to the media, which began to characterize the public image

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12 For a discussion on the “re-gayng” of AIDS, see Pollak et alli (1992), Watney (1994) and Weeks et al. (1996).

of the NGOs. Much of Brazilian AIDS activism was also influenced by long-established civil associations. They brought together people with a political trajectory who had questioned the military government. Closely linked to these earlier civil associations, the *Associação Brasileira Interdisciplinar de AIDS* (ABIA), created in 1986, and the *Grupo Pela Vidda* (GPV) were founded in Rio de Janeiro by people who also had high-profile political trajectories. They became leaders of national importance during the epidemic (Silva 1999; Valle 2000). This was the case of Herbert de Souza (*Betinho*), who was also HIV-positive and hemophiliac. To set up ABIA he assembled people with public credibility, such as Herbert Daniel, a writer who had been in political exile until 1981 and an independent sexual politics activist who discovered his HIV+ serologic status later on. Although other NGOs – such as the numerous GAPAs that sprang up all over the country after the founding of GAPA-SP – were also important, ABIA and GPV are ideally placed here to provide an insight into how certain left-wing trajectories influenced the emerging AIDS-related social worlds. However, ABIA and GPV should not be seen simply as the paradigmatic model for understanding the diversity of Brazilian “responses” to AIDS. Since the mid-1980s, many AIDS NGOs have been created throughout the country. NGOs quickly achieved public visibility and demonstrated their political capital by becoming the agencies responsible for mediating and representing civil society. They illustrated the manifold social demands left unaddressed by public health policies and authorities.

Although most Brazilian AIDS NGOs emphasized a universalistic discourse and were open to everyone who want to join, gay men, some of them HIV+, and lesbians made up the majority of the founding members of these civil organizations. In other contexts, this also happened (Epstein 1996; Weeks et al. 1996; Sívori 2007; Gould 2009). In fact, discourses on homosexuality and a rather ‘camp’ ethos were present in many NGOs in Brazil (Valle 2000, 2008). These aspects would influence some groups, becoming a crucial factor in either facilitating or hindering personal affiliation to NGOs. As soon as it became apparent that LGBT activism was not incompatible with AIDS politics, a new kind of activism began to bloom in the mid-1990s (La Dehesa 2010; Simões & Facchini 2008; Valle 2013).

Brazilian AIDS NGOs, such as ABIA, GPV and GAPA, were able to perform a central role by providing a particular source of meanings, cultural discourses and political ideas on the epidemic. These NGOs emphasized the need to generate solidarity (*solidariedade*), a central ideological “weapon” loaded with political and symbolic meanings that could counteract the disempowerment caused by bigotry and AIDS stigmatization. These ideas were further developed by some of the first NGO leaders, especially Betinho and Herbert Daniel, who synthesized the position defended by ABIA and GPV. Betinho rejected the “clandestine” life imposed on HIV-positive people (Souza 1994). Herbert Daniel took a political stance against “civil death”, the predicament faced by HIV-positive people assailed by prejudice, stigma and secrecy (Daniel 1994). They emphasized the need to approach AIDS as a human rights issue, which was particularly important for two reasons. First, *solidarity* was an idea with broad cultural significance that could mitigate the negative discourses circulated by Brazil’s mainstream media about AIDS. Secondly, this approach set out a strong ideological agenda to contest and criticize Brazilian health policy. The civil response to AIDS was thus much more immediate and direct compared to governmental practices (Galvão 2000).

Perhaps it was the high incidence of HIV transmission among hemophiliacs and the wider impact of the blood transfusion issue that led to the success of civil pressure in Brazil. By contrast, demands from gay activists were unable to elicit immediate systematic responses from health authorities. Blood became the key issue propelling social and political mobilization around AIDS at national level in the late 1980s. Many Brazilians began to fear HIV infection, either because they had received a blood transfusion or because they would perhaps need one in the future. HIV infection by blood transfusion became a social problem since it highlighted the poor conditions of blood donation, the limits to Brazilian health policy, and the hugely profitable blood market. When Herbert de Souza’s brother, Henfil, a famous cartoonist and also hemophiliac, died from AIDS in 1988, the plight of hemophiliacs triggered widespread public concern. Subsequently, Brazilian hemophiliacs sued the government over their HIV infection (Valle 2000), predating and anticipating the rise of the “judicialization of the right to health” (Biehl & Petryna 2011). In France, a similar

problem emerged after national concern in relation to high incidence of HIV infection among hemophiliacs in the mid 1980s (Carricaburu 1993), which helped to consolidate a discussion on bioethics, also linked to early public debate on genetics in the country (Rabinow 1999).

One of the factors that explains this growing social and political awareness concerning blood and HIV infection was the way it was described as a ‘national’ problem, rather than one related to a particular group morally condemned for their sexual practices and life-style. The dilemmas surrounding blood donation and transfusion emphasized universalistic values, while HIV infection through sexual intercourse was assumed to be a problem for gay men only. *Solidarity* was only given, therefore, to those for whom people felt the need to have genuine compassion. However the issues surrounding blood transfusion led to the recognition of Brazilian AIDS NGOs as important political agents in the areas of health and citizenship.

### **(Un)governing AIDS: prevention, treatment and the rise of partnerships**

During the 1980s, Brazilian health authorities could be described by their failure to confront the epidemic (Parker 1990; Galvão 2000). Without rigorous epidemiological reporting, AIDS cases increased while treatment and clinical attention were limited by the critical conditions of Brazil’s public healthcare structure, which suffered from a lack of health professionals, limited funding and a derelict infrastructure (Valle 2000, 2013). It was only in 1986 that AIDS cases were obligatory registered. The Ministry of Health sponsored HIV prevention campaigns, which circulated technical information as part of public health policy. At this time, official HIV prevention campaigns reproduced prejudiced ideas, negative imagery and stigmatizing representations very similar to those published by the Brazilian media. In 1990-91, a prevention campaign centered around one particular sentence: “If you don’t take care of yourself, AIDS will get you.”<sup>13</sup> This phrase had a significant cultural resonance for Brazilians over the years. For Herbert Daniel from ABIA and Grupo Pela Vidda, this prevention

13 “Se você não se cuidar, a AIDS vai te pegar.”

campaign was a political insult to “people with AIDS,” representing them publicly via an *aidético* who was nearly ‘dead’ (Daniel 1991). Brazilian activist discourses highlighted an emerging self-reflexivity and a process of identity formation, which would strongly engage “people living with HIV/AIDS” throughout the 1990s. Meanwhile, World Health Organization (WHO) recognized that AIDS was already a “pandemic” and argued for a Global Strategy (GSA). This was launched and sponsored by the Global Program on AIDS (GPA) in 1987 (Bastos 1999). The GSA was to be implemented locally in response to each country’s pattern of HIV infection. GPA/WHO expected most countries to commit to setting up their own National Aids programs and governmental health policies to respond to the epidemic. GPA strongly encouraged communitarian measures against AIDS, based on the direct participation of civil society, community-based organizations and NGOs in the implementation of the GSA program. “People with AIDS” (PWA) were considered important social actors in the local success of the GSA, an innovative approach for national health policies, which normally avoided partnerships with civil society (Altman 1994; Bastos 1999).

Moreover, *solidarity* became the ethical principle defining the defense of human rights against AIDS discrimination and stigmatization. Jonathan Mann, the head of GPA/WHO, was perhaps the leading proponent of *solidarity*. He emphasized the need for global collaboration in “responses” against AIDS and reiterated the importance of the involvement of community-based organizations around the world. This position resulted in the direct involvement and funding of AIDS NGOs and the voluntary sector. A close collaboration and socio-political affinity between GPA/WHO and some Brazilian NGO leaders became clearly apparent in 1988. As Galvão (2000) pointed out, Brazilian activists who attended the meeting *Opportunities for Solidarity*, held prior to the Sixth International AIDS Conference (1989), decided to organize the first National AIDS NGO meeting. Located at a strategic point between local and global levels, ABIA was one of the entities responsible for organizing the first two Brazilian NGO meetings. In 1990, the idea of *solidarity* was definitively incorporated into the ideological agenda of Brazilian NGOs. But this was also present in France (Fillieule & Broqua 2000) and other countries as well. A global culture of HIV and AIDS knowledge, language, principles, identity

categories and morality seemed to resonate widely through transnational relations and was re-appropriated in local contexts. However, the political implications of solidarity proved more problematic. At national level, *solidarity* as a principle was not ideologically contested by most AIDS NGOs, but their political practices operated according to a completely different dynamics, crucially linked to disputes for hegemony. Though strengthened through global relations and networks, the meanings attributed to *solidarity* were locally and historically elaborated through biosocial disputes.

Brazilian NGOs were the social agencies who eventually brought about an AIDS policy embedded within the Global AIDS Strategy developed by the GPA/WHO. AIDS activists openly denounced the lack of responsibility shown by the Ministry of Health, precisely when the *Sistema Único de Saúde* (Unified Health System) was launched in 1990. Under this system, federal responsibility was extended to all national public health policies, including HIV/AIDS, while state and municipal local authorities were charged with providing primary health care. However, Brazilian health structures have been dogged by serious problems in services, care and material resources. In a period marked by the lack of effective anti-viral drugs, public clinics and hospitals became overloaded by the rising demand for AIDS treatments. On several occasions, public demonstrations were organized by AIDS activists. This conflict helps explain the tense relationship that developed between the National AIDS Program and many of the leading Brazilian AIDS NGOs for several years (Galvão 2000).

In 1993, Brazil signed an agreement with the World Bank through its Ministry of Health, which allowed the gradual funding of Brazilian AIDS NGOs. In 1998, a second agreement was signed, which lasted until 2002 and focused on HIV prevention projects, implemented by the AIDS social movement (Bastos 1999; Galvão 2000). *Partnership* therefore became a central concept in legitimizing these institutional relationships between government and the NGOs, which began to compete for funding through project applications submitted to the Brazilian AIDS Program (Galvão 2000; Valle 2013). In short, the previously strong tension between the Ministry of Health and Brazilian AIDS activist groups decreased significantly after these global financial agreements as partnerships began to be promoted in the mid-1990s. João Biehl uses the term 'Activist State' to define the political shifts

implemented by the partnership between the Brazilian government and AIDS activism (2007: 68-72). HIV prevention was mainly carried out by AIDS NGOs, while HIV treatment was a public health policy aimed at Brazil's HIV+ population, registered and monitored through HIV testing and treatment protocols. This context evinces the idea of governmentality (Foucault 1979), related to the regulation of population, national statistics and epidemiological estimates, which has been an important step of “labeling from above, from a community of experts who create a ‘reality’ that some people make their own” (Hacking 2002: 111). This situation was coterminous with the positive effects generated by public health policy in the late 1990s, when the Brazilian AIDS Program was highlighted as a successful model of HIV prevention and treatment by UNAIDS/WHO.



Public Demonstration, 1988<sup>14</sup>

While conventional treatments were available via the public health system, importing drugs and distributing them freely was the result of a long struggle by AIDS NGOs, politicians and later on the negotiations between Brazil's Ministry of Health, the WHO and the World Bank. In 1991, AZT started to be distributed through the public health system. It was not until 1996, though, under President Fernando Henrique Cardoso, that a new law was passed guaranteeing free access to and distribution of AIDS drugs to people with HIV. According to Biehl (2007), the Brazilian Ministry of Health has prioritized a model of ‘pharmaceutical governance’ with an emphasis on the provision of antiretroviral drugs rather than HIV prevention. In 2014, nearly 400,000 Brazilians were taking antiretroviral drugs (Brasil 2014: 58),

<sup>14</sup> “Give Solidarity a Hug.” Public AIDS demonstration organized by ABIA on the Corcovado, Rio de Janeiro, 02/12/1988 (source: ABIA).

drastically reducing the rate of deaths caused by AIDS. Along with diagnostic testing, antiretroviral therapy needs to be underlined here since it affects the ways in which identities and subjectivities are created around HIV and AIDS.

## Creating Biosocial Worlds

From the late 1980s, we saw the formation of heterogeneous biosocial worlds related to HIV/AIDS across Brazil. These biosocial worlds included a large and diverse group of people connected to each other through interactions and networks of different sorts, mostly created through the historical configuration induced by the epidemic. Social suffering and the experience of illness formed an increasing part of private and public contexts, while more and more people tested for HIV and subsequently enrolled as patients in health services. Across Brazil, numerous AIDS biosocial worlds were formed by hospitals, HIV testing centers, health units, NGOs, societal networks, patient associations and groups, government institutions (offices and health departments), religious settings, and places for social recreation, such as bars, parties and nightclubs. Most of my informants interacted with each other due to the social experience motivated by HIV/AIDS. They lived in different areas of Rio de Janeiro, though many came from other neighboring towns. Some also lived in other Brazilian cities, regions and countries, but were able to meet in certain situations and events, especially activism-related contexts. These assemblies of people effectively formed a singular geography of places, locations and events at different social levels (local, national and global). New relations and socialities were motivated by a biological condition, therefore, which became visible through heterogeneous experiences of illness and social suffering:<sup>15</sup> “In this hospital, where I’ve been treated for two months, I wouldn’t say that I’ve got friends there, but they are good colleagues. We chat and laugh. We tell each other jokes, talk about what’s going on in our lives. We talk and comment on this illness. We exchange experiences of what happened to me and what happened to him, but there” (Júlio; HIV+, 32; gay man; middle class; higher education degree; North Rio; no links to AIDS/NGO; hospital client.20/03/1998).

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<sup>15</sup> ‘Biosocial world’ is an analytical construct for apprehending the objective and symbolic relations historically materialized in concrete place and locations, here used in relation to the AIDS epidemic.

As part of my fieldwork in a Day Care unit, I noticed how relations were established and maintained among HIV+ clients treated for CMV (cyto-megalovirus) and Kaposi's sarcoma. They would regularly meet at certain times and on certain days of the week. During their treatments, they would engage in casual, sometimes humorous conversation, which also involved the nurses working in the health unit. Relations formed in the Day Care unit would sometimes transcend this setting. Sociality among HIV+ patients in health clinics plays a considerable role in creating particular subjectivities. It also contributes to the emergence of specific views and practices concerning the body and the experience of illness, which are then socially shared. The conditions and limits of personal health care and biomedical treatment also inform the ways in which socialities are created and performed. Social background and cultural affinity have played an important role in the creation of social links between HIV+ clients or with health professionals. However, AIDS NGOs and patient groups have contributed more to the creation of socialities and relations.

The 1990s saw a dramatic expansion of AIDS NGOs and activist groups in Brazil. This was a period of intense social and political mobilization (Galvão 2000; Valle 2000, 2013). Some NGOs played a major role at local or regional levels, such as the different GAPA groups, inspired by the first Brazilian NGO in the area. Organizations were gradually set up in rural towns. An ideological agenda was typically used to differentiate between these Brazilian AIDS NGOs. While some were described as more politically oriented, many others were simply considered service-based organizations. In sum, a specific social movement came into being, a biosocial activism with many internal differences in terms of ideas, goals, practices and membership. This diverse social scenario clearly reflects the heterogeneous modes of HIV transmission in Brazil. The biosocial worlds present socialities and biosocial collectivities formed by people from a variety of trajectories and backgrounds, connected by the interplay between societal and cultural issues related to gender, sexuality, race and ethnicity, class, and particular life-styles. Perhaps civil agencies like the AIDS NGO were 'factories' for making new relations and forms of biosociality that produced communalities, informed by social trust and shared experience, but also shaken by conflict and disputes. These complex biosocial worlds reveal the equally complex articulation of health/illness, biomedicine and new meanings and practices of life, affected by the strong social impact of

biomedical technologies surrounding HIV/AIDS, including diagnostic testing. Collectivities, groups and networks thus brought together Brazilians (and foreigners) with different serologic statuses who were able to create, dissolve and recreate these same societal forms and aggregates continuously. Many authors show this same complex articulation in different national contexts, although we must respect cultural singularities (Pollak 1988; Ariss 1997; Fillieule & Broqua 2000; Fassin 2007; Nguyen 2010; Gregoric 2013 etc.).

To gain a better understanding of the Brazilian biosocial worlds related to AIDS, I shall focus here on one important NGO, located in Rio de Janeiro, the *Grupo Pela Vidda* (GPV).<sup>16</sup> As a highly professionalized NGO, sponsored by international funding agencies, GPV stands out as one of the preeminent Brazilian AIDS NGOs at national and global levels. Many Brazilian NGOs have been inspired by GPV activist ideas and practices. Founded in 1989 by Herbert Daniel, a leading member of another AIDS NGO (ABIA), GPV developed a unique trajectory as the first Brazilian mutual-help group based on health activism and volunteer work. One of the first Brazilians to make his HIV+ status public, Herbert Daniel emphasized the importance of a discursive sphere of “living with HIV and AIDS” (Daniel 1994). He rejected the label *aidético*, popularized in the news media, questioning its definition as a social identity, while also contesting ‘civil death’ – that is, social forms of AIDS discrimination and prejudice:

We all get sick. Everyone will die. Yet when a person has AIDS in Brazil, evil and powerful tongues say that we are *aidéticos* and, for all practical purposes, provisionally dead until the final hour of passing arrives. I, for one, discovered that I am not an *aidético*. I am still the same person; the only difference is that I have AIDS. An illness like other illnesses and, like a few of them, loaded with taboos and prejudices. As for dying, I haven’t died yet – I know that AIDS can kill, but I also know that prejudice and discrimination are much more deadly. May death be easy for me when it comes, but I won’t let myself be killed by prejudice. Prejudice kills during life, causing civil death, which is the worst kind. They want to kill people with AIDS, condemning us to a civil death. For that reason, disobediently, I am striving to reaffirm that I am very much alive (Daniel 1994: 39-40).

16 VIDA is “a Portuguese acronym for Enhancement, Integration and Dignity of PWA, suggestive of ‘VIDA’ – life in Portuguese” (Grupo Pela Vidda, undated; cited in Valle 2000). See <http://www.pelavidda.org.br/site/index.php/quem-somos/>

Daniel asserted and defended ideas of citizenship, human rights and democracy, based on *solidarity* as a social and political premise that highlighted a robust defense of *life (vida)*. Considered from a political/activist point of view, these ideas could be found side-by-side with a reflexive understanding of illness, serologic status and life, considered within a broader existential dimension. Here we see how life resonates with the value given by biopolitics (Foucault 1998, Rose 2007; Fassin 2009). In 1989, chosen as the Green Party candidate for the first Presidential elections in 30 years, Daniel identified himself on Brazilian TV as homosexual and HIV-positive. The Grupo Pela Vida owed a great deal to his seminal activist ideas, which privileged a ‘political awareness’ of life, illness and the AIDS epidemic.

Since GPV was created, the NGO has highlighted political activism through public demonstrations and collective events imbued with strong emotional language, informed by ideas of a common global struggle against the epidemic and inspired by international AIDS activism, as advocated by ACT UP, for example (Epstein 1996, Gould 2009) and AIDES in France (Fillieule & Broqua 2000). In 1989, GPV organized the first known public protest of “people living with HIV and AIDS” in Brazil. AIDS NGOs such as GPV worked to construct a politics of solidarity embraced by emotional work through cultural discourses, sociality and embodiment, mostly presented through public expressions of anger, which appear very often in health and biosocial activism<sup>17</sup>.

In 1991, GPV organized the first “National Meeting of People living with HIV and AIDS” (also called *Vivendo*) in Rio de Janeiro – still today an important Brazilian activist event, where I have conducted fieldwork several times, even recently (2014). In the heyday of *Vivendo*, more than a thousand people used to attend at the event, including activists, volunteers, researchers and health authority workers, many of them coming from abroad. *Vivendo* has been an important context to learn about the latest scientific and biomedical developments and therapeutic strategies against AIDS. Brazilian activists perform a mediating role in these collective events. They also legitimize the authority of scientific knowledge and biomedical practices (Rabinow 1996a, 1999), circulated through transnational flows

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<sup>17</sup> Rabinow found the same in relation to people with muscular dystrophy in France (1999: 37). See also Epstein (2007).

of knowledge, which are crucial to HIV/AIDS, but also to genomics in the new political economy of vitality (Rabinow & Rose 2006). In fact, the transnational mediation of biomedical knowledge confirms the contemporary struggles of health activism to participate directly and be heard in scientific research and clinical trials. This echoes the situation of earlier mobilizations over AIDS drugs research, licensing and industrial production in the United States (Epstein 1996), but also intersects with global processes developed in Brazil in relation to AIDS vaccines and clinical trials (Bastos 1999). GPV and other Brazilian AIDS NGOs were keen to assimilate, mediate and recreate biomedical and scientific knowledge from an activist perspective. Activists could be defined as AIDS experts. Scientific and technical knowledge, considered as 'AIDS information,' has been socially circulated to HIV+ people through booklets, magazines, and newsletters, such as the *Boletim Pela Vidda*, the *Cadernos Pela Vidda*, the *Boletim ABIA*, the *Boletim Vacinas Anti-HIV* (published by GIV) and the *Revista Saber Viver*, which show real expertise on biomedical knowledge.

Needless to say, political activism constitutes just one aspect of these biosocial worlds. Sociality needs to be highlighted as well. In GPV, *solidarity* was to be invoked by "people living with HIV and AIDS", considered a broad social label by the AIDS NGO that included HIV + people and their "friends, relatives, lovers and anyone who feels that his or her everyday life has been affected by the epidemic." GPV has been open to everyone, therefore, regardless of HIV status. This organizational model was a resounding success and became a blueprint for other Brazilian NGOs. In fact, it is very difficult to define GPV. It is not simply a patient association, nor a peer group, and the idea of 'self-help' does not fit with the GPV proposal. It is not a drop-in center. It is not restricted to health advocacy or legal advice, although both are provided by the NGO. Basically its advocacy of "the defense of the rights of people with HIV and AIDS" was the main campaign issue in GPV's work and turned out to be a highly strategic political element in the NGO's attempts to generate social effects in society (Valle 2000). The NGO also maintained an AIDS hotline. GPV is quite unique, therefore, and combines activities with many different aims and organizational forms. It is also socially heterogeneous in terms of sexuality, gender, race, age and class, although some people are more underrepresented than others. Since the early 1990s, gay men and heterosexual women have made up the largest

proportion of the NGO's membership, which is quite uncommon in AIDS NGOs in North America and Western Europe. Very early on, a 'women's group' was created, composed by women with different HIV serologic statuses. Heterosexually identified men always comprised a small number of GPV's participants. From the mid-1990s, more people of lower income and poorer backgrounds volunteered at the NGO and took part in GPV activities. In conclusion, sociality in GPV very much reflects the complex and heterogeneous shape of the epidemic in Brazil. It also shows how a biosocial world has been evolving around HIV/AIDS in the country.

While political activism was central to GPV, activities centered around sociality and discursive practices of a reflexive ethos were privileged from the start. Regular meetings united people with different HIV serologic statuses to socialize or discuss a wide range of topics and themes with no formal 'therapeutic' aim. Activists used to say that their aim was not to provide 'counselling' as such, although some meetings were in fact coordinated by volunteers with a degree in psychology. Topics mirrored the interface between the sociopolitical and personal dimensions of AIDS. Themes related to citizenship and activism could be chosen along with others deemed more 'experiential,' such as prejudice, HIV disclosure and 'sexuality.' These internal meetings and activities stimulated the incorporation of the meaning of 'living with AIDS,' as understood by GPV, taken as a collective, non-individualized approach to the epidemic. The experience of 'living with AIDS' was addressed by an ethos of 'togetherness' or 'shared experience' (*convivência*), which united a heterogeneous collectivity of people with no pre-established identity and irrespective of HIV status. These contexts looked to generate a broad understanding of a particular ethics that minimized or questioned identity as a societal focal point. For participants in the NGO, therefore, no obligation or importance was attached to their identification as HIV+ or HIV- (or even specific sexual identities), although using the category *aidético* was strongly rejected and indeed corrected. Embedded by solidarity as a principle against AIDS, as far as GPV activists were concerned, *togetherness* needed to be stimulated through sociality.

Furthermore, these activities and meetings functioned as central spaces of 'confessional technology' (Foucault 1998; Nguyen 2010). Facts, accounts and narratives backed by personal experience were normally presented. These activities were crucial in terms of engendering discursive practices

of awareness and reflexivity among GPV members (see Altman 1994). Perhaps the most important aspect of these collective meetings and activities was the chance for volunteers and members to foreground personal narratives and discourses that, above all, revealed wider social and cultural understandings of AIDS. Sometimes mediated by an ideological framework absorbed in GPV or other NGOs, participants were able to express their perspectives, though these might diverge among themselves, according to their own heterogeneous trajectories and backgrounds. Subjectivity was created through sociality and practices of self-awareness and reflexivity related to the experience of 'living with AIDS.' Highlighting the importance given by GPV to a new conceptualization of life against 'civil death' and discrimination, activists used to repeat a sentence created by Herbert Daniel at the end of some activities, before he died in 1992: *Viva a Vida!* ('Long Live life!'). It was a powerful symbolic and moral statement of the societal responses against AIDS. Closely linked to these GPV activities, the sentence worked as a poetic coda, but also operated as a speech act that could be heard, for instance, recently in 2014 at activist events like the 17<sup>th</sup> *Vivendo* – the *National Meeting of People Living with HIV and AIDS*, organized by GPV -, which shows strong symbolical reference, a sense of communality and historical endurance.

With a unique trajectory as an AIDS NGO, the GPV example provides a valuable insight into the creation of biosocial worlds linked to the epidemic in Brazil. Although the GPV model is not necessarily generalizable across the country, it proves useful in an anthropological analysis of illness, sociality, activism and the politics of life. While the NGO's ideas of 'living with AIDS' were clearly politically and socially inspiring, embracing an ethos of 'togetherness,' they were also shaken by the controversies provoked by different understandings of this 'experience.' 'Life' was disputed through social and political struggles in these new social worlds in which people were defined by their biological condition. What identities, subjectivities and truths have come to the forefront in relation to 'living with AIDS' in Brazil?

### **Becoming HIV+: diagnostic testing and clinical identities**

According to Susan Sontag, "with the most up-to-date biomedical testing, it is possible to create a new class of lifetime pariahs, the future

ill” (1989: 34). Notably, HIV testing<sup>18</sup> can be seen as a turning point in the process of identity formation and personal change for infected people. Like earlier practices of serologic identification (Löwy 1993), HIV testing has to be considered from a social and cultural perspective. Some social science studies have already discussed this topic (Patton 1990; Waldby 1996; Ariss 1997). João Biehl’s ethnography (Biehl et al. 2001, 2007) and my own research (2000, 2002, 2013) have foregrounded HIV testing as a key event in terms of understanding sociality, identity formation and group-making processes in relation to HIV/AIDS, though we have focused on different social contexts in Brazil.

Since public policies can “shape the way individuals construct themselves as subjects” (Shore & Wright 1997:4), the technical categories used and circulated in governmental practices have also influenced how individuals identify themselves. This aspect of social identification through public policy pervades many levels of social life in contemporary societies, including health and illness. Medical practices and biomedical technologies do not limit themselves to defining illness, its etiology, diagnosis and treatment. Biomedical practices and technologies have simultaneously had evident social effects on the creation of identities in institutional settings, as well as in locations of intimacy and sociality. I agree with Gibbon and Novas that “novel biological, genetic or medical knowledge and technologies shape identity and forms of identification” (2008: 6). For these authors, following Rabinow (1996a) and Hacking (2006), genetics allowed space for the creation of new identities and group formations. This was equally true of AIDS, although defined as an infectious disease. For Rose (2007: 13), “the laboratory has become a kind of factory for the creation of new forms of molecular life.” All clinical practices and biomedical technologies related to HIV/AIDS (testing, antiretroviral drugs, PCR, CD4 cell counting, genotyping, etc.) can potentially contribute, therefore, to the processes of biosocial and identity formation. Their positivity is located in a continuous, reaffirming process of individual – and sometimes collective – insertion in institutional clinical practices through which their dominant strength and power in other locations and other areas of life is disseminated. Hospitals, clinics and testing

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<sup>18</sup> Three HIV antibody tests (Elisa, Western Blot and the Immunofluorescent antibody assay) have normally been used in Brazil.

centers provide institutional spaces that operate as foci for larger processes of medicalization and subjectification that are also reproduced in other contexts, including the home, the school and peer groups. Under the sign of rationalization as a wide-ranging, normative process (Foucault 1979), guided by the State and its public policies, groups and individuals have been defined and identified various times during their social and biographical trajectories. These forms of (bio)definition and (bio)identification have had significant impacts on the social and cultural processes related to the AIDS epidemic in Brazil, as they had with earlier diseases, including syphilis in the 1920s and 30s (Carrara 1996), but also in relation to genetic diseases in Brazil (Santos & Maio 2004; Santos et al. 2012).

Following Martin (1994: 163), I examine the practices of HIV testing as an important feature in a complex mediation between different forms of “cultural understandings in wider society” and particular forms of codified knowledge on HIV/AIDS, including scientific terminology and vocabulary, clinical ideas of the body and sexuality, and HIV prevention techniques. As Bourdieu (1990) asserts, codification may be just one of the ways in which technical and scientific knowledge, sustained by different power structures, spreads through society. A social practice like HIV testing and an institution like a testing center (hospitals, health care units, and AIDS NGOs, for example) can produce mediation of codified knowledge through “documents”, such as HIV test results. But mediation implies that a part of techno-scientific codified knowledge is apprehended by an empirical process of loss and gain: in other words, much knowledge is lost in the blurred process of incorporation and much gained in a different form by those agents involved in this same process. Hence the mediation of codified knowledge largely relies on its simplification and particular (biosocial) appropriations.

Although the first HIV tests arrived in Brazil around 1985, they were limited to a handful of private laboratories and a few public clinics and research institutions. As in other large Brazilian cities, HIV testing was slowly introduced in public diagnostic testing centers in Rio de Janeiro during the 1990s. At this time, Brazilian NGOs questioned governmental plans for large-scale compulsory HIV testing and, informed by North American activism (Patton 1990: 36), argued that HIV testing should be a free-choice decision. When the World Bank reached the financial agreement

with the Brazilian Ministry of Health, HIV diagnostic testing was definitively included in the country's public health policy for AIDS. During the 2000s and 2010s, diagnostic technology has played a central role in HIV prevention and has been widely championed in Brazil (Valle 2002, 2013; Biehl et al. 2001; Cardenas 2014), including public campaigns of oral HIV testing, sometimes conducted by Brazilian NGOs such as GPV.<sup>19</sup>

When I carried out fieldwork in a public testing center (CTA) in Rio de Janeiro, identity issues arose during one of the various stages of the testing process, the *aconselhamento* or 'counseling' phase, which emphasized a collective dimension. Usually a group of 10 to 15 individuals were involved in the activity. Most clients were men from a poor or lower middle-class background. According to the health professional leading the session, the client would find out whether he or she was a 'positive' person (*pessoa positiva*), an 'HIV-infected person,' an 'HIV virus carrier' or a 'negative' person (*pessoa negativa*), who "was not infected by the HIV virus." The counsellors explained how to 'read' an HIV test result, whether it was 'reactive' (*reativo*, *reator* or *reagente*) and therefore 'positive,' or 'non-reactive' (*não reativo* or *não reagente*) and therefore 'negative.' The symbols of positive (+) and negative (-) were normally written on the chalkboard to help clarify the differences in serologic status.

All these categories had clear medical or clinical meanings, which would be confirmed and reinforced in the continuation of HIV testing, but also in the future if the client proved 'positive.' Consequently, the counsellors discussed what it meant to be a 'carrier' (what to do next, where to go to, and so on). In this case, she advised on the need to prevent infections if the client was HIV+: "treatment is fundamental." In addition, the counsellors also stressed that treatment options were available to an HIV+ person, if done 'quickly' in order to 'keep healthy' (*preservar a saúde*). While explaining the impact of HIV on the immune system, therefore, the testing practitioners also presented the case of the 'healthy carriers' (*portadores saudáveis*) or the

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19 It was not until a public clinic was set up – one specialized in diagnostic testing for HIV and DST (COAS: *Centro de Orientação e Apoio Sorológico*) – that HIV testing became more accessible to the Brazilian population. In 1997-98, there were three CTAs (Centers of Anonymous Testing) in the City of Rio de Janeiro. For a current study on public HIV testing centers in Rio de Janeiro, see Cardenas (2014). This author estimates 515 CTAs in Brazil (up to 2012, according to data from Brazilian Ministry of Health). In 2014, I was also able to observe a public campaign of oral HIV testing, called *Mix da Prevenção*, conducted by GPV professionals and volunteers in Central Rio – Cinelândia. Oral HIV testing uses oral fluid to check for HIV antibodies.

'asymptomatic HIV carriers' (*portadores assintomáticos*) who were HIV+ but had not 'developed AIDS.' Adopting a perspective that questioned the direct cultural association, between AIDS and death, the counsellors also stressed the possibilities of living well with the virus, stressing the fact, for instance, that immunological markers for HIV disease progression (such as the viral load count) could be monitored: "...the less virus there is in your body, the better. You live a better life." We can now see how clinical categories were used in an empirical setting, but were related to a range of facts and dilemmas facing CTA users. 'Living with HIV' was represented through the projection of a life that could be managed through enhancement technologies (Rose 2007: 18): AIDS drugs, clinical tests and immunological markers. As one counsellor told the clients: "... there are better chances to maintain a person at the stage which they currently present, the healthy carrier." Counsellors emphasized how clients could rationalize their lives in order to carefully preserve, manage and regulate their health condition through rigorous biomedical treatment and health care. Following Rose: "Technologies of life not only seek to reveal these invisible pathologies, but intervene upon them in order to optimize the life chances of the individual" (2007: 19).

HIV diagnostic testing can be seen as one of the primary stages in a progressive incorporation of codified-dominant knowledge, discourses, and materialities on HIV and AIDS – an institutional foundation to identity formation. The identities in question are different from the more popularly known terms, such as the *aidético*, which was culturally constructed in wider society. The practice of HIV testing relied on a difference produced by a serologic technology, which would provide substantial grounds for cultural discourses of classification and identification, presented by the contrastive, medically-defined categories of 'positive' and 'negative.' However, the categories used for HIV testing in Brazilian laboratory settings, both public and private, expressed a technical vocabulary that contrasts greatly with the terminology employed by HIV testing center users, especially those from low-income groups.

HIV testing categories given to health service clients, such as 'reactive' or 'non-reactive,' were codified terms indicative of their laboratory origin. While they expressed similar technical meanings, they were eclipsed by other categories: *soropositivo* ('seropositive') and *soronegativo* ('seronegative'). These biomedical categories would become pervasive in clinical and HIV

testing settings, but they would also be used and circulated widely in other settings, especially AIDS NGOs where agents preferred the clinical and biological meanings to culturally loaded categories like *aidético*. As constitutive parts of AIDS-related biosocial worlds, these clinical and laboratory settings proved to be highly relevant to the use and diffusion of categories, conceptions and materials based on technical-scientific frameworks and practices in a way that allowed the social conditions necessary for processes of identity formation.

In my ethnographic fieldwork, the large majority of my HIV+ informants rejected the popular category *aidético* as negative, pejorative and offensive, although some reported other, more subtle meanings. They did not use the term in everyday life, preferring others, especially *portador* (carrier) or *soropositivo*. Some of these informants did not have any form of contact with AIDS NGOs, but, on the contrary, were linked to public hospitals or other clinical settings. According to their accounts, *aidético* was symbolically informed by other identities. On one hand, some of these identities had an illness as their basic reference (Pollak 1988; Sontag 1989), such as cancer, tuberculosis and leprosy (*canceroso*, *tuberculoso* and *leproso*). In Brazil, these categories were culturally constituted by stigmatized identities, emphasizing a condition of disease, bodily decay and death. On the other hand, *aidético* was historically related with 'deviant' and promiscuous sexuality (Seffner 1995; Valle 2002). Cultural discourses on AIDS were simultaneously accompanied by the strong circulation of sexual identities (homosexual, bisexual and heterosexual), the social recognition of which had been until then highly specific and restricted, though widely disseminated through public health programs, the news media and AIDS activism. Popular sexual categories were also linked to the *aidético*, such as *bicha* (a popular term used to describe sexually passive men). I believe this explains how personal strategies of secrecy and a dynamics of silencing HIV/AIDS as a topic (Pollak 1988; Carricaburu & Pierret 1995; Small 1997) were maintained in order to 'pass' without the risk of being blamed for possessing a 'discredited identity' (Goffman 1990) like *aidético*. As a result, categories such as *soropositivo* were considered worthy insofar as they neutralized the negative moral meanings embedded in the imagery of the *aidético*:<sup>20</sup>

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20 The *aidético* emerged at the expense of previous cultural stereotypes, meanings and moral values related

I don't call anyone *aidético*. ... I think this is a pejorative term. Among ourselves, we have to treat each other with more affection. It's less offensive to call someone *seropositivo*! Less aggressive... But lay people don't know what *seropositivo* means. [...] *Aidético* is closer to disease. Pow! It's like a smack in the face! *Seropositivo* breaks away from this meaning. *Aidético* is a word that sounds like... It's like calling a guy a homosexual or a faggot (*bicha*)! [Laughs] This is an offensive, aggressive way of referring to a man. (Eduardo, HIV+ heterosexual defined man; low income; secondary school; AIDS NGO member; Rio suburbs; 14/01/1998).

*Seropositivo* and *soronegativo* soon became clinical identities by which people and individuals were labeled, classified and culturally represented. Since the early 2000s, other categories have been also used, such as *casal sorodiscordante*, (serodiscordant couple; Maksud 2007), *indetectável*<sup>21</sup>, *coinfectado* (coinfected; for instance, a person with HIV and hepatitis C), etc. Actually, these categories depend on the combination of different social and cultural dimensions. First, we should consider the ideas and practices of health professionals, which are grounded in biomedical criteria and who maintain hierarchical power relations with people with HIV and AIDS. These clinical categories have frequently been used to help in the construction of the self as well as the social experience of being HIV-positive. They have to be mutually considered if we wish to understand the emergence of these clinical identities (Valle 2000, 2002). Indeed, they could be called biosocial identities. Clinical identities refer to the particular uses of images, meanings, discourses, materialities, substances (HIV drugs) and, therefore, truths on and of *soropositividade* (HIV seropositivity). Basically they are central to the understanding of modes of subjectification related to HIV and AIDS, partially connected to clinical settings, but also influenced by sociality and participation in biosocial worlds in Brazil, which here include NGOs, societal networks and the like. In Brazil, these biomedical categories with universalistic meanings were socially appropriated and redefined by other interpretations and practices by HIV+ people, placed in particular settings, contexts and situations, especially in the biosocial worlds in which they were socially engaged. By their own means and practices, people press

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to sexuality which served beforehand to position some people in hierarchically inferior socio-structural niches: that is, those connected to homosexuality, prostitution, poverty, and so on (Fry 1982).

21 A HIV+ person with undetectable viral load

“from below, creating a reality every expert must face” (Hacking 2002: 111) – including, of course, experts like health professionals. When Hacking refers to ‘making up people,’ he is also contemplating the personal agency historically entangled by power relations in particular social situations. So social formations and processes influence the making up of people while these same people disagree with or contest the regulation of life, experiences and their own social practices. We are dealing, therefore, with the ways through which people create their subjectivities in variable forms and particular contexts. In fieldwork, I noticed how some HIV+ people would use different means and strategies to challenge scientific knowledge, biomedical ideas and practices, or the enhancement technologies provided to them. Although the biological condition was socially recognized to understand life, some informants would reject biomedical treatment. They refused to take AIDS drugs, questioned the side effects provoked by antiretroviral drugs like lipodystrophy<sup>22</sup>, and appropriated biomedical treatment to make it their own. In fact, biology was not just accepted, it was also contested. Among the HIV+ people that I met and interviewed, some forms of local biological knowledge would emerge and coexist with the dominant biomedical knowledge. In sum, biological knowledge and biomedical practices and technologies were appropriated and sometimes resisted in the Brazilian biosocial worlds related to HIV/AIDS.

### **Conclusion - Making up “people living with HIV/AIDS” in Brazil**

For an AIDS NGO such as Grupo Pela Vidda, the category “people living with AIDS” was not so similar to the label PWA normally found at global level. Firstly, “people living with AIDS” (PWA) was a political category used in Anglophonic countries (Altman 1994). When AIDS was associated with gay men, the idea of “people living with AIDS” was effective for political reasons since it contradicted assumptions that HIV infection and AIDS-related deaths were exclusive to gay men. Additionally, PWA implies a communitarian aim, the politics of which has resonated at a global level from international meetings to transnational arenas of funding, policy-making

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22 Lipodystrophy characterizes different changes and gradations of body shape, specially related to fat distribution. See: <http://www.aidsmap.com/Lipodystrophy/cat/t616/>

and justice, such as UNAIDS/WHO. For Rabinow and Rose, “individualizing and collectivizing subjectifications are also mobile and transnational” (2006: 215), though they can be informed and indeed contested by particular models of patient activism. In Brazil, “living with AIDS” was a controversial political issue in AIDS biosocial worlds and referred to disputed identities and struggles around subjectification. This issue shows particular historical and cultural aspects in Brazil, when compared to other countries (Altman 1994; Fillieule & Broqua 2000; Fassin 2007; Nguyen 2010).

Located in São Paulo, a Brazilian AIDS NGO called *Grupo de Incentivo à Vida* (GIV) promotes ideas of HIV+ experience and identity similar to those found in a global PWA perspective. For reasons that had less to do with political antagonism than with ideological differences about the meanings of ‘living with AIDS,’ activists from GIV and GPV had distinct perspectives that caused mutual suspicion and criticism until late 1990s. For GPV, the idea of ‘living life positively’ implied a generic attitude towards life, which included the political sense of self-making as AIDS activists. GPV attached importance to the personal and political impact caused by AIDS, but was open to anyone, regardless of HIV status, informed by *solidarity* as a societal principle against the epidemic. GIV, on the other hand, emphasized HIV+ identity and the personal experience of “living with AIDS,” considered as a biological condition. It offered activities accessible only to HIV+ people. For both GPV and GIV, *solidarity* was incontestable and resonated global AIDS activism and also ethical and societal principles stressed by WHO. However the idea of “living with AIDS” has a different meaning for the two Brazilian AIDS NGOs and was open to conflict, which conveyed different societal experiences and practices.

One question that can be highlighted is the meaning given to *convivência*, a Portuguese word difficult to translate but that can be rendered as ‘living together,’ ‘familiarity,’ ‘conviviality,’ ‘togetherness’ or ‘shared experience’. From early on, GPV stressed the importance of *convivência*, aiming thereby to unite people with different HIV serologic statuses in the same activities, meetings and spaces of mutual support. Internal activities were aimed precisely at this sense of communitarian experience, which had a social focus not so different from previous historical homosexual organizations in Brazil or abroad (MacRae 1990; Pollak 1988). Sociality was mainly informed by this sense of togetherness, disregarding HIV status. However

*convivência* gained another meaning in the AIDS biosocial worlds during the mid-1990s and consolidated in the 2000s. Later on, it was progressively differentiated from “living with AIDS,” which was experienced by HIV+ people alone. We see how categories, ideas, identities and values can change their meanings historically. Certainly, representations and practices are not stable and undisputed, especially in highly heterogeneous complex social settings. Hence, biological condition, as defined by diagnostic testing, acquired a crucial importance in terms of understanding sociality and identity formation. One of my main interlocutors explained:

Even if a seronegative person wishes to live with AIDS, even if he wants to show solidarity; even if he gets on well with someone with AIDS, living with AIDS really means to live with the virus, to live with the problem of medicine, to live with this dilemma that involves medicines and quality of life. A seronegative person does not live with this. He doesn't need it for his survival. He doesn't need it. He can take part in the struggle. He can be an active person. He can be a very important person in this struggle, but [...] ...those people, who were there in the GPV, they think and say that they live with AIDS, but they can't live with it because they haven't got the virus, they're not seropositive. So the sensitivity of someone who lives with the virus is greater. Or the perception of the predicament of living with AIDS. It's different for some people from GPV who are seronegative and insist that they live with AIDS. They can even live together with people who live with AIDS. (Eduardo; HIV+ heterosexual man; married; 42 year old; lower middle class; secondary school; North Rio; 14/01/1998)

Notably, AIDS activists appropriated biomedical knowledge and depended on diagnostic testing and biomedical technologies to legitimize biosocial difference. In fact, biosocial identities were reinforced much more by the universalistic premise supplied by biology, though a degree of ambivalence can be found here, since the biological condition would erase the kind of particularism mostly produced by societal processes. In the mid-1990s, identity, experience and HIV empowerment became highly politicized issues in Brazilian activism and the AIDS biosocial worlds in general, but this was common in other national contexts as well (Epstein 1996; Fillieule & Broqua 2000; Gould 2009), although anthropological analysis must highlight the subtle differences in the meanings, practices

and “responses” to AIDS. In some Brazilian NGOs, ‘positive’ members accused ‘negative’ staff members of trying to control power and economic resources. This also reflected a wider criticism of the bureaucratization affecting AIDS NGOs. This happened as well with the French NGO AIDES (Fillieule & Broqua 2000) and the North-American GMHC (Kayal 1993). In fact, the conflicts between NGOs over identity can be linked to broader ideological disputes and the co-existence of different models of AIDS organization. While the discourse of “living with HIV and AIDS” was made public by GPV, it was only later that HIV+ people became widely visible as political agents. In 1995, the RNP+ (“National Network of People living with HIV and AIDS”) was set up at the time the 5<sup>th</sup> *Vivendo* was being organized by GPV in Rio de Janeiro. Basically “living with AIDS” became problematic and life was considered from different perspectives. This Brazilian HIV+ network produced a sharp internal division within AIDS activism and exposed a moral and sociological divergence between the experience of “living with HIV” and the ethics of togetherness (*convivência*). Life was described and differentiated by illness and biological condition. AIDS was voiced and experienced by HIV+ people in public contexts, defying “silence and invisibility by becoming emphatic embodiments of the disease” (Comaroff 2007: 203). They would present their biosocial singularity through diverse forms of sociality and discursivity, stimulating people to pursue their own practices of self-modeling and reflexivity. New identities and subjectivities have been forged through this focus on a biological condition unable to be shared.

RNP+ Brasil is composed of individual HIV+ members from all over the countries, in contrast to AIDS NGOs, such as GPV, but similar to HIV+ networks like the Global Network of People living with HIV (GNP+) and the International Community of Women living with HIV/AIDS (ICW). The RNP+ has prioritized HIV-positive identity politics and empowerment related to global PWA politics. These networks were widespread in Brazil, subdivided in regional and smaller coalitions, and have developed more recently into other forms, such as the *Movimento Nacional de Cidadãs Posithivas*, a network of Brazilian HIV-positive women created in 2004, which is now found in most of the country’s states. A National Network of Young HIV-positive people represents yet another level of social and political mobilization, focusing on a specific category of people, defined by serologic status and

age (Cunha 2011). These are some of the new developments over the past twelve years, which have produced social unity as well as political fragmentation.

Persistent tensions between the different models of identity construction have operated in Brazil since the early 1990s (Valle 2000, 2002), therefore, and have shown a particular way of dealing with sociality, agency and experience in relation to HIV/AIDS. The creation of RNP+ and its ideological dispute with AIDS NGOs like GPV showed the social effects of a wider process of identity formation in relation to the epidemic. In the 2000s, the conflicts caused by identity politics and the differences between models of “living with HIV and AIDS” have apparently weakened. As a matter of fact, these recent changes in identity politics correlate with strong articulation between global and local practices. Although some AIDS activists and Brazilian health authorities show mutual distrust, they also follow the same politically “appropriate language” supported by global WHO guidelines (UNAIDS 2015), which reveal a clear ambivalence between AIDS global policy, national public health, and local AIDS activism. As a “global” category, *People living with HIV* overshadowed local meanings and identities, such as those ones encouraged by GPV in the early 1990s.

To conclude, the experience of illness and the problematics of life have turned out to be a sensitive point of focus in the sociopolitical dispute generated by an epidemic with strong moral connotations. In Brazil, bio-social worlds were historically created around HIV/AIDS and united people from diverse trajectories and backgrounds who became active in NGOs, social networks, clinical settings, laboratories and elsewhere. Identities and subjectivities emerged and were shaped by the social circulation of biological knowledge and biomedical technologies. These were social processes through which people, groups and organizations positioned themselves, sometimes inspired by ideas of *solidarity*, but also confronted by disputes and conflicts concerning the biological condition as the ‘true’ experience of “living with HIV.” Furthermore, while “people living with HIV” have been defined as a biosocial collectivity here, they also constitute a political community that has struggled for rights and citizenship. Can we really believe, though, that a biosocial and political category like “people living with HIV and AIDS” encompasses all Brazilian HIV+ individuals? In fact, many ‘people’ remain separate from governmental policy and activist practices, as

Biehl (2007) has pointed out. Nonetheless this societal predicament cannot be used to downplay the political and social effects generated by biosocial activism in Brazil, which has struggled directly through the politics of life to oppose the stigma and ‘civil death’ so aptly described by Herbert Daniel.

Revised by David A. Rodgers

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*Carlos Guilherme do Valle*

Federal University of Rio Grande do Norte

cgvalle@gmail.com